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Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Gynaecological cancer in Australia

TUESDAY, 1 AUGUST 2006

SYDNEY

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Tuesday, 1 August 2006

Members: Senator Moore *(Chair)*, Senator Humphries *(Deputy Chair)*, Senators Adams, Allison, Carol Brown and Polley

Participating members: Senators Abetz, Barnett, Bartlett, Bernardi, Mark Bishop, Bob Brown, George Campbell, Carr, Chapman, Colbeck, Coonan, Crossin, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Fielding, Forshaw, Hurley, Joyce, Lightfoot, Ludwig, Lundy, Mason, McGauran, Milne, Murray, Nettle, O'Brien, Parry, Payne, Siewert, Stephens, Stott Despoja, Watson, Webber, Wortley and Wong

Senators in attendance: Senators Adams, Allison, Carol Brown, Ferris, Humphries, Moore and Webber

Terms of reference for the inquiry:

To inquire into and report on:

Gynaecological cancer in Australia, and in particular the:

a. level of Commonwealth and other funding for research addressing gynaecological cancers;

b. extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer;

c. capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions;

d. extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers;

e. extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers; and

f. extent to which experience and expertise in gynaecological cancer is appropriately represented on national health agencies, especially the recently established Cancer Australia.

WITNESSES

Committee met at 9.01 am

HACKER, Professor Neville Frederick, Director, Gynaecological Cancer Centre, Royal Hospital for Women

SHINE, Professor John, Executive Director, Garvan Institute of Medical Research

SUTHERLAND, Professor Robert Lyndsay, Director, Cancer Research Program, Garvan Institute of Medical Research

DUNCAN, Ms Carmen, Fundraising Manager, GO Fund

VRISAKIS, Mr Aleco, Chairman, GO Fund

CHAIR (Senator Moore)—Good morning. Today the Senate Community Affairs References Committee continues our inquiry into genealogical cancer in Australia. We acknowledge the traditional owners of the land and welcome you to Parliament House in New South Wales. This is the first day of our hearings in Sydney, and the committee look forward very much to the upcoming discussion. We appreciate the efforts people have made to be with us today. As you will have noticed from the program, the committee have asked some individuals and organisations to appear jointly today. We are hoping as much as possible to make this a discussion, to continue our investigations. We want to maximise the opportunity that people have to contribute to our inquiry and to get the best possible result.

I know you have had information on parliamentary privilege and the protection of witnesses. We prefer, as you would expect, to have evidence given in public, but if for any reason you would like to give evidence in a private capacity let us know. The committee have all your submissions in front of us. We are going to have some opening statements and then we will move to discussions. Professor Hacker, you will kick off?

Prof. Hacker—Thank you very much for the opportunity to present to this inquiry. I believe this is a very important inquiry for the women of Australia and I am delighted to see that it has such bipartisan support. I read with great interest the proceedings of the 2005 inquiry leading to the report *The cancer journey: Informing choice* and was disappointed with the lack of gynaecological input. So I commend the committee for focusing specifically on gynaecological cancer on this occasion. I think the inquiry is timely, because there are a number of important and emerging issues in this field.

Gynaecological oncology was first recognised as a subspecialty of obstetrics and gynaecology by the Royal Australian College of Obstetricians and Gynaecologists, now the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, in the mid-1980s. Gynaecology is unique among surgical disciplines in having a special three-year training program leading to a Certificate of Competence in Cancer Management. No other surgical subspecialty has such a formalised approach to cancer care. Following the advent of subspecialisation, multidisciplinary gynaecological cancer centres were established in all capital cities except Darwin and fellowship training programs were developed.

In general, I think it would be fair to say that gynaecological oncology is very well organised in Australia by international standards. We have a number of cancer treatment centres that are the equal of anything overseas and our fellowship training programs are highly sought by overseas candidates. We have some excellent research groups and dedicated fundraising foundations. However, all of these centres, research groups and foundations are working in isolation. The research groups in particular are significantly under-resourced and rely disproportionately on charitable donations. I believe a national body to provide coordination and leadership would be a significant advance for the women of Australia and an important strategic investment for this country. I fully support the creation of a national gynaecological cancer centre, as initially proposed by Margaret Heffernan at the roundtable discussion in February. I see such a centre as being the linchpin to coordinate research, education and advocacy for gynaecological cancer in Australia.

CHAIR—Thank you. Would anyone else like to make an opening statement?

Prof. Shine—I would like to point out in a preliminary sense, certainly from the perspective of the Garvan Institute, that the enormous progress we have seen worldwide in medical research in general over the past decade provides enormous opportunities for us to understand a complex disease like the gynaecological cancers and provides the opportunity to develop far better ways to diagnose and treat this sort of disorder. 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.

CHAIR—Professor Sutherland?

Prof. Sutherland—I would enforce what John said and perhaps identify the relative distribution of funds and the emphasis on ovarian cancer research, details of which are in the submission. In the cancer research program at the Garvan we cover wide aspects of different forms of cancer. The ovarian cancer joint program with the Gynaecological Cancer Centre is relatively recent and has informed us, as well as other people, of the paucity of funds that are going to this area relative to the mortality of the disease. So, whilst we have made very significant progress in understanding the development of various cancers, how to diagnose them and how to treat them, some have been more tractable than others. That is emphasised by the five-year survival that we see in ovarian cancer versus, say, breast or prostate cancer. Clearly, there is a real need for us to investigate in much more detail the biology of this disease and develop techniques that will allow us to make an earlier diagnosis so that women can be treated in an earlier phase of the disease. This would be a real advance.

CHAIR—Mr Vrisakis?

Mr Vrisakis—Thank you again for the opportunity to give evidence to this inquiry. I am the Chairman of the GO Fund, the function of which I have briefly described in my written

submission. I should perhaps have said in that submission that the mission statement of the GO Fund is beating gynaecological cancers. Unlike the gentleman to my right, I am not in the medical profession. I came to be involved in this cause because my wife had an ovarian cancer that fortunately was diagnosed at an early stage and was only borderline.

I came to realise through my association with Professor Hacker that the early diagnosis of ovarian tumours, from which my wife suffered, should not be fortuitous and it was in her case purely fortuitous. 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. That is the theme of my written submission to the committee and, much more importantly, other submissions to the committee provide, in my respectful submission, overwhelming support for that conclusion.

I want to add only two other short points. First, submissions to the committee, also in my respectful submission, provide overwhelming support for the establishment by the Australian government of a national gynaecological cancer centre not only by the substance of the authoritative submissions that you have before you but also by the medley of gynaecological cancer organisations that have made submissions. This highlights the need for unification and coordination through a national gynaecological cancer centre which should promote efficiency, economy and effectiveness.

My second point is that the 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. I am aware that this has been proposed by at least one other submission to the committee. The use of such a fiscal measure to promote desirable areas of activity properly within the competence of the Australian government has many precedents. You would be aware of course of the promotion of the Australian film industry through the use of such fiscal measures, of the encouragement of the purchase of productive machinery through accelerated depreciation rates and, somewhat closer to my heart—and I am not being facetious in saying this—of the encouragement of the Australian thoroughbred industry through providing a tax write-off for brood mares of 12 years of age or more.

CHAIR—I am interested in that correlation, Mr Vrisakis. We will not go there—it just leapt to my mind. I do apologise for drawing that to the committee's attention.

Mr Vrisakis—I hope I am not being facile in saying, as my final point, that it seems to me that if the government encourages greater funding from the private sector through giving increased tax deductions then that is more efficient from the government's point of view, because the government thereby forgoes only that part of the dollar that would otherwise have been paid in tax, as against the full amount of the dollar if it came from Treasury itself. Thank you very much for listening to me.

Ms Duncan—I thank you for giving me this opportunity as the newly appointed fundraising manager of the GO Fund.

CHAIR—Congratulations.

Ms Duncan—Thank you. One of the not only surprising but staggering facts that I have noticed in my new profession is that when I have approached the corporate sector for donations there is a widespread ignorance about ovarian cancer in particular and gynaecological cancer in general—half of them cannot pronounce it, as I have just had the problem.

CHAIR—Do not ask them to spell it.

Ms Duncan—No. This is not limited to men unfortunately. It includes powerful, highly intelligent and well-read businesswomen. Nearly every woman that I have approached has quoted the pap smear as the test that will predict if they have ovarian cancer. One, and only one woman, mentioned CA125, and as you would now all realise that is not a definitive test either. I think there is an almost 1950s approach to gynaecological cancer in this country. It is still attached to the mentality of: 'Let's put it under the bed. It is one of those cancers.' It is almost dirty, so people really do not want to mention it. Having had breast cancer five years ago, I realise there is a vast difference in the awareness and education between the two cancers—not to mention the survival rate.

I think this has a very important link to the mental attitude of the patient. Everybody you know has been touched in some way—a relative, a mother, a friend—by breast cancer. Over the past 10 or so years—thank God—a very positive spin to breast cancer has developed. From almost the very minute it is first diagnosed, people say: 'You can beat this. Look at mum. Look at Auntie Val, look at the girl down the road, across the river'—it is a positive attitude. As we know, this positive attitude is so very important for fighting cancer. But this is not so with ovarian cancer. It is not as common. There are not the reassuring facts and figures. The silent killer immediately creates more fear, more stress and in itself is more debilitating for curing ovarian cancer. Early diagnosis would enable treatment that could possibly bring our survival rate to a comparable par with breast cancer—which is 85 per cent, as we know. A high percentage of the money that we raise at the GO Fund goes directly to the Garvan Institute for the very purpose of finding a blood test that could be used as the basis of a screening program.

I will go back to the question of raising money. An attractive tax incentive scheme similar to the one which encouraged so many wonderful Australian films to be made in the seventies would be beneficial to our cause. I support the statement by my chairman, Aleco Vrisakis, and would like very much to see increased tax incentives for donations to cancer, which I am sure would encourage a policy of funding in the corporate sector. Having lived in the US for many years, it is really disappointing to see the lack of support from companies in this country towards not-for-profit charities, such as the GO Fund. We really need to stir them up, get them going and give them some incentive. Our mission statement, as you have heard, is beating gynaecological cancer. I hope that it will become a recommendation from each and every one of you, not only to beat it but to give us the stick, the money, with which to fund it—and beat it.

CHAIR—We will now move to questions. We are hoping to make it as informal as possible, but I remind senators, as I must—Senator Humphries, as you taught me to do—that we are on a time frame.

Senator FERRIS—One of the key themes that has come through all of our submissions not just from today but in all of the submissions, from Melbourne and Perth, has been the shortage of funds for research. Yet when you read the submissions many of them come from what appear to be well-meaning but diverse groups that are doing the same sorts of work. Given the scarce resources—which we have all just heard about and which comes through in the submissions—it concerns me the degree to which collaboration occurs between all of these groups.

I am very aware of the work done between the Garvan Institute of Medical Research and your hospital, Professor Hacker, but I notice that there are many Melbourne based research institutes. One popped up in the current issue of the *Women's Weekly*, in a great series of interviews—that is, a group which calls itself the Ovarian Cancer Institute. I have not seen a submission from these people; I do not believe we have one. Could you talk to me generally—any of you who want to make a contribution on this—about the degree to which there is even-handed collaboration between all of the groups using the scarce resources. Maybe I should start with Professor Shine and then Professor Hacker.

Prof. Shine—I fully endorse—I think we all do—your concerns that there is perhaps not enough collaboration. Of course, research is often driven by the researcher and a lot of innovative research has to come out of the individual researcher's own creativity, and there is a degree of competition in that. It is not restricted to ovarian cancer, by any means; it is across the spectrum of medical research. 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. Certainly the Garvan is very committed, as are most other groups around the country, to collaborating wherever we can. The collaboration is initially most important between clinical based activities, such as Professor Hacker's and the more laboratory based activities, as we might see at the Garvan, because there you can bring the new knowledge that you get about the molecules that are involved in cancer together with real patients, questions and outcomes.

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.

I know that is a long answer to your question and I apologise for that. I would just like to add that I think that major granting agencies, such as the National Health and Medical Research Council, are very aware of the issue of enhancing collaboration in order to be more effective and are putting in place different granting schemes and approaches to encourage that—for instance, by trying to put aside certain amounts of money to target schemes where you have major collaboration to compete in that scheme and by trying to bring those activities together. In a broader sense, we have seen that in this country with the cooperative research centre program, which has been running for many years across all aspects of science. I think that approach has slowly filtered down to most modern medical research. If you are going to be successful—and

we certainly like to think that we are—you have to be collaborative, have that critical mass and interact with your peers very closely.

Senator FERRIS—So the current plethora of institutes does not concern you?

Prof. Shine—It concerns me in that there could always be more collaboration. No-one wants to reinvent the wheel. Having said that, the funding is so competitive, nationally and internationally, that only those groups that are effective will, in a sense, be self-sustaining, and that drives a lot of collaboration. The other side of the coin is that, if someone has a new idea or something a bit way out, they have to be able to set up their thing and be a champion of their particular cause as well. But time will tell. They will be successful only if they can convince their peers that they are doing excellent research. That is not an exact answer to the question, but you need that balance.

Senator FERRIS—What concerns me, I suppose, are the scarce resources for all of the infrastructure costs that are associated with running a research team. Thank you for your answer. Professor Hacker, would you like to comment? Could you tell me whether you are working in any way with what appears to be the newly formed Ovarian Cancer Institute? It seems to be a Melbourne based group that is connected with the Royal Women's Hospital. Through the two hospitals, are you doing any work together?

Prof. Hacker—No, we have not. I had not heard of the Ovarian Cancer Institute until I read about it the other day.

CHAIR—In the *Women's Weekly*.

Senator WEBBER—Claire is keeping a tally on how often the *Women's Weekly* is mentioned.

Prof. Hacker—That is right. We do have some collaboration, but there is a national ovarian cancer project which was funded by the United States defence.

Senator FERRIS—Yes. Somebody has covered that in their submission, actually.

Prof. Hacker—That was a grant that the Queensland Institute of Medical Research received for a large sum, I think something like $2 million a year for three years. They are collecting information nationally and we are contributing patients and tissue—ovarian cancer tissue, blood samples—to that study. We will be able to use some of that tissue in research at the Garvan if necessary. So there is a degree of collaboration. We have had a collaboration with the Cedars-Sinai Medical Centre in Los Angeles, which is part of the University of California Los Angeles complex of hospitals. So there is certainly some collaboration going on. It would be nice to have more, and I think that that would be one of the functions of a national gynaecological cancer centre—to encourage and to bring stakeholders to the table and sit them down so that there could be some sense of common purpose.

Senator FERRIS—That leads me perfectly into this next question. How would you see that being structured? Currently it is within the national breast cancer grouping, and our submission from Dr Helen Zorbas shows the very good work that they have done. But I suppose it is somewhat puzzling that the National Breast Cancer Centre is doing this work—its title gives no

indication that it is actually working on other forms of cancer as well. I guess that brings up Carmen's comments about people's surprise about ovarian or gynaecological cancers generally. Would you see the work that the NBCC has done on, for example, the My Journey Kit, which is fantastic, being able to be moved across in an agreeable way to form your group? If that were to proceed, would there be an NBCC and then a similarly structured gynaecological cancers group? Is that how you would see it working, and would they cooperate, do you think?

Prof. Hacker—I think that is how I would see it working. They have set up an excellent model. There is no question about that. They have put a lot of mechanisms in place for advocacy and education in breast cancer, and I would like to see the same mechanisms and functions put in place for gynaecological cancer, because they have ovarian cancer under their control. Although it is not acknowledged in the name, it is presently under their jurisdiction. But of course there are other gynaecological cancers apart from ovarian cancers—cervical cancer, uterine cancer, vaginal cancer et cetera—that are also important cancers.

Senator FERRIS—And they are not covered within that structure?

Prof. Hacker—They are not covered within the current National Breast Cancer Centre.

Senator FERRIS—So would it be, do you think, an agreeable marriage?

Prof. Hacker—I think it is a model. I do not see it as a marriage, no.

Senator FERRIS—But, seriously, a lot of the work that has been done by the NBCC—and I emphasise: I think it is fantastic work—could be moved across to a new structure in, I would have thought, a pretty agreeable way. It is not as if it is competitive. One is the top and one is the bottom, you might say! I just wonder if there have been any informal discussions between you and them about that possibility.

Prof. Hacker—Not really, no. I think a true advocacy and educational group for gynaecological cancers would need to have a separate identity. I do not think that they want to change the name of the National Breast Cancer Centre and I do not see why they should change the name. It has a national brand now and everybody recognises it. They have done a fantastic job. But I think that we need the same recognition for the gynaecological cancers, because they are generally under-represented and underfunded.

If you look at deaths from breast cancer as opposed to numbers, there are about 2,594 deaths from breast cancer each year—I think that was 2001 data. But if you look at deaths from gynaecological cancer there were 1,480, so it is a significant proportion. Almost 60 per cent of the number of deaths from breast cancer occur from the combined gynaecological malignancies.

Senator FERRIS—That may not take into account some of the improvements in the breast cancer survival rates, because 2001 was a while ago and there has been some quite good work since then.

Prof. Hacker—Yes. We have seen very little improvement in the survival rate for ovarian cancer over that time whereas, of course, breast cancer survival has significantly improved. The group needs to be an autonomous entity but it should be modelled on the breast cancer model.

Senator FERRIS—Within the structure of Cancer Council Australia, do you think that would work satisfactorily?

Prof. Hacker—I would think that it would work very well. One of the problems in Australia, which has been identified in a lot of the submissions, is data collection—determining what data to collect and collecting it in a uniform way so that we can analyse our results and look at our trials. The FIGO group, the International Federation of Gynaecology and Obstetrics, each year publishes this annual report in which results from all around the world for all of the cancers are analysed. They have a data set. It would be very nice to be able to adopt this set nationally. We are introducing it at the Royal Hospital for Women in the near future. We have previously used the COSA data set, the Clinical Oncological Society of Australia, which several years ago groups decided to introduce but then, because of funding problems for data managers, it generally has not been performed nationally. We are going to introduce the FIGO data set so that we will be able to report our results to the committee, but it would be nice to have this uniform data reporting available around the country.

Senator FERRIS—I noticed the demographics that you gave in your submission on page 3. Is it likely that as the population ages an increase in gynaecological cancers will show itself? How does that fit with your comment on page 4 about the difficulty in getting gynaecological oncologists to adequately service the Australian population? Do you think that as the population ages you would expect to see more of these types of cancers? If so, what can be done to increase the number of oncologists?

Prof. Hacker—Certainly all of the gynaecological cancers increase in incidence with increasing age except for cervical cancer—it plateaus off. But uterine cancer, ovarian cancer and vaginal cancer all increase as age increases so yes, there will be a significant increase in the gynaecological cancers—except for cervical cancer, which with screening, of course, is being kept in check. The problem with country areas is that it is impossible to have a gynaecological oncologist in every town. The college originally estimated that there should be one gynaecological oncologist per half million of population. They have recently revised it down to one for 400,000, which means that in a country the size of Australia we should have about 48 or 49 gynaecological oncologists. We currently, I think, have 34 certified oncologists and there are another five or six in training positions.

For example, in our unit we provide an outreach service to the ACT. We go to Canberra once every couple of weeks and to Wollongong, and other centres go to other places. For major surgery patients have to travel to the big centres. There are centres in all capital cities except Darwin. There is no other realistic way to do it, because you need to assemble a multidisciplinary team of people in order to properly treat women with gynaecological cancer. Chemotherapy can be given in the bigger country towns. Radiation therapy can often be given in the bigger rural areas, but the major surgery needs to be done in the big centres. The pathology needs to be reviewed and the treatment plan developed in those major centres.

Senator FERRIS—Once we have had the opportunity to explore this proposed structure with some of our other witnesses, would it be possible to ask you if you could make yourself available on a telephone hook-up to come back and speak on any other issues that are raised by other witnesses in relation to this?

Prof. Hacker—Certainly.

Senator FERRIS—That would be terrific.

Mr Vrisakis—I want to speak in relation to Senator Ferris's question about the organisation into which a national gynaecological cancer centre could fit. Senator Ferris referred to Cancer Australia, which is a national body established by the Australian government in the budget 2005-06. It seems to me that it would be logical and beneficial to the causes that we have discussed—and by causes I refer to breast cancer as well as gynaecological cancers—if Cancer Australia could be at the head, with the NBCC and a national gynaecological cancer centre being coordinate bodies underneath it.

Senator ADAMS—An umbrella organisation.

Mr Vrisakis—The other thing I would like to say—and I hope not naively—is that to the extent that the Australian government establishes a national gynaecological cancer centre and funds it, the Australian government has a real say in the issue of collaboration because it is providing funding and an organisation which is going to conduct research.

CHAIR—Does anybody else have any comments on Senator Ferris's last question? I think it was a very general question, but it touched on workforce issues on the clinical side and the research side.

Prof. Sutherland—I want to return to the concern that the senator had in relation to diversity. I will make a couple of points. Senator Ferris, I want to get back to your concern about the plethora of different organisations that are doing research and their interactions. Firstly, there are some very good national collaborations that are working well. Professor Hacker identified the Australian ovarian cancer study, which is an epidemiological study that was funded out of the US. The comment to make there is that the fact that the US continually puts money into these sorts of epidemiological studies in Australia because Australia is best placed to collect this material—and because it cannot be done properly in the US—says something about the quality of the research that is conducted here. I think it is very important that we then capture the use of this material for our own ends and that it does not all just go back for the benefit of the United States. In addition to that, you have a submission from Professor Friedlander about the national trials group, which I think we would all endorse. There are models for other national clinical trials groups that have worked well, and this one should be supported.

The other point I would like to make relates to your concern about the lack of consolidation of resources and so forth. In New South Wales, through the new ministry for science and medical research and also through the Cancer Institute New South Wales, which is essentially modelling the plans of the ministry in the cancer area, there have been very significant decisions taken about hubs where research would occur and the consolidation of resources in infrastructure and expertise. I think this is essentially the model that is going to be rolled out nationally.

In our collaborations at the Garvan institute, we see this as the way to go and we totally endorse collaborative research. We cannot see that you can be internationally competitive in this country without that type of collaboration. We endorse it and we would like to see

mechanisms—fiscal incentives—that encourage it and bring people together to do more powerful research that requires the really expensive infrastructure, which we are able to provide.

Prof. Shine—It is an important point that you can only encourage this sort of collaboration; you cannot mandate it. There has to be an incentive to make it occur, otherwise it really is meaningless. Researchers can be very creative in pretending to collaborate in different ways to attract funding. There has to be a real encouragement to do it.

Senator FERRIS—I understand that the first group to discover the early test for ovarian cancer will have found the end of the rainbow, financially.

Senator ALLISON—Twelve or more years ago Australia had a national women's health policy, which just dropped off the agenda. Is this one of the reasons we find ourselves in the situation that we are in, where there are disproportionate amounts of money available for funding for women's health in various areas?

Prof. Hacker—We have not followed through very well, I think, on previous initiatives. That would be another reason to have a national gynaecological cancer centre—so that we can have policies and agendas that are agreed upon and followed through. While governments make initiatives but there is no peak body, they do not get followed through. I would like to refer to this year's presidential address at the US Society of Gynecologic Oncologists, and I can table this if you would like to have it. It was made by a woman called Beth Karlan, and on page 2 she says she would like to highlight some of the year's outstanding accomplishments. She talks about strategic alliances and partnerships that the SGO has formed with Capitol Hill and various other government relations committees. She says that the alliances and partnerships are positioning the society as leaders in the effort to increase funding for gynaecologic cancer research. She states:

> They are also providing new means for the SGO to aid in passing legislative language that directs the Department of Health and Human Services to establish a new program for education and awareness of gynecologic cancers.

I think that we need a peak body to do the same thing in Australia. The Australian Society of Gynaecologic Oncologists is very small and limited to gynaecologic oncologists—it does not have all of the stakeholders that are involved with gynaecologic cancer care and research—and I think is much too small to have any real political activity, but I think a national gynaecological cancer centre would fill that void. Beth Karlan also mentions that this year the Society of Gynecologic Oncologists have come out with four position papers, which I can also table. One of them talks about the SGO backing for continued research to identify accurate, reliable and effective early detection markers for ovarian cancer. They have also identified that as a priority area.

Senator ALLISON—What about Cancer Australia? How much interest has that organisation shown? I know it has just begun; I do not even know whether it is up and running, but have there been any discussions between you, RANZCOG or individuals about ovarian cancer or gynaecological cancer?

Prof. Hacker—I do not think gynaecologists or gynaecological oncologists have any representation on Cancer Australia, so we have not had any opportunity to have any discussions with them.

Senator ALLISON—As far as you aware they have not approached that sector?

Prof. Hacker—Not as far as I am aware.

Senator ALLISON—Thank you. One of the submissions I was looking at a moment ago says that 50 per cent of women diagnosed with ovarian cancer or other gynaecological cancers do not get adequate care and that it is unreasonable to expect GPs, even with the guidelines that are available, to do adequate diagnoses. If that is the case, how do we approach the question of diagnosis ahead of the universal screening which we hope is around the corner? If it is the case that only 50 per cent get adequate care—that is, by an oncologist gynaecologist—what happens to the other 50 per cent who do not? Who is caring for them? If they were all to be cared for by a gynaecological oncologist, doesn't that mean that we would need far more—unless you are all sitting around doing nothing—than the extra 14 such surgeons that the figure of one for 400,000 people would suggest is needed?

Prof. Hacker—If you had 49 gynaecological oncologists I think that would give each one a workload of something like 90 cancers per year, which is a perfectly reasonable workload for one individual, so no. I guess if they are not seeing all of the cancers then they fill their day by doing some general gynaecology, colposcopy and other things. Ideally, we would like to see them treating gynaecological cancer, which they are trained to do. Who treats the other patients? General surgeons sometimes, particularly in country areas, gynaecologists, sometimes GPs—

Senator ALLISON—Did you say GPs?

Prof. Hacker—From time to time anyway they may feel that palliative care is the only thing available to patients, particularly with advanced ovarian cancer. Whereas, if they were seen in a cancer centre, much more aggressive management would be given and there would be much greater prolongation of life, of course. But one of the issues is that the existence of the subspecialty of gynaecological oncology is very poorly understood by women themselves. If you asked the average woman on the street whether she had ever heard of a gynaecological oncologist, she would say no. One of the reasons for, or one of the functions of, a national gynaecological cancer centre would be to promote the existence of this group of doctors. After all, it is a three-year training program, at the end of which there is an examination and a certificate, and that certificate has to be recertified every three years.

Senator ALLISON—Professor Hacker, if I could just interrupt you for a moment, how reasonable is it to expect that patients of any sort really, women or others, know the subspecialty that they ought to be being treated by? Is it not a lot easier to get directly to GPs, who would normally be the referral agents?

Prof. Hacker—Yes. I think the GPs do know about it. At least they will usually send patients to gynaecologists who certainly know about it. If women knew of the existence of gynaecological cancer centres and gynaecological oncologists there would be more consumer demand to go to the right place. Anybody who has cancer will want to go to get the best

treatment if informed that there is a better treatment centre available. If you put to women, 'Do you want to have your treatment locally or do you want to go to Sydney or Melbourne?' of course they will say locally. But if you say that the best treatment is available in Sydney, Melbourne, Brisbane, Perth or wherever, then they will almost certainly choose to get the best treatment.

Senator WEBBER—It never ceases to amaze me that in the year 2006 we are still grappling with the issue of collecting data, but perhaps that says more about me than the challenges that are out there.

I want to look at the flipside of what Senator Ferris was saying. For one, I have learnt a lot in the brief time we have been doing this inquiry—perhaps not as much as my colleague Senator Humphries, but I have certainly learnt a lot and can appreciate what Ms Duncan says about the widespread ignorance, because it is amongst us sitting at this table as well. But, on the flipside of what we were saying about the need for a national centre and more money, what happens if we do not do that? Looking at the disease burden that gynaecological cancers are on women in Australia, what is the thread and where will it leave us if we do not act?

Prof. Hacker—I think we will go forward in the manner in which we are going, which is a whole lot of centres working in isolation.

Senator FERRIS—Hopeless.

Prof. Hacker—I do not think that we will have the incentive or the initiative to get together and collaborate.

Senator WEBBER—It is really time to make that step and that leap forward. In terms of the GO Fund and the representations you are making about tax deductibility and what have you, from a fundraising point of view, how important is it, therefore, that the government takes the first step and actually puts the money in and establishes something like a national centre, which I personally support? Do you get a sense that we would not be more likely to get that philanthropic approach from the corporate sector if they saw it as a government supported enterprise?

Ms Duncan—I think, at the end of the day, it all comes down to money, doesn't it? If the corporate sector think that they are going to be able to get a tax write-off to give $100, they are going to go for it. Those are the facts. The other side of the coin is that we are supporting cancer. It is a tax incentive to support cancer, and everybody is affected by cancer. It is not a tax incentive to support the thoroughbreds, or the cinema or the actors. It is to support cancer, so one can feel philanthropic about it as well as put the money in the pocket, as it were. That is my feeling. Also, I think we in this country really need to start encouraging that philanthropic mindset that we have never had. Individuals are fantastic, but we need the companies, the corporates, to now start taking some of the burden, and I think this is a very good way to do it.

Mr Vrisakis—May I add something to that, Senator Webber. I think people who are asked to donate money, be they individuals or a board of directors making an allocation of the company's funding for charitable purposes, want to know that the money that they are giving is going to be well spent. I hope you would not gather from what I said earlier that they are so cynical that the

availability of the deduction would be the prime motivating factor. I believe that the deductibility of the donation is a very powerful financial incentive, but the people giving want to know that the money they are giving—because it is out of their pockets to an extent—is going to be effective. Therefore, in answer to your question, the establishment of a national gynaecological centre, which palpably will improve the cause of research and the course of research above that which exists now, will itself be a very powerful factor in stimulating greater donations from the private sector.

Senator WEBBER—That is the kind of thing I want on the record.

Prof. Shine—If I could just add, it has certainly been our experience with philanthropic donation, both at the Garvan and perhaps nationally too, looking at the NHMRC, that donors are very concerned with ensuring that their donations are going to real research which is legitimate, competitive and internationally recognised. That is where government can have a role, because they control the National Health and Medical Research Council, the whole peer review process. But donors are also very interested in getting leverage for their investment. The NHMRC has found that, if they put $5 million towards a diabetes research initiative and that is matched by the Juvenile Diabetes Research Foundation or some other philanthropic group of concerned supporters, then everyone seems to win. They get the competitiveness, the analysis that this is real research, and both the government and the philanthropic community feel that they get leverage for their funding. That seems to be something which works very well across the spectrum of medical research activities. If you want to have a new initiative to encourage a particular area of research and you can provide some government support, but only dependent upon some matching philanthropic support, then it seems to get everyone on side.

Senator WEBBER—Finally, because I know others have some questions, in relation to the NHMRC, when we had the initial hearings in Canberra, I learnt a couple of interesting things. Probably like most women in Australia, I presumed that the Breast Cancer Centre dealt with breast cancer, so that was an interesting learning experience. But I also got the distinct impression from the NHMRC that they actually thought that they were making a significant contribution to research in this area and that it was all going very well. So obviously there is room for improvement there, if any of you would like to comment.

CHAIR—Has anyone seen the *Hansard* records?

Senator WEBBER—They seemed to think that they were spending lots of money on this.

Prof. Shine—The NHMRC, as the nation's primary research funding body, is spending significant amounts of money on research in general. With the recent government initiatives to increase that budget, that is going up. It is a little difficult to analyse, because the NHMRC funding is primarily what is called investigator driven and is primarily judged upon the excellence of the research proposals. Many times, many of those proposals are not specifically, for instance, in ovarian cancer research but are in research into fundamental mechanisms of cell biology that are very relevant for understanding things like ovarian cancer and other cancers. You can categorise it in many different ways, but fundamentally the NHMRC funds an underpinning research activity about basic health and biological processes, on top of which specific initiatives can be put in place in particular diseases. That varies from time to time depending on community and government requirements. Perhaps I am not describing that well.

Senator WEBBER—Then you can claim that you are actually making a significant contribution to everything.

Prof. Shine—I believe they are making a very significant contribution to everything, but what is often required is that, 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 there, and a little extra support targeted to that will produce a lot of outcomes.

Senator WEBBER—And we are at that point now?

Prof. Shine—I believe we are at that point now with ovarian cancer. It is a pity Senator Allison is not here, but I want to make a quick point about the issue. I do not believe it is a men versus women issue in priorities here. If we were talking about prostate cancer, you would have the same reaction from men. It is more a whole bunch of other sorts of things to do with, basically, community understanding of the disorder.

Prof. Hacker—Can I make the point that the major cancers in women are breast, colorectal, melanoma, lung, non-Hodgkin's lymphoma, cervix, uterus and ovary. Of those cancers, the only two that have a survival rate of less than 50 per cent are lung cancer and ovarian cancer. There is a very simple message about lung cancer: don't smoke. There is no simple message that you can give to women about ovarian cancer. There is virtually nothing they can do. Taking the contraceptive pill is the only realistic thing that is of some help, but they are still going to get ovarian cancer and it will still most likely be at an advanced stage when it is diagnosed.

Any dispassionate observer of these statistics would have to conclude that there is an urgent need to direct specific money to developing a screening test for ovarian cancer. When it is diagnosed in its early stages, it can be treated with surgery alone; it does not even require chemotherapy in many cases, and it has a high survival rate. So I think that you would have to say that the time is right to direct specific money towards a screening test for ovarian cancer. Having sequenced the human genome—and Rob can explain this better than I can—we are now in a situation where we do understand much more about the mechanisms, and I think it is a realistic thing to look. It is not quite like looking for the needle in the haystack. That is what research was like in this field before the human genome. Now we know specifically what genes are involved and abnormal in ovarian cancer patients, and I think it is realistic to think that a screening test can be developed.

Senator WEBBER—Professor Sutherland, did you want to add anything?

Prof. Sutherland—Not a lot to what Professor Shine and Professor Hacker have already said. John's point is correct: the NHMRC do take this broad view. I think if you searched their database for specific grants that said 'ovarian cancer' then another case could be made that perhaps there is not enough in that area, and that would be the same for several other cancers. The reality is that, despite the fact that we have quite a lot of money in the NHMRC budget, we could do with more.

I guess the other point is that, because of the sort of knowledge base that has developed, there are lots of opportunities now for this sort of translation of some of this basic knowledge into

applied outcomes, if you want to use those terms. We are in a situation now where we can theoretically develop screening tests or identify molecules that will identify the disease in its early stages, and we also have the ability to develop new treatments, so there are real opportunities there. It is a good time to make an investment. That is all I have to say.

Prof. Hacker—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 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.

Senator ADAMS—With your indulgence, I have just a few comments. I did not butt in on my friend Senator Ferris, but as a midwife and someone who has been a member of the Women and Infants Research Foundation in Western Australia and the Princess Margaret Hospital for Children Foundation, I am certainly right up to speed with the problem with fundraising. But I have some very good news from Western Australia. Finally, after fighting tooth and nail with every other research foundation in Perth for funding, we now have the Western Australian Health Research Institute. They have all decided to join together to form two research hubs.

Western Australia is undergoing quite a large health reform, as most states do, but we are going to end up with a southern health campus and a northern health campus, one on one side of the river and one on the other. The proposal is that the state government has put up $200 million for two research hubs, one situated at Sir Charles Gairdner Hospital and one at the new Fiona Stanley Hospital at Murdoch. At our Liberal Party conference at the weekend, we passed a unanimous motion that $180 million be asked for from the federal government.

Senator WEBBER—This is sounding alarmingly bipartisan, Judith!

Senator ADAMS—Yes, I know. It is a huge breakthrough because once again, just from what Ms Duncan said, the fight to get funding for research is just terrible. And having someone like Fiona Stanley in Perth, it is really difficult to undercut her. We have the University of Western Australia, the Western Australian Institute for Medical Research, Fiona's Institute of Child Health Research, and the Lions Eye Institute, and then the others are all coming in under that umbrella, so it is just huge for research. I am really excited, because gynaecological cancer will come under the Sir Charles Gairdner Hospital or Queen Elizabeth II Medical Centre. That is where King Edward Memorial Hospital and Princess Margaret Hospital will both end up, which is really good.

The second thing I would like to say is as a consumer rep for Breast Cancer Network Australia. I have told Jeannie, but I could not really let go that the My Journey Kit was developed by Lyn Swinburne and her group, and I actually had quite a lot of input into that. It is a fantastic thing and Lyn has agreed that Margaret Heffernan may have the property to develop the same thing for gynaecological cancer. That is a huge step forward. We just have to get the program funded, which we will try to do.

Senator FERRIS—It just needs the money.

Senator ADAMS—Professor Hacker, you are probably aware I come from a rural area. I have had breast cancer. I had to spend eight months in Perth having radiotherapy and chemotherapy, so the patient assisted travel scheme, or your IPTAAS scheme, is probably one of my biggest bugbears. Even though it is a state issue—it was handed over to the states in 1987—I am trying to get a Senate inquiry to look at all the different schemes and to see where we can go, because rural women, especially those with gynaecological cancers, are missing out badly. Our Indigenous population have real problems.

GPs in the country, especially in rural Western Australia, are becoming a rare commodity. What probably annoys me the most is that you will have a GP proceduralist who is the nearest specialist, therefore you will be sent to a small regional town. I am not knocking the people there. These people do their best, but why should rural women be denied going to an expert in Perth? It is really getting to me because so many of my friends have been diagnosed far too late and unfortunately they are not with us now. That is my thing, and I am very pleased to see what you have written here. Firstly, would you give evidence at a Senate inquiry if we get one up on patient assisted travel schemes? That is my first question to all of you.

Prof. Hacker—Absolutely. The IPTAAS form in New South Wales says, 'Is an escort required to be with the patient?' and 'Give a valid medical reason why'. The fact that the woman has cancer is a valid medical reason.

Senator ADAMS—Yes, but they will not wear it.

Prof. Hacker—You do not need anything more than that. 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.

Senator ADAMS—They will not take in psychosocial, this is the problem. I was in the Northern Territory speaking to the PATS clerk up there, and they have an issue that is causing a big problem in that a white person being sent to Adelaide or to Brisbane for further investigations—not just for cancer, but for anything—is not allowed an escort, whereas an Aboriginal person is. So we have this little thing going on up there, and they are having a dreadful time because people feel they are completely discriminated against. The case of escorts is huge. The other thing of course is the cost of travel; a lot of people are not travelling.

Prof. Hacker—The cost of travel, and having somewhere to stay once you get to the city. You have to have reasonably cheap accommodation for these patients. It is impractical to admit them straight to hospital. You need to see them; you sometimes need to do investigations, so they need to be able to come to the city for two or three days before their operation. Hospital administrators these days 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.

Senator ADAMS—Just in Perth alone, there is a seven-week waiting list at Crawford Lodge. It is a motel complex set up to take 64 country patients, but there is just no hope. We are trying to raise funds to get another facility built. They get a $35 subsidy, and $150 per night would probably be the minimum charge for accommodation anywhere else in Perth, and it is not just for one night.

Prof. Hacker—Yes. You could also get patients out of hospital a lot earlier if you had a step-down type facility, a cheap facility close to the hospital where they could stay. I think this is seriously lacking in the management of cancer patients.

Senator ADAMS—Psychosocial support is the other thing that is very difficult in a rural area. The other issue I would like to raise is lymphoedema. It is not just a breast cancer problem; it does occur in people who have had gynaecological surgery. Could you comment on the availability of physios taking up lymphoedema treatment in your state?

Prof. Hacker—There has been a significant increase in the availability of lymphoedema services in the major cities, but that certainly does not extend to the rural towns. 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. Infra-red scanning laser treatment has become available recently but, again, that is in the major centres. So there needs to be the opportunity to bring patients to the city for that treatment. Certainly physiotherapy skills are available in country towns. Those physiotherapists probably need to be specifically trained in lymphoedema management because it is a major problem with breast cancer as well as with the gynaecological malignancies.

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.

A lot of the psychosocial support, and often the palliative support, is a matter of giving appropriate information and giving helpful advice—being able to reassure women that the symptoms they are experiencing are not due to the cancer and then having a liaison back with that centre so that, if something arises where there is need for referral, she can call the relevant person in the centre, be it the gynaecological oncologist, the psychologist or the chemotherapy nurse. They would know her and she would know them. That is probably going to be the best way to deal with this problem of the lack of psychosocial and palliative support in rural areas.

Senator ADAMS—I come to my last question, which follows on from that. Now that a lot of the divisions of practice have practice nurses within their practices plus a multidisciplinary team, do you see that we could perhaps build on that? Rural GPs have to be everything to everyone and even their diagnosis is very difficult. The other thing that I would say is that, in breast care nurses, we have got a number of people trained to go into rural areas and perhaps they could double their role. They are dealing with the lymphoedema side of things plus the psychosocial side of things with breast cancer. That may be a way forward, because nurses in rural areas are a fairly rare commodity too. I wonder as to the divisions whether it might be a breakthrough to try to put with them the gynaecological cancers with a higher profile.

Prof. Hacker—It may well be. I do not know. GPs in country towns are so busy that I do not think they would have the time to focus on it, but maybe their nurses would. As for the breast nurses, it depends on how busy they are and whether they are fully occupied dealing with breast cancer patients. If they have got some discretionary time, certainly they would be a good group of nurses to bring to the gynaecological cancer centres to get them familiar with the issues involved there. But I think it takes time to become familiar with those issues. I think they have to go there for at least three months. I do not think you could do it in two weeks, because they would have to work around all the various multidisciplinary teams within the centre to understand the issues of lymphoedema, the issues of sexuality, the issues of menopause and infertility—all of the issues that occur with the gynaecological cancers—and the symptoms of the diseases and the symptoms of recurrence. All of those things are going to come up when you are alone. I think that one of the things that country patients feel is a sense of loneliness, in that nobody out there in their community has any idea about their particular condition. Our nurses in the city are frequently rung by these patients and are able to allay their anxiety over the phone. They feel that there is no-one in their own community that they can talk to. A nurse, particularly one who has had some oncology experience and who has then come to the city centres and understands the nuances of gynaecological malignancies, would be a very powerful resource for those country women.

CHAIR—Senator Adams has got her free, not paid, advertisements in.

Senator ADAMS—I thought I was restrained in not promoting Western Australia.

Senator HUMPHRIES—I want to follow up the questions that were asked of Professor Shine about the competition between different areas of medical research in Australia and how well we allocate between those different areas. Obviously, there is an overlay of what non-government fundraising actually produces and what governments may allocate in particular budgets in terms of areas of perceived priority. But, at the end of the day, do we get right the division of that pie between areas depending on actual need? If so, should we particularly restructure NHMRC processes to address that better? Should we do a matrix of some sort that takes into account the number of potential beneficiaries and a cost-benefit analysis of further research in that area to work out what actually are the areas where those dollars should be going?

Prof. Shine—That is an extremely good question, but it is an almost impossible to answer one in the sense that there are so many factors that come into play there. They range from the reality that in the public fundraising arena—my colleagues may disagree with me—by and large it is much easier to raise funds for research on issues like breast cancer and issues to do with children's health than it for issues surrounding, say, osteoporosis or diabetes, although these tend

to change with time and with public awareness. So there is a big differential between what the public are prepared to support and what the actual cost burden of the disease to society may be, and that varies a lot.

Within the other big variable I tried to touch on earlier was just where we are in a worldwide sense in research on a particular disease area. We all go through periods of time where research is building up, but it is frustrating; not too much is actually happening. Then we will reach a certain point in a research sense where there is a sudden insight into the disease, and new funds at that point in time can be very effectively applied to provide outcomes. All of those factors come into it. The NHMRC tries continuously to evaluate where research opportunities are in relationship to the cost to the Australian community of that particular disease or disorder, but fundamentally it is driven by the excellence of the research and this whole issue of competitive peer review funding. The philosophy has been there for many years—and it is the same across most of the Western world—that if you fund the very best research, at the end of the day that is going to give you the best outcome.

On top of that, there is always the government intention—and it is a very legitimate to put extra money into particular areas of research which the community believes are undersupported at that particular point in time. But it is really that complex mixture to make sure you have a strong base where you are funding the best Australian research based upon what the researcher is putting forward and as judged by his or her international peers coupled with an appropriate balance of : 'Yes, this is an area that needs funding because it is underfunded,' or 'This is an area of particular concern to the community.' It is just a dynamic, evolutionary sort of scenario. By and large, from my perspective, Australia does very well. The processes are very transparent, the arguments are very well put, and I think we do very well. But it is never perfect, because it is a changing scene.

Senator HUMPHRIES—So in calling for more funding you are calling for an enlargement of the pie, in a sense, not so much saying we should change the funding parameters to leave more for your particular sector?

Prof. Shine—The fundamental pie, which has been recently enhanced by the latest federal budget—as a researcher, there is never enough money, but on an international scale, we are doing okay, and I think we are getting good return from that—really should be for the core research activity of the nation. On top of that, we do need at times special initiatives where we believe there is a great need or there is a great opportunity. I think, as you heard from others here today, that the need is certainly there for ovarian cancer. With the Human Genome Project and the knowledge base we are accumulating at present, the opportunity is there with ovarian cancer to put some extra resources in.

Prof. Sutherland—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.

Prof. Shine—That is a very big point. You see many other well-organised community groups—and I have mentioned before the example of diabetes; Diabetes Australia and the Juvenile Diabetes Research Fund—and by putting some core catalytic dollars into the research pie, as Rob correctly says, we will encourage researchers to begin their careers in that area of research. They will then be very competitive across the broad base of the NHMRC and what you will see is an increase in research activity in that particular discipline.

Prof. Hacker—The research returns for breast cancer have been great, because we have now got an 85 per cent survival rate for breast cancer. But for ovarian cancer we are talking about a 40 per cent survival rate, and we have to do better in that field.

CHAIR—Professor Hacker, just before you go I will ask whether anyone has any further comments. But I would like to get some particular information. You mentioned earlier the issue of data collection. Through the cancer inquiry the issue of standard databases and effective collection of data came up consistently, in just about every hearing we had. You mentioned your intention to change the basis of the data that you are going to be collecting. You talked about the annual report. I will put the question on notice, because I am sure that there is a fair bit in the answer to this about the cost of changing the basis of the data from one series of collection to another and the standardisation of that. You are saying that your group is moving to this particular database, but that does not necessarily mean that all the other people who are collecting data across Australia are doing the same thing. Also, how do they interrelate? If you are collecting data under this model and people are continuing to collect data under the COSA model—which I know many places in Australia are—do they talk to each other?

In the cancer inquiry we heard consistently that different states had different forms of data collection, and they were just beginning to talk to each other. That was one of the more confronting things that came out of that inquiry—that we are busily working hard, all with the same passion and the same desire, but the information we are gathering is probably not at the optimum level. Do you want to have a go at responding to that now, or is it better to take it on notice? It seems to be an ongoing issue.

Prof. Hacker—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. As I said, there is an international report that comes out every three years. It is called an annual report, but it is really a triennial report of results around the world. 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.

CHAIR—Would it cost much to change so that all the various groups in Australia use that model? Would there be resources implications of that?

Prof. Hacker—I do not think there is a tremendous cost to change. The problem is that people do not have data managers, so they are not collecting any data for the most part. When I set up that unit at the Royal Hospital for Women in about the late eighties, we got an enhancement grant from the then Greiner government. Peter Collins was the health minister. We got something like $2.5 million annually of recurrent funding to set up a model unit, and part of that funding was for a data manager. So we were lucky, but most other groups have not had the opportunity to get funding for a data manager. They have done it themselves or they have done it in a sort of ad hoc way; but in general they have not been able to consistently collect data. Our data manager now has something like 5,000 or 6,000 patients on the books, and of course it is very difficult to keep the follow-up going for that number of patients. She is funded half time; she really should be funded full time in order to keep the database up to date. We can enter new patients, but following up the old patients is very difficult because of the manpower problem.

CHAIR—Is it possible to get some supplementary information from you about the issue of data management and data collection? You have mentioned it in the inquiry, but I actually have a particular passion as a result of the cancer inquiry on that segment of the whole basis, so it would be very useful to get some more information on that threshold issue.

Prof. Hacker—Yes.

Senator ALLISON—I am wondering, Professor Sutherland, whether you would like to indicate what level of funding should be available for research, both clinical and laboratory.

CHAIR—If you choose to.

Prof. Sutherland—How much money do you have? I think these are very difficult questions to answer. John and I were surmising about this when we were coming down. You might have seen some of the other initiatives where particular money has been put aside. The reality is that the cost of doing these things these days, whether it be setting up a trials group, which is one of the things that has been suggested, or doing that high-quality laboratory based research, has become very expensive. To make an impact I would have thought something in the region of about $10 million per annum would be something that would be required to move the thing forward in any sensible way.

CHAIR—Is that recurrent?

Prof. Sutherland—Yes.

Senator ALLISON—Is that just clinical or for both laboratory and clinical?

Prof. Sutherland—I would have thought across the board at this point in time. But I have not costed it. I am just plucking that.

Senator ALLISON—And from what we know, what is the current level of funding?

Prof. Sutherland—We do not know that. That is an issue. The reality is that we know what some of those bigger grants that have been funded from outside of the country were. So, for example, that which Professor Hacker alluded to—the Australian Ovarian Cancer Study—which

was funded by the US Army's ovarian cancer program, I believe was $2 million per annum. All that funded was the collection of something like 1,000 women with ovarian cancer and 1,000 controls. There is not a research component on that, to come back and actually use those samples. I stand corrected, but my understanding was that that was purely for the collection process and storing of the material and collecting the data. For them to now go on and actually use that resource to do additional experiments is add-on.

Senator ALLISON—I was not able to follow this up in my questions, but I was amazed about what you said about Americans coming here and doing study. Why is it not possible for them to do the same kinds of trials in the US?

Prof. Sutherland—This was an epidemiological study. They have funded several. Graham Giles and John Hopper in Melbourne have been funded for breast cancer, prostate cancer and colorectal cancer studies—in these cases, control studies and population based studies. I think a lot of it is to do with the American rules on privacy and also the fact that most of the American system is done in the private sector, so it is much more difficult for them to identify individuals and collect the data.

Senator ALLISON—It is amazing.

Prof. Sutherland—Plus the fact that Americans move around a lot more. Our populations in Australia are much more stable. It is perhaps easier here to get patients into cohorts and follow them longitudinally. That is the history of what has happened here. It is a reflection, I think, of, particularly in the earlier days, the quality of our teaching hospitals, the quality of our medical research and our ability to accumulate data in this country, which to some extent has been compromised by the changes in health care system. There are not so many clinical academics and so forth these days. That is my understanding.

Prof. Shine—As Rob says, the evidence is there. Rob and his group have been very successful, as have other groups, in competing with the US and US researchers because of the excellence of the research but also because of this ability to interact with an excellent public health care system. The records, the interaction and the databases are there.

Prof. Hacker—Many more women with gynaecological cancer, for example, are treated outside of cancer centres in the United States than here. It may be 50 per cent but I would think it was better than that in Australia. You quoted 50 per cent and you might be right. But much less than that in the United States get sent to cancer centres in the first instance. There are so many medical oncologists in the community and so many gynaecologist surgeons that it tends to be very decentralised in the United States.

Senator ALLISON—To be clear, are there no gynaecological oncologists in the private sector in Australia?

Prof. Hacker—No, most gynaecological oncologists do work in the private sector.

Senator ALLISON—But they also all work in the public sector. Is that correct?

Prof. Hacker—For example, at the Royal Hospital for Women, we do public and private patients in the one centre under the one roof. You can have a private room or you can have a two-bed room. But I do not move outside. I do not go next door to the Prince of Wales Private Hospital. I do not go to St Vincent's Private Hospital. All of the patients whom I treat are treated at the Royal Hospital for Women. That is true of many centres in Australia.

Senator ALLISON—Can you compare that with the United States? I am still not quite clear about how it is so different there.

Prof. Hacker—There are a lot of medical oncologists, for example, in private practice in the United States. What would typically happen with a patient with ovarian cancer is that she would have an operation done by a gynaecologist. It would be an inadequate operation. She would be then sent to a medical oncologist in private practice who would give her the appropriate chemotherapy, but with an inadequate initial operation. Often it is not until she has relapsed one or two times that she is sent to the academic centres where she becomes, if you like, available for statistical research.

Prof. Sutherland—It is really quite different to our system. We can trace, following informed consent, every patient who goes through Neville's unit. They are identified and their tissue goes to one pathologist. That information can be put on their database and come through into our databases. We take the tissue and do further development of those things. So it is much more streamlined here, and it does give us a competitive edge.

Prof. Hacker—I worked at the University of California, Los Angeles, for 8½ years and was the director of gynaecological cancer there for the last two years. The biggest single difference between working there and working here is the number of primary patients that we see here. I rarely saw a stage 1 ovarian cancer in the United States. I saw all the recurrent cases, whereas here I am referred patients with pelvic masses that I can operate on. We do not even necessarily have a diagnosis of ovarian cancer. We have to do an operation to make a definitive diagnosis. So although, yes, things could be better, they are much better than they are in many parts of the world.

CHAIR—We are at the end of our session, but I am keen, if there are other questions, for people to have the opportunity to put them on notice or to ask them.

Senator FERRIS—I have one question on something we have not explored—and this may be a difficult question to answer because you may not differentiate—that is, the extent to which women of non-English speaking backgrounds and women from Indigenous areas rate more highly in the statistics because of their reluctance, perhaps for cultural or language reasons, to seek treatment for symptoms. We have not touched on it, although you have touched on it in your submission, Professor Hacker. Is there any comment that you would like to make about that?

Prof. Hacker—I did work for three years in rural Queensland. It was for five years, really, but it was for three years in Far North Queensland, in Atherton. I was recently on a holiday in Bamaga, which is a Torres Strait island settlement. I spent a couple of hours at the hospital there and met with a woman called Doreen Stone, who is the sexual health worker at Bamaga. I asked her about attitudes to pap smears and problems that they have.

I also spoke to a couple of the young doctors at the hospital, who said that 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 a reluctance among Aboriginal women to have a pap 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. She said that, if they are going to run into you in the supermarket that afternoon, they do not want to do it. She said there are five settlements up there, all essentially within 10 minutes drive of each other. She was the only one qualified to take pap smears, apparently. She felt that, if there were people from other communities who worked in a different community, there would be much less reluctance to have pap smears.

The other thing she said was that they were happy to come up with sexually transmitted infections, because the testing for those is self-testing. They do not have to be examined. They self-test for chlamydia, gonorrhoea or whatever. It is possible to self-test for human papilloma virus. I think that 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.

I have brought with me three papers from magazines that came across my desk in the last couple of weeks, just while I have been thinking of the inquiry. One is *A report on the current status of European research on the use of human papilloma virus testing for primary cervical cancer screening*. There are a number of centres over there doing research on this issue. We should be doing more. I think the government needs to address this area of cervical screening, because we are still doing conventional pap smears every two years. I do not think we need to do them every two years. A lot of new technology is available now, and I think we should be doing the research needed to show whether they have a place in the Australian context.

Senator FERRIS—What about women of non-English speaking backgrounds who present at your hospital? Have you noticed any trend in reluctance by those women to discuss gynaecological cancers? How do they manage their cultural difficulties? Does that flow into treatment options and success rates?

Prof. Hacker—They certainly are more reluctant. Islamic women, for example, often defer to their husbands. We have a very good psychologist, whom we get to help on those sorts of issues. Our nurses are all familiar and skilled in counselling these women about treatment options. We do not have the same diversity of culture as there would be, for example, at Westmead and probably at Royal Prince Alfred, but we still see quite diverse racial groups and there are issues. We have a good interpreter service; we are able to access interpreters well. But those women certainly do have different attitudes from Western women.

Senator ALLISON—Just to clarify self-testing, is this a process which uses a tampon which is then sent off to a laboratory?

Prof. Hacker—Yes.

Senator ALLISON—How would that be managed? Would that be a GP arranged process?

Prof. Hacker—It could be through a GP; it could just be through a pharmacy.

Senator ALLISON—But there is no system at present to allow that?

Prof. Hacker—There is no system at present, no.

CHAIR—The committee is due to report by 19 October, so there is time to put supplementary material before us. Please do so, because we need to get as much information on record as we can. Would anyone like to make a final comment?

Prof. Hacker—We thank you for the hearing. A lot of important points have been made. The need for specifically directed funds for ovarian cancer research is fairly apparent. The point that Rob made about the flow-on effect that that has and the success that has been achieved in the breast cancer field is very impressive. We have a lot of good things going for gynaecological cancer in Australia. That came out in the example of the American experience. Gynaecological cancer is not even recognised in many parts of the world, so it is not that we do not have a good thing going, but I think we can make it better if we have a national gynaecologic cancer centre to harness all the expertise that we have here and coordinate the effort.

CHAIR—We appreciate your giving us your time this morning.

Proceedings suspended from 10.47 am to 10.59 am

FORTESCUE, Mrs Lisle Frances, Private capacity

WAIN, Dr Gerard, Former Co-chair, Gynaecological Oncology Service, Greater Metropolitan Clinical Taskforce

ROBERTSON, Ms Rosalind, Senior Psychologist, Royal Hospital for Women

HOBBS, Ms Kim, Social Worker, Westmead Centre for Gynaecological Cancer and member of Psychosocial Support Project

MILLS, Ms Jane, NSW Coordinator, NSW Psychosocial Support Project, Gynaecological Oncology, Westmead Hospital

CHAIR—I know that you have information on parliamentary privilege, the protection of witnesses and also the rules that surround private and public evidence. If you have anything you would like to say in a private capacity, please let us know and we will consider that. We have submissions in front of us from your project, from Ms Robertson and Mrs Fortescue. Ms Robertson, we were under the impression that your submission was a confidential one, but we believe it is now a public document. Is that right?

Ms Robertson—Yes, it was an error on my part.

CHAIR—That is fine. For the record it is important to have that clarified. We have your submission in front of us. You have seen the way the system operates. Senators do come and go, so please understand that that is how it works. I know that you have opening statements, so who is going to give them?

Mrs Fortescue—I will go first as a survivor. In my submission on page 2 under the heading 'What were my symptoms?', I state:

I was diagnosed in March 1998. In the previous October 1997 I had undergone my regular pelvic check-up and Pap smear. No problem.

Well, there was a problem but there was no means of knowing it at that stage through examination. The check-up took place at the Royal Hospital for Women at Randwick in the menopause clinic. I had first attended this clinic in 1980 at Paddington. An important aspect in any medical examination is that the person is experienced in the particular field under review. This doctor was a physician specialising in menopause and related gynaecological matters. Therefore, she was examining women daily and looking for unpleasant visitors. She always carried out a pap smear and ensured that I had regular mammograms. 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, A submission from the Curtin University School of Public Health mentions modifying lifestyles to reduce the incidence of ovarian cancer. I completely reject this proposition. If it was as simple as breastfeeding my son, drinking green tea or eating fruit and vegetables, I would not be sitting here today as a survivor. A diagnostic blood test for ovarian cancer is big-picture medical research. We are a wealthy country but, above all, we have the people, as you have seen with Professor Hacker, who, if provided with the necessary funds, will find the answers.

I believe that because of the human genome project in 2003, it is now only a matter of when not if. But, as Professor Hacker states, 'It is a matter of hands on the job and these technicians cost money.' As a result of this inquiry, this is the most important message which must be submitted to the parliament. It is essential that funding for the big picture is encompassed and that not merely token funds be provided to look as though something is being done.

Historically, gynaecological problems are unmentionables—'women's problems' as they have been known for generations of women. On questioning a group of variously aged women last Friday as an exercise for today, none of whom I knew, they knew nothing about ovarian cancer—as was my case. One 78-year-old woman even mentioned the words 'women's troubles'. If you look at the CWA New South Wales statement, on page 6 it states:

In many cases older country men would know where all the gynaecological parts on their sheep, cattle and horses are—

CHAIR—That was my favourite submission; I loved that one.

Mrs Fortescue—I see you have all read this. It continues:

... but would baulk at discussing similar organs in their women, and probably not even know where they are in the human body! Sadly, however, it is not just the men as many girls and women also have no idea and therefore do not know how to recognise any symptoms.

I believe this applies to all women and not to any specific group. It would be a rare woman indeed who could come before this inquiry understanding what it is all about. The minister for health is my local member. I have on several occasions written to him outlining my concerns. The minister has always replied, but the replies often leave me with a feeling of utter despair and hopelessness on behalf of women because of the inadequacy and confusion of the comments. For example, the minister advised in a letter in detail how ovarian cancer was now under the umbrella of the National Breast Cancer Centre. How on earth can one relate our sexy breasts to our gynaecological reproductive organs, which one cannot see and which are rarely, if ever, talked about in public? By combining the two, government is defeating the good which they believe they are trying to achieve and insulting those who are fighting the very hard battle to create awareness of ovarian cancer. Above all, women need a centre of gynaecological cancer and, until that occurs, we are at a terrible disadvantage and risk.

I regard the gynaecological cancer unit at the Royal Hospital for Women at Randwick as the model. This is because of Professor Hacker and his wonderful team. For those of you who do not

know Professor Hacker, he has devoted his life to gynaecological cancer. Originally, he was at the UCLA gynaecological cancer centre in California. This unit was the first of its kind in the world. At the time he was persuaded to return to the Royal Hospital for Women in Paddington, he was director in charge. He has now been at the Royal Hospital for Women for 20 years. When you have such a model of excellence it is essential it is studied and replicated in other centres.

I believe the collaboration between Professor Hacker and the Garvan Institute provides a unique opportunity for government to bring the treatment of gynaecological cancer into the 21st century and save the lives of Australian women. This inquiry should recommend funding for, firstly, such a diagnostic blood test via this collaboration; secondly, creation of a national gynaecological centre; and, thirdly, funding for an awareness realising that gynaecological cancer is a mystery to Australians. Thank you.

Ms Robertson—Thank you for inviting me to address the inquiry. I think, as we are all gathering, optimal care of the patient must incorporate both physical and psychological care as documented by several clinical practice guidelines available for the care of people with cancer. We have made some positive steps forward in this regard with the majority of the treatment centres adopting multidisciplinary approach to care. However, although these guidelines are in place, a number of challenges remain with regard to implementation of the guidelines. Many distressed patients remain unidentified and fewer than expected are being referred for counselling and support.

Few diseases precipitate as much anxiety and fear as cancer, and the overall experience of cancer can be seen as a series of stressful events as a person moves through the illness continuum. A significant group of patients experience heightened distress that persists and worsens over time. An Australian study recently found that 42 per cent of young breast cancer patients were diagnosed with depression and anxiety; that compares with a prevalence of nine per cent in the general population. Thus, it is important that psychosocial services are responsive across the illness experience and accessible beyond the acute treatment centre.

At present, much of the psychosocial morbidity goes undetected, and the care often is offered reactively—when the patient is actually in crisis. The benefits of early identification and intervention to minimise the impact of cancer and its treatments include faster recovery, fewer hospital complications and greater ability to cope with really difficult treatments. Treatment centres therefore need to have in place a strategy for routine screening of patients so that early identification of psychosocial distress can be achieved. It is actually quite rare for patients to self-refer.

The consequences of unresolved psychosocial problems for patients are well known and include: deterioration of quality of life, higher levels of pain and distress, reduced compliance with treatments, longer hospital stays, burdens for families, and a risk of suicide—which is 1.5 times higher in cancer patients than in the general population. I would therefore strongly recommend that a coordinated approach to psychosocial assessment of patients be implemented whereby patients are assessed by a specialist psychosocial health professional at critical times during the cancer journey.

Cancer patients' needs are great, and up to 40 per cent of patients report moderate or high levels of unmet supportive care needs, with a high rate of patients being depressed during

advanced disease. There is now a growing body of research focusing on the psychosocial aspects of cancer, and most recently there has been an increasing recognition of the importance of identifying unmet needs of cancer patients.

I believe it is important that we seek to clarify and understand the psychosocial needs, or probably unmet needs, of the gynaecological cancer patient. Gynaecological cancer has been fairly neglected in the psycho-oncology arena, and there has been a paucity of research addressing psychosocial aspects. I have looked at the research recently, and there have been a lot of studies looking at unmet needs of other cancer sites. We seem to be behind the eight ball with gynaecological cancer. I would propose that we do some sort of cross-centre study to consider and clarify this important aspect, because we really do not know what the needs of gynaecological cancer patients are at this point.

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. Up to 80 per cent of women report some degree of sexual dysfunction in the first year after diagnosis and treatment, and chronic difficulties are reported in 50 per cent of patients thereafter. 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.

It is important that there are opportunities to discuss sexual concerns with health professionals, because few patients will initiate discussion about sexuality issues. At the time of diagnosis, I think it is important that patients and their partners be involved in a discussion about the potential direct effects that treatments may have on their sexual function.

Other issues requiring a lot of consideration—and which were touched on earlier today—are that geographic barriers are a key issue in providing psychosocial support to patients. Descriptive 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. Indeed, specialised psychosocial support for all patients is not viable even in large metropolitan centres, so in rural and remote areas access to such services is extremely limited. Psychosocial care is not yet a routine part of oncology care. 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 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.

The other thing that was raised this morning was whether we are meeting the needs of Indigenous women and women of other cultural backgrounds in psychosocial care. Australia has one of the most multicultural populations in the world. Australians actually speak 193 languages. Language and cultural barriers and a lack of knowledge about health in general and about the Australian health care system limit the access of non-English speaking background patients to health information and supportive care. This can create significant psychosocial problems for

many patients and their families—and I think the concept of support outside the family may not be well understood within some cultures.

Utilisation of interpreting services is one of the strategies to improve the understanding of health professionals of the difficulties being faced by culturally diverse patients, but it is by no means an ideal solution to a complicated problem as there is a very high demand for interpreters. I sometimes find it very hard to get an interpreter on the day on which I really need one. A range of different health workers, I know, is available to support, interpret and advocate on behalf of Aboriginal and Torres Strait Islander people, but an increase for the liaison with these workers may assist in the care of gynaecological cancer patients.

CHAIR—Thank you, Ms Robertson. Would anyone else from your service like to make a statement?

Ms Mills—Thank you for the opportunity to address the Senate inquiry into gynaecological cancer. The NSW Psychosocial Support Project is a funded initiative of the Greater Metropolitan Clinical Taskforce, otherwise known as the GMCT. I believe there is a session after this so I will not go into detail about that. Essentially, this project operates within that framework, although the aim of the project is to promote and improve the provision of psychosocial support that is given to all women across New South Wales who are diagnosed with a gynaecological cancer. Obviously, we also believe it is important to extend that support to the families and carers.

Before continuing, I would like to outline what we mean by the term 'psychosocial support'. 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. That is, psychosocial care should be considered a fundamental core component of gynaecological cancer care accessed at all stages of the cancer journey and therefore provided by a range of services. In brief, the Psychosocial Support Project has, with—I might add—very limited resources, developed projects that have targeted women and their carers and families directly, and general practitioners, nurses and other allied professionals currently working in their area of gynaecological cancer care.

Our accomplishments to date—and I wish to table these—include the development of a directory of gynaecological oncology treatment and support services in conjunction with New South Wales and the Life Force Cancer Foundation. This directory informs general practitioners, gynaecologists and women about the specialist gynaecological oncology units, the linked rural clinics and psychosocial support services available across New South Wales. The project has also conducted state-wide health professional network meetings, and another is planned for this coming October.

The most significant accomplishment to date, I suppose, has been the development of the gynaecological cancer support website, and there are bookmarks referring to that—www.gynaecancersupport.org.au. This website includes, in addition to general information about the psychosocial issues of women, an online virtual community for women, an online support network for health professionals and an accredited e-learning continuing education course for general practitioners on psychosocial issues.

The Psychosocial Support Project is committed to improving and expanding psychosocial support for women and their families and carers across New South Wales, and believes the best way forward to achieving this is to continue to work within the existing GMCT model that includes the four specialist gynaecological oncology networks where women will receive integrated and comprehensive medical and psychosocial care from a multidisciplinary team. We recommend expansion of psychosocial services within each network to ensure the capacity to provide psychosocial support to every woman presenting at the specialist unit, including follow-up and the delivery of an outreach service.

We also recommend the capacity to follow up and support women and their families living in rural and remote regions beginning whilst inpatients and continuing after discharge; to continue in the role of education of GPs, gynaecologists and other health practitioners in the role of provider of psychosocial support; and, last but not least, funding to research and investigate what psychosocial interventions are effective and to implement those findings.

CHAIR—Ms Hobbs or Dr Wain, do you wish to add anything?

Ms Hobbs—I endorse what people before me have said and I do not want to reiterate any of that except to say that the provision of expert psychosocial support throughout the cancer journey is an ethical imperative not an added extra. I would like to take up a couple of other things that I read in the transcript of the hearing held in Canberra. The NHMRC representative spoke of the one-named, specifically funded Ovarian Cancer Project. I am an investigator on that project so I have produced for you a one-page summary of that. I think that leads on to consider more broadly that, as well as psychosocial support for women and their carers—and I think we have left that out a lot to day and they are equally part of the journey—we need collaborative psychosocial research.

To take up your point about psychosocial support and research, there is a beginning initiative in the establishment this year of the Psycho-Oncology Cooperative Research Group—I have a handout about that, as well—which in itself is a funding collaboration. The initial funding was provided by the Cancer Institute of New South Wales. It was enhanced by federal government funding under the Strengthening Cancer Care program, and the website of the cooperative group is hosted by COSA, the Clinical Oncological Society of Australia. So in itself it is a collaborative effort. Its aims are to bring together and encourage further collaboration between multidisciplinary researchers, both academic and clinical, in the psycho-oncology field, to develop large-scale multicentre psycho-oncology studies, and to have formal links with cancer clinical trials groups to include psychosocial studies as substudies of basic clinical trials. All of that is in the handout.

The Westmead Centre for Gynaecological Cancer has, over the years, been involved in a number of collaborative research efforts, and I think that is an important point. The number of gynaecological cancer patients is small and so we need to combine across our centres and indeed with other researchers in different cancer tumour groups to produce large-scale studies which have meaningful results.

CHAIR—We will move now to questions. We will table all of the documents at the end of the day.

Senator FERRIS—Mrs Fortescue, what are the three issues that came straight to your mind when you were diagnosed with a gynaecological cancer and which you believe remain unaddressed? Can you tell me them (1) (2) and (3), because we are looking at unmet needs here.

Mrs Fortescue—The first was the fact that I knew nothing about it. As I put in my submission, I am conceited enough to know that, if I knew nothing about it, this would apply to the majority of women. Bearing in mind that I was in the cosmetic industry and would have come into contact with thousands and thousands of women over a period of 40 years, I cannot believe that I had never heard of ovarian cancer.

Senator FERRIS—So that is the first one. What was the second?

Mrs Fortescue—I was very fortunate that I had wonderful medical care. I know of others diagnosed with ovarian cancer who have complained about the fact that the GP did not diagnose it. How on earth can the GP diagnose it? It is like winning a lottery if he or she does diagnose it. I am very conscious of the fact that the GP in my younger era delivered my baby and so knew all about me. Today women are very self-conscious. You really have to make yourself think to go and have a pelvic examination. There are plenty of women in this room, and I do not know how they feel but I made a decision when I became very involved in our business activities that every year I would have a pelvic examination. That occurred in about 1969, and I never departed from that. It comes back all the time to this blood test and the fact that the GP can test me for cholesterol, diabetes and all those things but not for ovarian cancer.

Senator FERRIS—Okay, that is the second. What was the third?

Mrs Fortescue—I was fortunate that my gynaecologist, who performed the initial hysterectomy, was in contact with Professor Hacker from the day I came under his care, because it was suspected that I had ovarian cancer, and although the CA125 was only 38 they hoped that it was not cancer. When I hear of anyone—and I am sorry for my friends at this table and others in this room—not being attended to by Professor Hacker and his team, I do get a bit frightened. He is undoubtedly the outstanding person on the world stage. I listened earlier when you were discussing the situation in America. There is nothing new I was able to learn. You have the Sloan-Kettering Cancer Centre in New York, but, here, Professor Hacker looks after us all. Had I been diagnosed in the RWH menopause clinic in 1997 I would have gone straight to Professor Hacker. The hysterectomy part would have been missed out. It is this awareness of the blood test that I keep coming back to.

Senator FERRIS—Thank you. Ros, to what extent do you think e-medicine will assist the opportunity for electronic conferencing and electronic communications between, perhaps, people in rural and remote areas and city experts such as you will help in this psychosocial area? Perhaps Ms Mills and Ms Hobbs might like to comment on that as well. We do now see a lot more evidence about the use of e-medicine, and I wonder how that might work for you in these very important areas.

Ms Robertson—I think that Jane, Gerry and Kim will agree that we would set up an e-learning course for GPs on the website that is on the little bookmark. I do not see why that could not be used in the same way. 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 think there are two ways of doing it. I think an e-learning course could be great. There is a section on the website for patients to check information and gain some more knowledge.

Senator FERRIS—What about chat rooms?

Ms Robertson—I think the human side is really what they wanted.

Senator FERRIS—You mean face to face?

Ms Robertson—Not necessarily face to face, as we are considering huge problems with the geographic isolation. As I said, a lot of country people ring me and other members of our staff, and I am sure the same happens with Kim. Maybe they might like to add to that.

Ms Mills—We have developed that website. In the flyer you can see that there are three password protected areas, one of which is specifically for women. There is a chat room there. There is an opportunity to post questions. There is an opportunity to just inform yourself about a particular area that you may be concerned about. There is also a password protected area for health professionals working in the area, with an opportunity for ongoing education as well as the opportunity to post questions, where colleagues can come together in a forum to discuss a particular woman or concern that they may have.

But, in terms of the learning, we have developed a new learning course for general practitioners. There are seven modules that look at psychosocial issues. Obviously the case study is gynaecological cancer but in fact many of these issues are relevant to working with anybody with a life-threatening illness. That is accredited by the Royal Australian College of General Practitioners, which is in the process of promoting that as much as it can. So it is happening. There are obviously other avenues, but it is a start.

Mrs Fortescue—Regarding what Ros just said, I think the telephone is great. I found that absolutely wonderful when I was diagnosed. Professor Hacker's team was available 24 hours a day. Something might occur, you would panic, you would get on the phone and you would get an instant response. That is very comforting. I can imagine it is good for people out in the country areas to be able to get on the phone—and, given everyone has mobiles nowadays, it is that personal contact. I mentioned in other notes I have prepared that it was a Lifeline type of operation which was a source for everyone.

Senator FERRIS—I found these submissions really comprehensive, so I will reserve my other questions.

Ms Hobbs—I will just add to the point about web based and technologically based services. I think it is the way of the future. The Cancer Council of New South Wales is emulating some of the good North American services, looking at telegroup counselling and things of that nature. We have done our thing with our website and e-learning, and there is a first for Australia: a national rural satellite symposium in September looking at specific needs of surviving and coping with cancer in regional and remote areas. That is a first for this country.

CHAIR—What is the date of that?

Ms Hobbs—It is on 23 September, from 9.30 to 12.30 eastern standard time. It is very early in Perth.

Senator FERRIS—If anything comes out of that that you want to send to us, we would be very grateful.

Ms Hobbs—I am happy to.

Senator CAROL BROWN—I want to follow up what Mrs Fortescue was just saying about the telephone service. Are you able to let the committee know how that worked? Who was on the other end of the telephone?

Mrs Fortescue—I was given a phone number in a sheet of instructions. If I had any problem I was to ring that number. Occasionally there would be a fellow who would answer the question or there would be one of the nursing staff, but I always got a response. That number was there and I was never let down at any stage. I suppose it still happens.

Ms Robertson—Yes, it does.

CHAIR—Ms Robertson, is that through your service? It is Royal Women's and Professor Hacker's process, but is that linking in the kinds of services you would provide to that hospital?

Ms Robertson—I have developed that role. 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.

Dr Wain—I would like to point out that all the networks around New South Wales are staffed with nurse coordinators or clinical nurse consultants. For example, our department would give every patient a brochure with the telephone numbers. I think it highlights the importance of the initial contact with patients at the major centres so that there is face-to-face contact with all of the staff at each of the centres. I am sure that all of the centres around New South Wales have this ongoing telephone contact. Once you have made the initial face-to-face contact with a patient perhaps having her initial surgery, it is very easy for Kim or Ros or anyone else to follow up and make contact with the patient, and I am sure that works in all of the networks around New South Wales.

Senator CAROL BROWN—Only patients or members of a patient's family can call?

Dr Wain—There are no limits on it. The directory has all the telephone numbers of all the departments, and I am sure all of the secretaries are used to receiving a whole range of calls. It can be limited to simple inquiries that can be directed elsewhere or there can be crisis situations that can be directed to specific circumstances. That is one of the advantages of the directory—it contains the contacts for all of these units around the state.

Ms Hobbs—We are happy to have calls from members of families and concerned significant others, not just the patient.

Senator CAROL BROWN—I asked that question because it would seem to me that as the patient is going through this they could have family members that may be prone to depression as well.

Dr Wain—Sometimes we get calls from patients who have an appointment in two or three days time—and our secretary would be used to recognising it—and they need to see Kim before they see the doctor. So it is a matter of being aware of the psychosocial needs, the variation in the psychosocial needs and the capacity of the system to deal with it. Sometimes there are acute emergencies that need to be seen by the local GP urgently—something like that. I think it is a matter of triaging the appropriate response and raising the awareness of the staff within each of the departments to the varying needs that come up.

Ms Mills—Whilst all the four gynaecological oncology specialist networks fulfil that role, it is true to say that possibly they do not have the capacity to follow up with every woman. I think that is your point. You found it valuable to receive a follow-up phone call—perhaps just, 'How are you going?'—maybe many months after your initial treatment when you have moved on to a different stage and find it difficult to seek assistance. So obviously if each of those networks could increase their capacity to follow up with each woman, that would be ideal. That would reach women in the country and so on.

Senator ALLISON—Ms Robertson, there are alarming statistics about depression in women diagnosed with either breast cancer or gynaecological cancer. How much of that depression is preventable by early intervention, by the ability to provide information when women need it and reassurance and so on? In your experience, are there good practices which can reduce that level of depression and poor practices which see it at high levels?

Ms Robertson—As Gerry just explained, seeing somebody before their surgery, for example, might alleviate some huge problems that they might come up with when coming into hospital to have major surgery. However, it is a complex question you have asked. I know this study was done by David Kissane, who is well known, and he was looking at early-stage breast cancer patients—so young women. He does explain in his paper that a few of them obviously had pre-existing depression. So if you have got someone who presents with pre-existing depression—that is, a history of depression over their life—then they are going to really strike problems if they are not identified quickly and carefully and assessed carefully.

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.

Senator ALLISON—Subsequent to our mental health inquiry earlier this year, I received some advice from a group that had done a study in Melbourne of the language of depression, arguing that these very high rates that you see are present in hospital populations of people at large and that there is very little awareness of that amongst health professionals—nurses, doctors and so on. Is that your experience too? Can you see a language of depression which might assist health professionals to deal with—

Ms Robertson—I think the language of depression can be very confusing. Is this what you are referring to? They come in and they say they are depressed, but of course they have just been diagnosed with cancer so obviously they are going to feel sad and distressed. We most often try to use the word 'distressed' rather than 'depressed'.

Senator ALLISON—No, I think this study was not of people who presented and said 'I am depressed'; these were people who did not say that, but you could understand from the words they used that that was probably the case. Anyway, I will leave that.

Ignorance about gynaecological functions, about sex, about women's bodies: to what extent does it make women 'distressed'—to use your word—to discover that there is so much they did not know? Mrs Fortescue, can you suggest to the committee ways in which we might bring this debate out into the public arena more—perhaps to get to women at a younger age, so that they are not afraid to ask the questions that might need to be asked in various circumstances?

Mrs Fortescue—The very fact that this inquiry is being held is one way of doing so. From the time that Professor Hacker came into my room and said, 'You're in remission,' I decided that if Professor Hacker ever asked me to speak I would always say yes. It is not easy, because every time I talk about it all I can think of is that in another three months time I have to go under another CA125 blood test. It is to raise awareness.

When I first went through menopause I could not find anything on the subject; in fact, the GP thought I was pregnant, which was utterly ridiculous. Then, I could find nothing, but now we all know about menopause. At the time I went through it I thought, 'How on earth does Mrs Thatcher get on?' And I just could not get out of my mind the question, 'How are we as women going to function if we are all going to feel like I feel at the moment?' None of us have a problem now and I think it is because of bringing it out in the open, with all gynaecological matters.

I attended a meeting of the New South Wales Cancer Council on HPV. I had never heard about HPV and the problems that it is going to produce. Professor Hacker made the point in one of his roundtable meetings that young girls are going to have to be conscious not only that they do not want to get pregnant but also that they have to look out for the HPV. And then I read, in an article in the *Sydney Morning Herald* a couple of weeks ago, about the problem facing older women who, because of Viagra, are now having a much more sexual life—their men are having a great time—and who, of course, do not know about HPV. So this Senate inquiry is the start of a new era for Australian women.

Senator ALLISON—Ms Robertson, can I ask you about a particular group of women that you must come across. I am referring to the ones we have heard about in some submissions who discover that they have a gynaecological cancer when they become pregnant, and they face not only having to terminate that pregnancy to save their lives but also the prospect, as you say, of infertility and then of being extremely sick. We are talking here about a massive assault on someone's mental capacity to cope. Can you tell the committee how many women you see in that group or how significant this is?

Ms Robertson—We don't see a large number in that group, fortunately. As was pointed out in the session this morning, most of our patients are in an older group, 50-plus, but of course we do

have the occasional woman who has a cervix cancer, and it is devastating for those people. Just dealing with the associated grief of not being able to have a child, particularly if they have had to terminate a pregnancy, is a very big problem. There is depression, and sometimes relationships break up.

Ms Hobbs—Can I add to that. What we see much more often is women whose diagnosis, usually of endometrial cancer, comes in the context of investigation for infertility. So they have sometimes had a 20-year-plus history of trying to conceive and all sorts of horrible, unsuccessful interventions, and multiple pregnancy losses. To then deliver the final blow of a hysterectomy in the context of cancer is a recipe for depression and ongoing distress.

Dr Wain—I agree; that is a much more common problem. The circumstances of pregnancy associated with gynaecological cancer are fairly uncommon. I doubt whether each of the four units in New South Wales would see it more than once or twice a year, even though it is tragic and intense at the time.

Senator WEBBER—I want to return to the challenges in terms of dealing with the psychosocial support of those from culturally and linguistically diverse backgrounds. Earlier, Professor Hacker said that probably the team from Westmead had even more contact with women from diverse backgrounds. Can you expand on the kinds of strategies we need to put in place to address their particular need for support.

Ms Hobbs—We have a very ethnically diverse population and we see a significant number of Aboriginal women as well. 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.

Apart from that, 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.

We offer a lot of support. We have a support group and that, by its very nature, is not available to women who are not fluent in English. So the provision of ongoing support to them is very difficult. It ends up being mostly in written form. It is quite difficult to conduct telephone interviews with an interpreter as well.

Senator ALLISON—How do you deal with that situation where the culture says, 'We don't tell mum she's got cancer'?

Ms Hobbs—We do a lot of careful work around, 'Is it possible your mum already knows this?' Usually they are happy to have a discussion about removing tumours. I find it is best to say, 'Let's ask your mum what she understands about the operation she has had.' More than half the time they will say, 'I have had an operation for cancer,' and you have avoided the problem. Where that is not forthcoming we talk about treatment of 'the tumour' and try not to bombard cultural sensitivities.

Dr Wain—There are well-established guidelines about breaking bad news to patients and the setting up of a situation where the family member, the interpreter and the health professional is there. That often breaks down the problem. When you are talking in the corridor with the family it is, 'Don't discuss this with mum,' and all this sort of thing. When you are in the room, the patient says, 'So, how did my operation for my cancer go?' and the balloon is burst. Often that discussion is so much easier to facilitate around the table, when we are not telling the patient in blunt, ugly words, but we are answering the patient's questions. Simple measures such as asking: 'Do you have any questions to ask me? Do you want to ask me why we are doing this operation?' Those sorts of questions can often break that highly emotive situation. It is something that comes up all the time.

Ms Hobbs—We might say: 'The treatment we want to give you is chemotherapy. Do you know anything about that?' They may then answer, 'Yes, that is the treatment people have for cancer.'

Dr Wain—There are leading questions. I was going to add to Kim's comments. I do not mean to trivialise it and I certainly do not mean this to sound trivial, but sometimes, regarding the patients who come to our department, we comment that the cancer is the least of their problems. 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.

Senator WEBBER—Picking up on some of the discussion we have had with Mrs Fortescue, I would have thought that, with a lot of those cultural barriers, we are near in terms of the research, but we are nowhere near that early intervention, early detection stuff in discussing what is a very personal cancer, so you are even more likely to get them at a much later stage.

Dr Wain—I am not sure that the evidence is available for that. It is certainly not my impression that that applies. Some of the circumstances are difficult and I think it highlights the knowledge about local services available. For example, 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 was really Kim's contact through local support services. 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. They get this highly complex cancer and they need to access very complex care, with surgery, chemotherapy and radiotherapy which goes on for a very long period of time. 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.

Senator ADAMS—Thank you very much for your submissions. I have found them very interesting. Having been a breast cancer patient with the breast cancer assessment team at Royal Perth and going through the system, the submissions back up just how important it is that anyone diagnosed with gynaecological cancer is given every possible support before they have their surgery—going into something and fully understanding it. It will take longer, as you are saying, with people from another background who do not understand the health system. I cannot emphasise enough the importance of the multidisciplinary team—in my case it was the breast cancer nurse—and just going through those couple of sessions I had before I actually went any further and just understanding it, being able to accept it and especially having an escort. That gets me back to my patient assistant travel scheme.

Your capacity to follow up and support women and their families afterwards is just so important, because you go out of hospital all of a sudden; you have had all that treatment; and where are you? There is no-one. You cannot get an appointment with the GP. GPs are too busy—the whole thing—especially in a small, rural area. And it would be far worse for anyone who lived right out in the bush, probably especially for our Indigenous people.

Mrs Fortescue, I was a little concerned, being a great supporter of the National Breast Cancer Centre, about your criticisms. I am just going to gently go through a little bit. In September 2001 the National Breast Cancer Centre were funded by the federal government to manage a national ovarian cancer initiative. They were considered the best possible organisation at that stage to handle this. The funding was to improve the health outcomes for women with ovarian cancer. They have done a terrific lot of work with their ovarian cancer programs. My question to you is: if they were to change their name to 'Breast and Ovarian Cancer Centre', would you be happier?

Mrs Fortescue—Yes, but I would be happier still—

Senator ADAMS—Yes, I know what you are going to say.

Mrs Fortescue—if it became the 'National Gynaecological Centre'. I do have a problem with being part of the national breast centre. I appreciate everything that is being done. Everything is important, and it is a step forward each time something occurs. But I do have a problem, and I think that anyone who has had gynaecological cancer of any type would feel much happier if they felt that there was their own centre, because the outcome nowadays for gynaecological cancer is far worse than it is for breast cancer.

And then we have been hearing about the multicultural women from other countries with difficulties. I assure you that I had the same feelings that every other woman does. It is not just language difficulties. It is not too far in our past that there was in the UK the married woman's act or whatever it was called. These things were hidden away. Your husband would have had to come with you. It would make me happiest to have a national gynaecological centre.

Senator HUMPHRIES—I just have a comment. I was looking through the booklet there at the directory of services, and I noticed that the Eden Monaro Cancer Support Group was not

mentioned. I know from my own experience that they are a very active group. I thought you might—

CHAIR—Another advertisement!

Senator HUMPHRIES—That is right.

Ms Hobbs—I must say that the Eden Monaro Cancer Support Group and every other one in New South Wales will be mentioned in the Cancer Council report on the effectiveness of support groups, about which there is something in this handout.

Senator HUMPHRIES—Very good. In the next reprint—

Ms Hobbs—It is not specific to gynaecological cancer groups.

Dr Wain—We were funded by the Cancer Council New South Wales to do a survey of all of the cancer support groups in New South Wales, and I think there were—

Ms Hobbs—One hundred and seventy-three of them.

Dr Wain—There were only three specific to gynaecological cancer. All of the others provide very good support groups. We have a major research report into how they are organised around New South Wales and, in fact, how patients who attend support groups get very 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. So it is not neglect to Eden Monaro; it is recognition—

Senator WEBBER—You could ask him what he was doing wandering across the border!

Senator HUMPHRIES—They wander across the border towards us, you see, so I have a pastoral interest in it.

CHAIR—Thank you very much, Senator Humphries. Do any of the witnesses have anything to add? As you know, we are not due to report until October, so, if there is any other information that you would like to share with us, please get it to us to get it onto the record. We have run out of time, but I would just like to put a question on notice to Ms Hobbs and Ms Mills, and maybe Ms Robertson as well, about your backgrounds. I think we did ask it at the roundtable. We talked specifically about workforce issues, and we have had some evidence—and I will be asking other witnesses—about numbers of medical specialists and so on.

Particularly in the area of social support, I am interested in the opportunities for people in the professional areas of counselling, social work and psychology. I am interested in where the training is, how many of you are there and those kinds of general workforce issues. Can I put it on notice to you to get back to us on that? In the overall scheme, your professions are sometimes forgotten when looking at those workforce issues. I would very much like to have some data on that. Would anyone care to make any final comment on the record in this session? Ms Robertson?

Ms Robertson—No, that's fine, thanks.

CHAIR—Mrs Fortescue?

Mrs Fortescue—I will add just one small comment. I noticed at the roundtable that Ms Heffernan made a comment about the cervical cancer vaccine from Professor Frazer. This is an example of the problem that arises when information does not really get out as accurately as it should. We were told that you should have the vaccine between ages nine and 13. Obviously, mothers would be immediately thinking, 'That means they're going to be promiscuous,' whereas in a talk I listened to by Professor Frazer he said that to have it between the ages of nine and 13 was the most effective time. It meant nothing about being promiscuous or anything else. It is this type of information that gets a little bit confusing once it reaches the public arena. If you have the vaccine between the ages of nine and 13, it could well benefit you at age 40 or something like that.

CHAIR—That reinforces your education message, Mrs Fortescue?

Mrs Fortescue—That is right. Yes.

CHAIR—Thank you very much. We appreciate your time.

[12.02 pm]

FRIEDLANDER, Professor Michael, Chairman, Australia New Zealand Gynaecological Oncology Group

MARTYN, Dr Julie Anne Kerr, Associate Program Manager, Australia New Zealand Gynaecological Oncology Group

BUSH, Ms Mercia Kathleen, Consumer Representative, Greater Metropolitan Clinical Taskforce

MAIDENS, Ms Jayne, Member, Executive Committee, Gynaecological Oncology Group, Greater Metropolitan Clinical Taskforce

MARSDEN, Professor Donald Eric, Co-Chair, Gynaecological Oncology Network, Greater Metropolitan Clinical Taskforce

WAIN, Dr Gerard, Former Co-Chair, Gynaecological Oncology Service, Greater Metropolitan Clinical Taskforce

CHAIR—Welcome. Thank you very much for coming before us today. I am sure most of you are experienced in this process. I know you have information on parliamentary privilege and the protection of witnesses. Also, if there is anything you would care to say in private we can talk about that. At the beginning of the session this morning we talked about the fact that we are combining witnesses for no other purpose than to get as many people as possible before us. There was no attempt to force groups to appear together. It was done purely so we could hear from as many people as possible. I thought I would put that on the record first off, before we hear from your two organisations. Would any or all of you like to make some kind of opening statement for the record? Who goes first is entirely up to you.

Prof. Friedlander—I would be happy to go first.

CHAIR—It is always difficult when we have a couple of professors—which one do you go to first?

Prof. Friedlander—I am the youngest professor here! First of all, thank you very much for giving us the opportunity to participate in the inquiry and also for holding the inquiry. I am representing ANZGOG, with Julie Martyn. ANZGOG was established towards the end of 2000 to facilitate collaborative gynaecological cancer trials across Australia and New Zealand. I think it is widely accepted that clinical trials, particularly phase 3 trials, are the only effective way of determining what the optimal approach to treatment is and the best way to define new standards of care. 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.

Until the formation of ANZGOG there was no facility or opportunity in Australia to carry out collaborative, cooperative trials. This was quite unlike the situation in every other developed

country throughout the world. It was clear that this deficiency had to be overcome. We secured support for the concept from all gynaecological cancer units around the country and all individuals involved in the treatment and care of women with gynaecological cancers. This includes gynaecological oncologists, medical and radiation oncologists, data managers, researchers, psychologists, social workers et cetera. The whole group got together and accepted the need, and 130 joined up in December 2000. We were supported by the NHMRC Clinical Trials Centre, in Sydney, who gave us invaluable advice, and we have continued to work closely with them since.

Initially, there were no funds available to establish ANZGOG. We were very fortunate in being accepted for provisional membership by the United States GOG. The US GOG are the foremost clinical trials group in the world. They have arguably made major contributions to the treatment of women with gynaecological cancer. We were accepted as provisional members. 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.

We have been able over the last five years to establish a very viable and effective clinical trials group. We have established very close working relationships and collaboration with all the major international gynaecological cancer groups throughout the world. Importantly, we are also part of what is called the Gynaecological Cancer Intergroup. This is probably one of the most exciting things that has happened over the last couple of years, in which it is recognised that we have to work together. Gynaecological cancer is a global problem. You require a large number of women to participate in clinical trials in order to obtain answers in a timely fashion. We all recognise the need to work together. We meet twice a year in different parts of the world. We set priorities and agendas and we establish and run trials that link groups across the world. For example, we are doing studies at the present time with GINECO, which is the French collaborative group; with the Scottish gynaecological cancer group; with the EORTC; with the US GOG and so on. This is really only possible because we have been able to establish ANZGOG. We are also now able to start to do studies in women with rare and uncommon gynaecological cancers. Clearly, you require people all over the world to collaborate to get answers there.

We have only very recently received limited financial support from the federal government, through the Strengthening Cancer Care initiative, and we have also received a grant from the Cancer Institute New South Wales. This has been very welcome, but it really does not provide sufficient funds for the ongoing running of the group. Basically, the funds were available for two years.

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 of recurrent funding to support infrastructure as well as funds for specific trials. I hope that as a result of this Senate inquiry we will be in a position to build up and expand ANZGOG and a clinical trials base in Australia. It is really the only way to make progress, through the running of clinical trials, and I hope that I can convince you at the end of the various questions why we think this would be a wise investment

that would benefit not only the patients we are treating today but also all our patients in the future.

CHAIR—Thank you, Professor. I call Professor Marsden. I am not quite sure whether it is your good looks or your age that gets you into this!

Prof. Marsden—My age does allow me to comment on what Professor Friedlander has just said because, when I first came back to Australia from the United States, the first attempt at a collaborative nationwide trial was going on. It was so full of compromise that it was really not terribly good but it was the first time that people throughout Australia had actually collaborated and then there was a massive void until ANZGOG came along. Professor Friedlander has somewhat understated the magnitude of the task to establish that group. It was largely due to his pressure that it came about.

In 2002 the New South Wales health department formed the Greater Metropolitan Clinical Taskforce, which covered a whole range of disciplines to address various issues. One issue was the number of burns units in the state. Just about every hospital had a burns unit, which meant that resources were being wasted, skills were not building up et cetera. Among those groups a gynaecological cancer subgroup was formed. The general goals were to involve clinicians in a process designed to better utilise resources, rationalise service provision, ensure equity of access and save or at least make better use of money. Our initial task was to develop networks within the area health services comprising tertiary referral centres, regional and rural hospitals and health practitioners of all sorts. In a specialty which had been traditionally territorial, we were surprisingly successful in having that concept accepted, and everybody that remembers our first meeting is quite amazed at how far we have come in the time.

As the submission that you already have details, we have supported highly successful nurses study days each year since our formation. These have been well attended by hundreds of nurses from both metropolitan areas and the country. I believe you have already heard of the importance of these nurses, particularly those in rural areas. We were able to finalise a process of treatment guideline developments that had been done over a decade before and to publish evidence based consensus clinical practice guidelines which were distributed to practitioners around the state. We have set up a process whereby these will be reviewed on a continuing basis to ensure that they are up to date. You have seen the directory of service providers, which is a relatively small thing and does miss a few areas; nevertheless it was a very important step forward.

Within each network we have sponsored once- or twice-yearly educational sessions for gynaecologists and other health care practitioners throughout our networks on gynaecological oncology. These have been particularly popular with rural practitioners. We have set up the internet based psychosocial support group that your heard about and also the continuing education program process for general practitioners, now accredited by the RACGP. This year we sponsored a very successful study day on palliative medicine, in association with the Sydney Institute of Palliative Medicine. Cancer Institute New South Wales has now provided us with some money to help us collate and publish the proceedings of that meeting as clinical guidelines for palliative medicine in gynaecological oncology, the first such guidelines that have existed.

In conjunction with Cancer Institute New South Wales we are developing a statewide data collection on gynaecological oncology. One of the questions that we are asked all the time is: are

the things that are being done making any difference? In reality we do not exactly know. There are lots of anecdotal evidence that this, that and the other happens, but in terms of actual outcomes each unit keeps records but they are not collated. There are all sorts of problems and in a multidisciplinary treatment environment it is quite hard to pull all these things together. So, in conjunction with Cancer Institute New South Wales, we are developing a database on gynaecological cancer. But we hope to go further than that because there is the International Federation of Gynaecology and Obstetrics, who publish reports—on, I think, a three-yearly basis—on results of treatment from various centres that subscribe to it around the world. There are no results for an entire geographical area and we hope that, through our networks and with the funding that we have, we will be able to develop a FIGO friendly database for the whole state and become the first geographical area in the world, rather than treatment centre in the world, to report to FIGO. That would enable us to know what we are doing and also to compare it with the best international standards.

Our linkages with rural doctors were a major problem, and rural doctors and rural people complain that it is hard to get access. Gerry, when he was chair, and I, when I became chair, attempted to set up these linkages. It was only about three months ago that we got a positive response from the rural doctors group accepting the offer of getting involved with us in helping develop better services in rural areas.

I will not keep going on, but one of the things that is very good about GMCT is that it provides a forum where all practitioners and consumers can contribute to the development and enhancement of services throughout the state. Prior to the advent of GMCT, everything was unit based, often personality based and personality driven. This is a forum where everybody has got together and worked, to my amazement, for a common good. It probably provides a prototype of a national forum that might help in the way that was mentioned by previous witnesses.

CHAIR—Dr Wain, are you wanting to add something to that in your previous chair capacity?

Dr Wain—No, I think Don summarised it very well. The New South Wales government supported this approach. It did come with a small amount of recurrent enhancement funding and that allowed for each of the services in New South Wales to achieve equitable care across the services. Some networks got more money than others. It left a small pot of about $150,000 which has in turn funded the statewide projects such as the psychosocial projects and the guidelines—we tabled the guidelines with our original submission. It has given the opportunity to keep those networks going. It was a small but worthwhile investment to bring these services together. I have just found on my shelf some of the original brochures—

Prof. Marsden—He thought it was some of the original money!

Dr Wain—They were the sorts of brochures we put out a few years ago to promote this around the state. There was also a video put out, and it reminded me that Craig Knowles was the minister who supported it. Would the committee be interested in looking at the video? It is a very short video that contains a couple of patients talking about their access to the services and how the services are organised.

We have seen throughout the period of four or five years a kind of concentration of patients towards the centres. I think it is the active promotion of these services by people like Mercia, our

consumer representative on the group, as the best way to provide cancer care and to network the services across the cancer journey, as patients will get perhaps their concentrated surgical services at centres and then the rest of their services through the network services around them. So this process has promoted that model of multidisciplinary care for patients. We have seen—I cannot show you—improvements in patient access to high-quality care across the state.

Ms Bush—You do not think when you are diagnosed with gynaecological cancer that you will be sitting before a Senate committee, but here I am.

CHAIR—That is one of the many joys of the diagnosis.

Ms Bush—I have been with the GMCT through a period of growth, and what you have heard other people say has certainly happened. I think that is a great achievement. I consider there are two weaknesses in the system. One is lack of equity for country patients. It is true we are trying to address that, but it is a big thing. The other one is clinical trials. I have been fortunate to be a patient on a clinical trial. It was of enormous benefit to me, and I would certainly like to see more done in that area. Those are my two concerns.

Ms Maidens—To follow up on what Don said, for anybody who was present at our initial meeting, we certainly have come a long way with collaboration. I think that has been a good thing. I also agree with the idea of equity for people in rural and remote areas. As a nursing group, that is certainly something we have concentrated on in our annual educational study days, which are attended by close to 200 nurses, quite a high proportion of whom come from rural and remote areas. Part of our funding proposal pays for the nurses to come to Sydney for our study days, so that is really encouraging for us. They can then take the knowledge back out to their areas. We realised that, whilst we all work in a tertiary referral centre and the women might have their initial treatment with us, a lot of them were then going back out to Wagga Wagga or somewhere like that and being followed up by nurses who had not had any training in gynae-oncology.

Prof. Marsden—The access of rural women to clinical trials is an issue, and I presume ANZGOG is looking at that.

CHAIR—Would you like to follow up on that point now, Professor Friedlander?

Prof. Friedlander—It is a very important question. It is difficult but we have started to address it. 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.

Senator ADAMS—As a rural breast cancer patient, nothing annoys me more than seeing an ad in the paper saying, 'We want volunteers for a clinical trial,' et cetera and, when I ring up and say I am available, I am told that as I live in a rural area it is too hard and they do not want my participation. That really annoys me because there are different issues for rural women that could be picked up in trials. That is the stock standard answer you get all the time. I have fights with the researchers and say, 'You just don't realise what you're missing out on.'

Prof. Friedlander—I am on your side; I fully agree.

CHAIR—Could you explain why that kind of response is given? What is the limitation to having rural women involved in trials?

Prof. Friedlander—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 the major barriers we are facing at the moment relates to trial insurance and who is going to insure the patient and the study. We are going through this in New South Wales at the moment. Victoria grappled with this and sorted it out, I think, but New South Wales has not. So it relates to insurance, research committees and ethics committees and having adequate facilities on site in the regional and rural areas to run studies. Things have changed a lot in recent years and now there are oncology units right across regional New South Wales, and they participate in clinical trials. The Cancer Institute New South Wales has been very good at this and has provided data managers and research nurses in all these regional areas. Things are changing for the better, but it is taking a long time.

CHAIR—Dr Martyn, would you like to make a statement?

Dr Martyn—Yes, I would. The contribution I would like to make to the discussion also relates to clinical trials. Professor Friedlander has already spoken about the valuable contributions that cooperative groups make to clinical trials and I would like to talk about the operational aspect of running clinical trials, because I think it is probably not well recognised just how expensive it is to run clinical trials. Most of the studies that ANZGOG currently runs are international cooperative group trials. As Professor Friedlander said, we collaborate with groups in Scotland, Belgium, France and the US. Data from the US suggests that the average cost per patient of running a clinical trial is $US7½ thousand, so it is close to $A10,000 per patient to run a trial, and we look to benchmark ourselves against that standard. Using the figures from our last four trials, we are operating at about half that—that is, $A5,000 to $A6,000 per patient, which is still a reasonable amount of money.

The way in which our clinical trials are funded is that we receive grants from our international collaborative partners. So we are looking at running costs of around $5,000 to $6,000 per patient, and the grants we are currently getting are around $3,000 to $4,000 per patient. The grants generally come from the pharma companies whose product is being used in the study, and that does not even begin to address the clinical trials that we would like to run and for which no pharma support would ever be forthcoming. So we are looking at having to subsidise the cost of running clinical trials with money received from grants and donations. Around 30 per cent of our costs need to come from elsewhere, and we have been pretty successful in doing that. ANZGOG is in fact growing very well. We have got great support, and Professor Friedlander has single-handedly been instrumental in bringing in most of that money.

So that is the financial situation. The other thing I would like to say relates to where that money goes, and we have already heard a bit about that. Through an international collaborative group study, the ANZGOG Coordinating Centre is involved in the overall project management. So, generally, we are looking at 20 to 25 clinical centres around Australia and in New Zealand that we are working with. We are involved in the contract negotiations and insurance issues, as we have just heard, and there are the regulatory approvals and the auditing and monitoring of the studies—all of these aspects make up part of the central costs.

For a locally developed study, which we certainly would like to do more of, we have to add in the costs of developing a clinical trial protocol and setting up and maintaining the database, and then there are the statistical analysis, report writing and publication aspects of it. Those are just the central costs. At the site levels themselves there are of course costs associated with running clinical trials. There may be extra patient visits, extra tests scheduled and the cost of the research nurses or data managers employed to run the trial. So from the central funds received a portion goes to the sites to help offset some of those costs, but I know that it does not come close to covering it.

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

Senator FERRIS—Professor Friedlander, why has it been so difficult to get NHMRC money for clinical trials, given their likely successful outcome in terms of lowering the overall cost of servicing cancer patients?

Prof. Friedlander—That is a very good question. I think the NHMRC have in the past supported trials. But it is not really a level playing field when you are going out to get a grant because you are not only competing against other clinical trials but also you are competing against basic laboratory research. There is a very limited amount of money available.

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.

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.

Senator FERRIS—Would that still be administered through the NHMRC?

Prof. Friedlander—I think they would be one of the groups out there. They would obviously have the experience, but it is more the basic science experience. There may be other groups who may do it.

Senator FERRIS—Is it difficult for a woman to take part in a clinical trial? Is there much involved? How do you select them?

Prof. Friedlander—There is a lot more work involved in participating in a clinical trial for the doctors, the nurses and also to some extent the patients in that occasionally it requires more hospital visits and it may involve more tests over and above what you would normally do in the course of standard treatment.

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. So I think adhering to the simple principles and audit are very important.

It is not particularly difficult, but it is very time-consuming. It can often take at least an hour to explain the clinical trial and go through a process. In a very busy clinic, when you have a waiting room full of people, it is often a disincentive to try and recruit because of the complexities and the time required. Fortunately, most of the people who we work with are very dedicated. If the trials are there, they do try and recruit.

Senator FERRIS—I was reading in your submission some of the international comparisons. We do not seem to do terribly well by international comparison, do we?

Prof. Friedlander—No, we do not. We have started very late. We have only been in the business for five years and we are doing very well for five years. We need to at least double our recruitment. To date the problem has been not ideas or concepts but money to run the studies.

Senator FERRIS—We had some evidence earlier today that suggested that we should have a separate gynaecological grouping where the emphasis could be on that particular form of gynaecological grouping rather than as it is now, in the NBCC. Do you have a view on that? Perhaps I will ask Professor Marsden as well. Do you think that would help your work?

Prof. Friedlander—I think what would help our work—and I am not being facile—would be to have more money directed to research. I do not really think it would make a lot of difference, in terms of the narrow area that I am working in, where that money was coming from as long as we were working together and it was clearly being directed towards trying to improve outcomes through clinical trial research. I do not have a strong feeling about it as long as it is done. I think it has to be done. As to whether it is done as a separate entity or as part of the NBCC, I think one could argue the pros and cons.

Prof. Marsden—We do believe that gynaecological cancer has specific problems and so on that are separated from some of the other forms of cancer. The reason we held our palliative medicine in gynaecological cancer seminar was because we felt there were major deficiencies in

this area; there were things that were specific. Yes, there is likely to be benefit from a national grouping of gynaecological oncologists—perhaps not specifically for research, but for development of support and services and so on. I do think that in a very small way the GMCT group has been a great success, as I said before, by bringing people together in a forum where they can talk and put aside, to a large extent, their ego-driven approaches to things. Such a thing would be useful nationwide.

Senator FERRIS—My second question relates to the use of telemedicine. Professor Marsden, do you see e-communications as being useful in the area that you work in, and do you see this as being an opportunity to value-add that form of communication?

Prof. Marsden—Yes. As I think you have probably already heard, in our own unit some years ago we started a telecolposcopy 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 telehealth 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.

However, I do not think that email or the internet substitutes for personal contact. Somebody was saying before that this is the way of the future. It is going to be part of the future, but I do not think it is the way of the future. It is just a way of facilitating some things that could not be done before, but it would be a sad situation if we spent so much money on it that we forgot that what we really need is human contact.

Senator ALLISON—Professor Marsden, can you inform the committee a bit more about the guidelines that you have produced. Are they out now to all GPs? Are all GPs using them? How do you follow up the distribution guidelines? We are still hearing the GPs are not doing well in this area.

Prof. Marsden—There are two separate sets of guidelines. I think Dr Wain got quite a bit shorter over the last year under the weight of pressure over the cervical screening guidelines. The guidelines I am talking about are guidelines that go to gynaecologists and other people directly involved in treating gynaecological malignancy. They are not diagnostic guidelines; they are telling you the best way treat this particular tumour is blah, blah, blah. We have distributed them to all gynaecologists around the state. On the other hand, there is the other thing, the national guidelines for cervical screening.

Dr Wain—I was not going to talk about them.

Prof. Marsden—Weren't you? You don't dare?

Dr Wain—I will be meeting with the group on Thursday to discuss them.

CHAIR—With that hat on, we are going to get to know you very well, Dr Wain.

Prof. Marsden—You might ask him onto your committee.

Senator ALLISON—Sorry, just to be clear: there is no clinical guideline for a GP to assist to diagnose or to advise that a patient with a suspected ovarian cancer, for instance, ought to be referred to the gynaecological oncologist.

Dr Wain—There are lots and lots of guidelines around the place and we need to be clear about what guidelines we are talking about. The guidelines that Don was talking about were in a published book that we have put together about the management of all gynaecological cancers in New South Wales. It is the suggested management across the networks. It has been widely distributed, and I think most of the units use it more or less. It is a sense of getting agreement about management of patients, that hospitals can rely on the services providing consistent clinical care and gynaecologists in the country, for example, can get some sense of what is going to be happening to a patient—that sort of thing. They are fairly loose guidelines; they do not fit into the format of the formal process that the NHMRC would require for formal endorsement of guidelines. These really were practical guidelines for use in the clinic, and that is the guideline booklet that we were talking about before.

CHAIR—And 'we' is the GMCT?

Dr Wain—Yes. The National Breast Cancer Centre's ovarian cancer program—and I am sure we will be discussing that later—has produced a set of guidelines for GPs about the assessment of a woman who has symptoms that may be suggestive of ovarian cancer. I am sure when the submission is up we will be talking about those. The third set of guidelines is a set of guidelines relating to the management of cervical pap smear abnormalities, and I will take the opportunity to talk about that on Thursday.

Senator ALLISON—Thank you. Ms Bush, I would have asked you about why it was that being involved in the clinical trials was beneficial but I think the answer has been given already—unless you want to add something to it.

Ms Bush—I was in the psychosocial clinical trial. As was said previously, it was like spending an hour with you on a number of occasions. I felt that it was about making decisions about your treatment and about giving information to doctors. I felt that it gave me a lot of time with the oncologist and that I did not need to have lots of other services, that it was all dealt with in those times. I think it would be great for people in the country and for other women. For anyone who has had cancer, it is the anxiety, and this was a great way of reducing your anxiety. You felt very secure about what was happening and how you went about making your own decisions. I thought that was an enormous boost for me.

Senator ALLISON—Thank you. Ms Maidens, from a nursing perspective, Professor Hacker told us this morning that nurses who are working pretty much on their own with patients in rural areas, in particular, ought to spend a minimum of three to four months in a gynaecological cancer centre working with psychosocial supporters, oncologists, gynaecologists and so on. Your one-day session sounds a little inadequate in the light of those comments.

Ms Maidens—It might sound inadequate but, compared with what they were getting before, which was nothing, we have had nothing but absolutely positive feedback from all those nurses

out there who, up until then, had had no help at all. Last year we had it over two days. That required a lot of logistical organisation on our part, so we have decided to go back to one day. The first two times we ran the study days we did a needs analysis and asked the nurses out there what information they would like and how we could help to make things better for them. As a result of that we produced a textbook on gynaecological cancer nursing that a lot of the nurses out there are able to buy and have access to.

The other positive thing to come out of the study days is that the rural nurses get to know who the clinical nurse consultants or the care coordinators are in the major tertiary centres where the majority of the women have their treatment. We always provide them with a contact list of our details so that when they get back to their rural area they know who to contact and how to get more information. I do not really know how practical it would be for somebody to come and spend three or four months following us around.

Senator ALLISON—In a sense, it sounded to me like a postgraduate qualification as much as a training session. Are there opportunities for nurses to do that?

Ms Maidens—At the moment, no. Currently there is a graduate oncology nursing certificate that is run by the College of Nursing in Sydney. Some of the universities also have graduate certificates. They cover cancer nursing under a large umbrella, but there is nothing that is specific to gynaecological cancer, which is why we took the initiative to write the book as a starting point. We hope to have some affiliation with either one of the universities or the College of Nursing to promote a package specific to gynae-oncology so that at the end of the day they will come out with a certificate or with some sort of recognition that they have this speciality in gynae-oncology. We are working through that at the moment.

Senator ALLISON—If I can press you a little more—it sounds like a recommendation to me—you would not be opposed to an accreditation in this specific subgroup?

Ms Maidens—No, we would welcome it.

Senator ADAMS—Ms Bush, could you explain your role as a consumer within your organisation. What exactly do you do?

Ms Bush—I attend meetings and I am part of the decision-making process of what we will do with the little money we have, how we will allocate it, in what sort of projects. I have also had one experience—you have the guidelines for the resources—when the department of health was not able to get its act together and publish it. Gerry and everybody else had put pressure on but it was held up and, as a consumer, I could ring up and say, 'I would like to make an appointment with the minister and get this thing moving.'

Senator ADAMS—That is what I wanted!

Ms Bush—Within 20 minutes I received a phone call to say it was under way; I did not need to make the appointment. I see my role as something like that. If it is needed, I can directly do something to further these things.

Senator ADAMS—Professor Marsden, you said that you were receiving a great deal of support from rural doctors. What about the divisions of general practice?

Prof. Marsden—We are getting some support, but not as much as we would like. All of those things are issues we have to work on. To a large extent, we have been working on getting the networks up and running, so there is plenty of room for support there. We are not getting great support from the rural doctors; we are just starting to get support from the rural doctors.

Senator ADAMS—I think the divisions should be pushed pretty hard. They get a considerable amount of federal funding and they certainly are very active in regional and rural areas, so that might be a way to go.

Dr Wain—There are 35 divisions of general practice in New South Wales. About 1,200 women get gynaecological cancer and only about 300 or 400 of those live in rural areas. Each particular division that often consists of 300 or 400 GPs will not see a large number of individual patients with gynaecological cancer, so it is very hard to put a numerically uncommon tumour on the work plans of these divisions. Cervical screening is a much bigger priority because it affects a larger number of their population. Cancer services in a rural town are a big issue, so gynaecological cancer services have been incorporated as the provision of cancer services. I think it is asking a little much for each of the 35 individual divisions to pay a great deal of attention to this.

Senator ADAMS—My question was really about disseminating the information. That was more what I was getting at. They have got the key to do it, they are paid to do it, their computers are all up and running, so I think it is certainly a very good way to go. How many gynaecological cancer patients tend to develop lymphoedema later on? You probably do not want to talk about this but it is important.

Prof. Marsden—Behind me is Mary Ryan, from our unit, who conducted probably the first proper study on this. Basically, 20 per cent of patients who have had pelvic lymph node dissections, about 60 per cent of women who have had groin node dissections have varying degrees of lymphoedema. Dr Wain says it does not happen at Westmead. The degree varies, but those are the sorts of figures, and if you add radiation to the lymphadenectomy the figures go much higher.

Senator ADAMS—With the enhanced primary care item number, I need some support here to get increased sessions. At the moment there is no way for physios, because they can see one lymphoedema patient compared to five normal physiotherapy patients. In Western Australia we are running into huge trouble here. I feel that if we could get some support with that enhanced primary care item number and if we could get more sessions, it would make such a huge difference to this issue.

Prof. Marsden—We need more sessions and we need more physios trained in this.

CHAIR—In the particular skill.

Prof. Marsden—That is another problem: a lot of people go to physiotherapists who do not really know how to manage lymphoedema. That is a major issue, because if it is not treated aggressively from the start it gets progressively worse.

Senator ADAMS—So it is a cost to the health system, from what I am looking at. If these primary care numbers could be pushed up at the start, we would prevent a huge problem for the health system as far as dollars go later on.

Prof. Marsden—Yes.

Ms Maidens—It is also something that is not readily available in the public sector. A lot of women have to pay to go to private centres to have their lymphoedema treated.

CHAIR—Professor Marsden, is that study you referred to on lymphoedema public?

Prof. Marsden—Yes, it has been published. There have been two papers published on it.

CHAIR—Can we get copies of those? Can they be tabled? There have been particular issues with lymphoedema raised by the committee and we have not received much evidence on that, so that would be very welcome.

Prof. Marsden—Yes, Mary will give you a copy.

CHAIR—Thank you very much. We appreciate that.

Prof. Marsden—She will probably sell it to you!

Senator CAROL BROWN—I have a question to Professor Friedlander. In your opening statement you talked about the need for a commitment for ongoing recurrent funding, and Dr Martyn also talked about the need to raise the level of patient pool in the trials from three to 10 per cent, at a cost of about $1.2 million. What I want to be made clear to me is: is that the figure that you were thinking about in your opening statement or did you have a completely different figure in mind that would be required for adequate funding?

Dr Martyn—That is just the historical level. That is based on the cost of running our previous trial, so I do not think we could say that that is the exact amount we would need here on in. It is really just an indication.

Senator CAROL BROWN—If you were to go to the federal government to ask for some recurrent funding that you felt was adequate for your work, would you have any figure in mind?

Prof. Friedlander—It depends on the number of studies you are doing, and I guess the other thing to say is that in Australia we have been very fortunate to have the goodwill of all our colleagues in various units who have actually been running studies and accepting a minimal amount of money as payment. I do not know how long that goodwill will last.

We have much bigger problems in New Zealand, where they cost it to the dollar and then they knock us back. An example is the new study we are about to open with intraperitoneal

chemotherapy for women recently diagnosed with ovarian cancer. It is not using any new, fancy drugs. It is the same drugs just given via a different route. It was costed to the cent in Auckland and it was $NZ8,000 per patient, and we were offering nothing. They had to reject going on, whereas in Australia we have in many instances been able to involve others. The unis have accepted that and have paid the costs, but I do not know how much longer that will last. I think you are looking at at least $2 million plus a year to run a viable clinical trials program.

CHAIR—Thank you very much. We do apologise we do not have more time, because we could go on. Of course, we are seeing Dr Wain again. Are there any comments you would like to add on record today? You know that we can have evidence or any supplementary comments you would like to make for the next couple of weeks, but would anyone like to make any other comment that we have not had a chance to get from you in our questions?

Ms Maidens—Coming from a rural background, I would like to make the comment about somehow increasing the travel allowances paid to women to come from—

Senator WEBBER—Have you two caucused or something, Ms Maidens and Senator Adams?

Ms Maidens—I wrote it on the train coming in.

CHAIR—It is a critical aspect.

Ms Maidens—It is a critical aspect. There are lots of women out there in rural areas who do not want to come to Sydney because they cannot afford to. They do not want to leave their local area or, if they are happy to leave their local area, they still cannot afford to come to Sydney for their treatment. So they might be getting treated by a general gynaecologist out in a rural area when really they should be in a tertiary referral centre. So if they are getting more funding incentive to come down I think that is very important.

CHAIR—To provide that support.

Senator ADAMS—And we have not collaborated, either!

CHAIR—Thank you very much.

Proceedings suspended from 12.54 pm to 2.01 pm

FRANCIS, Ms Jane, Program Manager, Ovarian Cancer Program, National Breast Cancer Centre

ZORBAS, Dr Helen, Director, National Breast Cancer Centre incorporating Ovarian Cancer Program

CHAIR—Welcome. We have received your submission, which we have numbered 44. You have received information on parliamentary privilege and the protection of witnesses and understand the rules about in camera evidence, if you choose to give evidence in that way. If either or both of you wish to make an opening statement please do so, and then we will get into questions and discussion.

Dr Zorbas—Thank you for the opportunity to address this inquiry into gynaecological health in Australia. We have read with interest the submissions and also this morning we have heard some of the submissions to this inquiry. We would like to address some of the aspects relevant to the National Breast Cancer Centre and its Ovarian Cancer Program which may assist your deliberations. As has been stated before, the National Breast Cancer Centre was established in 1995 by the Australian government to improve outcomes for women with breast cancer. It was to do this by translating evidence into practice. Its remit was to cover all aspects of the disease continuum: risk factors, genetics, early detection, treatment and supportive care.

The centre's successes in breast cancer exceeded expectation and provided extraordinary value for money. It was on this basis that 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. This integration can be seen at all levels of our organisational and advisory structure. Our board of directors has both gynaecological and breast cancer consumer and medical representation. We have a small group of elite international advisers who ensure that we stay at the forefront of knowledge, who provide input into our strategic and business planning and who can advise on individual issues.

In the area of gynaecological oncology, our international adviser is Dr Maurie Markman, who is professor of gynaecological medical oncology at the MD Anderson Centre in Texas. Other international advisers who have broad expertise in cancer, including women's cancers, who work with us are Professor Patty Ganz at UCLA, Professor Jeanette Ward in Ottawa, Canada, and Professor Alan Rodger in Scotland. Our ability to maintain a leadership position is also supported by a clinical expert advisory panel that provide advice in their discipline and act as media spokespersons for the centre if required.

In ovarian cancer our clinical expert adviser is Dr Peter Grant, who is the head of the Department of Gynaecological Oncology at the Mercy Hospital for Women in Victoria and chair of the gynae-oncology section of the Royal Australian and New Zealand College of Obstetrics and Gynaecology. Professor Michael Quinn provides advice through our implementation advisory group. I am merely stating the extent to which we have input into our programs. Additionally, we have access to a range of experts relevant to gynae-oncology who have been

part of our advisory groups, particularly our ovarian cancer expert advisory group, which was chaired by Dr Gerry Wain, and also specific working groups.

Our advisory and working groups are multidisciplinary. They all include consumers and they focus on particular aspects of our work such as guideline and standards development, monitoring and data collection, information and communication, improving service delivery, communications skills training, psychosocial care and survivorship issues, and there are more. The Ovarian Cancer Program has worked effectively and productively with partner organisations, as Jane will speak to in a moment. Since 2002 Jane Francis has worked with the centre as the manager dedicated to the Ovarian Cancer Program. Jane is a senior member of our staff, and her project, staff and resource needs are fully integrated into our work program.

As well as senior project officers and project officers, the centre also has high-level in-house expertise in epidemiology, general practice, health services research, communication skills, multidisciplinary care, media and information involved in specific ovarian cancer projects or activities. The centre's successful model has been acknowledged as one that should be adopted to improve outcomes in other cancers. The principles underpinning the way the centre works are not disease specific or organ focused. The significant achievements of the centre's Ovarian Cancer Program over the past five years—they are outlined in our submission and Jane will highlight them in a moment—as well as the centre's leading work both nationally and internationally in aspects of care which are vital, such as multidisciplinary care, psychosocial care and communication skills, apply to all cancers and are testament to the transferability of the model.

I would like to take a moment to identify the key principles which underpin the model—in other words, the way we work. Our work is evidence based and our processes are rigorous. Our information and recommendations are thoroughly researched. They are up to date and based on the best available evidence. We value our reputation as a credible, trusted organisation. Our work is national in focus, which means that rural and urban, private and public settings are considered in the development and implementation of resources and projects. Our approach is inclusive and collaborative. Our work program is determined through very broad consultation with key stakeholders. We have a proven track record in bringing together people with divergent voices and views for a common purpose. We are not combined with any particular clinician, with any group, organisation, hospital or government. Our independence is vital to our credibility. Our work is outcome oriented. We assess the need. We define the problem. We develop innovative solutions. We implement them and we evaluate them. Perhaps most importantly, our focus is patient centred. We do not just pay lip-service to consumer involvement; we actively explore and respond to the needs of women and their families. We involve consumers in our work to ensure its relevance.

We are also clear about what we do and what we do not do. While we undertake qualitative and health services research, we do not do benchtop research. We are not active fundraisers. We work with governments, researchers, health professionals, cancer organisations, clinical colleges and consumers to improve the outcomes for women through the translation of evidence into improved clinical and supportive care and also by informing policy. We have a track record and a successful model, a wealth of expertise, a sound infrastructure, and years of relationship building which have achieved much in a relatively short time for women with breast cancer and

women with ovarian cancer. Although there are some significant differences, there are also considerable synergies between these women's cancers.

Importantly, the centre has demonstrated a commitment to addressing particular effects of cancer treatment and survivorship issues which relate specifically to women. For example, we are currently developing resources to assist women with issues of sexuality and body image, menopausal symptoms as a result of cancer treatment, and fertility issues. We have developed a psychosocial distress tool to identify women who might be at risk at an early stage. And we are developing evidence based recommendations for GPs about the management of lymphoedema of both upper and lower limbs as a result of treatment.

The model and experience could readily be capitalised on and extended to include other women's cancers. It is vital that we work with Cancer Australia to coordinate activities so that effort is not duplicated and to ensure that the limited resources and expertise in this country are maximally and effectively utilised for the benefit of cancer patients.

Ms Francis—Thank you for the opportunity to speak to the inquiry today. As Dr Zorbas has indicated, my role in the centre since 2002 has been to coordinate all aspects of the work of the Ovarian Cancer Program. This is an important role, and I feel that I bring to the program not only an understanding of the evidence and research about ovarian cancer but also a personal appreciation of the impact of a diagnosis of ovarian cancer on both the patient and on family members, having lost my mother to the disease some 28 years ago.

From the inception of the Ovarian Cancer Program, we acknowledged that we needed to work with experts in gynaecological cancer care. We have heard a lot today about a collaborative approach to working, and I think this is one of the achievements of the Ovarian Cancer Program.

We convened an interim steering group to develop the strategic directions for the work of the Ovarian Cancer Program. Right from the start we involved representatives from gynaecological oncology, such as Professor Neville Hacker, Mr Robert Rome, Dr Gerry Wain, Professor Michael Quinn, Professor Ian Hammond and Associate Professor Margaret Davy. We brought together people from across Australia. We also included experts in medical oncology, such as Professor Michael Friedlander, and in areas of research and general practice. We worked closely right from the start with consumer groups such as OvCaAustralia. We also included people involved in psychiatry and psychosocial care. We sought feedback about the strategic directions developed by the interim steering group from other key stakeholders right across Australia.

In 2002 we formed an ovarian cancer expert advisory group, chaired by Dr Gerry Wain, head of the Department of Gynaecological Oncology at Westmead Hospital. This was formed to oversee work on key projects. The idea was that this would provide us with a platform on which we could build the future work of the centre on ovarian cancer. This group included many of the gynae-oncologists involved in the interim steering group and also other people. We extended our consumer representation, our general practice representation, and we also included expertise in guideline development. This was through the involvement of Emeritus Professor Tom Reeve. The centre has also worked collaboratively with experts in ovarian cancer, as Helen has said, and working groups were formed to oversee and to provide advice on specific projects.

We succeeded in bringing together experts from relevant fields from across Australia who were prepared to come together to support a national program. We have continued to work in this way not only with certified gynaecological oncologists but also with medical and radiation oncologists, with those involved in psychosocial care, palliative care, nursing and genetics. We work with consumer groups, with individual women who have ovarian cancer, with their partners and their carers, with general practice through divisions of general practice, and with organisations such as the Lymphoedema Association.

As Helen said in her submission, I will be highlighting some of the significant achievements that our program has made since 2001. I think these achievements will highlight the collaborative approach of the centre and the partnerships that it has formed to work for improved outcomes for women in Australia with ovarian cancer. I have some resources here. They were made available to support our submission, but if you are interested we can provide copies for each of you.

The centre worked with the Australian Cancer Network to develop the *Clinical practice guidelines for the management of women with epithelial ovarian cancer*. These are the first ovarian cancer guidelines in Australia. Following approval of those guidelines by the NHMRC in March 2004, the centre conducted a national series of seminars for health professionals to raise awareness about the guidelines and also to encourage adoption of key recommendations. The seminars had the support of the college, RANZCOG, and involved gynaecological oncologists in each state. In the financial year 2005-06, nearly 700 copies of these guidelines were disseminated to clinicians across Australia.

To support of one of the key recommendation in the guidelines—that is, that women with ovarian cancer be referred for treatment by a gynaecological oncologist in a multidisciplinary gynaecological cancer centre—the centre developed a web based national directory of gynaecological oncology services in 2005. This was developed with the input and review of every gynaecological oncologist in Australia. It provides information about treatment facilities across Australia plus contact details and, so we can raise awareness of gynae-oncology as a subspecialty and awareness of the important role of gynaecological oncologists in the treatment of women with ovarian cancer, we also provide a link to a list of those gynae-oncologists in each state.

We recognise the importance of general practitioners as sometimes the first point of contact for a woman with symptoms that may be ovarian cancer. In 2005, based on the clinical practice guidelines, the centre developed a guide to assist general practitioners in the assessment of symptoms that may be ovarian cancer with a step-by-step process to follow in the investigation of symptoms. This guide was disseminated to over 22,000 GPs across Australia. It continues to be the most widely disseminated guide from the whole NBCC resource list, with nearly 2,000 copies disseminated in 2005-06. It is regularly requested as the key resource for GP education sessions, and it will be used for a teaching session for GPs to be held at John Hunter Hospital in Newcastle later this month.

In 2005, the centre launched the first national guide for women diagnosed with epithelial ovarian cancer. The guide includes information on things from diagnosis through to treatment and palliative care. It also has personal perspectives from women who have been diagnosed with ovarian cancer, their partners and their carers, and it includes examples of questions that women

might want to ask when they are talking to their doctor about their treatment. The guide was developed by a multidisciplinary working group, with input from women with ovarian cancer, their partners and their carers. I will quote a letter that we received following the launch of the guide. I will not use their name, but it was from the husband of a woman who provided input into the guide but unfortunately died before it was published. He wrote to us and said:

R would have been delighted with the results. This publication is a credit to all those who were involved, and it contains just the sort of information we searched for when R was first diagnosed with ovarian cancer in 1986.

Between the launch of this guide in February 2005 and the following month, March 2005, nearly 1,500 copies were disseminated. We had 350 calls for the guide and other information in the first three days following the launch, 160 copies were downloaded from our website in the first week after its launch, and it was still in the top 10 resources downloaded in the period July 2005 to June 2006. We actually had to reprint the guide, and 1,500 copies were disseminated between July 2005 and June 2006.

The centre has also developed and disseminated fact sheets for health professionals, but also for women, about the risks and symptoms of ovarian cancer and also the role of the tumour marker CA125 in the diagnostic process. The fact sheet on CA125 is actually in the top 10 resources downloaded in the last financial year.

During 2006 the guide about familial aspects of breast and epithelial ovarian cancer has been revised. This has been disseminated to all GPs across Australia. We had buy-in from every division of general practice to ensure this was disseminated. The centre is now going to translate this guide into a web based decision tool, and this will help to support discussion between women and their doctor about the risk of ovarian cancer based on family history.

The centre has also been involved with Ovarian Cancer Awareness Week since 2002 and we have always worked closely with the leading consumer advocacy group, OvCaAustralia, during awareness week. In awareness week this year, the centre and OvCaAustralia collaborated to conduct the first national Ovarian Cancer Consumer Forum. This is for women with ovarian cancer and their partners and families. We developed the theme of the forum from a supportive care survey that we had invited women to participate in, and we used the forum as an opportunity not just to provide information but also to give women and their partners and carers an opportunity to tell us issues of concern to them so that we can take those forward in our work plan.

During awareness week this year, the centre also promoted an awareness message about possible symptoms of ovarian cancer. The release that we issued was picked up media across Australia, with resulting television interviews and also radio and print interest. Interestingly, there was quite a bit of pick-up through regional radio and print, and this helps to get the message out to women beyond metropolitan centres.

We have also heard today a lot of talk about the need for consistent data and data collection. The centre commissioned the Australian Institute of Health and Welfare to develop a comprehensive report about ovarian cancer in Australia. This is still in confidential draft at this time, but when released it will really be the first of its kind in reporting about ovarian cancer in a number of key issues.

The centre is also working with gynaecological oncologists to gather information about how ovarian cancer data is collected currently. So we will be looking at databases across Australia to help inform work in standardised data collection and reporting.

There has also been other evidence given today about the role of websites and communicating through different mediums. When we first started the program back in 2002, we had a designated website set up; www.ovariancancerprogram.org.au. We established this to provide information not only to health professionals but also to consumers. We make copies of our resources available on the website for download. From 431 visits—that is not hits but actually visits, people using the site—logged at the end of December 2002, the site now registers over 3,000 visits per month, with a peak in March this year of 5,747 visits.

We have introduced some innovations such as podcasting to enable women to access information about familial risk of ovarian cancer and treatment that was presented at the ovarian cancer forum, and they can also log in and listen to an ovarian cancer survivor's personal perspective.

The centre also communicates regularly with over 200 people in the area of ovarian cancer through an electronic newsletter. We invite submissions from groups working in ovarian cancer. One of the things that will be in our next newsletter, for example, is information about the trial in ovarian cancer of intraperitoneal chemotherapy, which Professor Friedlander mentioned earlier.

The centre will continue to build on its achievements in ovarian cancer in 2006-07 in projects that cover areas such as multidisciplinary care, assessment of familial risk for ovarian cancer, development of standards for facilities providing IP chemotherapy, a speaker's kit to promote the adoption of the GP guide for assessment of symptoms that may be due to ovarian cancer, and a new electronic resource which will give health professionals a chance to look at the latest research in ovarian cancer.

We are also going to translate our facts sheet about ovarian cancer for women from culturally and linguistically diverse backgrounds. To make sure that we are helping to raise awareness and provide the appropriate evidence based messages, we will be working to provide information about ovarian cancer through a roadshow.

To continue our work in data, we will be looking at the establishment of a data set for ovarian cancer following our work that we are doing in surveying databases this year to promote the collection of standardised information about treatment nationally across Australia. Thank you.

Senator FERRIS—Firstly, can I congratulate you on the range of material that you have given to us here today and also the package of material that Dr Zorbas sent me. Given all of this material, how is it that when a previous witness, Carmen Duncan, goes around talking to people, looking to raise money for ovarian cancer, people say, 'I do not know what you are talking about'? How could it be, when so much material is available through a specialist resource, that this particular form of cancer is so poorly understood by the community? In spite of all the work that you do, could it be that, because of the fact that ovarian cancer is not incorporated in your name, the NBCC, the people who become really well informed are those who are touched by it and not those who ought to know about it? Have you thought about that?

Dr Zorbas—We have. We also feel that our name is possibly a barrier to the widespread knowledge and acceptability of the fact that we do work in areas other than breast cancer. In fact, quite coincidentally, we have commissioned over the past couple of months a social marketing branding agency to interview some of our key stakeholders to seek their views and input about how they view our work in breast cancer and ovarian cancer and about our name and what recommendations they should come up with in terms of branding and marketing. So I think it has been acknowledged for some time that our name does not perhaps give due weight to the work that we do in ovarian cancer and other cancers more broadly. I think that you are right though, to a certain extent, that human beings, being what we are, only pay attention to those things that are of interest to us or that affect us. It may be that most people will not be interested in something until it comes close to home. Breast cancer, because it affects so many in the population, is higher on the radar than ovarian cancer, which touches relatively fewer people in the community.

Ms Francis—We have actually had that sentiment expressed to us in letters from consumers saying, for example, 'I considered myself to be well-educated medically, but it was not until ovarian cancer became something personal that I started to take more notice of the information that was available.'

Senator FERRIS—We had evidence from the health department at the beginning of this inquiry and I asked them about a public campaign—something that might be similar to some of the campaigns that have been run for breast cancer, doing self-examination and so on, and they told me that I should ask you. They said they would act on a recommendation that came from an agency such as yours about whether or not they thought there should be a broader campaign conducted in the community on some of the symptoms which I think you have identified on one of your sheets there. I notice that fatigue, for example, is characteristic in 50 per cent of diagnoses. I wonder whether you have given any thought to the possibility of running a national awareness campaign and if you could put something on our record about that.

Dr Zorbas—We have considered that as part of our work program, but I should identify up front that our work program is not something that we develop in isolation. We certainly take advice from the broad consultation with stakeholders involved in our work every year. It has not been identified as a priority area by our stakeholders for the centre to have a public information campaign on ovarian cancer. What we have done to date is work with OvCaAustralia, particularly around Ovarian Cancer Awareness Week, where we come out with a single message. What we do not want is fractured or disjointed messages coming out at a time where there is focus on a disease. So we have worked very closely and successfully with them and brought attention to the issues of ovarian cancer, to the symptoms of the disease and the importance of putting it on the radar for GPs and for women around Ovarian Cancer Awareness Week.

What we are doing this coming year, as Jane alluded to, is using the opportunity of a commercial enterprise, visiting in the vicinity of 15 to 20 regional towns across Australia, and using that opportunity to take some of our key messages in both breast cancer and ovarian cancer to the women in those communities. For us that is an efficient way of getting those messages to women and using the powerful drawcard to bring women into those opportunities.

Senator FERRIS—Do you have any idea of why the stakeholders would have taken the view that they did about an awareness campaign?

Dr Zorbas—You might want to provide some insight into that, Jane; my understanding is this. Where the evidence around any particular symptom is still not available to us, we would not mount a public awareness campaign. We are still waiting for the outcomes of that trial we heard about this morning that is under way in Queensland, where they are collecting data from a number of women. If we could find a particular group of symptoms, for example, that were more significant when pooled together, that could give us an important key message. The message around early detection is around symptoms that are vague and common, and it is not a simple, clear message about awareness or screening or anything that you could put into a clean package for women. Unfortunately, that is the case at the moment.

We have worked more on the other side, in working with the general practitioners. We have put a lot of energy into that because we want them to have it on their radar, to think, 'Maybe this woman could have ovarian cancer and we should be appropriately investigating her.' But our advice has been that, where there is not a strong evidence base, there would not be a lot of gain in going out with a huge public awareness campaign.

Ms Francis—I think that is correct. We have also had feedback from women themselves who said it is very hard. There is no definite call to action. As Helen said, we have to be careful that we are not unduly alarming women. So I think that we have taken, if you will, a responsible approach. The focus on Ovarian Cancer Awareness Week has been very successful. As I said, we have had great pick-up of our message from regional as well as metropolitan areas. We have also worked closely with OvCa to indicate that women should be aware of symptoms but that they should also think in terms of the persistence of symptoms—not just to think, 'I've had a pain in the side today, so I might have ovarian cancer'. So we have tried to put it in an evidence based and responsible approach.

Working with the GPs was recommended to us by our groups and our stakeholders, so that doctors could at least consider, 'Could it be ovarian cancer? Someone has come back to me; this is their third visit.' So that, rather than just saying, 'We don't know what it is,' they actually take some steps to investigate. We think that that has been important and I know that OvCa has had feedback as well that our GP guide has been very well received.

Senator FERRIS—But characteristically—and we heard the evidence this morning—people are either diagnosed late or misdiagnosed. So, whilst I accept all of that, almost everybody who goes to a GP and presents with some symptoms which are on your list there—50 per cent of them being a chronic fatigue set of symptoms—and who are subsequently diagnosed with ovarian cancer are diagnosed late, unless they are assertive and ask for a CT scan or an ultrasound or something like that. So while I accept all of that, and I think it is very valuable and the work that you are doing is extremely valuable, you are not getting to the women who are at an early stage. You might be informing GPs, but their mail is probably like our mail—it is a pile this high every day. Therefore I question whether this reactive way of dealing with it, from the top down rather than from the community up, is actually the right way. But I will leave it at that.

Senator CAROL BROWN—Can I ask about the guide that you send to GPs? Do many follow up? Do you have feedback from GPs themselves? You mentioned that you have received feedback from OvCa, but what do you do to see if it is helping GPs or they are using it?

Dr Zorbas—The fact that we keep getting orders for resources means that GPs are wanting it and using it. Also, we are not just sending them out; we are making sure that they are taken into practice by some implementation strategies, through divisions of general practice. For example, in this financial year we will develop a speakers kit that will hopefully be used in the divisions themselves. It will enable one general practitioner to educate other general practitioners within their division about the use of that guide as well as some of the other resources that we have on ovarian cancer. We almost always try to not just let the information go into a vacuum; we need to follow it up and make sure it is being used.

Senator CAROL BROWN—In which year did you send that guide out?

Ms Francis—In 2005.

Senator CAROL BROWN—We have had evidence presented here, as Senator Ferris has indicated, that women have had to go back time and time again, feeling unwell, and the correct diagnosis has not taken place. Is there any other measure to see that what you are putting out is actually working—that there is a greater rate of earlier detection?

Dr Zorbas—There are two things to say about that: it is not just the detection but also the appropriate referral, which that guide really emphasises. We were talking at lunch with Dr Gerry Wain, who suggested that the referrals that he has been getting over recent times are much more appropriate. He is getting more referrals of women with cancer. That is anecdotal and we need to investigate that at a national level. It would seem to us from the feedback that we are getting that, drip by drip, we are getting through to the general practitioners, and they are vital in this process.

Ms Francis—When we did some seminars to promote the practice guidelines, we also involved general practitioners. We invited general practitioners to participate. Even before we had that guide developed on the basis of the guidelines, I had general practitioners at those seminars saying, 'That's been really useful. Instead of thinking, "I haven't seen many ovarian cancers," when women come to the surgery I'll now start to think, "Maybe I should be considering this—maybe there's something I can do."' Again, it is anecdotal evidence, but I think it does support that there has been an impact on the thinking of general practitioners. It is a very difficult disease. Women may present with symptoms that they have had for only a few weeks and yet the disease may be well advanced. It is very hard, but least if the GPs can have something to help them say, 'I've asked about the family history; I've looked at the symptoms; I now need to consult a gynaecological oncologist,' the woman may at least go forward, have treatment to relieve her symptoms and have a better outcome than just being sent away again. As I said, it is a factor of the nature of the disease as well. We need to have awareness so that women can be promptly referred for appropriate treatment.

Senator ALLISON—We heard this morning that 50 per cent of women diagnosed with ovarian cancer receive inadequate treatment, mostly because they are not referred to gynaecological oncologists. Is that your understanding too? How do you overcome that situation? What are you doing to deal with it?

Ms Francis—That is our understanding based on some research that was done in Australia. The work that we are doing, in terms of the GP guide and the web based directory, will help to

raise awareness and ensure that health professionals consider an appropriate referral to a gynaecological oncologist. We have had support from the College of Obstetricians and Gynaecologists in terms of promoting the guidelines, but they also have a link to our web based directory so that gynaecologists coming to their site can see that information is available to guide their referral processes. As Helen has alluded, these things do not happen immediately, but there is certainly some indication that people are becoming more aware of the role of the subspecialty and also the fact that, as we say in the guidelines, even if it is an inadvertent discovery of ovarian cancer, perhaps during surgery for something else, they can now be advised that they should seek that appropriate referral rather than just saying, 'There's nothing we can do.' Those sorts of things will spread over time.

Senator ALLISON—Regarding the guidelines that you have produced, are they quite explicit in saying that, even for stage 1 of ovarian cancer, a woman should be referred to a gynaecological oncologist? Is that your line, as it were?

Ms Francis—Yes.

Dr Zorbas—Absolutely.

Senator ALLISON—That is a very high number—50 per cent having surgery with gynaecologists, general surgeons or even GPs, as we heard this morning. How do we overcome that?

Dr Zorbas—I think educating general practitioners is No. 1. There is also a very strong move in this country towards multidisciplinary care and centres of excellence with multidisciplinary care. That does not necessarily mean that all people need to be in the same physical environment, but it does mean that there is a team approach to care. I think it is going to be accepted as the gold standard before too long—if it is not already—that nobody with cancer should be treated by clinicians working in isolation. They should be part of a team working with expertise around them that they can draw on and tap into so that the patient has the benefit of that team approach to care. That is happening across Australia to varying degrees. New South Wales and Victoria are perhaps a bit ahead of the game compared to the other states purely because money was put into their programs in cancer care earlier. At a national level too there is a real commitment to multidisciplinary care.

Senator ALLISON—That does not tell me that some women are being treated inadequately. Sorry to keep coming back to you on this, but sometimes we get a bit bogged down in the multilevel care or whatever it is and away from quite an important principle—that is, that people need to be treated by the experts here whom we are talking about.

Dr Zorbas—Sorry if I have not been clear about that, but the multidisciplinary team would have identified expertise. Therefore if a general practitioner sees someone with an ovarian symptom which looks like it could be cancer then the mindset will be such that they will directly refer that patient to a multidisciplinary treating setting for gynaecological cancer or whatever cancer it may be.

Senator ALLISON—I will mention the elephant in the room—that is, that almost everyone is saying that ovarian cancer should not be treated through the Breast Cancer Centre; that there

should be a gynaecological cancers centre to bring together not just ovarian cancer but all the other gynaecological cancers, of which there are at least a dozen. We have heard that you are doing good work on ovarian cancer; that you are not organ focused, as you put it; and that your model applies to everything else. But can you see some value in having a gynaecological cancer approach perhaps within Cancer Australia rather than tacking it onto breast cancer?

Dr Zorbas—I think what we need to do in this country, if I can just step back from that question a little, is really ensure that we are capitalising on expertise and resources. I cannot emphasise this enough—it is the approach and the model of the NBCC that is the most successful; it not necessarily because it has focused on breast or any other cancer. I feel it would be an enormous waste not to use something that is tried, tested and true, and which we know has the ability to add enormously to the improvement in cancer outcomes. This is not associated with any particular group or even discipline; it manages to sit above all of the individual interests. It is because of that credibility, independence and authoritative status that you can get buy-in from both the clinical and the consumer communities. I think whatever it is needs to be very carefully thought through in terms of rationalising, consolidating and building on positives where there has been a wealth of experience.

Senator WEBBER—In your submission, you talk about the overwhelming demand you have for the material you produced on breast cancer in other languages. You say you are working on that for ovarian cancer. How is that going?

Dr Zorbas—That is part of this year's business plan.

Senator WEBBER—We are halfway through this year. Or is it a financial year plan?

Dr Zorbas—It is for the financial year, yes.

Senator WEBBER—It said 'in 2006' and I thought: 'Well, we're in August now. We must be getting close to something.'

Ms Francis—We have already started to put that process in train within the centre. We are getting quotes. As I said, we are translating that fact sheet. That is happening.

Senator WEBBER—I am not sure which one of the two of you it was—and I apologise for being a little bit late back from the lunch break—who was talking about the work you were doing not just in breast cancer and ovarian cancer but in other areas. Is that work in other gynaecological cancers or is it other education work?

Dr Zorbas—Some of the work is generic across cancer. On the psychosocial guidelines, for example, that we developed initially for women with breast cancer, it soon became quite obvious that there was no reason to limit that support to women with breast cancer. They became generic cancer guidelines. They are for the psychosocial care of adults with cancer, for example. The information that we are now developing for consumers is also around generic cancer. Communication skills training is another area. Breaking bad news is applicable to any cancer patient, for example. The discussion of the transition from curative care to palliative care is, again, transferable across all cancers. The work we are doing in multidisciplinary care is relevant across all cancers. The principles that can guide cancer care in any cancer are there.

Senator WEBBER—With your indulgence, I have two more short questions.

CHAIR—Two more.

Senator WEBBER—In response to a question from Senator Ferris, you talked about the awareness week. I am from Western Australia—and Senator Adams might correct me on this—and most of the information ovarian cancer that comes to me is from GAIN rather than from any awareness week thing. Perhaps those of us in the west are missing out on something.

Senator ADAMS—Yes, you are right.

Senator WEBBER—Is that something that highlights the need for that public education campaign that Senator Ferris was working on? Any comments you have on that would be welcome.

Ms Francis—I would hate to think that the west was missing out on something.

Senator WEBBER—Not as much as we hate to think that!

Ms Francis—We disseminate our information widely and make it available to all media, and we have had media coverage in the west through the *West Australian* and other print media. I know that GAIN has a high profile in the west. If you look at how the awareness message and the reach has grown since 2002, you will see that when we first started to be involved we had a couple of print stories and four radio interviews and that for the last awareness week we had national coverage. It does go national. I am sorry if it does not happen in the west, but we are getting that national interest from various TV stations, print and radio.

Senator WEBBER—That is reassuring.

Dr Zorbas—Sometimes a lot of the awareness raising is through organisations that are fundraising. That is not something we do. That is possibly where you are getting some of that information from. It could be through fundraising activities.

Senator WEBBER—My last question is this. I guess it is the reverse of Senator Allison's question. What has been put to us is that there is a need for a specialist organisation. You have a view, and I accept that. The flip side of that is that, if we made your centre the national centre, would that then diminish your focus on breast cancer? You are recognised Australia wide for that. It is a very prevalent cancer in women. Would it detract from that?

Dr Zorbas—I would like to think that we could do it all well, and I think we can. I think that breast cancer will always have a need. There are large numbers of women who are affected by the disease annually in this country, but it would be criminal not to use what we have learnt from breast cancer—it has led the way, there is no question, in all aspects of care—for the benefit of other women with their cancers. I think we would continue to make gains. We would make leaps in other areas because you are coming from a much lower base of information, support and care.

In breast cancer, the gains are going to be smaller because we have come a hell of a long way but there is still work to be done. I do not think they are mutually exclusive; they all gain from

one another. In fact, when we had the consumer forum this year, one of the things that was most daunting for me was the sense of deja vu. We were hearing from women with ovarian cancer and their families the same stories that we heard from women with breast cancer a few years ago—the same issues, the same needs, the same lack of supportive care, the same lack of information availability. There is so much commonality in these areas that I think it is that experience that will benefit all in the end.

Senator ADAMS—Does your organisation have any connection with Cancer Australia?

Dr Zorbas—Cancer Australia is established as a known organisation in that it has a chairman and an advisory council but it is not a real entity yet. The CEO has not yet been announced and therefore it has not got going so to speak. Our relationship with Cancer Australia, having said that, is that I have had discussions and conversations with it and met with the chairman, who is very interested in our work and how we might feed into and add value to Cancer Australia. A number of members of our board have been invited to be members of the advisory council. A member of our staff is also a member of the advisory council, our GP coordinator. So in some ways, although it is not established as such, we have links and a relationship of sorts with it. We look forward to working with them. It is a long awaited entity. We need coordination of the cancer effort in this country and, hopefully, it will deliver on that.

Senator ADAMS—The composition of the board is not representative but of people who have expertise in various fields. Do you consider that that composition is adequate to achieve the results they wish to achieve?

Dr Zorbas—As you would know, the appointments are ministerial appointments.

Senator ADAMS—I realise that. What is missing?

Dr Zorbas—I do not think I can comment on what is missing because I do not have a clear understanding of the final structure of the organisation. I do not think that the advisory council is meant to have representational cancers, for example. It remains to be seen how the organisational structure will look and how the different cancer needs will feed into that advisory council, so I really cannot comment beyond that.

Senator ADAMS—There has been quite a lot of criticism that no consumer has been appointed. Have you got any comment about that?

Dr Zorbas—Jocelyn Newman is on it.

Senator ADAMS—I realise that, but it is a little unfortunate that a number of consumer organisations feel that Jocelyn Newman is a very high profile person but they have not got what they term a 'consumer' from the wider field. Jocelyn is an expert in what she does. I am sure she can represent them but I had a number of letters from constituents about it when the composition was announced.

Dr Zorbas—I do not know whether the intent was to have representational groups on the committee because it would be impossible to do so. I am sure there are other groups who would feel equally that they are not represented on it but I think the answer will come when we find out

how these groups feed into providing advice to Cancer Australia. I suspect that a lot of energy will be put into ensuring that consumer voices are heard and provide input into the workings of Cancer Australia.

Senator ADAMS—I have a question on the current funding arrangement for your organisation. How are you funded?

Dr Zorbas—About 93 per cent of our funding comes from the Australian government. We do get some donations and we apply for grants, for example, and we might be successful. That would make up the other seven per cent of our funding, but the vast majority of our funding is from the government.

CHAIR—Would either of you like to have any further comment on record?

Dr Zorbas—I think that is all.

CHAIR—I know you have studied the submissions. If anything comes out I am sure we will be hearing from you. We do appreciate the support you have given to this inquiry from the very start. Thank you very much.

[2.56 pm]

LANCASTER, Ms Tish, Member, Cancer Nurses Society of Australia

RYAN, Dr Mary Elizabeth, Member, Cancer Nurses Society of Australia

CHAIR—Welcome. I know that you have received information about witness protection and information about how the hearing operates. Do you have any comments to make on the capacity in which you appear?

Ms Lancaster—I am the former deputy chair of the Cancer Nurses Society of Australia. I am a clinical nurse consultant in gynaecological cancer. I have worked as a cancer nurse for 23 years and I have worked in gynaecological oncology for 11 years.

CHAIR—That sounds very tiring!

Dr Ryan—I am a clinical nurse consultant in gynaecological cancer. I have worked in the area of gynaecological cancer for 17 years and as a clinical nurse consultant for the last 12 years.

CHAIR—We have your submission, No. 20. Either or both of you may like to make an opening statement and then we will get into discussion.

Ms Lancaster—In the interests of time I do not propose to rehash our submission.

CHAIR—We have read it, we promise you.

Ms Lancaster—There are some points that I would like to highlight and also some points that have been brought out during this morning's discussions. First of all, I would like to highlight on behalf of the society that gynaecological cancers are really a number of diseases and today we have really only heard about ovarian cancer. They are a disparate group of diseases with differing presentations, treatments and outcomes.

Nurses from a very wide range of practice settings care for women with gynaecological cancer. It is not just nurses in the large tertiary centres but nurses from community and primary health backgrounds; nurses from regional, rural and remote areas; nurses working in general medical and surgical units that are not cancer specific or even perhaps gynaecology specific; and nurses from palliative care and support areas. In recognising this diversity of nurses it is our proposal that not every woman that has gynaecological cancer will be cared for by a specialist nurse. They may come in contact with a specialist nurse at points in their cancer journey but many of the side effects of treatment and sequelae of their disease will be managed by non-specialist nurses.

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.

We believe that the intimate nature of nursing care that is involved for women with gynaecological cancer well places nurses to identify the needs of women, to address some of those needs and to make appropriate referrals to other health practitioners that may also assist in addressing those needs.

One of the issues that we would like to highlight from this morning's presentations is the issue of women living in rural and remote areas and the access that those women have to specialist nurses or generalist nurses. It is our proposal that at some stage women should have access to a specialist nurse but that the nurses they may well come into contact with for the remainder of their cancer journey will be generalist nurses from those areas, and those nurses should receive the same support and levels of training and levels of education as nurses in specialist centres.

While I come from New South Wales and recognise the huge areas that New South Wales covers, in areas like Tasmania there is only one specialist gynaecological cancer centre. Women from all over the state go to that centre in Hobart, then they might go out to regional areas around the state, including places like Launceston, Burnie and Devonport, to have their chemotherapy and the remainder of their follow-up care. There are not specialist gynaecological oncology nurses in those centres. It is my understanding that they are seeking funding to support a specialist gynaecological oncology nurse position in Hobart, but at the moment they do not have that in that unit.

We are all aware of the really vast areas that Western Australia covers. Women come enormous distances to Perth for their treatment in specialist centres, but the follow-up is often difficult because of the tyranny of distance and also the cost. I would like to put the issue of the cost and transport on hold and speak about that a little bit later. For women in Western Australia with gynaecological cancer, the gynae cancer specialties are in Perth. But it is my understanding that even out of Perth there are only three gynaecologists. That makes it very difficult for women to have any sort of continuing, long-term follow-up. It is often the nurses in those areas to whom the women turn, especially when managing the long-term side effects of treatment, such as lymphoedema, chronic bladder and bowel dysfunction, ongoing menopausal symptoms and those sorts of things.

There was brief mention this morning of vulnerable groups 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.

This morning we were speaking about clinical trials and women being enrolled in 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.

The wealth of information that we have discussed that is available to women with all sorts of cancers and indeed anybody with a cancer diagnosis is not often translated into many other languages. It might be translated into what we call common community languages, which include things like Arabic, Italian, Greek, Vietnamese and Chinese, but there are many other languages for which there is no written information.

Women of socioeconomic disadvantage have a great deal of difficulty in accessing services simply because they cannot afford to get there. I am not even talking about people in rural settings—I am talking about people who live in big cities. If you are in a position where you cannot work because of your illness, perhaps your partner has taken time off to look after you or your children and there is no regular source of income or the regular source of income is Centrelink payments, sometimes it is not even possible to afford to get to a treatment centre in a big city. They are relying on community transport or friends or family to bring them. For some people who do not have access to a family member or friend with a car, they are travelling on public transport when they are very unwell.

Mental health problems are a significant issue for a number of women. As we heard this morning, for some of these women cancer is just another problem in their very busy lives. It is almost that a diagnosis of cancer does in fact afford them some access to some sort of health service and supportive community services that they have not been able to access before.

In talking about women from non-English-speaking backgrounds and from immigrant and refugee backgrounds, this morning somebody asked a question about pap smears for those women. 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.

People think of common examples like Muslim women. That is fairly easy to get around because we have a lot of female doctors, nurses and other healthcare workers who can often do that sort of thing. In most hospitals there is usually someone who can meet those needs. But there are cultures where it is just not acceptable for anyone to deal with that sort of thing. It is seen as their husbands' business.

In some cultures it is not appropriate for women to seek health care themselves. It is the dominant male in their family who decides whether or not they seek health care—that is, either their husband or their father. If a woman has a gynaecological problem they may in fact find it difficult to discuss it with the dominant male in their family. That delays them seeking health care. In some cultures cancer is not a word that is commonly used because it is associated in that culture with death. So they just do not use the word at all. They are the cultures that ask that the diagnosis not be disclosed to the woman.

It is in those areas and some of those aspects that nurses are very well served to address. As I said, nursing services are 24-hour-a-day services in hospitals. In outreach services, many of the

people who do after-hours on call in rural and remote areas are in fact nurses. So they are often the people who are the first port of call for some women.

We have also heard several times today about knowledge of gynaecological cancer and women saying that they had never heard of ovarian cancer until they got it or until they know somebody who gets it. I think that is not particular only to ovarian cancer; I actually think it is particular to many cancers. Breast cancer is bandied about all of the time. Most people have heard of breast cancer. Most people have heard of lung cancer because of the association with smoking. There are many cancers that people had never heard of until they get them or until they know somebody who has them. So I do not think that is particular to ovarian cancer.

I think nurses are very well placed in a health promotion role for all gynaecological cancers. When you look at things like endometrial cancer, which is in fact the most common gynaecological cancer in Australia, the greatest modifiable risk factor with endometrial cancer is obesity. So, in terms of health promotion, nurses are well placed to address that sort of issue. They are well placed to look at issues of smoking and quit smoking initiatives, and smoking is implicated in the development of cervical cancer.

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.

Nurses are very well placed to promote good nutrition and a healthy lifestyle. That sounds almost a little simplistic, but I talk about healthy eating habits to an extraordinary number of women after they have had their surgery, for example, or when they are about to embark upon radiotherapy or chemotherapy. It gets down to the basics of five pieces of fruit and vegetables a day. Many women have not had that in their lives, so asking them to do that now is actually a big deal. I had a woman who said to me the other day, 'You must be joking; I couldn't possibly eat all of that.' So there are some very basic health promotion activities that nurses are very well placed to engage in.

I will defer to Mary to address the long-term sequelae of treatment for gynaecological cancers. I would just like to speak a little further on the issue that Jayne Maidens spoke on this morning about educational programs for nurses caring for women with gynaecological cancer. Mary and I were also part of the GMCT initiative where we gained some funding for a study day for nurses to come to Sydney. We have done that for the last three years now, and we still have recurrent funding for that. Anecdotally, we had had a lot of nurses approach us to ask, 'Why isn't there a course for nurses in gynaecological cancer?' We had the feeling that they should be looking at a generic cancer course rather than at a very specific one, so before we actually approached an educational institution we thought we would do an educational needs analysis to see exactly what these people were asking for, what they really wanted, whether they were prepared to pay for it and how much they were prepared to pay.

I will give you some examples of the people who came. As was mentioned this morning, about 200 nurses attended each day. Sixty-eight per cent of them came from the public sector, 15 per cent from the private sector and three per cent from non-government organisations such as the cancer councils. They are the nurses who work on the help lines there where patients ring in to ask for support or for information about their cancer.

Fifty-eight per cent of them came from the greater Sydney metropolitan area, 18 per cent came from regional New South Wales, 10 per cent came from rural New South Wales and 14 per cent came from interstate. That was very interesting, because we were not funded to do this for nurses from interstate and we did not advertise it interstate, but these people found out about it and were really keen to come. We said, 'You can come for free but we cannot fund your air travel or your accommodation.' They said, 'That's fine; we're happy to do that.' So the funding we were successful in gaining funded travel and accommodation for New South Wales nurses from outside Sydney.

When we look at them by workplace and by speciality—this is nearly 200 nurses each time—we see that only 42 per cent of them came from specialist cancer units, be that gynaecological oncology, radiation oncology, palliative care or medical oncology. So 58 per cent of them were non-specialist cancer nurses, and they were all looking after women with gynaecological cancer. They might see only one or two patients a year, but they felt that it was an area in which they lacked knowledge. They wanted more information and access to the people who worked in those units so that they had someone to ring up if they needed to ask questions. It was a very experienced workforce that we were looking at: 53 per cent of them had been registered nurses for 20 or more years—so more than half of them had been nursing for more than 20 years—and 78 per cent of them had some sort of higher qualification in this speciality, be it a speciality certificate, a bachelor's degree, a graduate diploma or a master's degree. So we had a very experienced and fairly well-educated workforce that was coming along.

We asked them several questions about how confident they felt in addressing particular issues relating to gynaecological cancer. I will not go through all of them, but 66 per cent said that they were either very or moderately confident about talking to women about gynaecological cancer in general. Only 18 per cent said that they were confident in talking to women about genetic susceptibility, and only 29 per cent said that they were very or moderately confident about addressing issues such as clinical trials—that is, explaining what a clinical trial was, how it worked and what the advantages might be to the woman. They were fairly confident in addressing common practical issues that nurses routinely address with women, such as bladder and bowel problems, the emotional impact of cancer, pain management, sexuality and body image, and fertility. But, when it got down to things like lymphoedema, menopausal symptoms, sexuality—those sorts of things—they were less confident in addressing them.

We found that we had a very experienced workforce—they were very well educated in their specialty—and that they felt confident in addressing common symptoms and common issues relating to gynaecological cancer but that they were less confident in addressing the more specialised issues. We asked them how long they would like to do a course for, if it were available, and how much money they would be prepared to pay for it. Quite a lot of them—60 per cent—said that they would like a course that went for six to 12 months. There were other ranges of things. The other most common one was that 15 per cent said they would like to do a course for one week. That reflects the nature of the nurses who were there: some of them came

from very outer rural New South Wales—very remote areas of New South Wales. Realistically, doing a course that went for six to 12 months was not possible, but coming into the city for a week was possible for them. When we are looking at offering educational opportunities for nurses, we need to consider a whole range of factors which include where they are from, their locality and what sort of practice they are working in. Often nurses will tell you that they would love to go to a certain course or a conference but that there is no-one to fill in for them while they are away—the ward or the clinic would run short if they were not there—so they cannot go.

We are also looking at things like age and family factors. The nursing workforce in Australia is an ageing one. In New South Wales the average age of a registered nurse is 48, and that is similar not just across the states but in other developed countries. So nursing is an ageing workforce and with that sort of age come family responsibilities with children, elderly parents and that sort of thing. Those are all the factors that impact on the way nurses seek out educational opportunities.

I know it was brought up this morning, but I would like to highlight the issue of travel for patients from rural areas. While this was addressed during last year's Senate inquiry, it is really very difficult for many people to travel to large city centres for treatment, even with the reimbursement that is provided. For some people who live in country areas that are doing it tough, the idea of even picking up a phone to ring me in a specialist centre is difficult. I usually say, 'You hang up and I'll ring you back,' because they just cannot afford the phone bill. If they want to have a long chat about something that is a problem for them, they cannot afford it. I cannot emphasise enough the needs of people from rural and remote areas, but also people who live in big metropolitan areas but are not from comfortable backgrounds. It is those women who will never really be represented at hearings like this.

Dr Ryan—While Tish has focused more on broader nursing issues, I wanted to speak more about the experience of women living with gynaecological cancers based on some nursing based research that has been done in the centre. Firstly, my PhD, which I completed last year, focused on the experience of women with recurrent ovarian cancer. While it has been brought up in just about every submission, I did want to point out the persistence of women to achieve a diagnosis of bodily symptoms which they know are abnormal. From my own study I learnt that some women had to continue going back to doctors for up to 18 months complaining of symptoms before they were able to achieve a diagnosis. Such was their frustration that, while they were shocked by their diagnosis, they were actually relieved in the end to have found a cause for their symptoms.

Of course, we have just heard from the NBCC and the ovarian cancer support program how they are educating GPs. My concern initially was that the education needs to be carefully tailored so as not to create a scare campaign, but I just heard from Jane Francis that they are considering this. In my experience of working in gynaecological cancer over the years, we have seen advancements in surgery and new treatment options becoming available for women and therefore women are living longer with ovarian cancer. Indeed, some of the women I interviewed for my study lived up to 15 years with ovarian cancer. While the average age of women who develop ovarian cancer is early 60s, the most recent statistics, from the Australian Institute of Health and Welfare, indicate that around 1,300 women were diagnosed with ovarian cancer in 2001 and 20 per cent were aged below 50, so a lot of them were still in the workforce.

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 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. And, once again, another issue that arose from the study included the need for support in country areas. So while the women in my study felt supported when they were in the large tertiary institutions, within a unit dedicated to the care of women with gynaecological cancers, they described a lack of services when they went back to country areas and even faced difficulties being heard when they felt there was a possibility that their cancers had recurred.

The second piece of research, which was on the prevalence of lower limb lymphoedema for women with gynaecological cancers—and this issue was brought up earlier—highlighted that there was very little published research into the prevalence of lower limb lymphoedema and its incidence in women following their treatment for gynaecological cancers. And, while we had felt that women were receiving adequate education, we learnt from this study that they were not. Some of the women we interviewed for the study had never heard of lymphoedema and were actually diagnosed as a result of this study. So the study highlighted not only the personal impact of the condition on women but also the enormous gap in knowledge about the condition in the medical and broader community. And there is a huge lack of available resources to treat the condition when it is diagnosed. That is all from me.

CHAIR—I am not sure whether there are any questions we can ask after those amazingly detailed and very valuable statements that you have made. I might change the order this time and get our resident nurse to ask the first question, because I know she will be burning to ask questions.

Senator ADAMS—Thank you. With respect to the role of the specialist nurse, what do you suggest, as far as scholarships go, could help a number of these experienced nurses to become specialist nurses in these areas?

Ms Lancaster—There are some scholarships available and as years go by there are more and more available to nurses. The Cancer Nurses Society of Australia provides some scholarships but we are limited by our income as to how much we can provide. The Cancer Councils in some states provide scholarships for nurses. In New South Wales the New South Wales Cancer Institute provides scholarships for nurses, and there are other funding bodies in each state that provide scholarships. As I said, the difficulty is probably in finding something that is tailored to

the needs of a particular nurse. And to be fair, nurses in specialist gynaecological cancer centres will be looking at very specific educational opportunities but those in rural centres are probably seeing not just women but all sorts of patients with all sorts of cancers, so their needs are broader. For example, in Victoria, the Cancer Council provides courses for nurses in breast cancer and in prostate cancer.

There are some courses like that around but they are very much tailored to the big issue cancers. So the issues include not just funding but being able to access the funding, and, as I said, things like being able to be relieved from your workplace, being able to leave your family and being able to get your husband to look after your kids for a week, two weeks, a month or whatever it is.

The College of Nursing in New South Wales provides a graduate certificate in cancer nursing. The University of Sydney has just started up a master's program in cancer nursing. All the other states and territories in Australia, other than the Northern Territory, have master's programs in cancer nursing. So it is not for a want of opportunity. It is more the practical issues related to it, although, as I said, these nurses were very specific about wanting to do a gynaecological cancer related course.

Senator ADAMS—Is there any way that we can get universities to pick that up as a diploma course, or something that is not quite as involved? To do a master's will take them out of the workplace for so long. Where can we go for a practical solution that may be able to be funded from somewhere that will help us get people on the ground who are capable of doing the work that we need?

Senator FERRIS—Maybe an external one through Deakin, UNE or somewhere like that?

Ms Lancaster—Most of them are external programs. I think that the GMCT model that we have here in New South Wales is a good start. They are only a day, but it is a good start—that we are able to fund the nurses from out of Sydney to come. The feedback that we get is that they are so grateful. They write all over the forms, saying, 'Thank you so much for organising the airfares and the accommodation for us,' and that sort of thing. It is reimbursable, but they are willing to pay for it up front. They are just so grateful that they do not have to incur those expenses to attend.

Senator ADAMS—Could you put forward—I know you do not have it here—the package that you send out to attract them? Could we have that sent to us for the inquiry?

Ms Lancaster—Yes. We have, as previously mentioned, the six gynae-oncology units in New South Wales. Each one of them has a nurse consultant. We have very good and extensive networks of our own, with not just other cancer nurses but also women's health nurses, community nurses, palliative care nurses and generalist nurses. We use those networks and get them to distribute it as well. This year we even had someone from New Zealand. She found out about it and paid to come over from New Zealand just for one day. They are very keen.

The other thing that we did in trying to fill the gap—because there were these nurses who were very thirsty for knowledge—was that we developed, as Jane Maidens or perhaps Don Marsden mentioned this morning, a textbook on gynaecological cancer for nurses and allied

health professionals. It was almost easier to write a book—and I know that sounds silly because it took 18 months of our lives to do it—than to approach an educational facility with a proposal for a curriculum. That has been very successful, and our publisher gets very excited about it and has recently had a request to translate it into Spanish for the South American market. So it turned out to be a whole lot bigger than we thought it would.

Some of that was because we asked some of our colleagues from overseas to write chapters. That gave it an overseas market, so it has not just been a local thing. It has had this enormous spin-off that we did not ever anticipate. The nurses who come to the study days, the nurses who work in our units and even the junior medical staff really love it, because it is a practical, evidence based, woman centred approach to gynaecological cancer.

Senator ADAMS—That sounds really good. Getting on to lymphoedema, how can we promote the problems associated with lymphoedema as far as getting a practical solution to giving women a much greater opportunity to be treated? That seems to be the biggest problem.

Dr Ryan—Yes, it is. It is a huge problem in terms of educating practitioners and being able to provide facility for lymphoedema management to happen in hospitals. It is a time-consuming process and it is specific. I had an interest in what happens to women as a result of gynaecological cancer treatment, so I am not a lymphoedema practitioner but I think there are a few. They are not limited to physiotherapists either. OTs, physios and nurses can be trained as lymphoedema practitioners. The garments that are required are expensive too.

Senator ADAMS—Very.

Dr Ryan—There needs to be an injection of funds from somewhere to be able to provide the expertise to manage the condition and to educate people that it is a possibility that can occur, so as to try and prevent the degree of disruption it can cause or reduce the effects of it.

Ms Lancaster—It is also expensive not only with the garments but with the very time- and labour-intensive treatment. Many hospitals do not have lymphoedema practitioners. When you approach the physiotherapy or the occupational therapy department they will say, 'Where's the money coming from to do that?' When I first started at the hospital where I work 11 years ago there was no-one there managing lymphoedema. It was very difficult for me to access those services outside the hospital for those patients and it was very expensive. There seem to be more lymphoedema practitioners in private practice than in public hospitals, although that could be a perception rather than a reality. Whichever allied health professional takes responsibility for it they will always say: 'Where is the money coming from to set it up in terms of time in clinics? Where is the money coming from to train someone to go and learn how to manage lymphoedema?' It is an incredibly costly, timely, laborious treatment.

Preventative education is probably the key to really getting on top of it, and early recognition of lymphoedema. We are fortunate now in the hospital where I work 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.

Dr Ryan—I would like to table two publications that arose from the study as well.

Senator ALLISON—I have a question about lymphoedema and prevention. Your last comment made me think about a personal case that I know of where the lymph nodes were removed even though on examination that turned out to be not necessary. I recall, I think it was at the Austin Hospital, talking with cancer specialists there about PET scans. They demonstrated how easy it was to show whether the cancer had actually reached the lymph nodes. My question is: are we avoiding that technology in order to save money at one end but spending it on a substantial number of patients who may not have had to undergo that treatment at the end of the day?

Ms Lancaster—I think probably our medical colleagues would be better placed to answer the question about the technology. However, PET scanning is funded for some things and not for others. But there is a technique you may want to ask them about as well which is called sentinel lymph node biopsy and which is now well established in the treatment or management of breast cancer. There is a growing interest in its use in gynaecological cancer, and that looks at minimising the number of lymph nodes that are removed.

Senator ALLISON—Then let me ask the question again but perhaps you could answer it from your perspective. What are the preventive measures that should be in place? Is it to get in early with the appropriate massage and treatment and so on?

Dr Ryan—It is awareness. It is hard to know whether you can actually prevent lymphoedema from occurring. As a result of this study, we became aware that a lot of women did not know about lymphoedema. Even though we felt that we had told them, they would put it back that they had not heard of it. We developed a bookmark to give to all women who had had lymph node removal after gynaecological cancer surgery. We put on that bookmark the things to do to avoid the risk of developing lymphoedema. We borrowed all of those points from what has been recommended to women with lymphoedema and from what the women told us when the lymphoedema developed. A lot of women told us it was following a plane trip or cuts. We use those techniques but they have not been measured clinically.

Ms Lancaster—A lot of what we recommend are simple measures. There are things like not going barefooted, to use an electric razor rather than a blade razor to shave legs, to wash a cut or scratch with soap and water and put on some antiseptic, to not wear very tight knickers, to see a GP for antibiotics if there is an infection in the leg and not to leave it because that can exacerbate it or set it off, to seek immediate attention if the leg is swelling and not to put it off until next week. That is what a lot of women do. They are busy with kids, families, jobs and that sort of thing and they do not get to the GP until next week. In our unit it is certainly a recommendation to wear compression garments when flying. It is really about some simple preventative measures and early attention if they think their leg is swelling.

Senator ALLISON—You remarked that people were hungry for the information that was available to them on the one-day event. That suggests that, at least up until that knowledge was gained, there was inappropriate treatment being administered or an inappropriate response.

Ms Lancaster—I think nurses in general are very keen for educational opportunities and it is something that, in general, they do not get. The more junior you are the less likely you are to get out to those sorts of things.

Senator ALLISON—The doctors go off for their seminars but the nurses miss out. Is that the basic story?

Ms Lancaster—Yes, although not for the more senior nurses. I cannot say that I miss out. Certainly, the more junior you are the less opportunity you have for those sorts of things. In industrial awards there is provision for study leave, conference leave and that sort of thing but, once again, it is being able to backfill the position. The workforce shortage—and that was something highlighted this morning—is significant, especially for people who work in smaller units in country areas. There is no-one to backfill their position if they are not there. In addition, there is no funding. Lots of nurses fund themselves to go to courses, conferences and that sort of thing. They are willing to do that but often there is no-one to backfill their position so they cannot go.

Senator ALLISON—I understand.

Senator HUMPHRIES—I have been thinking about how confusing it must be in the hierarchy of the hospital board to have a nurse who is actually a doctor. It must confuse the patients and other people.

Ms Lancaster—And the doctors.

Senator HUMPHRIES—That is for another day. What is the situation with the nurses with cancer backgrounds? You have 700 members. How many nurses are there in total with cancer qualifications?

Ms Lancaster—That is very hard to say. I do not think anybody would be able to give you that number. Some nurses with cancer qualifications have trained overseas. Our membership is reflective of nurses who identify themselves as cancer nurses but that is not all-inclusive. There are many nurses who work in cancer settings who do not belong to a professional organisation. The nurses registration boards in each state collect data about nurses' backgrounds each year when nurses re-register, but a lot of them do not actually include cancer. Cancer might come under 'other'. You have things like midwifery, intensive care, emergency department, general surgery and that sort of thing and in some states the actual cancer qualification comes under 'other'. I do not know that even the registration boards would be able to provide you with that information.

Senator HUMPHRIES—Are you aware of a serious shortage of cancer nurses in this state, for example, or is it much the same as for other categories of nurses?

Ms Lancaster—I cannot give you the quote at the moment but there is one that I can send to you that says that cancer nursing has been identified in Australia as one of the top 10 specialties in shortage.

Senator HUMPHRIES—Do you see the recent announcement about more training for nurses as going any way towards relieving that?

Ms Lancaster—Federal government funding for what is known as EdCaN, which is a cancer education program for all levels of nurses across Australia, is certainly going a long way towards

addressing that. That program will be set up in such a way that it looks at the content of cancer that goes into undergraduate programs, and that will go right up to specialist/master's level preparation for nurses in cancer.

Senator HUMPHRIES—I assume there is not really much of a role for oncology nurses in individual doctors' practices—maybe in health centres but not necessarily in private practice?

Ms Lancaster—We were talking earlier about multidisciplinary cancer care, and that is recognised as the best model of practice. Multidisciplinary care happens not just in the bigger cancer centres; there are certainly rural cancer centres which will have a specialist nurse, or more than one specialist nurse, with an oncologist. It might be a visiting oncologist or there might be an oncologist on site. Certainly, in some of the bigger regional areas in Australia, that is their model of care. Rather than a fragmented approach of care in individual practices, it is the multidisciplinary care, in terms of a team approach, that is seen as the model of best practice.

CHAIR—Thank you very much. If you think of something you would like to add, please get in contact with us, because you shared so much information in that contribution. We have got the documents you have tabled. Thank you for your patience.

Proceedings suspended from 3.47 pm to 3.56 pm

BAIRD, Dr Phillip, Private capacity

CARLESS, Dr Alan, Private capacity

VAN ASTEN, Mr Mark, Managing Director, Diagnostic Technology Pty Ltd

GRAVES, Dr Debra, Chief Executive Officer, Royal College of Pathologists of Australasia

MEDLEY, Dr Gabriele, Cytopathology Advisory Committee, Royal College of Pathologists of Australasia

WRIGHT, Dr Robert Gordon, Chairman, Cytopathology Advisory Committee, Royal College of Pathologists of Australasia

CHAIR—Thank you very much for coming and thank you for your patience. As always, there are so many people who want to share their knowledge with us that we often run out of time. I reinforce that we have put you all together in this session because we want to hear from as many people as possible. It is not presuming that you have any common interest or anything like that; it is just for the sake of making sure we can hear from as many people as possible.

I know that you have received information about the protection of witnesses and the way the process operates, and that you know about the way that we work. We will make this as informal as we possibly can. Have you all given evidence to Senate inquiries before? There are nods. We have unlimited time now, so we can go on until we finish. I invite any of you to make an opening statement and then we will go into discussions. For the sake of convenience and by no means giving priority, Dr Baird we will kick off. You picked the right spot there.

Dr Baird—Firstly, I would like to thank the senators for this opportunity to come and talk to you. I appreciate the privilege it gives me as a medical scientist and a medical practitioner to talk to you all about an area of health that I have been involved in for my entire professional life. I would like to go on record to say that, in fact, I am an independent consultant. I have no commercial organisation behind me and there is no business that I am linked to that would benefit from what I have to say today.

My professional connections in terms of gynaecological cancer are threefold. Firstly, as a specialist pathologist, I am involved in the diagnosis and clinical management of cancers of the female genital tract. I have been doing that since 1976 and I continue in that active role at the present time. Secondly, as a medical research scientist, I have participated in and supervised many research projects since 1976. This has included supervising master's degree students and PhD students for the University of Sydney and in particular in relation to papilloma virus and cervical cancer. Thirdly, as a consultant to the legal profession in Australia, I have been involved in many cases of medical negligence regarding the misdiagnosis of cancer, and in particular I have been able to see the problems and the failings of the systems that we have in Australia, especially in relation to cancer of the cervix.

I am sure that you have all been inundated with information regarding many of the gynaecological cancers, but what I would like to do in my short presentation now is to focus your minds on cancer of the cervix. This is an area of my own interest and research background as well. I think there is some information that you may not be aware of, and I will try and be a little black and white with it—and I apologise for that, but it is difficult to give you all the grey areas.

My first point is that I think it is generally unknown that if you took the current conventional pap smear program that we use in this country at the moment and, as it were, discovered it for today as a good idea and brought it to the regulatory bodies as a new screening test, it would not be accepted. The reason for that now is that we have developed over the years many criteria of sensitivity and specificity et cetera which we accept and demand from a screening program. That is not to say that the pap smear program has not had a benefit; it has. It has an enormous benefit for women worldwide, particularly in the First World. However, the point needs to be made that the test would not satisfy the modern demands for a screening test.

Secondly, worldwide, all major research bodies now, including the WHO and IARC, accept that the papilloma virus is a causal factor for cervical cancer. You and I know that Ian Fraser was recently lauded for his work on a vaccine. What I said in my written submission to you is true: 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.

Thirdly, we still have a problem with morphology in this country, yet we rely on it. I have a paper from Dulcie Coleman's lab in England—and she is regarded as a major international worker in terms of cervical cancer—which she published this year. In that paper she looked at 76 women with invasive cancer and she found that over 50 per cent of the smears were reported incorrectly in the UK. She has shown that over 60 per cent of these women had a false-negative pap smear. This is relying on morphology alone. She went on to show that the legal evidence for breach of duty of care was proven in 50 of those 76 cases in regard to the service that those women were relying on in the UK. This tells us that we have to look at screening in another way other than by just morphology alone—and this is a current report as of this year.

CHAIR—Do you want to table that report?

Dr Baird—No, it is just a photocopy, but I can give you the reference.

CHAIR—That is fine.

Dr Baird—In a recent ABC program, *The Health Report,* Norman Swan interviewed Dr Marion Saville from the VCS in Melbourne and he asked her about various aspects of cervical cancer. She said something that I thought was very important. She said that, yes, the rate in Australia is very low, and it is probably one of the lowest in the world—and that is true—but she went on to say something which I think is significant in the discussion around this point. Often people will say: 'Our system works. It's fine. Look, we've got great rates.' That is true, we have. But what is overlooked is what she highlighted, and that is that hundreds of thousands of women

in this country are being overtreated and overdiagnosed for things that are not really abnormal and going to cause cancer. This is the hidden cost in our community that a lot of health economists do not take into consideration. She admitted that DNA testing would resolve a lot of that overtreatment and overinvestigation for the low-grade abnormalities. Morphology will not do it and will not do it in a cost-effective way.

The third thing I would like to say is that there was an article in the *Medical Journal of Australia* this year regarding a study in Far North Queensland out of Cairns Base Hospital where 12 women had presented with invasive cancer. They investigated this and they found that none of these women had had a pap smear. Some of them were from other ethnic groups, and that was one of the factors, but remoteness was the real issue. The authors said that the incidence in that area of Australia is 10 times the national average and the mortality is five times the national average. Why is this the case? They suggested it was due to remoteness and a lack of access to the service, and also cultural issues regarding the collecting of pap smears. All of these issues that I have highlighted say to me that we really need to look seriously at the way we think about and design a screening program for cervical cancer. If we believe that papilloma virus is important—as we must, because we have just said that we want a vaccine—then we must test for it. The rest of the world is moving into that area. Surely we need to look at that.

In your terms of reference you have said that you want to look at funding of research, education, medical services and treatment. Cervical cancer is preventable. It is not like some of the other gynaecological cancers which are more difficult to prevent. We know what causes it. We know we can get access to the precancerous areas of the body. We know we can identify the virus. We can prevent cervical cancer completely because we understand it. The Koch's postulates—which is a scientific way of saying, 'Is this virus linked to this disease?'—was satisfied in the medical literature many years ago.

The challenge is: do we have the political will, through your offices, to implement changes in the way we think of this disease in particular? If we can, 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. The doctor wins because, as Alan I am sure will say, doctors do not want to be pap smear collectors—female doctors in particular, because they tend to get all of the patients and collect pap smears all day. They do not want to be doing that; they want to manage real diseases. DNA technology allows the doctor not to do that. Laboratories will benefit. 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.

Dr Carless—I am representing myself today, but I am also in a sense representing pap smear takers and their patients. I am going to try to speak to the issues that I have seen develop over the years which have led to our system being highly effective at controlling what would otherwise be an epidemic of cervical cancer, but at what I consider to be too high a cost. I am talking not just in terms of the dollar cost of the programs—it has been a relatively inexpensive test to perform if you do not count the opportunity costs of the doctor's time and also of the patient's time.

I am sure that a lot of women in this room would strongly identify with me when I say that it is a bloody nuisance to have to go and have a pap smear taken. It is even more of a drag to be told to come back in six months time because it was not quite right. What does 'not quite right' mean? How long are you going to spend awake at night wondering what that little phrase could possibly mean? So the whole pap smear system has been a bit of a problem. I have been involved in pap smear taking since I was a medical student at the Royal Women's Hospital in the 1960s. In those days we used a very ungainly speculum—it was not a bivalve speculum; it was a simple duck-billed speculum—and we used a wooden tongue depressor.

The efficiency of collecting cancer cells for that system was extremely inadequate, but we did the best we could, and then gradually the technology slowly evolved into what we have today. When I came back to increasing the number of pap smears I was taking—my practice has been partly organising services and monitoring them and partly providing them, about equally divided, through my career—I found that we were being asked to split the sample. I asked: 'Why is this so? Why do I have much greater complexity?' I was being told that I had to be very careful about layering the sample I was taking onto a slide and then spray it immediately. While the woman was waiting for the next phase of the test, which is a bimanual examination, I was having to put the remains of the sample I had just collected into a jar and shake it to wash all the cells off into the liquid in that jar. I asked the pathologists who came to visit me: why do I have to do this? Why can't I simply do a wet collection, and simplify the whole process and get it over and done with much quicker?

The dry slide collection technique is a very fussy technique. If you do not do it right, you get a bounce from the pathologist—'Collect the specimen again, unsatisfactory.' The wet collection is much less likely to produce that, but I was putting a good proportion of the sample of possibly cancerous cells onto a dry slide and sending it off to the laboratory with this wet sample. I did not get a satisfactory answer from the pathologists. I now honestly believe that the only answer as to who gains from splitting the samples—we are the only country in the world who does it—is the pathology industry. It is certainly not the patients, it is certainly not the general practitioners.

Arguably, sample splitting and the way we have been doing it lately is detrimental to the discovery of cancer because the best part of the sample goes first onto a dry slide and gets collected in a high layer of cells, many many more layers than you would need to stack up paper to this height. You have to look down through those layers in order to find the cancer cells at the bottom, whereas the wet sample collection technique allows you to see what is called a mono layer. In fact, you can pre-screen it with computer imaging to get an even more efficient result. So I was angry about that and my passions were aroused.

I am absolutely passionate about cancer prevention. Phil says that if I did not spend so much time doing pap smears I could do more treatment of cancer. That does not thrill me, to be quite honest. I would much rather prevent cancers than have to manage cases of cancer, even though it does give you a lot of satisfaction to make an early diagnosis. To me, it gives me much greater satisfaction to think that my overall practice was preventing these cancers ever getting to a stage where they needed aggressive treatment, because that is what the name 'primary care practice' is really all about—being efficient in preventing cancers.

I happen to believe that going forward in Australia, the only way we are going to get health advances is by focusing relentlessly and rigorously on efficiency measures. We cannot afford to have inefficient measures because, every time we have gotten inefficiency, we are blocking a new program. If we become more and more efficient, we can liberate dollars from existing programs and put them into new programs. I believe, for example, that we have to find the funds for a national bowel cancer screening program that is advancing now beyond its pilot stage. This is just as important to women as it is to men. So to make room in the overall budget for health care dollars, which I think will eventually be capped—we just cannot afford to grow it and grow it and grow it—and for new cancer-screening programs, we have to make our existing programs state-of-the-art.

To me, in cervical cancer screening programs, that means right now that we stop this stupid split sampling. We stop any repeat testing at frequent intervals that is a result of worried well going and asking for tests every six months. They should not get Medicare reimbursement for tests that are unnecessary and they certainly should not be encouraged to have tests just simply because the pap smear taker is inadequately trained—and I see quite a lot of that—or because the technique that they are being asked to use is impossibly difficult, or almost so.

I think we need to have a much more efficient test. We need to do what the rest of the world is doing, and stop splitting the sample and just go direct to phial and test what is in the phial. That should be 100 per cent of the sample that the doctor has taken—or the nurse. I have trained nurses to take pap smears in my practice because I recognise that not all of my patients want to be screened by me. But, in general, I think doctors should be the ones that provide all services for their patients. If you are going to be a really good primary-care doctor, you should offer everything that your patient needs in primary care. You should not have to be sending patients off to a gynaecologist or, as Phil said, sending them off to the female doctor in your practice who has a reputation for being good at taking pap smears.

All the male doctors in all the practices in Australia should be offering cervical cancer screening to their patients. If they are not doing it now—and I know many of them are not doing it now because I have spoken to them in my capacity as medical director—it is partly because it is difficult and takes a lot of time, and that means their hourly earning rate drops. Whenever a person comes in asking for a pap smear, they get a lot less for the unit consultation in dollars per minute than they would if they simply came in and asked for a prescription. They do not want to do it for those reasons. They do not want to do it because they are worried about getting sued, as one very good doctor was. She was sued when the pathologist missed the abnormal cells and she relied too much on the pap smear. I would have to say that she was using it inappropriately as a diagnostic test, from my recollection of the case.

The whole problem is that that particular case does stay in the minds of doctors. They are worried that they will be sued. They are worried that they will be accused of being inappropriately interested in their patients' genitals. I am sorry to say it, but that is a real fear in the minds of some of the older male doctors that I talk to. They are worried that their technique will be regarded as unsatisfactory. Their percentage of inadequate pap smears is monitored these days by the pathologist—rightly so. We give them points out of 10 for the pap smear taking technique, in effect.

Doctors do not necessarily want to subject themselves to this sort of thing. If we could, at some stage, move to self-collected samples, that would be good. In the meantime, if we could get rid of split sampling, that would be good too. I commend to this committee both those strategies for making the whole cervical cancer screening process more efficient.

CHAIR—Thank you, Doctor. Mr Van Asten?

Mr Van Asten—Thanks very much for the opportunity to address this committee. I am the Managing Director of Diagnostic Technology and we do have a commercial interest in this area. I am the Australian partner for a US company called Digene Corporation. They manufacture a hybrid capture 2 HPV DNA test. That has been available in Australia on a private fee basis for the last eight years. It is considered around the world as being possibly the gold standard for DNA testing for high-risk HPV, or the types of HPV that cause cervical cancer. The test has been utilised on a private fee basis in Australia, until there is an endorsement by MSAC and NHMRC as a test of cure for pre-invasive cancer treatment, or CIN 3. The test has received endorsement to be used to show a doctor or a woman that treatment has been successful or that there is no HPV remaining, so it is difficult to see why we cannot use it to define a level of risk or to detect the disease.

The US FDA approved the test in 2004 as a primary screen for women aged over 30. In this setting, the test is performed alongside the pap smear, and it has been shown to significantly improve detection of cervical disease. The American College of Obstetricians and Gynecologists have endorsed this use, and recommend that the screening interval be extended from one year to every three years if a woman is negative for HPV. In many countries—the UK, 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.

The potential cost saving to the screening programs along with benefits for women under this scenario would be significant. Currently the screening program in Australia cites the estimate that, if every woman were to participate in a screening program, 90 per cent of all cervical cancers could be prevented. This estimate is actually based on overall performance and limitations of the pap smear. 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. This accuracy is the basis of being able to extend screening intervals out beyond five years. Some investigators are predicting that HPV DNA testing, along with the vaccine, will result in a scenario where women will only need to be screened three or four times in their life, with 100 per cent confidence that they would never get cervical cancer.

Cytology is a 50-year-old technology from a time when the cause of the disease was unknown. Since the cause has been outlined, the use of HPV DNA testing has grown significantly around the world. As Dr Baird has mentioned, it has been endorsed for use by IARC, WHO and a number of other organisations around the world. In Australia, Diagnostic Technology has previously submitted two MSAC applications for review: one for the low-grade pap smear management triage in 2001 and 2002 and the other for screening in 2002 and 2003. Both applications were rejected but with specific comments or exceptions, including the fact that there is evidence for potential use in particular subpopulations, mainly older women, and that it could

be reassessed after particular international studies were completed and that data in Australia was available that was not known at the time of the submission.

The evidence used in these MSAC submissions was limited to data from 1999 to 2002. Since then there has been an explosion of information in this area with over 500 publications cited. Disappointingly, apart from a small indication for the use of test of cure, the broader utility of HPV was not being researched or considered during the recent NHMRC guideline review. This review is cited as being the most updated information on screening and management practice but it references the 2002 MSAC data as being the relevant piece of information for not considering HPV triage and the management of low-grade pap smears. Of note, the guideline review group did not evaluate the use, even though MSAC cited specifically that HPV could be more effective in detecting the underlying level of disease in abnormal pap smears. If that rate of disease was over 10 per cent, HPV DNA testing would be more effective.

The Australian data not available at the time of the MSAC submission has shown that, after two years of follow-up of management of women with low-grades, the actual rate of underlying disease is 9.38 per cent. It is commonly known that there is an additional 30 to 40 per cent of high-grade disease in these women yet to be diagnosed that would result in a rate of underlying high-grade well over 10 per cent and within those levels of effectiveness stated in the MSAC. This knowledge is derived from well-recognised studies performed by the national cancer institute of the United States called ALTS. This study is also cited in the NHMRC guidelines but its recommendations were not considered as an option in the review. Even though MSAC referenced the need for further analysis, no steps have been taken over the last four years to review the data and the recent review process did not exploit the opportunity.

Within MSAC's terms of reference there is an allowance to recommend for an interim item number to perform research on promising technology. We believe that Australia has lost valuable time to access promising technology that could have immense benefits for women in their efforts to safeguard against developing cervical cancer. In the early nineties, there was a lot of confusion about how we could screen individuals for hepatitis C. At that time we did not know what the causative agent was. Once it was known, every effort was made to utilise the knowledge for the best interests of the population.

It seems ironic that, in a period where we are about to introduce the vaccine, we have full understanding of the natural history of cervical cancer and the role of HPV DNA, we are still willing to rely exclusively on the pap smear and recognise its limitation as our primary cancer prevention strategy. It would be beneficial in Australia, as in many other countries, if we could develop a vehicle in which we could assess, research and trial strategies that could take us beyond the publicised confidence of preventing 90 per cent of cervical cancers into a situation where cervical cancer could be a thing of the past.

Dr Medley—I would like to talk about two points; firstly, as we are on the subject, I will talk about the cervical screening program. The pap smear program in this country has been very successful, and I do not feel it is necessary to go into any detail about that at this point. But I would like to stress the importance of reviewing the cervical screening program as a whole to avoid the piecemeal type of review that has been going on recently, where it is being dealt with at the edges. Central to reviewing the pap smear program, we believe that the implementation of a national cervical register would be an enormous improvement over the current system of

having a series of registers in different states that collect different data. If women move from state to state they are not able to take advantage of the register. I think the register is central to providing the sorts of data we need to make important decisions about this program.

Organisation and optimisation of the screening program requires the consideration of a number of issues that we have already heard detailed. The first main issue is the new technologies, which have been mentioned here previously. The first is the liquid based cytology, which will be combined with automated prescreening using a machine. The shortage of screeners is unlikely to improve in this society, because the advent of the vaccine probably suggests that people would not be entering into a career as a pap smear screener at this point. So there is a workforce shortage, and I believe that regardless of the vaccine the program will need to continue for some time. These prescreening devices will allow the scientific workforce to concentrate on possibly indefinitely abnormal samples. That would optimise the workforce.

Even ignoring the very large body of evidence that surrounds the possible or definite advantages of liquid based sampling on screening performance, the practical issue of the availability of molecular testing—which has also been alluded to—on a single sample for viral and other microbiological agents has been recognised. HPV testing has been spoken about by Mark, and a considerable body of literature now exists about its role in cervical cancer screening and in the diagnostic and management pathways relating to cancer precursors and established disease. These two arms of it are those for primary screening, triage and test of cure. Moving to the HPV vaccines, whom to vaccinate and how often and the influence of vaccination on the screening frequencies are questions that require input from several scientific disciplines. It is likely that recruitment to vaccination may miss a similar section of population to that which fails to participate in the screening program. If this is allowed to occur, it is unlikely that vaccination will, in the Australian setting, deliver significant advantage over the current program. The vaccination of males as well as females, I believe, should be considered in this context, since they harbour the reservoir of infection within the community. I think it is important, when you are vaccinating for any disease, to consider the reservoir of infection as well as the people who overtly manifest the infection.

Clearly, the cost implications of new technologies will necessitate an offset, and that should be achievable by a significant increase in the screening interval. This will be made possible by the more sensitive diagnostic achievements. I think we will be able to delineate at-risk and not-at-risk women, and I imagine this will enable the screening interval to be lengthened considerably. This has been done already in some countries like the Netherlands, which has done a lot of research.

The second issue, which is relevant to this college, is the actual shortage of pathologists. As predicted some 20 years ago, there has been a progressive decrease in the available workforce of pathologists. You will find data—and Dr Wright will refer to it—of numbers in this regard. This shortage is going to manifest for two reasons. Firstly, there is an increasing disease burden occasioned by an ageing population, involving particularly malignant disease and to a lesser extent the various transplantation and replacement techniques that are currently an expectation in our community.

Secondly, the increasing sophistication of surgical, chemotherapeutic, molecular and genetic technology has increased the diagnostic input by pathologists in each case. An example of this is

the examination of tissue removed in a case of breast or ovarian cancer. In addition to the original tumour, there is a complex mapping of the tumour itself, the examination of a large number of lymph nodes when the sample is received, the multiple sections that need to be examined and the subsequent immunoperoxidase reactions that are necessary and require a large number of slides to be examined by pathologists. An example of this is the sort of complex technology that is implemented when you are looking for the reasonableness or otherwise of recommending the use of Herceptin in the treatment of breast cancer. Complex molecular testing is required before this can be advised. The implications of this are these. Thirty years ago, when I started in pathology, to diagnose ovarian cancer we might have looked at one or two slides of the tumour. Nowadays the pathologist may look at 30 to 50 slides in that same woman with that same tumour.

The other factor is the considerable increase in monitoring and recording the performance of scientific personnel, particularly in relation to gynaecological cytology. This has imposed a very significant time cost on both scientists and pathologists. Whilst in no way denying the immensely beneficial effect of the continuing assessment, quality improvement and education that is now a significant part of the life of a pathologist, I believe that this is a very significant impost on the pathologist's time and therefore has aggravated the problem of the shortage of pathologists. Thank you.

CHAIR—Thank you, Dr Medley. Dr Wright?

Dr Wright—Thank you very much for the opportunity to talk about some of these workforce issues, with a few pointers. I think it should be recognised that for practical purposes every cancer in Australia that is diagnosed is diagnosed by a pathologist looking at the case microscopically and macroscopically. Every pap smear is supervised by a pathologist and all the data sources on which our research endeavours start come from pathological diagnosis and categorisation. It is mandatory to report cancers to cancer registries and categorise them, and that is done by specialist pathologists. Similarly, where fresh tissue is required for research studies, that is always selected by a pathologist at the time so that the tissue diagnosis is not compromised and the advantages for the patient in the research can be maintained.

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. We are producing approximately 55 new pathologists each year in this country, of whom 30 are anatomical pathologists or tissue and cell pathologists.

The whole issue was looked at by AMWAC in a major review in 2003 and 2004. It was recommended that there be 100 new training positions each year for five years, but so far we have only 39 new trainee or registrar positions. In the 10 years prior to 2003, it had been estimated that 70 training positions had been lost nationally. It is often a quite straightforward decision by administrators to cut a position like a trainee pathologist because the impact on a whole hospital service is unlikely to be felt if you lose a position of that type. It is only many years later that the impact of that decision will be felt because, by and large, trainees do not have a direct patient care responsibility or it is generally an indirect patient care responsibility.

There are currently more than 70 vacant positions that have been unfilled for many years. In fact, personally, I have just moved from private practice back to the public sector in the state of Queensland. The position I now occupy at the Gold Coast Hospital was vacant for three years. It is estimated that about 129 positions for trainees can be filled almost instantly. Laboratories have indicated that they would do that. The problem is funding, and I think most of the funding for public hospital positions comes from state health budgets. There are some positions in private practice and these have been funded through special funding from the Commonwealth.

It should be noted, as you have heard already, that there is an ageing population and that there are services that need to be met. The traditional solution for a quick fix has been to look for overseas trained specialists, but there is an international shortage. In fact, I discussed with our CEO that there seems to be a migration of Australian specialists to the UK, which has improved its professional services somewhat in recent times and has made it easier for Australian pathologists to practice. Thank you again for allowing me to share the specific figures with you. It is certainly a trend that can be reversed and probably will be.

CHAIR—Thank you very much. That information was overwhelming. We will go to questions. If you think that there is something that we are not picking up in the questions or if there is a point that you wish to raise, please do that in that process.

Senator ADAMS—I come from a rural area. I was a little bit shocked about you wanting all doctors to do pap smears for their own patients. What is really happening, especially with a lot of our regional medical services, is that they are grouping together and having practice nurses working with a multidisciplinary team, specifically to try to ensure that the whole community has their pap smears. Nurses would have the dedicated job of following up and doing all the pap smears. So I was a little bit surprised about the way that you felt about it. As far as pathology goes, I know exactly what you are talking about and how time consuming it can be, but I do not quite know where we go from there. As far as saving the health dollar goes, obviously it has been proven that pap smears can be done far more efficiently with the new technology that is available. Can the two of you, Dr Van Asten and Dr Carless, please help me in how we can take that forward?

Dr Carless—Yes. I will kick off. Thank you very much for allowing me to correct myself. The point I was trying to make is that doctors should offer the pap smear to their patients. If you have a particular relationship with your doctor and he has seen you through a whole lot of things, he should offer you the opportunity to have him take the pap smear. 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.

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. It is always part of the pap smear or it always was in the way I was trained to do them. I have become aware in my recent role of at least one occasion where the nurse did detect an abnormality by manual examination that, sadly, was not properly followed up by the medical profession. I think the nurses are quite capable of doing highly efficient pap smears. I just wish they could do them direct to phial rather than have to fuss around with dry slide preparation techniques, which I think are a real bugbear for whoever takes the pap smear. But I think they can do them highly efficiently. I think they can be

trained to do as efficient an internal examination as any doctor, certainly as any female doctor, if you are worried about the length of the fingers, which is a factor. I am sorry to get so intimate about all this.

Senator ADAMS—I was a midwife, so I understand.

Dr Carless—It is important that we recognise that, because members of the medical profession sometimes use it as an objection to handing it over to the nurse—that they would do a better job—but I do not believe that. I think the best pap smear is always done in the most relaxed atmosphere that you can provide.

Senator ADAMS—I agree.

Dr Carless—If the most relaxed atmosphere is with the doctor whom you know well, so be it. You should not have to send a woman off to a gynaecologist—which is a big point I am making—or to send them off to another member of the practice whom they rarely see. You should be able to either offer it yourself or let them go to somebody of their own choosing, and that second person, in my opinion, could often be a practice nurse because they are highly efficient and they often do a wonderful job.

Mr Van Asten—I think Dr Baird alluded to the potential here for, I suppose, both technologies: liquid cytology, or collection by liquid, and HPV identification. It is often cited in introductions to performance of the cervical screening program that most of the women in Australia who get cervical cancer have never had a pap smear. That is generally cited in about 25 to 30 per cent of the cancers. It probably means that most of the women who ultimately die come from this group. But, as far as cervical cancer is concerned, about 25 to 30 per cent are women who are part of the screening program. The remainder, say, 30 to 40 per cent, are women who have had pap smears at some time in their life but not often enough to be seen to be compliant.

To come back to your issue about rural settings or remote regions, I would dare say that in many of these situations there has been some form of service at some time; it is just that obviously the frequency has not been sufficient to give the type of security that is necessary. I suppose with modern technologies—DNA testing or HPV identification—firstly, you do not have to do it as frequently, so the services do not have to be there as often as they needed to be.

I have to state, at least for this committee, that when you are doing DNA testing or this type of testing it has to be at the relevant age. You do not use this testing on young women where frequent contact of HPV is common. The utility of DNA testing, at least, increases with age. If you are talking about population beyond age 30 or 35, the overall rate of those women who are persistently infected with high-risk HPV is where the disease will be found, and that is in the area of five to six per cent, maybe eight per cent at the highest. These are the same rates of positivities you also get in a cytology program. So you are using the risk factor for the development of disease, or precancer and cancer, to define those women who need more suitable attention. Again, coming back to the environment, if you could minimise the amount of resources you need and have better tests you could better apply the services to the appropriate people.

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. I will ask Dr Baird to add any comment from his point of view.

Dr Baird—I agree with what has been said. One point that I would make additional to what Mark has said is that the sensitivity of the DNA technology renders it robust in difficult circumstances, like cultural issues. It is very clear that if a woman inserts a tampon overnight and then sends that off to a laboratory for DNA testing, it is a very suitable sample.

Senator ADAMS—I was going to ask about contamination.

Dr Baird—As Mark said, that has been tested and published in many countries, so there is no reason why that sort of technology could not be applied to that type of sample. So the DNA technology opens up a lot of issues that have been the bugbear of the conventional pap smear collecting programs. It resolves them very easily and effectively—plus you can centralise the testing so that you know that the laboratory is accredited to do that sort of testing, the transportation of the sample is not a problem et cetera.

Senator ADAMS—Is there any further comment on that issue?

Mr Van Asten—Regarding an overview on what Dr Baird said about sensitivity, I would not mind tabling a publication. One of the most recent publications was in the *International Journal of Cancer.* It was an overview of both European and North American studies on HPV testing as it compared to cytology. HPV testing was more sensitive than cytology. HPV testing was 96 per cent, whereas cytology averaged out at 53 per cent in all the studies. I can table that.

Dr Medley—I think it needs to be understood that HPV testing is a test with a high sensitivity but not quite such a high specificity. That means that it is very sensitive in detecting disease, but not all positive HPV tests indicate that there is active disease present, because the virus may be present without active disease. 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. Those two modalities of screening or as a triage are the two ways that I think the test has been used in various places.

CHAIR—So you should have both?

Dr Medley—I think that both can be utilised, perhaps under different settings. The other thing I would like to mention—

CHAIR—I am terribly confused.

Dr Baird—It is the same methodology, just a different clinical—

Dr Medley—It is the same test, it is just using it in a different context. If you were in, say, the Northern Territory screening an Aboriginal population, then perhaps you would use it in the screening modality where, culturally, self testing is appropriate, and those women who tested positive could subsequently be tested further. In the sort of population that we are dealing with every day you may have a 40-year-old woman who has a doubtful pap test. That woman may even have been sent for colposcopy and nothing is seen. You may then do an HPV test, and if it is negative you can say to that woman, 'You probably have an inflammatory disease or something that is not of serious life threat to you, and you can go away and have another pap smear in a year or two.' If it is a positive test, you would then advise that she should be investigated further because she may have a lesion higher up in the cervical canal, for example. So it is very useful. I would like to talk about the split sample for a minute.

CHAIR—I was hoping you would.

Dr Medley—The issue with a split sample is what Dr Carless calls the dry slide. It should not be a dry slide, because in fact the smear is put on the slide and the slide should be sprayed with fixative immediately. So it is not a dry slide.

Senator ADAMS—You did say that before.

Dr Medley—In our society, under our Medicare framework, the liquid based cytology is not a rebatable test, so if a woman chooses to have that she pays for it herself. The only rebatable test is the slide test, the pap smear. Unfortunately, this is why the two things are done together.

Dr Wright—In our Medicare schedule, the pap smear has a unique place. It is the only screening test which is authorised by the minister specifically. All other tests in the Medicare schedule are for testing patients with symptoms and all other screening tests do not have a Medicare item—for example, bowel screening, breast screening. They are part of another health budget, another health program, so I was highlighting the fact that this is a unique test in our schedule.

CHAIR—It is a historical situation. When it was introduced it was given to Medicare.

Dr Wright—Yes. Part of our submission emphasising the need for a national pap smear screening register was to allow our community flexible opportunities to evaluate these changing technologies with a database that was held nationally rather than regionally. The data is hard to reassemble and takes some time. If you had a research centre based around a centralised registry system it would be possible for Australian women to get the benefits of more immediate testing strategies, which has not been possible up until this time, especially in an era when the vaccine is coming in. One of the issues that comes up is: the population of women are being vaccinated which will prevent them, we believe, from getting diseases with HPV 16 and 18 but we do not know how much at risk they are from other papilloma viruses that they are not being vaccinated against. The idea of having a central based register would be particularly valuable to Australian women and the Australian community as well as researchers, obviously.

Dr Carless—I want to clarify one point for you, Senator Adams. You talked about contamination of samples and interference. It is not a problem with DNA testing because you can pick a needle out of a haystack with that, but it is a real problem with the traditional pap smear, if you have got blood or inflammatory cells. It is especially a problem with the conventional pap smear where you have to layer everything you take off the cervix on the slide and you have a mixture of these cells. With the cells of interest, the cervical epithelial and glandular cells, being overlayed by inflammatory pus cells, if you like, and blood cells, it becomes very difficult to read a slide. Whereas with the direct-to-phial liquid based cytology, there are techniques for improving the sample to make them far more sensitive to the presence of cancer cells.

Senator ADAMS—Coming back to the DNA testing, I am thinking outside the square for more remote areas—I am sorry I am focused on that but that is a huge problem. If we can somehow get a cure or something like that, it is going to help so much. You were saying that probably around 30 years of age and older was the most satisfactory age for the DNA. What about younger—I am thinking about 15- or 16-year-old girls who are having their first children and, in some cases, have already had their first child? Will it work for them?

Mr Van Asten—I do not think so. The fact is that on exposure to high-risk HPV the minimum amount of time to cancer is nine to 10 years. Generally, you present or you get a preinvasive cancer which can exist for 10 years before it goes on to cancer. Our program in Australia is the reduction of the incidence and obviously mortality rate of cancer, and the way we do it is to try and find that preinvasive state. So you have a 10-year period in which to detect and to treat. If memory serves me right, there are only ever one or two women under the age of 25 who get cervical cancer in Australia in any one year, and putting resources into that area would probably not be appropriate.

Dr Medley—The issue is not whether the test works; the issue really is that, in 15- and 16-year-old girls, the human papilloma virus and infection is a self-limiting disease. They get it as an infection, their immune system copes with it and it goes away. When I say that one of the things we need to do is look at the pap smear program as a whole, I think you have to integrate the various things you are going to do. For example, if I were queen I would not start pap smear screening until at least 20 or 21. I would certainly not be screening 15- and 16-year-olds, because currently they are being identified as having the disease and they are having treatment which I think, to put it frankly, is somewhat mutilating. I think perhaps they should be allowed to have the HPV infection and let it get better.

Dr Carless—In my personal experience with screening very young girls, you not only have a worried young girl on your hands; you also have a worried mother on your hands and you have to deal with their collective anxiety when you raise the issue of potential cancer, and all they have is a self-limiting condition. It has been a by-product of our screening system as it is, and I thoroughly agree with Dr Medley that it is one of the things where we could find efficiencies galore.

Mr Van Asten—The UK has recently altered its initial screening age to 25 with screening every five years. Again, they are one of the sites that are actively investigating how to implement primary use of HPV on top of triage and doing both, if you want to call it that. As far as its utility is concerned, from country to country, the determining age is really wherever your peak

incidence of precancer and cancer is. In some developing countries where first sexual activity occurs very early, you do want to introduce it in the early 20s or at 25. With the data we have, I do not think there is strong evidence to support any use certainly before 25, if not before 30. If you do introduce it, you are using a modality that has a high rate of detection of those who may have the disease, and that is why you can delay it to the point where you can detect the disease.

Dr Medley—It is important to know that the cultural factors play a big influence on the age incidence of cervical cancer. For instance, in Nauru, where sexual activity commences early, the diet is poor, diabetes is frequent and the immune status is often not good, women of 21 and 22 are dying of this disease. It is relevant also when you are considering specific cultural subpopulations. This occurs particularly, obviously, in New Zealand and in Australia, where you have ethnic populations that have high incidences of disease, poor nutrition and poor immune systems. One has to individualise certain aspects of the program, but within a whole. For instance, the data on which the National Health and Medical Research Council guidelines were published did not include data from the Northern Territory, which probably has the highest incidence of any state in this country, which again emphasises the need for a national register.

CHAIR—I think we heard that evidence in Canberra.

Senator ALLISON—I am sorry to appear a bit thick, but is DNA analysis different from liquid based cytology and different from the conventional pap smear? It is? Okay. What are the barriers, at least in terms of a Medicare rebate, to switching from the conventional pap smear to the liquid based cytology?

Dr Medley—Money, I would say.

Senator ALLISON—Is it more expensive?

Dr Medley—It is more expensive because the equipment used for it is expensive. There are two main types of liquid based cytology available and both of them have equipment implications. I may be cynical in this but I have been in this industry for a very long time and it is my impression that the cost of liquid based cytology would be up to almost twice as much as what is currently the rebate for a conventional pap smear.

Senator ALLISON—You would expect that to come down over time, nonetheless?

Dr Medley—I personally would expect it to come down because as more people are having it the cost of the consumables ought to get cheaper. I think the same applies. At the moment if a patient is paying for a DNA test it is somewhere in the vicinity of $90 to $100. If somebody is paying for liquid based cytology it is somewhere in the vicinity of $30 to $35. I think the 100 per cent rebate on the current pap test is $21.60. That is what the Commonwealth pays. So if you are looking to introduce tests that currently cost these other sums of money you have to look at the whole program so that you can get offsets so that the program does not go absolutely crazy in its costs.

One of the problems with screening programs the world over is that if it is successful then it is innately a suicidal program, because the more successful it is the fewer patients will get that disease and the lower will be the perceived need to continue to spend all that money on

screening—it ceases to be a problem in the community. That is what has happened with the pap smear—it has been so successful and we have so few cases of cervical cancer at the moment that the Commonwealth and other places must wonder why they are spending all this money on the program. Unfortunately, relaxing on the program in the absence of a successful vaccine would lead to a very slow incremental increase in the disease again because there is evidence that the viral infective factor has increased its prevalence in society rather than decreased. This is why the whole thing has to be considered as a package.

Senator ALLISON—We got some insights into the liquid based versus the current pap smear arrangements in Canberra where a pathologist told us that he was, firstly, quite accustomed to doing the pap smear and therefore he was better able to read the slide than the liquid based cytology, but that, secondly, having bits of blood and other stuff there actually provided a bit more of a picture about the general health of the woman concerned, and that this is a reason not to move away from this kind of technology.

Dr Medley—In Britain liquid based cytology has been introduced as the standard. But in Britain the unsatisfactory rate of smears was somewhere around 10 per cent of all smears, which meant that 10 in 100 women would have to go back to the doctor and have another pap smear—with not only the cost of taking the smear but of reading the smear in 10 per cent of cases. In this country—and I have tried to investigate it and I have not really found out why—the unsatisfactory rate has never been more than around two per cent, so the perceived cost benefit that they have in Britain for introducing liquid based cytology as the standard of care is not a cost benefit that we would achieve in this country. It is the lack of any cost benefit that has persuaded MSAC not to introduce it.

Senator ALLISON—If I can come back to DNA analysis again, what are the basic differences here? You say that is more conclusive, almost 100 per cent right—is it?

Dr Baird—It is highly targeted. You are identifying particular fragments of DNA in a very specific way.

Mr Van Asten—Go back one step. At the time of collecting a pap smear, where you are taking cells from the cervix and either putting it into a liquids collection or on a slide, you can then take a second sample from the same site, from the cervix, using a brush. You collect the slides and put it again in a liquid solution, and this goes to the laboratory where it is analysed for the presence of specific HPV types that have been shown to cause cervical cancer.

Senator ALLISON—So this has got nothing to do with the self-collection technique?

Mr Van Asten—You can collect what is more of a vaginal specimen than a cervical specimen.

Dr Baird—You can take DNA from any sample you like. It is not a problem. You chemically remove the DNA out of any type of cellular material; it does not matter.

Mr Van Asten—For the sake of clarification, it is not a test of the patient's DNA or for genetic predisposition or otherwise. This is looking for the presence of HPV. It is also detecting it at a certain level that has been shown to increase the risk of cancer.

Senator ALLISON—So which test picks up precancerous cells?

Dr Medley—The pap test actually looks at the morphology. We see the cells on a slide and we have certain criteria that say it is likely that this type of cell indicates that this woman has a precancerous lesion. There are other influences that make this quite difficult to do, particularly with the traditional slide, such as inflammation, infections and things like those. The pap smear is the one that looks at the cells and says those cells look as though they come from a precancerous lesion. 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 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.

Mr Van Asten—That is why we recommend it in an older population because at that point any transient infections should have gone away and then what you are looking for is the women who may have a persistent infection, as defined as being that this infection or virus has been there for more than one, two or three years. There is data to show that if women have persistent infections within five to six years one in five of those will have evidence of preinvasive cancer. It is an estimation of future risk as well as solidifying if there is any chance that there is something there at present.

Senator ALLISON—Doesn't raising the age at which pap smears are conducted to 21, 25 or whatever it is—I think you are recommending 21—remove an opportunity for those younger than that to know they have the infection and to take precautions to make sure it doesn't spread? I realise that some people deal with it, it goes and they do not have it any more. Is there not a need to stop that recurrent spread of the infection itself?

Dr Medley—The issue of spread is one that is really very difficult to talk about and think about. It has great social implications, as you can imagine, particularly when older women are identified as having this virus for the first time. To my way of thinking, I believe it is important that young women who develop this infection are not stigmatised by it. There is a stigma associated with a sexually transmitted disease causing cancer and I think that is a very upsetting thing. It has been taken as a measure of promiscuity in a way which is completely inappropriate, because it is estimated that some 80 per cent of males and females will at some stage, if they are sexually active—and I do not mean hyperactive—harbour that virus.

In essence, knowing about it is not going make a huge difference to the pool of virus in the community. Hopefully, that is going to be controlled by the vaccine in the future. It is like having a cold or glandular fever, for instance. If you have a disease that has to get better by itself—and 80 per cent of people have it at some stage anyway—I would prefer not to be stigmatising those young women. Apart from suggesting to them that they do not have unprotected intercourse, there is really nothing else you can do. It is part of the spectrum of diseases that unprotected intercourse risks, such as chlamydia, gonococcal disease and even syphilis. I am not in favour of young women having pap smears, because I see pap smears every day from young woman who

may have had one, two or three episodes of treatment for their HPV disease by the time they are 20 or 22 and I worry about their future fertility.

Senator ALLISON—What is that treatment?

Dr Medley—If someone is diagnosed as having just HPV, the guidelines now for management would indicate that, if you have a biopsy—that is, a small pieces of tissue taken that verifies that what you have is just HPV disease—you should be allowed to go away and, hopefully, your body will deal with it. You will have another pap smear in 12 months and, hopefully, it will go away in the next one or two years. If the person managing the case feels that this woman is at a higher risk, the forms of treatment are, firstly, destructive. The area of the cervix that harbours the disease, which is actually quite a small strip of the cervix, is destroyed by electrocautery, maybe by laserisation or, under some circumstances, by what is called a 'cold knife cone', where a cone of affected tissue is taken from the cervix.

Senator ALLISON—How does that affect the competency of the cervix?

Dr Medley—This is my concern. I think that it can affect the competency of the cervix, particularly if the condition is repetitive. If you have destructive cervical management of a lesion once, twice or three times, I think the competence of the cervix can be affected. This is why I would prefer to see that young women with disease that is not life threatening be allowed to heal themselves, whereas, of course, for older women who may have persistent infection and established, life-threatening, precancerous disease that treatment becomes appropriate.

Dr Carless—Senator Allison, I would like to comment on your pathologist's statement that he preferred the sample to be sent to him as an air-dried slide because he could learn more from that. I have no vested interest in any of the technologies or techniques that are used, I can assure you. My interest here is in better practise of medicine and I think that is absolute rubbish. With all due respect to whoever told you that, it is rubbish. You can learn far more from a sample sent in a phial. We have already mentioned the possibility of simultaneously screening for important infective diseases other than human papilloma virus, and one of the most common ones is chlamydia. These days, if I ever take a pap smear from a woman under the age of about 30, I recommend that we also screen for that disease because it is very prevalent. It is a cause of infertility and it is easily treatable with simple antibiotics that are quite harmless. We can also screen for gonorrhoea in the same sample.

Senator ALLISON—And you cannot do that with a dry smear?

Dr Carless—You cannot screen for anything except early stage cervical cancer with a dried slide. It is a useless sample for anything other than its original purpose as designed by Dr Papanicolaou.

Senator ALLISON—I raised it not because I believed it but because I wanted you to have a chance to put—

Dr Carless—Thank you for the opportunity.

Dr Medley—In all fairness, what your pathologist probably said is that it does require a relearning process to learn to interpret the cells that come in liquid. It is not that he is going to learn more. Once he masters the art of looking at the liquid based samples, he will be just as competent in that regard.

Dr Baird—It is not rocket science. It can be done by computers—and it has been proven that you cannot read these dry slides by computer.

CHAIR—I think we should review the *Hansard* to see what the pathologist actually said. I cannot remember, and we are all arguing over what he said. Perhaps it would be useful if we checked what he said. I do not have in front of me what he actually said, and we have a number of professional witnesses here, who have not seen what he said, interpreting what he did say. Could I ask that you have a look at the evidence we had in Canberra, because we had a considerable discussion, as Senator Allison has mentioned, about these issues. If you have comments when you read what the pathologist said—with what the doctor said and with all the evidence before and after that statement—it may be that that could be useful. People are getting heated now about—

Senator ALLISON—No, we are not getting heated; no-one is getting heated.

CHAIR—I thought the witnesses were getting heated—

Senator ALLISON—Let us say engaged.

CHAIR—about what the pathologist said.

Senator CAROL BROWN—You talked a little bit about the percentage of pap smears that returned in-doubt results. I was wondering whether you keep information on pap smears that were given the all clear but then were not all clear.

Dr Baird—The false negative rate.

Dr Medley—Yes. The laboratories have a very close monitoring system. Dr Wright has a copy of the performance standards. The laboratory keeps the results of pap smears and monitors any subsequent tests that are done to determine the accuracy or otherwise of that test. This again is where a national register would be a help, but the state based registers of course are central to this. If a woman has a negative pap smear and she develops a high-grade abnormality, a high-grade precancerous lesion of the cervix, within four years, that information is fed back to the laboratory, regardless of where the subsequent investigations are. Laboratories have to go through a process of reviewing those pap smears critically, and the results of these reviews of the so-called false negatives are collated and sent to the RCPA quality assurance program. They become part of the laboratory's data for these monitoring processes.

The pap smear program is probably the most highly monitored program of any that you could think about. We have an enormous amount of statistical stuff that goes on in the laboratories, where we review material constantly; we put in the correlation statistics; and we go back and show our screeners where we were right and where we were wrong. That is a quality circuit that we try and establish.

Senator CAROL BROWN—So if they were DNA tested first, there probably would not be any false negative rate?

Dr Baird—Very few.

Dr Wright—The benefits from the DNA testing are that it is regarded as having a very powerful negative predictive value. So, if you have a negative result, it is of great benefit to the women. It is that aspect of the testing that we believe Australian women are not receiving full benefits from at present. A negative prediction with a doubtful smear can reassure a woman; whereas a positive test can cause problems because it may be a false positive test. But the negative predictive value is what we believe Australian women are not getting the benefits of currently; whereas that is occurring in many other countries around the world.

Dr Baird—Your question can also be answered this way. When women who have developed cancer have gone back and looked at their pap smear history, and extracted DNA from those of their pap smears that have been reported as negative, a high number of those are positive for high-risk DNA. So, if they had had that test done at that time, even though the smear was negative they would have been identified as people who should have been monitored.

Senator CAROL BROWN—That is what I was trying to get at. If it were positive, they could go and have their pap smear.

Dr Baird—Or they could have other tests.

Dr Medley—A colposcopy. Usually nowadays, with an abnormal pap smear, if it is just a viral lesion the woman is sent away for a year, according to the new guidelines—

Dr Baird—Under 30.

Dr Medley—to be reviewed in a year. If there is evidence of a significant precancerous lesion, worse than just HPV infection, then that woman is usually sent for a colposcopic evaluation. At the colposcopy, the colposcopist will look at the most abnormal area of the cervix with a magnifying lens—a magnifying microscope, actually—and will take a biopsy from that area, and that will usually confirm what the pap smear has indicated is the lesion. If the pap smear has been abnormal and the colposcopy examination does not reveal anything then the only thing that is open to the gynaecologist is to take a sample of the cervix, called a cone biopsy, which is quite a significant process. This is one of the areas where the triage effect of the HPV vaccine would be useful. If, in those circumstances, instead of doing a cone biopsy you did an HPV test, if it were negative it would be very reassuring; if it were positive you would have an indication to go on and do further tests.

Mr Van Asten—We are talking about the stigma of HPV and the commonality of it. When we talk about false positive results we have got to be careful. The reason for the test is that we find CIN 3, or precancer. Any time you find a positive result and you do not find CIN 3 that is considered a false positive, because you are not establishing the disease. Cytology can predict disease as well, and out of 120,000 abnormal pap smears—be they slightly abnormal or seriously abnormal—of those 120,000 or 110,000 women, 10,000 women will be confirmed to have high-grade disease. So, for every 100,000 women who come in with an abnormal result, you would

confirm 10,000 CIN 3. By the same analogy, if you want to use it, with an appropriate aged population, for every 100,000 HPV positive women, you would find those 10,000 women but, because you are improving the sensitivity, you would find an additional five—or however many. But you would still be left with women who were positive but with whom you could not determine if there was the disease.

There are indications that there are limitations to the diagnostic process of colposcopy. Because it is driven by a doctor determining where he is going to take a sample, there may be disease that he is not seeing yet. That is where the prognostic value comes in because, with subsequent monitoring, as long as that woman stays positive, ultimately you do find a good percentage of precancer in those individuals.

As far as the stigma is concerned, it is interesting that the latest guidelines are starting to suggest that, for anyone who has an abnormal pap smear—be it mildly abnormal, a possible low grade or definitive low grade—the message now is, 'You've just got a viral infection. It is likely to go away.' Five years ago, when we put the MSAC submission in, one of the points that was used to counsel caution in the implementation of this strategy on HPV concerned the psychosomatic issues of telling a woman she is HPV positive. I think that is an indication of how much things have changed in the last four or five years. Now within the screening program we are actively telling women who have a low grade, or possible low grade, pap smear, 'It is more than likely a viral infection that is going to go away.' And when you look at those, only half those women actually have HPV. So we are running the risk of over-estimating; there is a sort of balance. But it is important that everyone in the community understands it is a very common virus that we are all going to get. Getting it is not necessarily the issue; it is whether or not you have a risk of developing disease from it.

An analogy is that—and we are lucky we have vaccines to prevent this—before we send our kids off to preschool or kindergarten we are aware that if they are not vaccinated they are going to come in contact with rubella, measles and mumps. We have vaccines that we can put in place to minimise that, but those viruses, just as readily as HPV, can cause serious morbidity and death. Now that we are looking at the factors before sexual debut, we have the ability to vaccinate girls—or boys, if that is to be the case—to prevent a big part of the impact of HPV, or at least the main types of HPV. But, as Dr Wright says, we do not know what is going to happen with the other HPV types, and screening is going to be with us for the foreseeable future. There is no coming back from the sense that a screening program is needed, even with the advent of the vaccine, if we want to maintain the type of reductions to cervical cancer we have.

CHAIR—I would really like it if people took the opportunity to have a look at that evidence taken in Canberra because we have raised it and it was an important element of the discussion around the testing and the various processes. I thank you all. I apologise for keeping you so late but I think people were engaging in the process. If there is any other evidence you would like us to have, be aware that we will not be reporting until October. Thank you very much.

Committee adjourned at 5.26 pm