



COMMONWEALTH OF AUSTRALIA

# Official Committee Hansard

## SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

**Reference: Gynaecological cancer in Australia**

THURSDAY, 3 AUGUST 2006

MELBOURNE

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**SENATE**  
**COMMUNITY AFFAIRS REFERENCES COMMITTEE**

**Thursday, 3 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, Fierravanti-Wells, Forshaw, Hurley, Joyce, Lightfoot, Ludwig, Lundy, Mason, McGauran, Milne, Murray, Nettle, O'Brien, Parry, Payne, Siewert, Stephens, Stott Despoja, Watson, Webber, Wong and Wortley

**Senators in attendance:** Senators Adams, Allison, Ferris, Humphries and Moore

**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.

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**Committee met at 9.02 am**

**CHATHAM, Ms Elizabeth, Director, Women's Services, Royal Women's Hospital**

**QUINN, Professor Michael, Director of Oncology/Dysplasia, Royal Women's Hospital**

**BOWTELL, Professor David, Peter MacCallum Cancer Centre/Australian Ovarian Cancer Study**

**GRANT, Dr Peter, Chairman, Gynaecological Oncology Committee, Royal Australian and New Zealand College of Obstetricians and Gynaecologists; and Head, Department of Gynaecologic Oncology, Mercy Hospital for Women**

**JOBLING, Associate Professor Thomas William, Head, Gynaecological Oncology Unit, Monash Medical Centre**

**NARAYAN, Associate Professor Kailash, Peter MacCallum Cancer Centre**

**CHAIR (Senator Moore)**—I open today's hearing and welcome everyone. We are the Community Affairs References Committee. We are going to have a slightly different format today, we hope, which is going to involve a panel session. I am sure that most people giving evidence will be very experienced at this kind of thing, and it will flow through. I know that you have information on parliamentary privilege, the protection of witnesses and the ability to go in camera if that is something you seek to do.

We have your detailed submissions, and we appreciate those because it is a large chunk of effort to sit down and put those things into the committee. Rather than asking each group to speak to the whole process, what we are going to do is have a range of key issues that you have identified in your submissions and work through those. All your submissions seem to focus on terms of reference a. and b., which unsurprisingly focus on the issues of funding and the adequacy of screening programs, treatment services and wider service programs. Of course, we can range over those, but your areas seem to focus very deeply on those issues.

We will give all of you, or any of you, a chance to make an opening statement on record and then we will go into questions, if that is okay. At this first session, we are aiming to go through until around 10. We are renowned for going over time, so please do not get stressed if there is something you want to say and we are getting close to that time. Do you have any comments to make on the capacity in which you appear?

**Prof. Narayan**—I also provide radiation oncology services for all three gynaecological centres in Melbourne.

**CHAIR**—And they are the three we have just had mentioned: Monash, Mercy and the Royal Women's Hospital?

**Prof. Narayan**—Yes.

**CHAIR**—You have an opportunity to make an opening statement before we get into the core evidence.

**Prof. Quinn**—I forwarded my opening address to you so that you have it in writing. I am grateful to the Community Affairs Reference Committee for the opportunity to attend this hearing and I applaud you for the amount of time and effort you are spending on this very important issue. I want to highlight a number of key areas but, in doing so, I think you should be aware that there is a feeling amongst the cancer community in Australia that there is a vacuum in cancer leadership. I think the reasons for this—and we can observe this—are that the Cancer Strategies Group has not met for two years, the National Cancer Control Initiative has been disbanded, the Australian Cancer Society has just appointed a new CEO, who is obviously trying to find his feet, and there has been an inordinate delay in the formation of Cancer Australia. That was part of the present government's election platform in 2004 and so far more than \$5 million of budgeted funds have not been used.

In addressing the committee today, I would like to highlight what I think are the three key areas for the future of care of women with gynaecological cancer in Australia. The first is clinical research, the second is basic science research and the third is service delivery. In terms of clinical research, I think it has been a huge struggle to get the Australian and New Zealand gynaecological oncology trials group off the ground. I know this inquiry is well aware of the background of how we raise funds to develop the infrastructure for this group, but there is no doubt we need consistent funding. I stress the term 'consistent funding' because so often organisations within the Australian context get funded for one or two years, without any guarantees, and one cannot plan any realistic clinical research on that basis.

The model that the Gynaecological Cancer Intergroup has is something that we should seriously consider in Australia. The Gynaecological Cancer Intergroup comprises members from 14 countries, who meet twice a year to develop international research trials in gynaecological cancer. Many of those countries get a seat at the table on the basis of funding the clinical research infrastructure. In other words, governments are part of the whole process, they have ownership of the process and I think having an ownership of the process gives them a commitment to the process.

Our biggest issue, as you would be aware, is in data management for clinical trials. We would all agree that data management needs to be centralised, which it is currently at the NHMRC trial centre in Sydney, but it has to be peripherally supported in the contributing centres. How can we improve survival rates without properly conducted clinical trials? Finally in this area, I think surgical trials are very difficult to undertake in Australia. We are dependent so much on pharmacy and industry to fund our trials that key issues around surgery are often not dealt with. I think centralisation and an overview of effort is urgently needed.

I have provided this inquiry with an example to highlight the problems that we have. Last August I went up to the National Breast Cancer Centre. I made a presentation to the executive of the Cervical Cancer Coalition, which was aimed to bring all the players around HPV vaccination into the same arena, talking to each other. We envisaged that community members, GPs, gynaecologists, pathologists, immunologists, public health experts, industry and government, under the auspices of the NBC, would meet together to ensure the safe and effective roll-out of



the vaccine in Australia. The NBC heartily endorsed this concept, took it to government and it was readily pitched.

Here we are a year later and the vaccine has been through the TGA and been passed. We are well aware, particularly the gynae cancer community, that the general community and the professional community are completely uneducated about HPV. We are lagging in our educational programs. We have the opportunity of establishing an excellent HPV vaccine roll-out, but until we get the education right I think we will be wasting our time. This highlights the need to establish some central body to overview all matters related to women's health.

Secondly, in terms of basic science research, the major problem we have is a shortage of academic positions in gynaecological oncology. The reasons for this are disparate, but the wide gulf in income for academics compared to nonacademics has to play a part. I think all academics in medicine in Australia face recruitment problems, not only in gynaecological oncology, but one area that we have not done well in is in research training, in that it is not part of our subspecialty training program. I think also that the few laboratories in Australia that are occupied with basic research in this area often duplicate their scientific effort, and the need for a central body to ensure collaboration, nonduplication and useful use of funds seems to me to be very rational.

The establishment of a research institute dedicated to women's health, and in particular gynae cancer, would in many ways lead to an enhanced effort, improved outcomes and better value for the Australian dollar. Such an institute would not just be around basic research, however, but would include public health aspects, epidemiology, social sciences and the very important aspects of community education and professional education.

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

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

Furthermore, the ongoing continuous assessment of what we do needs to be emphasised, not only in evaluating such broad measures as survival outcomes but to ensure that the morbidity, both physical and psychosocial, is kept to a minimum. I believe that women with cancers of the breast and bowel and gynaecological cancers have similar support requirements, particularly relating to sexuality, body image and sexual functioning. The adoption of a combined model of care within a central surgical unit, I believe, has much to offer, and this is what we are planning in the new women's hospital in Melbourne.

What about rural care? I think the provision of care to non-metropolitan women has to be balanced by the knowledge that a minimum number of women with gynaecological malignancy need to be looked after by any given gynaecological specialist to ensure that high standards are maintained. The model of a central referral with satellite follow-up clinics in the local area seems to be working reasonably well, but we have never had evaluation of this model. The use of dedicated gynaecological cancer nurses to serve these communities seems overdue. There is an overall need for more gynaecological oncologists and, to do so, we need more training positions at the state level and an ongoing audit of manpower.

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

The development of a national gynaecological cancer centre and/or research institute seems to offer a framework for leadership within this area, and I urge this inquiry to give it serious consideration. A partnership using the expertise and the experience of the National Breast Cancer Centre would seem ideal. Thank you for your time.

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

**Dr Grant**—Thank you very much for the opportunity to address the inquiry. Professor Quinn has covered many of the issues that I was going to talk briefly about, but there are a couple of issues that perhaps are worthy of mention. The outcome for women with gynaecological cancer, particularly ovarian cancer, has improved if this involves the care of a gynaecological oncologist. That seems to be the data we have. As Michael mentioned, gynaecological oncology was the first cancer specialty to develop multidisciplinary care as a routine part of the care of women in Australia.

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

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

**CHAIR**—Thank you, Dr Grant. Professor Jobling.

**Prof. Jobling**—Thank you very much for the opportunity. I would like to concur with both Michael's and Peter's thoughts on the whole process, and I am really pleased that we are able to address you. We all have similar difficulties in the provision of care to our patients. Indeed, Michael and Peter have both articulated the three main areas that I feel are seriously lacking in the provision of care to women in this country—that is, the basic service provision which, as Michael said, is really not a Commonwealth issue so much, but it does impact on our delivery of service; education and awareness; and basic clinical and basic science research.

In our own area of endeavour in the demographic centre of Melbourne we are seriously lacking in the ability to look after women with pre-invasive disease of the cervix. That has been a long-term problem for us which we hope to be able to address in the not too distant future. In terms of the ability to provide some specialist care to our women, we have always had an ad hoc type funding for our fellow in gynaecological cancer, and we hope we will be able to improve that situation.

Peter has talked about rural care or the concept of being able to provide care to women in the peripheral areas. I have recently been involved in an education program, which was aired through the Rural Health Education Foundation from Sydney, to try and improve the awareness in gynaecological cancers and, in particular, ovarian cancer throughout the country. All of these endeavours could be coordinated through a national gynaecological cancer centre, and we would hope that, with the goodwill from all of the major players in the country, which are broadly represented by the Australian Society of Gynaecological Oncology, we could best coordinate that.

We had our national meeting in May and there was a groundswell of goodwill. We all believed that if we worked together we would be able to do this in a cooperative fashion, both research and provision of care. I do not think that I need to say too much more. I have submitted my thoughts on paper from where we stand. Data management is our second biggest problem. We do not have a data manager at Monash Medical Centre. We are, supposedly, the biggest health care network in this state and yet we have no data management whatsoever, so we are unable to tell our patients how we compare to our opposite numbers north of the Yarra and I think that is really an appalling situation.

I believe that if all the units in the country had a common database and a well-coordinated data management system, we would be able to say, both to the community at large and to each other, 'Yes, we are reasonably good at what we are doing and we're all pretty well up to the mark.' But at the moment I do not think that any of us can say that. That is my biggest issue at the moment.

**CHAIR**—Thank you. Professor Narayan?

**Prof. Narayan**—Thank you, Senator. Over the last 10 or 12 years, we have been the representative of gynaecological oncology services in Victoria's three centres. We have been meeting here to do a once-a-week consultative clinic, so we have had enough opportunity to interact with each other and develop themes which are common. I do not have to repeat anything that has been said because I absolutely concur with what has been said.

Having said that, I want to say briefly that the radiation oncological aspect of gynaecological cancer is completely ignored in this country. I do not know of many radiation oncologists, except us two, who solely practise in gynaecological radiation oncology. Elsewhere, it is done in a sporadic fashion. We have demonstrated that, with specialised care and expertise, it is possible to improve the treatment results.

We have met, for a period of six months, for about half an hour once a week, every alternate week, and we were hoping that we would be able to get a better base that suits all of our needs. We jotted down all the points. We got the pathologists also involved, so that we could have a common reporting structure in pathology. Having got it all together, I do not know, myself, any programming or anything, but I learnt Access and I designed the form and I started a database. Other people also wanted to do the same and have a common database, but for various reasons they were not able to maintain it. Of course, they may be maintaining the surgical patients database.

I could not find any data manager myself, but after hours I stuck with it and I collected data, and I have evidence to show that, with diligent data collection in a collaborative fashion, you can demonstrate improved outcomes and you can reduce toxicities; but since I could not find any data manager, I had to do it myself after hours. I realised that, for creative people, to create something is their individual problem. It is not a society problem. If you have a painter and you take away all the pastel colours and the oil colours that he has, he will still pick up a charcoal and do something. He cannot help himself.

It is the same thing with us. We need to be able to do things, because this is why we are where we are. If facilities are not provided, you cannot stop us. It is just that we cannot do a good job. So I realised that creativity is not a social problem, it is an individual problem. But in a civilised society the patronage to the creative people has always been provided by states, or the kings or the rulers. Things specifically related to radiation gynaecological oncology, I will cover as and when the time arises. For the opening statement, I am happy to conclude here.

**CHAIR**—Thank you. Ms Chatham.

**Ms Chatham**—The Royal Women's decided to give a combined opening statement, and Professor Quinn has done that.

**CHAIR**—There is nothing you wish to add at this stage?

**Ms Chatham**—No, thank you.

**CHAIR**—That ranges across just about all the issues in our terms of reference. It was suggested by the secretariat that we look at the funding aspects first and ask questions in that area for about 20 minutes, if that is okay, and then move on. Unless there is great disagreement, we will proceed down that line. Senator Allison.

**Senator ALLISON**—Yesterday in Sydney we were told that patients in country hospitals, even where there were gynaecological oncology units, were waiting an average 10 weeks for surgery, and that many were spending a great deal longer than that, and this was contrasted with city hospitals, where the wait was something like two to three weeks. In case we do not get

anyone who is representing hospitals in country Victoria, are you able to tell the committee whether casemix funding here prevents that kind of waiting list? What is the situation?

**Prof. Quinn**—In Victoria, the three units have worked together to try and cover the state, so that Monash looks after women from Ballarat, Mercy goes up to Bendigo and the Royal Women's goes up to Albury-Wodonga, to Geelong and is about to start in Gippsland. I do not think we have the same waiting problems, because it allows the local general practitioners, local medical oncologists and others to refer to us directly. We do not do a lot of operating in these centres. We prefer major cases to come into our hospitals, where we operate on them, and then we do follow-up clinics in the community.

I do not think in Victoria we would ever see women in the country wait 10 weeks for an operation. There are no gynae oncology units in country Victoria, but there are gynaecology centres, and I think the links are so well established now, hopefully, that for rural women the disadvantage that is certainly present in Western Australian, Queensland and so on does not exist so much in Victoria.

**Dr Grant**—In our referral areas, the wait time for women notified to us, needing our assessment or assistance, is the same as it would be for city women, which is in the order of four weeks or less.

**Senator ALLISON**—That is reassuring.

**Ms Chatham**—Firstly, I would like to commend the committee on inquiring into this important issue. I concur that there might not particularly be a problem in Victoria but I know that in non-cancer gynae surgery there are often long waits for women in the country. I think that is a really good argument for a stand-alone women's hospital, because I think a generalist hospital or a base hospital has a lot of competing demands, and often women's surgery has to compete for surgical time and, for reasons of inequity or whatever, they sometimes do not get equitable access to theatre time.

**Senator ALLISON**—That was certainly a theme: that it was the theatre time that kept on being cut. I think it was 10 per cent each year.

**Ms Chatham**—In a competitive environment for access to that expensive resource, often gynaecological services are seen as the poorer cousin to other things.

**Senator ALLISON**—In relation to the funding for research that you mentioned, Mr Quinn, you said that there is not the same availability of money for research into surgical procedures and that pharmaceutical companies obviously have a commercial gain through their research. What typically happens with applications for research into surgical techniques?

**Prof. Quinn**—I might pass this over to Tom Jobling, because Tom has first-hand experience of this in terms of setting up a laparoscopic hysterectomy trial for women with endometrial cancer.

**Prof. Jobling**—Classically, the NHRMC has not looked kindly upon surgical trials because historically perhaps they have not been very well run, they have not been able to attract good

support from the industry and also surgery is a peculiar science, if you loosely call it a science. It is hard to compare one operator to another, so broadly speaking it is not as easy as giving a drug A or a drug B. With regard to the funding of surgical trials, of course there are a lot of consumables. It is expensive, you have to have people doing the operations and there is quite a difficult process involved in accruing patients for surgical trials.

We have a pretty good model with this current trial on the management of endometrial cancer, comparing laparoscopic to abdominal or open surgery. The funding has come from the various cancer councils around the country, as well as Johnson and Johnson and Tyco Healthcare, which are two giant American pharmaceutical companies. They are also instrument makers and providers of prosthetic equipment for surgical services. The trial is well run and it will hopefully be a good model for how other surgical trials can be run.

I think that the best place would be a national gynaecological cancer centre. I do not want to harp on it too much, but if you have a central body to coordinate and distribute funding for these things, it is going to be easier to run than having it run out of one centre or being initiated in one centre—in other words, if you have a collective group such as the Australian and New Zealand Gynaecological Oncology Group; we coordinate clinical trials in drugs and things through that body. If we have a national gynaecological cancer centre, the surgical people will all be together, and there are only 35 of us, or thereabouts, so we are a pretty easy group to get together. It is not like herding cats. We are very excited about this whole concept of a national gynaecological cancer centre, because we are a very collegiate group.

We have a lot of goodwill and people get pretty enthusiastic and, like all trials, the ability to accrue is directly proportionate to the enthusiasm of the investigators. Surgical trials are hard to get up and running, but if they get going they have the potential for good outcomes. This is a really good body, I believe, to coordinate clinical surgical trials.

**CHAIR**—Professor Narayan, do you have a comment on that?

**Prof. Narayan**—Yes, thank you. I want to illustrate the point of the trial and having a central body. Over the last five or six years we have known that the figures stated for cervical cancer are not appropriate, and we have found out that certain aspects of cervical cancer explored by MRI are far more accurate in the general practice. Based on the initial results, we decided to do an Australia-wide trial, so we put forward the trial. It went through the ethics committee and so on and so forth, and was considered to be a very good trial. There was interest from America, Singapore and New Zealand.

The trial started under the auspices of our radiation oncology group, but most people could not join because it was not funded and there is no local data management facility. Somehow it started. The situation changed dramatically only last week when Peter MacCallum Cancer Centre became an active affiliate member of the Radiation Therapy Oncology Group of US—RTOG. What this means is that, if there are trials which originate here but are adopted by RTOG, or if we want to join an RTOG trial, then RTOG has central funding from the National Cancer Institute, and per patient they get certain funding, and that funding is available internationally.

I sent emails to the American people who wanted to join the trial but could not because they did not have any funding, and within five minutes they replied, ‘Oh, good. Now that you’re a

member, we will put this trial to RTOG and we'll all be able to join.' So you can see that, having worked for two or three years and been completely frustrated about such a good study which has the potential to change the staging system and the management of cervical cancer worldwide, we were not able to do anything and yet within minutes the situation has changed. I am very hopeful that over the next six months the American centres will be able to join the trial and we will be able to complete this study. This is just an illustration.

**CHAIR**—Professor Quinn, would you like to comment on Senator Allison's question?

**Prof. Quinn**—I was going to bring up the question of radiation oncology, as well as the surgical side. We had one surgical trial—and Tom will be aware because he was one of the leaders in this area—but it took three years for that trial to get up, when it should have taken 12 months. The reason it took three years was because there was no money. It was sent up to ANZGOG, it was endorsed, but at that point ANZGOG did not have infrastructure money. We have now had some money from the federal government and also from the New South Wales Cancer Institute, so that has allowed us to get this trial up and running. But it should have been running three years ago, I think we all agree.

**CHAIR**—Yes, Ms Chatham, is this on the same point?

**Ms Chatham**—Yes, it is on the same point. A central body to disburse research funding would provide better equity across the types of women's cancers that there are. I think you do see funding going to types, such as some of the more obscure things like vulval cancers. We have to be able to provide an equitable approach to the broad band of cancers that women have.

**Senator ALLISON**—Can anybody suggest to the committee the level of funding that ought to be found for research into this area?

**Prof. Quinn**—There are two separate areas: it would be funding for clinical trials and then funding for basic research. We have worked out an annual budget for clinical trials in Australia through ANZGOG: if they received between \$2 million and \$3 million a year in funding, then we would be able to do the trials that we would want to do in Australia. For laboratory based research, it is a little harder to estimate because there is not a huge number of laboratories in Australia doing gynaecology cancer research, but I believe that if you provide the money then the researchers follow the money. We saw that in breast cancer and, if we do it in gynaecological cancer, then I would see the basic science research increasing also. I think \$10 million is a conservative and realistic figure in terms of our basic science, as it stands at the moment.

**CHAIR**—A total of \$13 million?

**Senator ALLISON**—Would that be just in Victoria or Australia-wide?

**Prof. Quinn**—No, that would be Australia-wide; \$10 million in Victoria would be terrific! I think that, nationally, that would definitely kick-start things and it would then start to springboard.

**Senator ALLISON**—This is annual funding we are talking about, presumably. How does that compare with the current level?

**Prof. Quinn**—On an NHRMC basis or Cancer Society?

**Senator ALLISON**—If we compare \$13 million, and you are saying that that is more than what we have—

**Prof. Quinn**—I know that the Senate has already received a submission about the fudging around where this money actually goes to.

**CHAIR**—That was not a technical term for ‘fudging’.

**Prof. Quinn**—Sorry. But you would be aware that there are grey areas in the funding.

**CHAIR**—Sure.

**Prof. Quinn**—We believe that most of the funding is in fact not being directed towards gynaecological cancer but to breast cancer, because they are often lumped together. It is hard for us to say how much is being spent but I think the estimate was about \$6 million maximum per year. It was around that figure. So this would double that, which would be a great start. But it is the consistency of the funding: you cannot just fund for one year; it has to be ongoing commitment by governments to say, ‘This is something that we need to support for 10 years.’

**Senator ALLISON**—To what extent in funding terms is the difficulty related to Commonwealth-state arrangements? We have seen federal leadership in setting up Cancer Australia, although it is very slow. Would you like to see some sorting out of responsibilities for research and for delivery of services and, if so, can you make some suggestions to us about what you would like?

**Prof. Quinn**—We need to have a centralised body. There is no question that, if you have a body overseeing things, you get a better bang for your buck. I think that is what the vision for Cancer Australia is. In fact, in the Cancer Australia and the coalition platform it says:

Cancer Australia will submit a National Cancer Research Plan for endorsement by the Government.

I would think that we would want to be part of Cancer Australia with having a national cancer plan for gynaecological cancer under a national gynaecological cancer centre. So I think the research has to be at the Commonwealth level, with some infrastructure support from the states for data management. The cancer councils do that, to some extent, but not enough.

**Dr Grant**—Adding to what Michael said, I think that apart from the research, service provision is being looked at in many different levels and, in particular, data levels are important. It is really difficult to hear about all the individual bodies—both state and federal, and then within health services—that are trying to work out the same problem without communicating about it. Data management is the thing that stands out in my mind and, at the moment, I am aware of at least three different levels of service providers that are looking at the same problem without really knowing clearly what the other one is doing.

**Prof. Jobling**—Can I get back to the issue of coordination of research and what prospers research. Michael alluded to the fact that if you have ongoing funding which is committed and



corralled and coordinated by a dedicated gynaecological cancer research centre rather than a pimple on the breast cancer arm, I think you will find that the research is fostered in a much better coordinated way. I did my basic training in cancer in the UK, and one of the stark differences between the United Kingdom and this country—I cannot speak about the US, but I expect that it is the same—is that our trainees in gynaecological cancer do essentially no basic research. They would not have set foot in a laboratory from when they were a medical student, so they have no concept about how to do it.

In the UK, as part of their training, they will have to do a doctoral thesis of some form or another and, as part of that, they will do basic science research. Our trainees do not do that because (a) they are required for service provision and (b) there is no money with which they can say, ‘Okay, I can put my grant application into the National Gynaecological Cancer Centre because I’d like to study this aspect or that aspect within the local framework between either here and the Mercy or the Women’s and Monash.’ If they are in Victoria, then they are trainees in Victoria.

If we have a situation where we have guaranteed funding for research, whether it be surgical or basic science, and it is funding that they know that they are going to have a fair chance of getting at, I think we will find that our trainees will be more inclined to do some basic research and that will drive the whole thing in a far more beneficial and coordinated fashion.

**Ms Chatham**—In relation to your question, Senator, about the federal/state boundaries and how they get on, I think there is a significant issue in the way that health care is provided in the states. Federally they seem to have a disease focus. They have identified obesity, breast cancer, mental health, a whole range of important diseases that need work, but if you do not fit into those strategies it is difficult to get funding. Also, I think that federally we lack a women’s health policy or strategy that things such as research et cetera could come under. Federal leadership around women’s health—and, of course, gynae services and gynae cancers should be heavily embedded in that—is obviously lacking. The state often has a different approach from the way health care is delivered in the federal framework. We have a different state framework and there are clashes in relation to how to go forward, how that then rolls out in research and services.

In Victoria we have a population framework in the delivery of health care, or we try to, and there are many good things about that, but then we have the federal health agenda of disease processes coming up against it. I think the funding models are, significantly, medical models and it is difficult to provide multidisciplinary social care with the traditional Medicare frameworks.

**Senator ALLISON**—We came up against this question for Aboriginal communities where there is no access to Medicare funding for a whole range of even new programs because they are funded in a different way.

**Ms Chatham**—State and federal funding processes are very different, and they do impact on how we deliver services every day.

**Senator HUMPHRIES**—Can I clarify what you are saying about the research funding model. I do not think Cancer Australia was envisaged as a research funding allocator or distributor. I might be wrong about that, but I do not think that is the case. You are talking about

the National Gynaecological Cancer Centre being an allocator of research funding. Are there any other precedents for that within Australia's funding model for research?

**Prof. Quinn**—Not within the Commonwealth. The Victorian government seven years ago developed the CBCRC, which is a centre for breast cancer research under the auspices of Cancer Council Victoria, and they provided \$10 million over three years to kick-start five research groups into breast cancer. That has been enormously productive and I think that is a very good model that we could look at nationally as opposed to at a state level. But I just want to bring your attention to the *Strengthening Cancer Care* document. It says:

*Cancer Australia*, in conjunction with the National Health and Medical Research Council, will guide this research programme. Key organisations, such as the National Breast Cancer Centre and the National Ovarian Cancer Network, will also be consulted. *Cancer Australia* will submit a National Cancer Research Plan for endorsement ...

So the vision, I think, was that this would be driving Australian cancer research.

**Senator HUMPHRIES**—Yes, I agree about driving research and planning for it. I am not sure it necessarily was going to allocate it.

**Prof. Quinn**—I think you are right. I do not think there is any pot of money that goes to Cancer Australia for allocation, but I think they are supposed to provide the overall strategic leadership.

**Senator HUMPHRIES**—Do you think we would have to establish equivalent centres for other areas of speciality that are covered by NHMRC's umbrella? If we are going to set up an area for national leadership with gynaecological cancer, we would have to do it for others as well, would we not?

**Prof. Quinn**—I think that's a very reasonable question. People say immediately, 'Oh, you've got to have every stream covered.' Why not? Why do we have to say that, if you have a breast cancer centre or a gynae cancer centre, we cannot have a prostate centre or a bowel centre or a lung cancer centre? That is not unreasonable. If it is an effective use of Commonwealth and state moneys then we should be endorsing it, I believe.

**Ms Chatham**—And general gynae, too.

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

**Senator FERRIS**—I would like to explore this recommendation for a national centre for women's health research. There has been quite a lot of evidence given over the last two days in

Sydney about how a structure like this would work. We also had evidence from the National Breast Cancer Centre. One of the difficulties that they currently have is that, whilst they provide excellent work on ovarian cancer, because ovarian cancer does not figure in the title of the organisation, only when people are touched by it do they know that it even exists within that structure. Understanding turfdom issues, which always play a part in these sorts of things, whether they are geographic or organisational, I wonder if you could just reflect for us on how the fact that ovarian cancer work is hidden, if you like, within the National Breast Cancer Centre currently impacts on the public education areas that you have referred to. I ask all of you, because I am sure it is an issue that touches all of you. It is an issue that was raised in Sydney and I would like to explore it if I can.

**Prof. Jobling**—I am not sure that I fully understand what you are asking me, but my impression is that we have been a bit lost in the National Breast Cancer Centre. I may well be wrong, but, looking at the funding, I gather there was \$20 million allocated in 2002 and I think about \$4½ million or \$5 million of that went to ovarian cancer research, and the broad perception within our area of endeavour—gynaecological cancer—was, ‘What happened to the other money? Why has that not been distributed to ovarian cancer research?’ In terms of public awareness, you are absolutely right. The incidence rates are relatively low compared to breast cancer and so it does not get as much airplay as breast cancer, and certainly breast cancer is a major health issue; I am not trying to say it is not. But the mortality rate is, of course, only about a third that of ovarian cancer, case for case; so I suppose those of us that are a bit passionate about ovarian cancer research would argue that we need to be stand-alone so that we can maximise our efforts in terms of public awareness, education and directed research.

**Senator FERRIS**—And you would see the modality of the NBCC being able to establish another agency on gynaecological cancer, for example?

**Prof. Jobling**—A stand-alone gynaecological cancer research centre, yes.

**Dr Grant**—There may be two issues in the NBCC controlling or being the funding structure through which ovarian cancer is managed. One is the perception of how it is managed within the specialty itself—the doctors and the paramedical and the people who work in the specialty and how it is perceived by the community as a whole. Certainly one of the causes of some angst is that people working within gynaecological cancer feel, ‘We have no representative body with our name on it that we can take forward.’ For the same level of funding, whether an individual body will make our community knowledge and standing or community education any better, I do not know. I think that is really an issue of expanding our education services rather than just changing the name of who does it. The individual body is important. Something with our name on it is very important because we can feel as though we have a say in how things are managed and directed, where the priorities are, but the issue of knowledge and understanding in the community, I think, comes back to the actual level of funding and how well the message is put out.

**Senator FERRIS**—Perhaps before we go to Professor Quinn: the NBCC made the comment that they believe that it may be possible for them to expand into this more generalist centre, and in fact they have commissioned a branding agency, they told us, to look at changing the name of their organisation. My concern about that is that, if we lost the words ‘breast cancer’ from their title, it may in fact suggest that breast cancer no longer should have that priority, and I think that

would be unfortunate. I think, as you clearly do, that two organisations would carry very important messages.

In your comment on that issue, Professor Quinn, could you tell us how you would see some of the existing bodies that have been established around the place fitting within that structure. For example, I noticed in the *Women's Weekly*—I declare an interest—the emergency of an ovarian cancer institute, which I had not been aware of before. We asked some questions of witnesses in Sydney, but they were not able to tell us a lot about that. Could you tell us how you would see those existing structures fitting within the overall framework of a national gynaecological centre.

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

In response to your question, I believe that the model we should have is a partnership with NBCC. I think there should be two separate institutions, but we should be able to draw on their considerable expertise in this area, particularly around the community and community education. But I think the National Gynaecological Cancer Centre would be responsible for a much broader approach to gynaecological cancer, and that would include the basic research groups—the Ovarian Cancer Institute, the OCRF and all the players in the basic science—and ANZGOG, the Australian and New Zealand gynaecological oncology trials group, under one umbrella. It would have education for the community through OvCaAustralia, or the Ovarian Cancer Network Australia, and then we would have the very important areas of the social sciences and the epidemiological aspects, together with data collection.

I do not think it should just be a very narrow gynaecological cancer centre. It should be as broad as possible so that we can encompass the areas that we do badly, which are social sciences and public appreciation of statistics. We want to get data collection, so we need to do that. Doing that under that one umbrella, for me, is a more attractive way of—

**Senator FERRIS**—You would see that fitting under Cancer Australia?

**Prof. Quinn**—Yes, without a doubt. This is a good opportunity for the new Cancer Australia to perhaps show some leadership in this area.

**Ms Chatham**—I think that how Senator Ferris described ovarian cancer, as sort hidden within breasts, says a lot about the state of women's cancers in Australia—that is, breasts are acceptable and easy to talk about in the press but it is publicly less acceptable to talk about uteruses and stuff like that. That is why it needs to be changed to have a separate institute. I also think that the way the National Breast Cancer Centre is set up—the way they have organised themselves; the niche consumers and working with the community to sell their message and do their work—is a fantastic model for a stand-alone gynae centre.

**Dr Grant**—I would still like to broaden the subject a bit to look at the other gynaecological cancers and pre-cancers as well because, while ovarian cancer is important in our eyes, I think

there are going to be enormous changes in our screening paradigms and funding for screening services, particularly in cervical pre-malignant disease, in the next five years. That is where some overriding or controlling body that can look at the whole issue of gynaecological health—women's cancer—is important, and some of the infrastructure that the NBCC provides is enormously important in that.

It is also important that we be seen to have our own name as a point of reference for women and people looking after women and also for government, to ensure that what they are putting in is actually used and has some outcomes that are measurable and appropriate.

**Senator FERRIS**—I do not for a moment criticise the NBCC in any way, because I think they have done a wonderful job and the material that is available on gynaecological cancers—ovarian cancer et cetera—is fantastic when you find it, but it is a tops and bottoms argument. You do not go looking for a gynaecological cancer publication on a website that says 'breast cancer', unless somebody directs you to do so. That is my point.

Professor Quinn, could you tell us a little bit about the Ovarian Cancer Institute. We do not have a submission from them. I am asking you, but if anyone else wants to comment, that is fine.

**Prof. Quinn**—I am very happy to enlighten the committee. The laboratories at the Royal Women's Hospital came into being in 1996, and we called ourselves the Gynaecological Cancer Research Centre, the GCRC, and that was our brand name and our funding. About 18 months ago our community representatives advised that we needed to change the brand and that we should be concentrating on ovarian cancer, because that is the key part of our laboratory based research. So, with their advice, we changed our name to the Ovarian Cancer Institute, under the umbrella of the Women's Cancer Foundation, which is our community based fundraising.

But it gets back to the issue that this is us out there in the community raising money for research which is not available from other sources. About 70 per cent of the money that comes in to us is raised by the community. For Professor Jobling's laboratories, it is exactly the same, if not more. We are dependent on the community to help the basic science research. We need help in this area, because Tom and I spend a lot of money trying to raise funds for our laboratories when we should be looking after patients.

**Senator FERRIS**—One of our fundraising witnesses said that, despite all of the material that is around in the community on gynaecological cancers, when they knock on the door of corporate Australia, the response is, 'Ovarian what?' Given all the statistical information that we have about this disease, it is an extraordinary thing that breast cancer is very well understood but other gynaecological cancers are not. I suppose that simply reinforces the points that you have been making this morning.

While I have the floor for a minute, could you take us through the blood test trial that you have recently announced, and I think it is referred to in some of the media that I have read. Are you able to tell us anything about that?

**Prof. Quinn**—Yes, I am happy to do that. Basically, the laboratories over the last seven years have been using a technique called 'proteomics', which is looking at proteins that are produced by genes. A lot of the research in relation to ovarian cancer in Australia is about genes. We are

downstream of the genes, asking: what proteins are these genes producing in cancers and can we identify those proteins and use them as a marker for the presence or absence of ovarian cancer?

The concept is that there will not be one magic protein product but that you will need lots of protein products, and the idea is to put as many of those protein products into the one test and then a woman will have a profile of the proteins that she is making at any one point. Our initial results indicated that we can identify women who have cancer and women who do not have cancer, but this is just the start. What we then have to do is to get to women who are going to develop cancer so that we can pick them up before that cancer develops. That is the next stage, and we are going to do our studies in high-risk women—women who have genetic mutations—to see if we are able to pick up cancers earlier in those women.

If that works—and that will take at least two years—then we have to do a community study. A community study will require more than 100,000 women to volunteer so that we can say, ‘Yes, if you’ve got a cancer, this test will pick it up pretty well,’ or, very importantly, ‘If you don’t have a cancer, then the test won’t say you have a cancer or vice versa.’ So the false positives and the false negatives are very important for the community, so that we do not lull women into thinking, ‘Yes, I’m okay. My test was negative,’ and in six months time they get a cancer, with symptoms that they otherwise would have gone to their doctor with.

**Senator FERRIS**—This is the perfect opportunity to follow up the questions that were responded to earlier about how is this funded. Clearly, this is a very important piece of work. This is a very good opportunity for us to ask, ‘How is this being funded?’ Have you managed to get some international funding for it?

**Prof. Quinn**—We have such support as BOOTS—‘breasts, ovaries and other things sacred’—which is a group of women in Geelong who raise money, and have done for the last five years. They provide a research scientist for our laboratory.

We have ROCAN, which is a Rotary group, who also provide us with a scientist, a postdoctoral fellow, in the laboratory. So we have these community partnerships that we go to, and they go out there, and they are fantastic. These are women who are out raffling, and making cakes, and organising balls and functions, and they are fantastic. But we have to depend on them. We have an annual budget of \$800,000 and about \$600,000 of that comes from the community. It is amazing.

**CHAIR**—What is the name of that work again?

**Prof. Quinn**—BOOTS.

**Senator FERRIS**—How about some of the international collaboration that could follow something like this? It just staggers me, going back to what we heard about a minute ago about the five-minute email response. Is this the sort of thing that you could do internationally? Could it have some international collaboration, or do you want to make this Australian women only?

**Prof. Quinn**—We want to make any potentially useful test available as soon as possible, so we do not have an Australian flavour to it. We want this to hurry up. If we doubled the funding, it would take half the time to get it out there. If we tripled the funding, we would get it out three

times as quickly. It is all down to money. We could do it all here, but if we had international partners we could do it much more quickly. The Mercy Hospital is helping us with this research, also.

**Dr Grant**—Australia is regarded with absolute envy overseas because of our bio laboratory, particularly for ovarian cancer specimens, which is an enormous resource for research along the lines that Michael is doing, funded from overseas.

**CHAIR**—Is that the US Army?

**Dr Grant**—Yes, DOD grant funding. That is the biggest biospecimen resource in the world. And it should be things that we can make use of here in Australia, but there are significant problems with funding to be able to look at this resource.

**Senator FERRIS**—How have you got on with your appeal for volunteers to give the blood samples? Has the fact that you have had to charge people for that inhibited it in any way?

**Prof. Quinn**—The answer is we do not know if it has inhibited people. We have had a wonderful response. We have 1,250 women already on a database, and about 200 men, so men are volunteering as well.

**CHAIR**—In Victoria?

**Prof. Quinn**—There are women from interstate who have wanted to be involved as well.

**CHAIR**—The message has gone out across the border.

**Prof. Quinn**—Yes.

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

**Senator ADAMS**—Yes, we are the world leaders.

**Prof. Narayan**—And everybody says we are world leaders and then we take a step back, almost always, and try to seek approval from the international community. When are we going to get over this inferiority complex that we have? That is all I need to say.

**Senator FERRIS**—Thank you. That is a very good contribution.

**CHAIR**—Are there any more comments on Senator Ferris’s question?

**Prof. Jobling**—The only thing I would say is that there are groups overseas doing very similar work to what we are all doing, and so the laboratory set-ups are similar. In contrast to what my colleague Professor Narayan is saying, it is a bit of a numbers game, too. For instance, the Ian Jacobs collaborative group with the North Americans is looking at 200,000 women and they will get those numbers much more quickly than we will with our population. I think international collaboration is good and, if it can be achieved, would be a wonderful thing. For any test in this country, whichever laboratory it comes from, whether it is Michael's or ours or the Sydney group, ultimately we are going to need big numbers; therefore, contacts with our colleagues overseas will be important, ultimately, because to do any meaningful study, looking at a broad population based study in well women, is going to need huge numbers. Ian Jacobs's original study on 22,000 women was pretty hopeless because they only got 11 cancers. You need hundreds of thousands of women to validate any assay for the required sensitivity and specificity data before you can go out and say, 'This is the test.'

**Senator ADAMS**—I would like to get back to the Gynaecological Cancer Centre. Have you done any costings on what it would cost to physically set this up?

**Prof. Quinn**—None at all. I think this concept has been ethereal. This inquiry has been wonderful, because it has focused the gynaecological cancer community into reflecting on what the problems are and what the solutions might be, and I think we have all believed that the solution could be an NGCC, but obviously none of us, to my knowledge, has sat down and worked out the dollars.

**Prof. Jobling**—I have got a few thoughts.

**Prof. Quinn**—You have, Tom! Sorry.

**Prof. Jobling**—No, not so much the dollars, and I would like to stress that this is not a partisan approach, but one of the key things is: where are you going to locate this centre?

**Senator ADAMS**—I was being careful about that.

**Prof. Jobling**—It is an issue.

**Senator ADAMS**—It is.

**Prof. Jobling**—It will have to come up and everyone will have their comments.

**Senator FERRIS**—Put it in Canberra. That will solve the problem!

**Prof. Jobling**—Yes, but it will not get many attendances. The Australian and New Zealand College of Obstetricians and Gynaecologists is located about 400 metres from this table, and it has an infrastructure; therefore, if you want to look at bureaucratic costs and infrastructure, the infrastructure probably exists, because we do not need a four-storey building to do this. We need a bit of a skeleton staff—a secretariat. And college meetings are all held in Melbourne, because College House is in Melbourne, so stakeholders are going to be reasonably coordinated in Melbourne. You have got Western Australia, South Australia, Tasmania, Melbourne. It is a logical place to set it up. The costs would not be great. I do not believe the costs would be great



at all for the infrastructure. No, we have not done figures. You may get a very different approach from the Sydney people or the Brisbane people—I do not know—but it would seem not unreasonable, given that, as I said, the college is located in Melbourne.

**Senator FERRIS**—We should not let the argument about location interfere with the principle, anyway.

**Senator ADAMS**—Yes.

**Ms Chatham**—We beg to differ. I think that the Women's Hospital would be a better place than a medical college, because it is a medical model once you get into a medical college. At the Women's Hospital we also have an incredible infrastructure, with the institutes already there, and I do not think you can underestimate the importance of industry partners. Within the health care industry is where the findings of the research are going to be implemented. The implementation of the findings is significant, after the research, and that will happen a lot more readily if the institute sits within a hospital such as the Royal Women's Hospital, which also has the infrastructure, the expertise, the scientists, the laboratories.

**Senator ADAMS**—We have had the biggest breakthrough in research in Western Australia as far as people working together. All of a sudden, our researchers from all the different bodies—whether it be Professor Constable with his eyes, or Fiona Stanley with the kids institute, or the medical research at Charlie Gairdner's, the University of Western Australia—have all of a sudden decided that, instead of fighting for funds, all their fundraises are going to the same corporates. The whole thing had just become a nightmare. With our health reforms, we are going to have two big campuses, one south of the river, one north of the river—which is always a demarcation zone in Perth. The state government have given them \$200 million towards putting one research hub south, one research hub north, and they are at the moment trying to get funds from federal government, plus all those institutes are getting together and raising \$55 million between them to set this up. It is going to be able to attract international researchers, funding the whole box and dice, because of the fact that they are working together.

Where I am coming from with this—knowing the fights that we have been thinking about between Sydney and Melbourne—is that you have all these different types of gynaecological cancers, these people have all their different types of research and Western Australia, being a smaller population, cannot stand alone any longer with all their little bits and pieces. But with an umbrella over the top, they can, and they can attract those researchers. It was something that I was looking at and I thought I would mention it because it is a huge breakthrough: they have been fighting one another for so long and it has been very difficult for our corporates. We have some very good corporates, but if they support this one and do not support that one and then support something else—there was a bit of a model there, if it was going to become a national gynaecological cancer centre. That does not mean to say that you have to all be in the one place; there can be an umbrella with two hubs to it. That was just something to throw into the melting pot.

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

**Senator ADAMS**—We have been trying to tease that out. Cancer Australia are apparently having their first meeting in September, so at least we have got that sorted, we think.

**CHAIR**—I think this is an appropriate time to take a short break and compare funding models. The next session will have the same panel; possibly a continuation of this topic.

**Proceedings suspended from 10.14 am to 10.29 am**

**CHAIR**—So that people know, I have thrown away the guideline of focusing on individual criteria. I think it is much better just to have questions and answers because we are getting the information we need and that you want to share with us. We are now being joined by Professor David Bowtell, who has expertise in this area. Do you have any comments to make on the capacity in which you appear?

**Prof. Bowtell**—Yes. I am the Director of Research at Peter MacCallum Cancer Centre and I am also representing the Australian Ovarian Cancer Study which has been mentioned a couple of times as a DOD funded program.

**CHAIR**—Professor, you have said that you will be submitting a written submission as well.

**Prof. Bowtell**—That is right.

**CHAIR**—Senator Adams had the call before we had the break. Senator, do you want to continue with questions?

**Senator ADAMS**—Certainly. Now that you have thrown away the guideline, I can get onto my favourite things. I am a rural breast cancer survivor from Western Australia. The biggest single issue that has arisen from my community consultation on the problem of access for rural people to specialist services is the Patient Assisted Travel Scheme. I would like to know from all of you, as far as your patients go, the problems that occur. I have read their submissions and picked up a few bits and pieces, but it is something that is creating chaos throughout Australia. It was thrown out by the Commonwealth in 1987 and the states have now all got their own little ways of doing it. As our medical workforce diminishes in rural areas, access for people that live out there is becoming harder. It is really about accommodation, travel, the escort—the whole thing. I would like to throw that open to the panel to perhaps give me some information.

**Dr Grant**—That is something dear to my heart, I am afraid. It is a huge issue, even in Victoria where travel distances do not bear comparison to Western Australia, New South Wales, Queensland and other centres. It has huge impacts on our patients and their families. While we provide outreach services as best we can, particularly on a consultative basis, I do not think as gynaecological oncologists that we can provide the whole gamut of treatment in rural centres, for several reasons: one is manpower issues.

To maintain skills, a gynaecological oncologist needs to see a quorum of patients. If you are in a rural centre and seeing three or four or five patients with a cancer in a year, your skills will not be maintained. You need to be seeing large numbers of people, in terms of an operative sense, to keep your skills up. Operating in rural centres where you then leave 24 hours later does not, to my mind, give women optimal care. So while we may see lots of patients—women and their families—and follow them up in rural centres, it often does involve coming to major centres.

That involves travel, which is expensive, and I do not think that the current funding in any way compensates for the funds that they need to outlay for travel. But in a particular family, having a young woman or even an older woman coming from a rural community by herself is absolutely overwhelming, and I think we have a real dearth of provision of accommodation

services for family in major centres. Income provision during this time of illness is also another real concern for patients from rural centres, if the partners come down here for a couple of weeks.

It takes a lot of social work and paramedical input to try and deal with all these extra issues and, unfortunately, the funding is just not there to allow us to do it properly. Focusing on purely the illness or the operation that we have to do is only part of the problem: I think there is a much wider problem there.

**Prof. Quinn**—There is another perspective on this, though, and that is the doctor going out to the community. There is no funding available for specialists to go to rural communities. We have all gone, off our own bat, to do clinics in the country for which we cannot be paid because the local hospital does not have the money, and our mother hospital does not want to pay for us doing clinics out there, so who actually pays for the personnel?

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

**Senator ADAMS**—Then it comes back to the Medicare rebate for that type of thing, as to whether you have practice nurses working with divisions of general practice that may be able to deal with this issue, or nurse practitioners, or getting around to the Aboriginal health workers. There is a huge issue arising there with midwives on antenatal care as well, on which I have been very strongly lobbied, being an ex-midwife. Does anyone have anything further on the assisted travel?

**Ms Chatham**—The breast liaison nurses give us a really good model of maybe a way forward for supporting rural women. I think women need to be under the care of specialists that are generally centrally located in metropolitan centres, but you could develop a statewide regional nurse practitioner or just gynae nurse or oncology nurse in a case management model, because the hospital episodes are just hospital episodes. The disease process for the woman is an everyday event, where she is managing her symptoms and her family. The fact is that they are women, they are often young and they often have other roles of caring for young children or elderly parents. You could place regional nurses to do that case management. It is not just the hospital episode that is important. At the Women's Hospital we do have family accommodation available for people visiting our centre. So there is that model, and maybe there is a role there for volunteers, not instead of nurses but as well as nurses, to support them in their community.

**Senator ADAMS**—Do you see the breast care nurses that have been trained having a dual role of being able to deal with gynae cancers, too?

**Ms Chatham**—I do. The volume of gynae cancer is probably not there for a regional nurse because she would be driving too far to capture enough people, but you could combine the role and further develop the role. But it needs to be outside hospital as well as inside hospital. A hospital such as the Royal Women's Hospital could offer statewide training and secondary consultation, and develop standards of care and support those nurses, because nurses working that way often will be very isolated. I do not think that they should be in a rural setting, hospital

based in particular. They might work at a base hospital as their home, but their knowledge base needs to be supported with professional development from the rural centre. I think that is a model that could work really well. It does not necessarily have to be Medicare funded, because the state can do it, but Medicare funding would make it happen in another way.

**Senator ADAMS**—Does the Women's Hospital have any guidelines for an extended-care nurse in the Hospital in the Home?

**Ms Chatham**—We run Hospital in the Home, and we use Hospital in the Home extensively in our oncology area. In fact, I think we have well-developed models of care, of nurses supporting women in their home environment. We do not have regional outreach nurses yet, but we have other models, particularly around CASA, Rape Crisis and stuff like that. There are other models that we could borrow.

**Senator ADAMS**—Would you be able to send details of those in to the committee?

**Ms Chatham**—Yes.

**CHAIR**—Professor Narayan, do you want to comment on that?

**Prof. Narayan**—Yes. I do not agree that the nurses who are trained to look after breast and ovarian cancer patients would be in a position to look after, for example, the patients who have cervical cancer, vaginal cancer, cancer of the vulva. The psychological need of these patients is totally and completely different from breast and ovarian cancer patients. The treatment toxicity profile is completely different from any of the other cancers that we have discussed. We have one nurse who has been with us for about 10 years and is trained in all of those things and when she is away I know that our care completely falls apart. So it is all very well that we must try and have combined resources so that we can cover large areas, but it is a recipe where you end up giving second-rate care.

**Prof. Jobling**—I would like to make one comment about the provision of gynaecological oncology nursing care throughout the country. I do not want to keep harking back to the UK, but they have good training programs for gynaecological oncology nurses. My alma mater, the Royal Marsden, had a magnificent program, and people used to come from all around the world to do an eight- to 10-week course in gynaecological oncology nursing specifically. So some of Kailash's concerns would be addressed because these people would be dealing with only gynaecological cancer.

To have those sorts of nursing skills in the community and in the peripheral areas would be a great asset, and I think the National Gynaecological Cancer Centre, just to go back to that, would be an ideal body to coordinate the training programs for these sorts of nurses. Part of the funding mix would be not just for medical things or research but also for training nurses like this, because at the moment in this country there is no proper course that a nurse can do for gynaecological cancer, that I know of, for which they get a certificate and have something tangible in order to say, 'Yes, I've done this and I'm qualified,' and then embrace it and go back to their own hospital and skill up other nurses.

That is the sort of thing which would make a seriously big impact, and the tyranny of distance could be overcome because, if possible, these people would be in Ballarat and Bendigo and Albury and Mildura. Sure, it may well be that the person is a midwife with broad gynaecological skills who can be skilled up to that sort of thing. I think this is yet another sort of ploy, or at least asset, that the NGCC would be able to provide.

I have a patient at the moment who is terrified of going home, because she has what turned out to be a pancreatic cancer and she is going to be dying in the next two to three months. She is terrified of pain and she lives 40 kilometres from Ballarat. She is asking, 'What's going to happen when I get my pain? Who's going to look after me? Who's going to help me?' and it is very difficult to answer those questions for that particular woman. We have not even talked about palliative care, and in the rural sector that is a very big issue.

**Senator ADAMS**—It certainly is. In relation to lower limb lymphoedema and the expense, can you give me examples of that. We have the Australian physios coming in later to give evidence, but how do your patients deal with that, especially looking at the rural side of it?

**Prof. Quinn**—Mercy has an excellent lymphoedema service, and I think that we all use it.

**Dr Grant**—It is the lymphoedema service for Victoria really. It is very labour intensive to run it properly. It involves men and women coming long distances for regular fittings of garments that often have a very short lifetime. While there is recompense and funding available for garments, it does not cover them completely—far from it—and we see lots of patients who have issues about not being able to replace or change garments, just because they cannot afford to. It is a real concern for them.

Our lymphoedema physios and the people working in the lymphoedema unit are just overwhelmed by the number of people. They would desperately like to see people more regularly and offer them more regular follow-up but just cannot. The waiting time for a lymphoedema assessment is progressively blowing out.

**Senator ADAMS**—But how do your rural patients get on?

**Dr Grant**—They have great difficulty because there is no rural provision of lymphoedema services. It is central, and so they have to travel back here.

**Senator ADAMS**—Just in my own area, people are waiting three to five weeks to get one physio appointment.

**Dr Grant**—Yes.

**Senator ADAMS**—That is of no use whatsoever with lymphoedema. The other one is with the EPC items, trying to push there that perhaps we can get more sessions for lymphoedema, because it is a chronic disease. It is not going to go away, but how do we do it? These are the things that I would like you to pick up on.

**Dr Grant**—Our lymphoedema service keeps telling us that the level of education, particularly of outside medical and paramedical people, is very limited in terms of management and

diagnosis of lymphoedema. Education is something that they are battling with, and they have limited funding. We regularly see people who just do not know how to assess, pick up or treat lymphoedema.

**Senator ADAMS**—So, once again, it is education. With the physios, of course, they would rather not do it because they can see five other patients in the time one lymphoedema patient takes.

**Dr Grant**—Yes.

**Senator ADAMS**—This, to me, is a chronic disease that is occurring more and more. It is going to cost the health system an awful lot of money; therefore, I feel it is one thing we should be putting more funding into.

**Prof. Quinn**—Prevention is very important.

**Dr Grant**—Yes.

**Prof. Quinn**—It comes back to your comments at the beginning. We wanted to do a trial in Australia of a less invasive removal of lymph nodes for vulvar cancer, which would reduce dramatically the incidence of lymphoedema, but we could not afford it. That just illustrates how far behind the eight ball we are.

**Dr Grant**—I think in time we are going to see a significant reduction in the incidence of lymphoedema, with modifications of our treatment protocols. We will, unfortunately, still see lymphoedema but I am hopeful that it will not be at the same level as in the past.

**Senator ADAMS**—Can I ask our radiation specialist here about lymphoedema.

**Prof. Narayan**—I have noticed in my own practice—and I am sure others will agree—that radiotherapy has improved in Victoria in gynaecological cancer over the last 10 years. The incidence of oedema secondary to radiotherapy has precipitously declined. This has come about because of systematic data collection and systematic review of what toxicity is produced where.

If I may expand, not just for lymphoedema but the other side effects, the majority of patients who we, in gynaecological oncology and radiation oncology, have to deal with have advanced cervical cancer, advanced cancer of the vagina or advanced cancer of the vulva. The peculiarity of these cancers is that, if treated properly, these are still curable cancers. In advanced cervical cancer, for example, the cure rate about 15 years ago was 27 per cent. Now—and I am about to publish the data—it is about 60 per cent. The complications were 27 per cent and now they are eight per cent.

When I was looking at complications, the interesting thing was that the majority of complications were occurring—particularly lymphoedema and pain related complications—in those patients who had disease recurrence rather than those who were cured. The impact of this is that advanced cancers, if they are curable, must be cured, even at a slightly higher price, because failing to cure them does not lead to immediate death. The patients linger on, and the

cost to the community of looking after recurrent cancer patients of these kinds is very high, which is not realised.

Improvements in reduction in toxicity have come about by refining radiotherapy. The radiotherapy refinement has come not because somebody did research overseas but through our own observation and our insistence that we need a specialised technician also to take part. It was after 10 years of my personal struggle with the hospital here that I was finally able to get a specialist brachytherapist trained. We trained her. But I cannot have her exclusively for gynaecological cancer. She must be shared with the brachytherapy of others, because it is not recognised, first of all, that there is such a specialty. She is the only radiation therapist who is trained in brachytherapy. The same can be said about the radiation therapy planner, but I have failed to get a specialised radiation therapy planner for gynaecological cancer because such an entity is not recognised.

Although the institute is very kind and we continue as an exclusive practitioner of radiation oncology in gynaecology because of the large size of institute, I am not hired and I am not trained and I am not funded exclusively for this purpose, but the institute allows me, as one of the radiation oncologists, to do this. The same thing can be said of the radiation therapists, but they do not exist. So at the moment I get radiation therapists whom I have to train in order to get my specialised things done, and it takes about three or four months. They are trained radiation therapists, but, in my peculiar ways, I have to train them. Then after about 18 months they are rotated out, so I get another set, and it is quite time-consuming. But, having made a database and having made a commitment myself—otherwise what else is left; if I am working for 20 years, 25 years of my life here, and if I do not enjoy what I am doing, my life is wasted—and in order to preserve that sanity—

**Prof. Quinn**—Just!

**Prof. Narayan**—Because I am reviewing data, it is necessary for me to have good data.

**Senator ADAMS**—Yes. You can share it with our data man down here.

**Prof. Narayan**—When we needed an MRI-compatible applicator, of course we could not find one, so we had to get the lolly ladies to do a raffle and get us \$14,000 and we bought that applicator. Things like this have helped us reduce the toxicity, and now of course we have the criteria, which we are going to publish so that the dosimetry in cervical cancer can be done, according to us, in the rest of the world.

Then we have got simpler things, and, again, this trained brachytherapist was useful. She decided to use the ultrasound, which is very cheap compared to an MRI scan, and we find that the planning done on ultrasound is as good as on an MRI scan, and the result would be that, once this gets published in developing countries, they can give radiotherapy as safe as we are giving, with very little cost. But all these things are what I call quality assurance and developmental work. Unfortunately, this kind of work does not come within the provision of services because it is not funded in this particular manner. It does not come in research because it is not sufficiently glamorous for me to write a grant and get money. So this part which deals with radiation oncology and the technique and the ongoing improvement actually does not have any category. I hope I have not got carried away!



**Senator ADAMS**—No, that is good.

**Senator FERRIS**—We understand your passion.

**Senator ADAMS**—It will be very interesting to see what happens when you actually publish your paper, and how much interest you get from those countries. Thank you very much.

**Senator ALLISON**—I go back to nursing. In Sydney over the last two days there was a bit of emphasis on training nurses, particularly to go out to regional areas, and we were told that New South Wales runs a one-day program once a year. They tried to take it to two but found that the nurses could not get the time off because of pressures of work. Professor Hacker proposed a model whereby nurses are accredited, so they have some sort of certificate at the end of the process, but that this would be very much a clinically based experience and it would be for three or four months, not two days. For the purposes of *Hansard*, the gestures suggest that this has support on the panel. Has that been tried in Victoria at all? Do you support that approach? If so, how would that be organised? What is the best mechanism for getting something going?

**Ms Chatham**—That has not been tried in Victoria, but I fully support a comprehensive education program with an accreditation certificate at the end, and a reaccreditation process. I think it has to be done with a university or in partnership with a university, whether it is with a cancer centre or a hospital like Mercy or Women's. Clinical experience and theory need to go together, and there needs to be ongoing supervision and support, because I think that, when working in isolation, you need to have structures around you to ensure that you have standards and that quality of care is maintained. Just because you are in Warrnambool, it should not be different to how it is in Sale. We would fully support a comprehensive training for these nurses.

These nurses could also look at, in partnership, managing lymphoedema. I think that is the answer, because of the chronic nature and the waits, and, with physiotherapy under the supervision of a medical officer in the city, I think lymphoedema could be managed with clinical practice guidelines. I think all those structures and systems need to be in place to ensure quality.

**Prof. Quinn**—We have a great resource in this hospital, and that is Professor Sanchia Aranda. She is the director of nursing education; she is a university appointee; she is on the board of Cancer Australia. She would be a perfect person to drive this educational process with the help of the gynae cancer unit, and I think it would work very well in Victoria. I think there is a commitment and an acknowledgment of the extreme importance of gynae cancer nurses in our community for the care of our patients, so I think that would be the model we would choose for Victoria.

**Ms Chatham**—And I think there is nurse interest. You would not find it hard to find nursing staff that would be interested in working in that type of model.

**Dr Grant**—Every second year there is a two-day course for gynaecology cancer nursing that is oversubscribed. Mercy runs it, and the level of involvement and interest from other nurses is very high.

**CHAIR**—Does that go interstate?

**Dr Grant**—Yes, nurses from Queensland and New South Wales come down for this course.

**CHAIR**—We had evidence yesterday that people are so keen to learn that, when a course is run, they find out about it.

**Dr Grant**—They come down for it, yes.

**Ms Chatham**—Can I say that two days is just a joke.

**Dr Grant**—It is an overview. It acts very much as a catalyst for further learning and also as a point of reference for people to be able to ring in if they have a problem. They know there is a network, and that is one of the things that has developed. There is a very informal network of interested nurses that I think would be happy to take this further.

**Ms Chatham**—One caution is that sometimes, with nurse training, you have to have a master's to do the next level, and I think that becomes a barrier to many nurses who would be very competent in doing it. The hurdles to get over to be able to become a gynae-onc nurse are so high that they actually cut out a lot of the people that may be interested; but it still has to be credible and structured.

**Senator FERRIS**—Would you see the NGCC doing that sort of work as well? Would that be another arm of their umbrella?

**Prof. Quinn**—This would be just one small spoke of the NGCC umbrella.

**Senator ALLISON**—I have a question about the HPV vaccine roll-out proposal that, Professor Quinn, you said had been ditched. Can you give the committee a bit more information about the reasons for that so that we can follow this up?

**Prof. Quinn**—I cannot give you any insight into that. Basically, I discussed this with the director of NBCC after I had gone to visit them, and she informed me that there was a clear message from government that NBCC was not to take on this role.

**Senator ALLISON**—We will follow this up with the department, but it is not your understanding that someone else has got the inside running for it?

**Prof. Quinn**—I am on the advisory board for one of the vaccine companies. Peter is on the advisory board for the other vaccine company. I do not think either of us are aware of any—

**CHAIR**—And you haven't heard about it?

**Prof. Quinn**—No, we have not heard, so it is unlikely that there are great moves afoot, which I think is really worrying.

**Ms Chatham**—There is the potential for this to go wrong. There is the impact of the take-up, and there could even be a resurgence in it because it is not managed and compliance is not dealt with, and it is culturally sensitive. There are so many issues. We could be throwing the baby out with the bathwater if we do not get this right. It is so important.

**Senator ALLISON**—What is the worst that could happen?

**Prof. Quinn**—The worst that could happen is that women stop having Pap smears because they get misinformation about the efficacy of the vaccine. That is the very worst thing.

**Ms Chatham**—And people will miss out on both, so there will be nothing.

**Senator ALLISON**—The other question I want to ask is about the multidisciplinary team approach. We heard yesterday that gynaecological oncology has been a leader in moving into this field but that there are still 50 per cent of women who receive inadequate care outside that discipline of gynaecological oncology. What are the barriers? Is it just lack of knowledge about which subgroup specialists women should be referred to or are there other barriers here in Victoria to seeing that those referrals take place?

**Prof. Quinn**—Women are at the mercy of their doctors. If a woman has symptoms that might relate to gynaecological malignancy, it depends on where her family doctor refers her, and that is either into the public or into the private setting. In particular, the private setting is an area that we have ongoing concern about because the cancer journey for the private patient is a lot more complicated than the cancer journey for the public patient. I think that there is a disparity in terms of multidisciplinary care between the public and the private systems, and I would certainly like that to be addressed. It is all about resourcing.

**Ms Chatham**—I also think that sometimes when we talk about multidisciplinary we are talking about three types of doctors—an oncologist, a radiologist and a gynaecologist—and that a full multidisciplinary team not only includes allied health but it also can include complementary and alternative therapies: palliative care, case management, housing, child care, interpreters and volunteers. I think we have to have a joint understanding of what ‘multidisciplinary’ means. In a public setting, we can fund that, but there is no direct federal funding for those sorts of services.

**Senator ALLISON**—When you talk about the public/private problem and resources, is it because the public cannot afford to cover those psychosocial supports and the full team or is it that women come to the public sector and find long waiting lists for—

**Prof. Quinn**—Women in the public sector are much better looked after than women in the private sector because the composite resources of a multidisciplinary team in a private hospital do not exist in this state. I cannot speak for other states.

**Senator ALLISON**—What are the resource problems that you describe?

**Prof. Quinn**—The resources are the multidisciplinary team. It is getting all the people to surround and address the complex psychosocial issues that that woman will have in the private setting. It is the social worker, it is the case worker, it is the community person, it is the volunteer, it is the sexual counsellor.

**Ms Chatham**—The sort of regional case management psychosocial model that is in desperate need, which is what I think is lacking at the moment—and we are only talking about in-hospital encounters—is not funded currently in Victoria.

**Senator ALLISON**—Is the answer to this question to require private sector hospital provision to do all this or is it better for us to focus on the public?

**Prof. Quinn**—There are a number of models, and I think it is very difficult to actually require of hospitals or providers any one thing. What we have to sell is: what is the advantage to the woman? This cancer that she has is not about operating, it is not about radiation and it is not about giving drugs; it is about the whole care of that woman and the impact on her and her family. The value of having a centralised service and a gynae oncology unit is the fact that the woman gets a holistic approach to her cancer. She is not getting one small branch of it. She is not just going to a medical oncologist, and that is it, which is what happens out in private practice land regularly.

**Ms Chatham**—But you do need the throughput volume to be able to afford that type of system. That is why it is so difficult in Bendigo.

**Senator ADAMS**—I really cannot cope with the fact that rural women have to go to the nearest specialist. It may be someone that is a general surgeon, and they have to go there and they miss that multidisciplinary team approach. For breast cancer in WA, ashamedly I say to everyone, ‘Go through the public system. Don’t touch the private system,’ because of that particular support that you have. When you go home, you only have to pick up the phone or send an email to whoever the person was that was coordinating all your treatment.

**Dr Grant**—I think there are very good working models that allow close interaction of the public/private within gynae onc units; an involvement of women who, for one reason or another, want to be managed in a private care situation but are still under the umbrella of a multidisciplinary team. I think one of the real problems with private hospitals or private medical care for patients with ovarian cancer is the people that are just never seen within any multidisciplinary care framework that may be able to offer some care in a private setting, if that is what the woman wants; but they are escaping the net. They are just treated to the side. Even though there may be multidisciplinary people involved in that particular private hospital, there is no mechanism for saying, ‘Hey, this woman should at least be looked at as a multidisciplinary management problem.’

**Prof. Jobling**—Part of the point that we may miss a little here is that the NHMRC guidelines—and if you want to take ovarian cancer as a model, that is the easiest one to address—really do state firmly that these patients should be looked after by a multidisciplinary team and that the whole idea of these models and programs and protocols and guidelines being put out into the community, and the medical community, is that we improve the recruitment of these patients into multidisciplinary care teams.

I think that that gets a groundswell of acceptance within the medical community for a while but then the message gets lost a bit, and then they send it to their mate who is a general surgeon, who looks at the woman with a bit of mass and goes, ‘Oh, yeah, not sure. We’ll have a crack at this.’ It really is to do with making sure that the appropriate patients are referred to the appropriate person. That is medical education. That is the National Gynaecological Cancer Centre working at its best to try and educate general practitioners and having forums for it et cetera.

In relation to the issue of private versus public, as Peter said, you can do it well in both sectors, but I think ideally it is done by gynaecological oncology people coordinating the team—as Michael and Peter have said, the whole team.

**Senator FERRIS**—It is an excellence model, isn't it?

**Prof. Jobling**—Correct. We do not have a psychosexual counsellor at Monash. I do not know whether you do.

**Prof. Quinn**—No.

**Prof. Jobling**—We have a social worker and we have an upper limb lymphoedema specialist but we do not have a lower limb lymphoedema specialist, so our patients would have to go to Peter.

**CHAIR**—Professor Narayan, do you want to make a comment on this?

**Prof. Narayan**—Yes. I think the problem is complex. But it is easy to understand, even though it is complex. The needs of breast cancer patients, ovarian cancer patients and others, which is the cervix, the vulva and the vagina, are very different. The numbers of breast cancer patients and ovarian cancer patients are quite large, so it is possible to have several centres involved in their care and still give good comprehensive multidisciplinary care.

In my unit last year we saw 330 cases. That is 85 per cent of gynaecological cancer patients who required radiotherapy in Victoria. I am already concerned that the state government is going for the integrated cancer centre, and there are three urban cancer centres and three rural cancer centres, so there are six centres. It is hoped that one urban centre and one rural centre will become self-contained entities. If that happens, then 330 cases—which is just about right from the point of view of a radiation oncologist getting involved and becoming a full-time specialist looking after these patients—it will fragment into 100-odd cases in each centre.

Other centres are not sure whether they have a trained person to handle that, but certainly, in whichever centre I will find myself, along with my colleague, we will not be in a position to continue this specialty as a specialist, because who is going to fund two specialists just for 100 patients?

**CHAIR**—That is fragmentation.

**Prof. Narayan**—We cannot just say that gynaecological oncological cancer patients have that much burden and therefore 'the private' and 'the public' and 'the rural land base', and they do not need to travel here and they do not need to travel there. Of course, if it is a matter of breast cancer, they may have to travel a little less distance, but if it is a matter of some of the other kinds of cancer, they may have to travel a long distance or they will not get good care. There is really no escape from this fact.

**CHAIR**—Senator Allison, do you have any other questions? We are rapidly running out of time, and I would like to dedicate at least 10 minutes to allow Professor Bowtell to talk about the DOD project. Should we do that now and then move back to other questions?

**Senator FERRIS**—We want to give him plenty of time.

**CHAIR**—I don't know about 'plenty'! It will just be getting it on record. Professor Bowtell, a number of pieces of evidence yesterday, and also this morning, referred to the project, which I know is only part of your work, but I was hoping that we could get something on record about the role of the trial.

**Prof. Bowtell**—Okay. Thank you very much for the opportunity to present, especially at the last moment. I want to begin by endorsing some of the comments this morning. One of the issues that has been raised is that of data collection and, whilst that is obviously very important in terms of determining best approaches to service provisions, our study would be enormously enabled by better processes for data collection. At the moment we have a network of nurses right around the country, essentially in a very time-consuming and laborious way, collecting data that we need for the study. If that were collected in a more centralised way, that would make a huge difference.

The second thing is the NGCC would be fabulous; no question about it. We have created, in the Australian Ovarian Cancer Study, something quite unique in the world, but there is no doubt that, if that had not been funded through a large grant from the US, that would not exist now. Australian funding has not been targeted for gynaecological research. It tends to be rather safe, in a sense. It funds very heavily on the basis of existing track record.

For AOCS, it involved a group of researchers who had excellent track records but in a different area, and we came together to do exactly what you would want: to form a consortium to tackle a problem. But it was a new consortium and it would not have been funded through the NHMRC. It subsequently has because we have demonstrated that we really do have a track record. But the idea of a funding body that was focused on the needs of gynaecological cancer research and that was prepared to be ambitious would make an enormous difference.

I am from a regional area, too, and I would certainly endorse the comments about the importance of getting things right for patients in regional areas. Things are probably a bit better in Victoria, but there are still very important needs in regional areas.

The last sort of general thing that I want to say is that I think you should be reassured that Australia does punch well above its weight in biomedical research. I think you have heard many examples this morning of how there is tremendous potential here that, with additional funding, could yield not just health outcomes but probably health economic outcomes. Australia does have a wonderful tradition in biomedical research, both clinical and more basic research, and there are great opportunities here where we can really make an international contribution.

I come at this from a particular perspective this morning. My background is in research in molecular genetics, and my lab is particularly focused on ovarian cancer. I guess I am bringing that personal perspective, but also as head of the Australian Ovarian Cancer Study. One of the things that strikes me is that we have heard quite a bit about breast cancer this morning and it is an interesting one to contrast with ovarian cancer because at just about every point along the patient journey breast cancer is better in terms of the way that it is managed.

There is a screening program for breast cancer; there is not for ovarian cancer. We have seen particularly the application of technology to improve that. Peter Mac just recently has

commissioned an MRI unit to provide MRI screening for high-risk women with breast cancer. So we are seeing the steady introduction of new technologies to progressively improve early detection in breast cancer that does not exist at the moment for ovarian cancer. The development of a proteomics based test would be an example of where technology could make a big difference. I will come back to early detection in a moment because I think that there is a particular angle for ovarian cancer that is very important.

At the moment there are two tests internationally—one in Europe, one in the United States—that can predict, apparently with a high degree of accuracy, which women with early stage breast cancer who are node negative are likely to relapse with their disease and therefore who are likely to benefit from adjuvant chemotherapy. This is using the benefits of the human genome to figure out genes that are predictive, along with clinical information, that can help guide clinical decision making. There is a huge clinical need, because the majority of women with early stage breast cancer and who receive adjuvant chemotherapy are really not going to get any benefit from it because they are unlikely to relapse: only about 15 per cent over 10 years will relapse. So a test like that is extremely powerful in terms of being able to target who needs to be treated more aggressively.

There has been a lot in the press recently about Herceptin. This is a drug that has been developed specifically to the biology of breast cancer and it looks like that is going to be a very important drug, not just in advanced disease but in early stage disease, in improving survival very significantly. That is based on a very simple paradigm that we have all been working on in the last 30 years: do the biology; figure out the important players; make a drug and give it to people. Thank God it seems like this is going to work for us in cancer. This is a particularly powerful example of that with breast cancer. Tamoxifen is another example like that.

The fourth area is risk management. In the last 10 years we have cloned some of the genes that are involved in high-risk breast cancer; mutations that confer a high risk of developing breast cancer and often ovarian cancer as well—so BRCA1 and BRCA2 genes that were cloned in the United States. Over a period of 10 years centres like ours and others have introduced these tests into clinical practice, figured out who needs to be tested, how best to test them in a rigorous way, and how to develop intervention strategies that minimise risk; not just deliver good news or bad news but if the news is that you are carrying one of these gene mutations, how best to manage them so that you can minimise the risk. I think that breast cancer is giving us the way forward in many respects of the molecularisation of cancer medicine, and that is what I would like to see happen for ovarian cancer.

With that sort of goal in mind, a collaborative which involved all of my colleagues here, except for Liz, was established—and colleagues throughout Australia—the Australian Ovarian Cancer Study, with a goal of identifying and recruiting in an ethically appropriate way 1,000 cases and 1,000 controls. That started in earnest in 2003. We promised the DOD that that is what we would get. As it turned out, we have got nearly twice that number. You hear about competition and duplication but I have to say that the collaborative spirit has been fantastic; and even collaboration amongst people who are also our competitors, who are working in some areas on the same sort of thing; they have provided samples to the Australian Ovarian Cancer Study because they believed in it. That is the reason why this study is the only program that has been funded by DOD outside of America, because of our particular ability to do these large-scale cohort studies.

The reason that these large-scale studies are so important has to do with a very simple issue in statistics. I will not go into any of the maths, because I do not really understand them myself. In statistics, if you are testing something, you have probably 10 variables. You want probably 100 cases to test that against to develop robust statistics. What we are doing with the modern genomic and genetic technologies is that we have thousands of genes and we want to ask, ‘Are any of these genes associated with risk?’ or, ‘Are any of these genes changed in their patterns of activation in cancers in, say, patients who do badly versus patients who respond to treatment?’ The only way that you can get around the statistical problem that that presents is to generate cohorts of thousands of patients, and that is why it is so important to do that in a collaborative sense.

AOCS was designed as a large-scale collaboration and has obviously been very successful. Within AOCS there are some very important research projects that were part of the original grant, and then also AOCS is a resource for projects going on well into the future—new projects. So it is both a resource and a research study. Research studies fall into three parts: one is to look at the epidemiological risk factors—environmental risk factors, oral contraceptive use, smoking, alcohol, those sorts of things—in terms of incidence of disease.

The second part was to look at genetic risk, to try and find genes that confer risk of developing ovarian cancer. We have probably identified most of the genes that confer a very high risk of developing ovarian cancer, but there is probably a much larger number of genes out there that confer low to medium risk. While they may sound less important, they probably are much more important because those genes or those mutations are probably much more prevalent in the population and, therefore, account for more cases, so it is kind of a slippery concept.

The third part of it was to look particularly at the tumours and the molecular biology of the tumours, using a technology called microarrays, and to try and identify gene signatures that would predict whether a woman would respond, say, to platinum treatment or not, and to try and understand the basis of the response to chemotherapy.

The last thing that I want to mention, which I think is very important when we talk about early detection in ovarian cancer, is the importance of genetics. There is a big difference between breast cancer and ovarian cancer, and that lies in the incidence of the disease. The incidence of ovarian cancer at any one time—if you had a group of women, say over 45 or 50—is around one in 3,000 to one in 5,000. It is at least an order of magnitude lower than breast cancer; and Michael touched on this. So what is very important is the issue of specificity here. If you have a test that is 99 per cent specific, gets it right 99 per cent of the time but one per cent of the time it has a false positive, test 10,000 women and you are going to get 100 positives. Of those, about three will have ovarian cancer. That is a major problem, because you have all the interventions that you go ahead and do on those 100, all the concerns, all the morbidity, all the cost.

I think what is extremely important in ovarian cancer is to try and triage the women that need to be screened, and I think that the secret to that is going to be in genetics. If you can identify the women who are likely to be at risk because of the gene mutations that they carry, so that you could then take those 10,000 women and filter it down to 1,000 women, now the dynamics change completely. Of the 10 women that are positive, three of them have got ovarian cancer. You go from three per cent to 30 per cent positive predictive value. So genetics, I think, has a



particularly important part to play, and this comes all the way back to the importance of these cohort studies.

ASES is a collaborative, but it is also part of an international collaborative now, to try and find these genes. As we find them, they need to be integrated into this sort of strategy. They would fit hand in glove with the kinds of tests that Michael is developing. Already we could do a lot more. We know that about 10 to 15 per cent of women who apparently have sporadic ovarian cancer in fact carry one of the mutations in BRCA1 or BRCA2. If we could identify those women through cheaper, more effective testing, that would have profound implications for their family members—their sisters and their daughters—and we could then start to spread out from these index cases. Obviously this has to be driven by the women in terms of whether they want it or not, but it should be something where there is an increased awareness of the possibility of genetic risk, and then mechanisms to allow people to be tested if they want to be tested, and then to spread out and find other people who might be at risk, and then to develop intervention strategies that cut the risk.

We know that, particularly once women have passed their child-bearing age, there are interventions that can very substantially cut their risk of breast and ovarian cancer. It is just a little plea: that when you are thinking about early detection, it is absolutely one of the holy grails of ovarian cancer research. But, because of the nature and the incidence of the disease, we have to develop better screening strategies so that we can really target the women who are most likely to be at risk.

**CHAIR**—Thank you very much.

**Senator HUMPHRIES**—I want to take a step backwards. I was pondering Professor Narayan's answer to that question about priority setting and how you actually get authority to put resources into a project like yours, which is producing dividends, and you have to measure in some way how you actually get that benefit. Can you imagine that we are now at the press conference where we are launching our report, and, for argument's sake, we recommend that there be a national gynaecological cancer centre and we recommend \$10 million worth of research funding a year, and all these things that you have urged us to put forward. A journalist says, 'Why is gynaecological cancer an area that deserves this level of priority at the moment? More Australian men than women are being taken by cancer each year. Indigenous health issues actually have a far higher mortality rate than non-Indigenous ones. Why is gynaecological cancer an issue that deserves this sort of special attention?' What answer do we give to that question?

**Prof. Narayan**—I do not think it is difficult to answer that at all. In my house, if I have four children and one of them is particularly keen and has shown the ability to play very good piano, and another person is not interested at all in any music related things and is moderately interested in playing sports, it is quite clear for me that the biggest dividend will come if I divert my resources to the person who is playing piano. If I value sports more than I value piano, of course, the answer will be wrong, but the dividends likewise are going to be small. It is not a matter of where you give. You only can give where you find that the circumstances are suitable, that people are able, and you will get more return on what you invest. It is as simple as that.

**Prof. Quinn**—Now you know why we call him ‘the guru’! I think that gynaecological cancer is unique in this country. In my submission, the private submission I made, I tried to explain to the Senate how it developed as a subspecialty and how the interaction of the subspecialists as a composite group works. I think we are unique because we are willing to cooperate on national trials. We have got a bigger picture about what is important in gynaecological cancer as opposed to the small, local issues that we all face on a day to day basis. I think there is a commitment from gynaecological cancer specialists to talk to each other, to talk to the community, and therefore they are an excellent model. The value-add, from my point of view, is the cooperation that we can all give together because we are a subspecialty that is very well organised. That is the way I would answer that question.

**Dr Grant**—I think there is also a potential for documented, clear-cut outcome improvement because we are so organised. I think particularly within cervical pre-invasive disease we can show where some of these interventions that people are talking about can save not only lives but money.

**Senator HUMPHRIES**—More so than with other diseases?

**Dr Grant**—Yes, the potential for saving lives and money. We have got 70 per cent of women with ovarian cancer dying of their cancer, and we have research that may mean that many of these women will not die of their disease or we can prevent it. The potential for impact on the women’s lives is enormous but it is also significant in terms of funding and health costs. So I think there are lots of different ways of looking at it but I think that, because we are so organised and we have a good infrastructure in the specialty or subspecialty, we can show that there are going to be outcome changes that have benefits for fund-holders as well.

**Senator FERRIS**—Surely a motherless family has a huge economic cost to the community, anyway?

**Dr Grant**—Enormous costs.

**Prof. Jobling**—The impact of ill health and morbidity in women in particular has a knock-on effect for the rest of the family. We just have to look at the family structure in our society. It is such that women do all the work, basically, and if that woman dies, the whole thing falls apart and the social consequences are dramatic. Also, the morbidity associated with ovarian cancer in particular is such that they may be alive at five years, but they have had three years of ill health. The actual impact in the community is very widespread. I think if we do make significant inroads into these diseases we are going to have a huge impact on the outcomes, and the overall benefit to society would be massive.

**Ms Chatham**—When you have well women, you have a well society, and motherless children have sequelae that go on for generations.

**Senator FERRIS**—I do not know whether anyone is able to comment on this, but I would like to get it on the record. In the years that I have been involved in federal politics, which is 20 in one form or another, I have never been lobbied by anybody about ovarian cancer. I wonder if any or all of you know anything about the way in which lobbying is organised in, for example,

the United States or Canada that you could helpfully put on the record, because clearly this is also going to be an aspect of the work that we are going to look for in the future.

**Dr Grant**—Most of my training was in Canada, and I keep in contact with Canada. There was a very effective lobby, both through medical and through community patient lobbying, to the government representatives that changed enormously the level of funding and awareness of ovarian cancer in Canada. I can provide to you names of, and contacts for, some of the groups that were involved in that lobby.

**Senator FERRIS**—That would be very helpful.

**Prof. Quinn**—The United States is a slightly different model. The equivalent of the ASGO is the SGO, the Society of Gynaecological Oncology, and they have a Women's Cancer Foundation—WCF—and the members of that foundation tend to be high-profile women who have had a gynaecological malignancy. They are very powerful women to spread the message and to also talk to lobbyists in Washington—because that is how business is done—who will then go to politicians and perhaps get outcomes. I think we all acknowledge that, if Kylie Minogue had had an ovarian cancer instead of a breast cancer, we might not even be here today because there would be lots of money pouring into ovarian cancer research.

For that model, I think that is one way that works very well. It would be nice if ASGO, our body, could provide that but we are only 34 gynae oncologists. We are a very small group. What is really worrying—and Peter knows this—is that we have no applicants this year to become gynaecological oncologists. Isn't that extraordinary? It is a real worry.

**Dr Grant**—We have major manpower issues in terms of the age of people who are currently subspecialists and funding for the training of subspecialists. A lot of centres may have had funding to train a fellow but they now have to use that funding for some sessions for a subspecialist in the unit, so they have no funding for training. We have no applicant in Australia for training as a subspecialist next year. There are lots of issues as to why, which we will have to take further.

**Prof. Jobling**—I think it is fair to say that we are better at lobbying corporate Australia than we are at lobbying Canberra, and we need to do our homework a bit more.

**Senator FERRIS**—It is not a criticism of you. It is amazing that you have to lobby as much as you do to try and get money to do your work, and I am interested in the way it is organised.

**Prof. Jobling**—It is easier to get money from corporate Australia, especially if you are on the nose, like big banks. It is easier for them to say, 'Well, it looks good, we'll follow that because we're getting good public relations out of it.' That is the reality. It is like tobacco companies and sport. It is just that they have to get their public relations machine cranked up and they can see that it is good value. Feel-good type stuff comes out of supporting women's cancer initiatives, so we are better at it with corporate Australia because it is much easier for them to translate it into their bottom line.

**Prof. Bowtell**—Particularly if you look at ovarian cancer, I think that the comment about lobbying is that it is evolving. Consumer advocacy for cancers is something that has really come

to the fore in the last 10 years. If you look at breast cancer, it has really taken off in this country over the last 10 years. The States, in a lot of things, tends to be in front of us. Perhaps the reason it has been a bit slower for some of the gynaecological cancers, particularly ovarian cancer, is that the disease works against us in a way. It is a less common disease and it has a much higher fatality rate, so there are fewer cancer survivors around to be those advocates, but I think you are going to hear this afternoon from a very effective group, which is one of these grassroots groups that have grown progressively in terms of their prominence and advocacy for ovarian cancer particularly.

**Senator ALLISON**—They got this inquiry going.

**CHAIR**—Thank you very much. One of the really sad things about these inquiries is that we always have to end, because there is so much more we could get from you. We are not giving our report until October, so if there is any information that you think would be valuable to the committee, please send it through to us so that we can respond. We will be meeting next week in Canberra about having some site visits, so I hope that that will be an available option for further discussion as well. Thank you very much. We will now move on to our next witnesses.

**Ms Chatham**—I would like to table a model of volunteer work in the cancer sector, which they have thought about transferring to gynae onc. It is a Victorian model. Another one is related to colposcopy. This is a collaborative paper that was written in Victoria, and it refers to service delivery.

**CHAIR**—That will be very useful, thank you. I know you are going to give us the stuff about the nurses, so that will be fabulous.

[11.37 am]

**HEFFERNAN, Ms Margaret Ellen, Private capacity**

**ROSENGARTEN, Ms Alexa, Sex Therapist, Austin Health**

**CHAIR**—Welcome, Ms Heffernan and Ms Rosengarten. Ms Heffernan, you know the drill; you have done this before. Ms Rosengarten, you have got information on parliamentary privilege and the protection of witnesses, and also about the privacy aspects, if there is anything that you want to go through on that basis. I apologise, before we start, for our limited time. I am sure that we could spend days with both of you, but please get in contact with us later. Do you have any comments to make on the capacity in which you appear?

**Ms Heffernan**—I am appearing in my role as a gynaecological cancer survivor and independent gynaecological cancer advocate, for which I take no remuneration, and I am also doing full-time PhD studies in community attitudes towards the HPV vaccine.

**CHAIR**—Thank you. We have your submissions and the various correspondence. I know that you would like to make a statement and then we will go into questions.

**Ms Heffernan**—Thank you. I will keep my statement brief because I know that you have got questions to ask us. First of all, thank you very much for the opportunity to present today. As initiator of the petition that has led to this wonderful opportunity for a women's health inquiry, I would particularly like to commend the Senate Community Affairs Reference Committee and the Senate in general.

Today I would like to argue strongly for the advancement of gynaecological health, particularly with the establishment of a national gynaecological cancer centre. I know that has been well represented in your hearings in Sydney and this morning with the gynaecological oncologists. I would like to demonstrate that a unified national approach will create synergy and overcome the imbalance created by the current diversified and inconsistent approach to research, education and resources. These independent and uncoordinated efforts are unwittingly creating barriers to effective collaboration; research of screening tests, especially in ovarian cancer; appropriate consumer resources and education; clinical education and resources; and treatment services, especially in the management of psychosocial and psychosexual needs.

It is interesting to listen to this morning's discussion—that the emphasis is on psychosocial—and I am delighted that Alexa Rosengarten is appearing in her role as sexual therapist because, as you will find, there are very distinct differences. I would like to put in context that the issues that relate to this inquiry were first raised in 1997 by Professor Neville Hacker in his presidential address to the International Gynaecological Cancer Society, where he discussed the features of gynaecological cancer that have not only been consistent in these submissions but also show differentiation to other women's cancers and reproductive cancers, in that the treatment impacts on reproductive capability, sexual responsiveness and body image.

Some of the solutions he offered nine years ago, internationally, are still to be implemented in Australia. His solution for a multidisciplinary team approach of both medical and non-medical personnel has been actioned, and some Australian gynaecological cancer tertiary referral treatment centres offer world-class medical and clinical care. But as we have heard this morning and also in Sydney, this is not common to every state in Australia, especially in Tasmania where gynaecological oncologists there are forced to manage women in mixed gender wards—which is highly inappropriate—let alone have access to services that some of us in the larger centres take for granted.

We still have needs, as again you heard this morning, in the appropriate servicing of care in the rural and remote areas, psychosocial and sexual needs, lymphoedema therapy, data management, health provider, patient education, and there is a lack of a national strategy for scientific research, which was elaborated on this morning. Therefore, a national gynaecological centre with appropriate government funding and support, that is equitable with expenditure for male and breast cancers, will substantially address these needs.

I would like to commend the National Breast Cancer Centre work. I know that they are feeling vulnerable at the moment, but I would like to put very strongly on the public record the commendation that we in the gynaecological health sector have for that particular centre in managing the psychosocial aspects of treatment and also starting the important work that needs to be done in ovarian cancer. While they are now seeking brand analysis and other issues like that—which I find disappointing, given that we have not had appropriate dialogue with them—I would like to comment that they are an extremely effective model demonstrating the outcomes that we are seeking. The gains that they have made in the treatment, care, resourcing and lobbying are largely due to the initiatives and vigilance of successive individuals and the model.

I will, however, respectfully suggest that it is no longer appropriate that gynaecological malignancies be managed by an organisation whose primary charter is the management of breast cancer or, in fact, any other cancer. However, the breast cancer model can be replicated and I can see enormous synergies and collaboration there. The barriers for gynaecological cancer management are myriad, as we again heard this morning. It is no longer satisfactory for the gynaecological cancer sector that recommendations from previous inquiries and reports are not acted upon. For example, in February 2002 the *Ovarian cancer in Australian women* report recommended the need to take immediate action on ovarian cancer. Four and a half years later, we are still waiting for substantial government funding for research, for an early detection screening test, and other interventions, particularly for our rural and regional women.

We can all reflect to what extent the recommendations arising from the 2005 inquiry impacted on gains for gynaecological cancer. But I might add that that is because gynaecological cancer had absolutely no representation to that inquiry, which is regrettable. However, you are aware of the AIHW data showing increases in gynaecological cancer by 14 per cent within five years, which is horrifying. I have already had a gynaecological cancer, but in my early 50s I am now in that very high risk age of detection. With an ageing population about to come into the apex of the baby boomer age, I think the 14 per cent increase in gynaecological cancer will be a minimum.

I commend you as a committee for taking the needs of this sector very seriously, and I seriously hope on behalf of every Australian that the recommendations in your report in October

for gynaecological cancer will benefit not only us but all reproductive cancers, as I know cancer voices will also demonstrate this afternoon. Thank you.

**CHAIR**—Thank you, Ms Heffernan. Ms Rosengarten.

**Ms Rosengarten**—Thank you for the opportunity to present to this inquiry into gynaecological cancer in my professional role as a sex therapist, also known as a sexologist. I work for the Austin Hospital network in Victoria. In my submission today, I would like to strongly urge the government to support women and their partners dealing with gynaecological cancer by improving access to trained sex therapists, sexologists. My role as a sex therapist entails providing psychosexual counselling to those experiencing sexual difficulties and sexual dysfunctions relating to physical, psychological and relationship issues. I work with both women and men, and provide individual or couple therapy.

Sex therapists, sexologists, provide counselling to support people to adjust to changes to their sexuality and sexual functioning, addressing grief, loss, shame, vulnerability, sexual esteem, performance anxiety, body image, relationships, intimacy and love, as well as supporting people to be able to explore sexual interventions to manage their sexual dysfunction, develop sexual negotiation skills and explore reclaiming being sexual again and finding sexual adjustment and satisfaction.

In my capacity, I see people with any health condition, including women and men living with cancer and cancer survivors. I also run workshops for people with cancer on reclaiming their sexuality and their sexual lives. I am also on numerous sexual health committees, as well as on the board of management for the international journal called *Sexual Health*. As a contributor to the petition that has led to this inquiry, I would also like to commend the Senate for their effort in making this inquiry come to fruition. Thank you.

My original submission focused on physiological and psychosexual and psychosocial issues relating to the impact of gynaecological cancer, so today I would like to begin with the notion that we now acknowledge that sexuality is part of total health. However, this is still poorly being translated into the provision of health care for patients' benefits. Health professionals are appreciating that sexuality and intimacy is an important part of people's quality of life and that the impact of illness can significantly affect people's sexual lives and relationships, especially in gynaecological cancer.

However, in general, many health professionals remain reluctant to initiate discussions with their patients about sexual concerns, and this sends a tacit message that their concerns are not valid, and I think that is reflected even within this inquiry. From what I am aware of so far, there has not really been anything much mentioned about psychosexual issues up until today. This sends a tacit message that their concerns are not valid, and this leads to asexualisation of their patients. Many patients suffer in silence, assuming that, if sexuality and intimacy are important, health professionals would discuss them. Consequently, many health professionals assume that, if a patient does not raise a subject, then there is not a problem. We tend to underestimate, though, the degree of sexual dysfunction and resulting emotional distress due to gynaecological cancer.

It has been found that ill people and their partners demonstrated a strong need to talk about their sexual concerns and many wished to continue sexual relations, despite their sex drive and/or their sexual performance being affected, and even, for some, when they are terminally ill. Consequently, most patients are relieved to be asked if they have any sexual concerns. However, most health professionals wait for the patient to raise the topic, which requires a lot of courage on their behalf. However, when health professionals do address sexual difficulties, it is not always easy for them to know how to offer solutions or respond. In part, this is because most health professionals lack adequate training and knowledge and consequently feel uncomfortable to address the topic, provide solutions, or refer to appropriate therapists for sexual counselling.

Even in a multidisciplinary environment, where psychologists are part of the team, psychosexual issues are still not adequately addressed, as there is a distinct difference between general psychologists and sex therapists or sexologists. This is why it is essential that we adequately educate and equip health professionals to be proactive rather than reactive in addressing these issues. Because of the current lack of knowledge and comfort among health professionals in relation to sexuality discussions, these discussions still tend to be ignored. I will leave you with this document. It is from a chapter I wrote called 'Sex and sex ability', where it lists some factors that make it difficult for health professionals to address these sexual concerns, and a chart demonstrating the process of asexualising patients.

Sexual wellbeing may be altered by both diagnosis and treatment of cancer and can have a deleterious impact on quality of life. This becomes a major problem, especially with regard to gynaecological cancers, because they are different to other cancers. These sets of cancers are imbued with a significant region of the body. For women, it marks their feminine identity, female organs and genitalia, sexual function, sexual satisfaction, fertility and, of course, are intricately woven into the fabric of intimacy and relationship dynamics.

Sexual dysfunction is often unrecognised and underestimated, and still goes untreated. For women with gynaecological cancer, the treatment, and especially the consequent treatment sequelae, leave women with a sense of loss of intactness to their bodies—their body image—which impacts on relationships. All of that then impacts on relationships and can cause low levels of sexual satisfaction, loss of sexual esteem, negative feelings such as being unattractive and unworthy as a sexual being, sexual disempowerment, and can even cause sexual depression. All of these factors are an essential part of the woman being treated and cannot be adequately managed just by general psychosocial interventions, and require specialist management and care for sexual adjustment.

For instance, I would like you to quickly imagine that you have just had treatment requiring surgery to your internal organs or genitalia, chemotherapy and maybe even radiotherapy, and are also taking other general medication such as antidepressants for coping with all of this. Note: all of these interventions are common for gynaecological cancer management. You are now experiencing grief and loss, grieving, and trying to adjust to the changes to your lifestyle, body and sexual function. You get mixed emotions of fear, anxiety, confusion, shame, anger, guilt, and possibly even feelings of being a burden to family and friends are present.

All of this that you are dealing with is, essentially, also invisible to everyone else, and often even to your partner. You may be experiencing loss of libido. Touch to your genitals now may have become painful, let alone considering any penetrative sex. You may have developed altered



sensations, such as numbness or hypersensitivity within your genital region, be disfigured due to mutilating surgery, and radiotherapy may have caused strictures to your vulva or vagina. Profound swelling due to lymphoedema may also have developed, and you are also finding it difficult or have lost the ability to orgasm. Added to this, you may be experiencing some urinary incontinence and sudden onset menopause, with its associated symptoms, causing mood swings, irritability, hot flushes, dry vagina, and impacting on sexual desire and altered identity.

On top of this, you and your partner are confused by, and possibly frustrated with, how to manage these physical changes and impact on your sexual relationship. Your partner is frightened too, is feeling helpless, and wants to help you but does not know how, and is also trying to adjust to all the life and sexual changes as well. Your partner is fearful to reach out to you sexually, as they do not want to hurt you and do not want to pressure you. However, over time you may start to wonder if they no longer find you attractive, and then you may feel rejected and worried that you will be abandoned. Meanwhile, memories of previously unrestricted sexual expression may trigger a sense of further multiple losses.

Your partner may also develop low mood or depression and anxiety, and some partners even end up with their own sexual dysfunctions due to the stress. For others, a pursuer/distancer cycle may develop in your sexual relationship, creating conflict and tension, and I have a handout to explain that. Communication may break down and misunderstandings and distance may result, often causing intimacy to diminish or even cease, and, in extreme cases, lead to divorce. How would you navigate being sexual with yourself or with a partner, or even start communicating all of this with your partner, let alone for those women who would like to establish a relationship? These sets of altered states are a huge issue for all women as a consequence of gynaecological cancer and treatment.

Sexual changes and dysfunction that may develop will depend on the location, level of malignancy and the extent of the cancer and the types of treatment that the woman requires. They will be either genitally related or non-genitally related, and these are already listed in my written submission that I have previously provided. Today I am also providing you with an easy-to-read list of possible specific gynaecologically related sexual changes due to types of cancer therapies, including reduced sexual desire; loss of vaginal moisture; reduced vaginal size; pain with sex, known as dyspareunia—that is the technical term; trouble achieving orgasm; and infertility.

Furthermore, sexual changes can be either short-term and temporarily induced, such as vomiting and nausea, constipation or diarrhoea, hair loss, and fatigue; or medium- or long-term issues, such as depression, anxiety, sequelae due to general medications—for example, antidepressants can impact on loss of libido and orgasmic ability—hormonal changes, continence difficulties, skin changes due to radiotherapy; or some may be permanent, as in post vulvectomy, hysterectomy, lymphoedema, colostomy, or urostomy.

Pain with sex can be a big problem for women with gynaecological cancer, and this may be induced by hormone changes as a result of treatment or surgery, or anxiety, and can impact on the ability to relax, experience pleasure, sexual satisfaction, be able to experience sexual desire and arousal, and tends to lead to avoidance of sex and affection. I will provide you with this document, which has a diagram flow chart to explain that more clearly.

A recent study by Schantz Laursen in 2006 found that 58 per cent of females with chronic non-malignant pain experienced no ability to feel sexual desire at all, compared to health-controlled females with no pain, who experienced the ability to feel sexual desire which was rated at 100 per cent.

Finally, ‘The cancer journey: informing choice’ inquiry of 2005 did raise psychosocial issues, but did not address psychosexual issues, and this reinforces how much sexual dysfunction is underestimated. Women with gynaecological cancer have a right to be sexual and be able to negotiate what is sexually right and not right for their bodies. Women deserve proper sexual information and appropriate sexual counselling. A multidisciplinary team approach is required, with trained sex therapists and sexologists. There is a distinct difference between general sexologists, and sex therapists and sexologists.

Today I would like to strongly urge the government to acknowledge the importance of psychosexual issues for gynaecological patients, regardless of their sexual preference, and their partners and provide funding for the employment of trained sex therapists and sexologists in all health care settings to enable appropriate interventions and early interventions and long-term support.

Currently the demand for psychosexual care is not being met by institutional health care settings and, furthermore, patients’ and their partners’ needs cannot be addressed with the small number of qualified sex therapists that currently practise across Australia. Thank you.

**CHAIR**—Do you have some recommendations in your paper, Ms Rosengarten?

**Ms Rosengarten**—I have a few case studies.

**CHAIR**—Put them on record. Do not go through the whole case study, but just the recommendations.

**Ms Rosengarten**—One thing I would like to recommend is the introduction of gynaecological cancer care nurses, similar to breast care nurses. The reason why I suggest this is that they provide a coordinated and integral key person for the woman to go to, and they also see the whole picture of how that woman is being managed. My experience of working with women with breast cancer is that those in the public health system get a breast care nurse and those in the private system do not. Often there is a tremendous lack of knowledge of the services that are available to women and often their treatment gets mixed and things are missed.

Gynaecological cancer care nurses need to be trained in relation to raising the topic of sexuality and addressing sexual concerns. My experience of working with breast care nurses is that some are good at this but that many still sweep it under the carpet, and this is a major concern. What I would want from a gynaecological cancer care nurse would be to provide education on sexuality issues, so women can be informed of what may occur at the level of what a woman wants to know and also be able to start implementing some limited information and some specific suggestions. However, they are not to perform therapy—and this is really important, because it can increase higher difficulty with senses of failure because they are not specific experts. Their key role would be assessing women and determining who would be more at risk for developing sexual difficulties, dysfunctions and emotional distress so that early

intervention by referral to a sex therapist could be implemented to prevent long-term sexual consequences and relationship breakdowns. Thank you.

**CHAIR**—Thank you. Senator Allison.

**Senator ALLISON**—The Austin is your employer. Are you the only one at the Austin who does this work?

**Ms Rosengarten**—I run the whole service for every health condition.

**Senator ALLISON**—Sorry, did you say for every health condition?

**Ms Rosengarten**—Yes, so I work across the three campuses. I see inpatients and outpatients. When I talk about ‘every health condition’, that can range from spinal cord injury to brain injury to stroke to cancer to renal transplant, diabetes, heart disease, cerebral palsy, multiple sclerosis, motor neurone diseases and even non-organic psychosexual dysfunction.

**Senator ALLISON**—For there to be adequate availability of your services, how many of you do there need to be?

**Ms Rosengarten**—I would not be able to put a number on it. Almost no hospitals in Australia have these positions established within their institutions.

**Senator ALLISON**—That is my next question. Are you a lone ranger, as it were?

**Ms Rosengarten**—No, I am not the only one, but there are very few. Part of the difficulty is that the health professionals who are good at responding to patients’ questions and concerns, or actually raise the topic with their patients and then identify that there are concerns, have trouble being able to refer, and this then exacerbates health professionals’ confidence to even bring up the topic, because, once they do, they do not know what to do with it.

**Senator ALLISON**—So it is better to ignore it?

**Ms Rosengarten**—There is a side issue of difficulty in even being able to refer. Sex therapy is still a very small profession in Australia, and a lot of sex therapists tend to deal with people who live in the general community, so they need to be trained up to deal with the magnitude of women with gynaecological cancers.

**Senator ALLISON**—What is your training? Do you come from a psychology background?

**Ms Rosengarten**—I have had two careers. This is my second career. The reason I have such an imbued understanding of gynaecological cancers is because in my first career I was a nurse, and I spent 10 years working in both adult and paediatric oncology, where I worked with both adults and children—not just teenagers but children with gynaecological cancers. So I have a very strong sense of all that women experience through their treatments and resultant sequelae. I then changed careers and became a trained therapist, and there is a training course in Sydney to become a sex therapist in Australia.

**Senator ALLISON**—It is fascinating. With all of the symptoms and the treatments that you describe, it seems an urgent, but also very difficult, task that you have in steering women and their partners through this process.

**Ms Rosengarten**—In seeing all my clients, I also educate health professionals, both within my organisation and externally, to be able to raise their awareness and to understand what the issues and consequences are and also to be able to support them to feel more confident to address these concerns. This is why I spend so much time educating health professionals.

**Ms Heffernan**—I endorse what Alexa is saying. As a survivor of a gynaecological cancer which was pregnancy induced, when I subsequently wrote my book and interviewed a range of women across Australia—and, in the 14 years since, speaking to many women with a gynaecological malignancy—once I raised the issue of the impact on intimacy and relationships, every woman said, yes, it had impacted in some way on their relationships. Some remained traumatised for many years, some were able to work through it and some divorced. I did not come across a high rate of divorce, but it certainly impacted on relationships.

It took a lot of communication and a lot of proactivity with their GPs as their first point, or a trusted person who could put it in perspective. I think the fact that your inquiry has allowed us to raise the issue of the impact on intimacy, relationships and sexuality is a really important step forward, not only for gynaecological cancer but also for the whole range of reproductive cancers.

**Senator ALLISON**—Indeed. Ms Heffernan, I acknowledge your role in this inquiry and thank you for initiating petitions and for bringing the issue to our attention. I think I am speaking on behalf of everybody in saying that we all feel this a very important inquiry, thanks to your initiation.

**Ms Heffernan**—It was a team effort, but thank you.

**Senator ALLISON**—Can I ask you, Ms Heffernan, about the National Gynaecological Cancer Centre that has been recommended by so many people, including yourself, and how it would, and ought to, relate to consumers. Given that consumers tend to already be consumers, if you like, and are in a vulnerable position, is there a role for a broader support network than for those who are already diagnosed with a condition and, if so, how is that brought to bear on an organisation such as that which people are recommending?

**Ms Heffernan**—I bring some academic background to this because, when I am not involved in gynaecological activities, I lecture in management at one of our universities. One of my specialisations is actually organisation structure and design. I am not going to claim that the whole concept of a national gynaecological cancer centre was my original idea, but once it was broached that we needed a national focus, ASGO—and you heard from Professor Jobling this morning—gave it unanimous support at their annual conference earlier this year.

Why is there a need for this? In my original submission on page 26 you would have noticed a summary table of existing organisations around Australia, and I have since found out through developments last week that this is not a totally comprehensive list. So there are many established and emerging organisations all trying to meet a need.

Ovarian cancer has been put up as being one of the main cancers, as evidenced today, and if we take that particular malignancy in itself we have the National Ovarian Cancer Network that certainly comes to the top of my mind when I think of professional organisations. However, in terms of the research, I know of four major centres around Australia involved in ovarian cancer research. We think of consumer groups in terms of other general cancers. As you can read here, there are a range of groups that are providing resources, education, awareness and so on.

This is doing several things: it is confusing the newly diagnosed patient; it is confusing those in the health sector that are looking for good information and who is credible; it is confusing for the carer; it is also confusing those who genuinely want to support and donate to some of these activities. There is also duplication of scarce resources. We are only a nation of 20-point something million and, in international terms, we are exceptionally small. I think there is now an opportunity for a centre to integrate everything that is happening, review it; who is doing what, where, how and why; what access to resources have they got.

Most importantly, the thing that worries me is that there is an absence of a strategic vision. I would like to say that, even though it is easy to talk about the negative side of oncology or cancer, I think that we should remain optimistic: now more people live than die from cancer. Unfortunately, with some of the gynaecological malignancies that have prompted this inquiry, they have hit very high mortality rates. I would hope that a nationally coordinated centre would be able to identify all the major players at the moment, review the resources and, more importantly, establish a strategic focus.

This morning we have heard at length about the clinical and research aspects of that, and the treatment. However, there is a big role for the community and resource issues around this. The terms of this inquiry address the rural and remote areas that Senator Adams clearly has experience of in Western Australia. We have resource issues about who is publishing what information, and where does this fit in.

Cancer Australia was established as the overriding group that would review and try and coordinate other activities. I think that a tumour stream, such as gynaecological, fits very nicely within that, next to breast cancer, to offer collaboration and coordination. Once gynaecological cancer is set up as an independent centre, it is legitimised, and opens up avenues for consumers and other providers and others in the health sector to go to that centre for support or expertise.

I am really concerned about our ageing specialists; we are going to lose a number of them in a very short time. For the first time ever, there has not been one expression of interest to come into this subspecialty training and, with a 14 per cent increase in cancers within five years, they are matters that need to be addressed. I think one of the problems is that, within medicine generally, gynae cancers are not seen as sexy; they are very complex cases with treatment. It is not like doing, say, general gynaecology: do a hysterectomy; check-up six weeks later; you generally get on with your life.

Management of any cancer is complex, but with gynaecological cancer you then have to do your specialty of gynaecology and then oncology and so on. It is highly complex. When I addressed ASGO, we were talking about the disparity in funding. Obviously commercial reality kicks in. The feeling is: why on earth would you choose to be a gynaecological oncologist when you could go and be, say, a gynaecologist and get paid \$17,000 for a hysterectomy in North

Shore Hospital and only get \$1,700 for a very complex ovarian procedure. If you are trying to establish yourself professionally, why would you choose this?

We are very lucky in Australia that we have high levels of care and very high levels of altruism among our gynaecological oncologists. However, we have now got to make it an attractive subspecialisation to come into. I also think a centre like that would give a lot of assurance and optimism to women—and their partners and families—undergoing these procedures: ‘Yes, I’m being well looked after and well managed. There’s a professional association there.’

You are all very aware of my naivety in presenting petitions, and I cannot thank you enough, as a committee, for the mentoring and support that you have given me over the last few months. I then looked back at recent inquiries to do with women’s health, and I must say that I was disappointed but I was not surprised that there was no submission from the gynaecological cancer sector—either the specialists themselves or we as advocates and supporters of that—simply because there has been no guidance in how to do it basically.

I think a well-organised gynaecological cancer centre will have multiple elements. It will be well organised. We as a group are going to need guidance from you in how to set the processes in train for lobbying government and how to present those arguments. But once they get themselves organised, we are going to have cost effectiveness and efficiencies; we are going to have a more coordinated output of these groups that exist. I firmly believe that hospital based centres should remain: in Sydney they have the GO Fund; the Royal Women’s Hospital have their foundation; Monash have theirs.

I think there is a place for them because the patient shortly after treatment wants a mechanism to give back; it is a natural thing that you want to do. However, we also need a national strategic vision. Until we get a strategic vision, and a properly coordinated, efficient, professional organisation, gynaecological cancer is still going to flounder, I think.

**Senator FERRIS**—Very briefly, could you address the issues of competitive turfdom?

**Ms Heffernan**—It has been a difficulty for 10 years with me. Shortly after my diagnosis, I chose to go back to my treatment centre and raise some money to help rebuild their ward to give public patients private facilities. I actually realised about a decade ago that the only way forward was to have some sort of national initiative. It incidentally coincided with Professor Hacker articulating his vision for gynae cancer.

As was mentioned this morning, even though there is good collegiality among our gynaecological oncologists—at ASGO they all seemed to have a common purpose; ANZGOG with clinical research and things like that—the reality is that when we see this proliferation of organisations around Australia, all vying for their share of the very small pie from the corporate sector or the community purse and wanting to demonstrate to the public, I think that competition outweighs the long-term benefit.

Last week most of us in the gynaecological cancer sector became aware of an ovarian cancer institute and then the badging of media articles with one of the organisations to the detriment of everybody else who is working in that sector. It was a great example of competitive rather than

collaborative forces at play, which was unfortunate because it actually destabilised the strategic purpose with which we are all approaching this inquiry. However, I think that once a national centre is established, it will review those activities, or encourage the review of them, and where they are aligned, and actually support them in what they are trying to do and take away that competition.

In Melbourne alone, we have two major research centres all vying for consumer dollars with their fundraising, and there simply is not the population. Therefore, the population gets fatigued with the same requests for money to support this and they then decide to go to other charitable activities. I think that a well-coordinated national centre would be able to look at it more strategically. Competition can be healthy, but not when it is trying to dominate the patch.

**Senator FERRIS**—We had some evidence in Sydney—from, interestingly enough, an organisation that is based in Brisbane—that talked about the need to step back and define the national priorities and then make research a competitive arrangement, I suppose. That is sort of what you are saying. Do you have a view on where a national centre would best be based? I know that the Melbourne-Sydney axis makes it difficult, and that you are south of the border, but do you think Canberra might be the best place?

**Ms Heffernan**—I am glad you raised the issue, Senator Ferris, because it is going to be the one issue around the establishment of a centre that is going to create very robust debate within the stakeholders, not just among the scientists and the medical oncologists but also among all the consumer groups that exist. When these discussions are had, we have to leave self-preference aside. We have to look at where the concentration of gynaecological oncologists is; where the concentration of population is; what organisations are already established whose infrastructure we can perhaps tap into. Professor Jobling mentioned one here in Victoria and I know they also exist in Sydney.

We then have to look at the tyranny of distance so that, for a lot of whatever money is donated to this group to establish, there are not a lot of overheads in the costs of people and whatever. At this point, because they have not had formal discussions at this level reviewing this, I think it should be equidistant to most of the main treatment centres. Unfortunately, Western Australia would not be considered as a location, with respect, Senator Adams. However, I think consideration needs to be given to equidistance, where established groups perhaps could be built on. We are going to have to have a very strong relationship with the National Breast Cancer Centre. However, with today's technology and whatever, there are also opportunities for a lot of virtual activity around this. I think it is really just this strategic executive.

On the issue of virtual distance, I would like to table this initiative. It comes back to the issues that were raised this morning about how to provide the rural and regional sectors with quality support and the resources they need. If we are bringing, say, practice nurses or gynaecology nurses or whoever in, there is a wonderful initiative that has been going for 15 years in New South Wales. It is funded by New South Wales Health, and it is the New South Wales Telehealth Initiative. They currently have 11 sites all over New South Wales, and you can see there that it is across the whole state.

Every month for one hour they all meet for breakfast, and in this case it is called the 'bug breakfast'. What they do is, through the use of technology—videoconferencing or computer

enhancements or whatever—have an hour of professional development. It could be one of the specialists based in Sydney talking about any issue. It could be a sexual health specialist. The theme for the month could be managing sexual dysfunction or managing pain or whatever. Given that that is set up already, I would love to look at using that as a model to try and address some of the rural-regional needs for gynaecological—

**Senator ADAMS**—Set it up in WA. I think they actually stole the idea.

**Ms Heffernan**—With the location of this centre, through the use of such technologies, even if it were based in Canberra or Hobart, that does not mean that others miss out. But it is going to be a very robust debate.

**CHAIR**—Thank you, Ms Heffernan. Do you have anything to add on that, Ms Rosengarten, from your specialty area?

**Ms Rosengarten**—As Margaret was speaking, I was thinking about a possible model, especially when considering rural patients. I also work with a spinal cord injury group. The Austin Hospital is the major spinal cord injury centre for Victoria. As a result, they have community spinal cord injury nurses, so all the patients who go through the system are followed up upon discharge for an extensive period of time. The nurses go out to people's homes and see how they are coping, following up any issues that might arise that often are not picked up within the hospital system.

I think this is a very pertinent possibility to consider, because often after women have surgery nowadays they are discharged very quickly because of the model of efficiency that we have. I will give you an example. There was a woman in her early 30s who had vulval cancer. She knew she had the cancer. She was informed that the treatment would just be a day procedure, and she was discharged the next day. She had two young children, one with attention deficit disorder. She was still bleeding, she was in a tremendous amount of pain and there was no support on who to access to help her cope with this. When she then went back to see her specialist, he told her that the cancer in her vulva was the size of a valencia orange. You can imagine the amount of tissue taken out, and she did not know that that was going to happen. The doctor also did not know, which is not their fault, but that is what they found when they got into her body.

I think that it is really terrible for somebody to be sent home after such significant surgery. Now, a number of years down the track, sex is still almost impossible for her. She was not provided with any psychological support on any level, let alone sexual support, and it has had an impact on her relationship. She has moved interstate and is still struggling to get these kinds of supports. If you look at having nurses who can go out to women's homes, potentially, or having gynaecological care nurses, then there could be much more integral intervention that could be better managed.

**CHAIR**—That is a kind of client focus in the whole process.

**Ms Rosengarten**—Yes, exactly.

**CHAIR**—Senator Adams.



**Senator ADAMS**—This will make you feel a little bit better. In Western Australia at the King Edward a menopause clinic has been set up for menopause after cancer. I do not know if the nurses there are trained sexual health nurses, but they certainly are working on those issues, and that is becoming a very popular area. That goes for breast cancer too, once you have your chemo and radiotherapy. From my own experience, I went through the public system, and that was one of the first things my breast nurse explained to me, because at that stage they knew that I was going to have to have chemo. It was just so well done. She did it so well and so easily. I did not really ask the questions, because I was too busy thinking about how I was going to deal with it and everything else that was going on, especially living a long way from Perth. The consequences of the breast cancer surgery I had to have were raised very early on.

**Ms Rosengarten**—Generally, what I find when I talk to patients—women and men—is that they are more comfortable talking to a nurse rather than a doctor, because the nurses generally make time.

**Senator ADAMS**—After the diagnosis, you have to come back and have your biopsy and all the other bits and pieces that go with it. They gave me two sessions with a breast nurse, which was really good. I saw the surgeon after that, but she came with me to see the surgeon. I think that person then became the telephone call: ‘Look, I’m worried about this,’ or, ‘Can you help me with this,’ or something else.

In my situation, I could drive into Perth and I had somewhere to stay. But my first question was, ‘Where do I park my car when I come for the appointment?’ That might sound strange, but to a rural person coming into the city, not knowing where they have to park their car is an issue. There are so many issues like that and their mind is probably more involved with other things rather than what is actually happening to them.

**Ms Rosengarten**—Yes, absolutely.

**Senator ADAMS**—Who is going to deal with what is on at home, and, being on a farm, there are so many things. But I wanted to say that, for us there, we now have the special menopause after cancer clinic set up, which is great, and it will deal with that. The public sector is brilliant. I have had a number of people go through the private sector—no multidisciplinary team. Psychosocial help was certainly there but the sexual side of it came from the breast nurse.

**Ms Heffernan**—Myself and my associate Annie Harper have permission from the Breast Cancer Network of Australia to adapt the My Journey Kit for gynaecological cancers. There are 3,000 women diagnosed annually. I put in a submission to the Department of Health and Ageing earlier this year for funding for it. At \$25 a head we can provide a kit that not only incorporates the basic materials similar to breast cancer but will actually build on it, using the latest material from the department of health, the psychosocial summary table. We would have material on psychosexual; each kit would be customised. This has the full support of Simon Lee’s ovarian cancer group; in fact, ovarian cancer is going to be the first iteration.

Regrettably, the department of health told me to go to the National Breast Cancer Centre for funding. It was not appropriate to do that because it has to be badged independently, and in fact we will be distributing it eventually through the Australian Cancer Council, hopefully. I am going to table that budget summary for consideration in your reports. But a kit like that can then

be customised by a state, detailing the services that are available, how to find your way through the system, the issue of travel, and questions you should ask.

When I was doing the original submission for the roundtable, I was looking at translating and interpreting services and travel funds and whatever. They exist, but they are hidden. They are managed by states or whatever. As you were saying, Senator Adams, your main focus is on the family, the business and all the other day to day things, and often as a patient you do not even think of other issues. This kit will extend that further and I would seek your support for it.

I have a comment on another resource, the HPV vaccine. I know that this afternoon you are going to be speaking with the two pharmaceutical companies who are going to deliver this vaccine to Australia—CSL and GSK. Both of their submissions address the what, the who and the why about the vaccine; not one of them addresses how they are going to educate the community. As part of my PhD research, I have been interviewing parents at this stage. Women cannot tell you what an abnormal Pap smear means. They have no understanding of what has caused it, what has happened to their bodies. Human papilloma virus is typical across the world. We have very low levels of awareness.

I was at a vaccine conference on Monday in Sydney and I said to both companies, ‘Australia is not ready to have a mass roll-out of this vaccine. We have a lot of work to do in educating our community.’ I would like to know from both CSL and GSK what collaborations they have with PapScreen, department of health and other providers about a coordinated and unified message, because the one thing that consumers and parents do not want to be part of is a competitive, commercial model where you have Gardasil versus Cervarix. Both of them have a role to play in our general health. They have not addressed the issues of how we are going to get the message out to young women that they are still going to need a Pap screen.

My concern is that we are going to fall into the issues that faced hepatitis B. It was 15 years before that was successfully implemented into Australia, for all the pitfalls that we are looking at now. I would ask you as a committee, in your considerations regarding gynaecological health, to consider how the adequate education of the community is happening around that vaccine.

**CHAIR**—Thank you both very much. I feel sure that we will be talking to you again. I have no doubt about that. As you both know, we are reporting in October, so if there is other information that either of you want to give to us, please do so.

**Ms Heffernan**—We appreciate that. Thank you for the opportunity.

**Senator FERRIS**—Maybe we might need to come back and ask you some questions when we review the *Hansard*.

**Ms Heffernan**—Yes, and I may wish to elaborate on some of the issues with more detail. I notice this morning that the issue of costing came up. I think the contributors so far in Sydney and Melbourne have been very conservative and talking very low numbers. I would be looking at three figures ahead of the million mark for the five- to 10-year roll-out, and I think that an initial minimum of \$25 million would be more realistic. However, we have a lot of work to do as a sector on some proper economic modelling and costing for you. Would you want that information before October?

**CHAIR**—We would.

**Senator FERRIS**—It would be useful if we could.

**CHAIR**—Thank you very much.

**Proceedings suspended from 12.34 pm to 1.02 pm**

**GOSMAN, Mr Alex, Director, Government and Corporate Affairs, GlaxoSmithKline**

**MOORE, Ms Danielle, Advocacy, Cervarix, GlaxoSmithKline**

**STREETON, Dr Catherine, Associate Medical Director, HPV Vaccines, GlaxoSmithKline**

**CHAIR**—Thank you for coming to appear before us. I know that you are experienced at attending these kinds of things so information on parliamentary privilege, the protection of witnesses and in-camera processes you know about. We have your submission. If any or all of you would like to put an opening statement on record please do so and then we will go to questions in the limited time that we have.

**Mr Gosman**—We will make some brief opening remarks. We all come from Boronia, which is out near Mount Dandenong, about 20 kilometres from where you can get a decent coffee. We are from the pharmaceuticals side. We are the second largest pharmaceutical company in the world. In terms of vaccines, we are a world leader in the production of vaccines. Every day we manufacture, primarily in Brussels, three million doses of our various vaccines. Over the last year we have invested \$US2 billion in our vaccine production, particularly with the focus on a potential flu pandemic, making sure there is capacity in case of a worst-case scenario. We have been a long-term supplier of vaccines to Australia, under whatever form our previous companies were before the merger that created GSK.

We are a leading supplier of vaccines to the Australian government immunisation program and we have established a reputation as being a reliable and secure source of supply for mass vaccination programs. I think it is worth noting that some of the government's own research has shown that for every dollar spent on a vaccine \$8 is saved further down in preventing disease. Our investment is focused on developing vaccines for important areas of public health need. Within Australia we were the first people to bring in vaccines dealing with whooping cough, hepatitis A and B and chicken pox. More recently we have developed vaccines for rotavirus, HPV and some innovative new influenza products. There was quite a lot of mention about our trial results last week. I will now pass over to Danielle who will make some comments in terms of our cervical cancer vaccine.

**Ms Moore**—We hope our submission to you is useful in providing some background. Some of the key points that we wanted to make sure stayed with you are first of all our excitement and our pride in bringing this vaccine into Australia. We think it has a fantastic place in preventing cervical cancer in Australia and we are very proud of it.

One of the messages that we hope you have about our vaccine is that HPV is a very tricky virus. It comes and goes throughout a woman's life. While there is a peak prevalence at around age 25 in Australia, there is also a further peak around the mid to late 40s as well. That is possibly suggestive of women entering new relationships later in life, with marriage breakdown et cetera. We believe that HPV is a disease that needs to be prevented throughout a woman's life. For that reason we have gone to great lengths to produce a vaccine that has the strength to be able to protect women up to the age of 55. While being able to vaccinate girls while they are in the school system and before they have been exposed to the virus is a key aim that we should all

be working to, we also recognise the need to protect women throughout their lives. Hence we have gone to great lengths to make sure that our vaccine can protect them up to age 55.

Another key point we would like to make about our vaccine is that while at the moment we cover strains 16 and 18, which are 70 percent of all cervical cancers, the exciting findings that we are getting through our trials and research seem to indicate that the vaccine will cover a bit more than those. More specifically, we are hoping it will also cover strains 31 and 45 and that would actually take our coverage from 70 per cent potentially up to 80 per cent. That is subject to further investigation and trials at the moment and we are very hopeful that we will be able to bring that trial data to the government later on.

At the moment our vaccine is with the TGA with a priority review, and we hope to have our vaccine on the market in Australia early next year. We will work through all of the government's processes to make the vaccine accessible and affordable on a very equitable basis for all women across Australia. Any questions that you have of us we would love to be able to answer. We have Dr Streeton here, our physician, who will be able to answer any clinical questions that you might have.

**CHAIR**—Do you wish to make an opening statement, Dr. Streeton?

**Dr Streeton**—No.

**CHAIR**—We will go to questions.

**Senator ALLISON**—This morning we heard from the groups of hospitals who have gynaecological oncology units here that a proposal had been put to the federal government to coordinate the release of HPV and to make sure that all of the other associated messages to the community were in place, such as that it would not mean an end to pap smears or that all HPV is covered et cetera. That was knocked back, to their surprise I think. In fact, they have invited us to ask you whether you have a coordinated plan in mind or how you think this will or should be handled.

**Ms Moore**—Absolutely. We have been talking to all of the state pap screen organisations and have also been in contact with the national pap screening managers. We have presented to their meeting and have been very open in answering a lot of their questions et cetera. It is a very key point and for the foreseeable future pap screening will need to take place, as it does now, in accordance with any changes to the pap screening program. But absolutely GSK will be advocating that women continue with their paps alongside having access to the vaccine. We will work with the pap screen organisations to make sure that message is very clear.

**Senator ALLISON**—So it is over to you. It is your responsibility to do this—is that right?

**Ms Moore**—It is a joint responsibility between—

**Senator ALLISON**—Who are the other partners?

**Ms Moore**—The pap screen organisations have done a fantastic job in increasing the rates of screening in Australia. That is something we would never want to compromise so we will work

with them as much as we can. Also through our GP education programs we will very strongly send that message as well—that women need to continue to have their paps.

**Mr Gosman**—In our preliminary discussions with the department prior to putting in a submission for the PBAC, we have certainly been addressing that point because that has raised a lot of questions. As Danielle has said, we have been quite consistent that the pap screen program needs to stay in place.

**Senator ALLISON**—So what is the size of your budget in awareness raising?

**Ms Moore**—We will have to take that on notice if we are able to provide that to you.

**Senator ALLISON**—But there is one?

**Mr Gosman**—I think it is appropriate that we have all our clinical control data. That is coming back to Danielle's point that we are talking about 70 or 80 per cent and those clinical trials are still ongoing. We certainly do have a budget, but I can come back to you on the specifics of that.

**Senator ALLISON**—Central to our inquiry is a high level of ignorance in the community broadly, but also amongst women. For instance, there are a lot who think that a pap smear protects them from ovarian cancer. That seems to be a very common situation. So we are talking about something that is probably a fairly large-scale need. Will you deal with the gynaecological oncologists in getting their advice on what you do, or will you just take your advice from the department?

**Mr Gosman**—When I say that, they have been asking us questions about rollout and what the implications are for other programs. But we will certainly be talking to all those people who have an impact. It needs to be said that we are one of many people who have an interest in this issue. So there needs to be a coordinated approach going forward. Of course the department also has an important role there as well.

**Senator ALLISON**—I am sorry to keep pressing you on this, but what is the process?

**Ms Moore**—The process to date has been that we have identified as many of the relevant interested parties as we possibly can and continue to do so. They include the pap screen managers and the department of health. There are also the state immunisation coordinators, the cancer councils and the gynaecological oncologists. There is a wide range of interested people. There will be a lot of people with a role to play in making sure screening continues to happen.

**Senator ALLISON**—I have a question about where you are at with the government on the cost of this. I think the decision was made that it go on to the subsidised vaccines list, or is that still pending?

**Mr Gosman**—No. We are still going through the TGA process. We believe we would be in a position to put a submission in late this year for examination early in the new year. That is the timetable GSK is working to with our vaccine.

**Senator HUMPHRIES**—That is still the PBAC, is it?

**Mr Gosman**—Yes. It still goes through the PBAC process. We have had preliminary discussions with the department to understand some of the issues that might come up during the assessment process. They have all been very positive. We are working our way through that process.

**Senator ALLISON**—Is it possible to indicate to the committee the likely cost of a dose?

**Ms Moore**—Not at this point.

**Senator ALLISON**—Not even an ‘in the order of’—\$300, \$10?

**Ms Moore**—Not at this point, I am afraid.

**Senator ALLISON**—How do you anticipate this will be rolled out? Will it be done through doctors in schools or will we just wait until parents take their 13-year-olds along to their GPs? How will it be progressed?

**Ms Moore**—That will be a decision for the federal government, once our vaccine has been through the TGA and the PBAC process. The one thing I could say to you is that it is more than likely to be a total cost to government of more than \$10 million a year. So it will need to go through the cabinet process.

With our vaccine, because we hope to cover women up to age 55 years, we will need to go through several processes. Obviously the national immunisation program is largely a school based vaccination program. We hope to capture girls when they are in the school system. All three doses can be given to them in a very practical, well-recognised rollout format. Then we will have to have further consideration of how we can make sure that our vaccine is as accessible as possible for girls older than those in the school age program.

**Senator ALLISON**—Are the clinical trials that have been conducted so far publicly available or not?

**Dr Streeton**—A number of the clinical trials are, but not all. We have had some recent data published in the *Lancet*, as of April, which was a 4 ½-year follow-up of our efficacy study that started back in 2001. Those 4 ½-year follow-up data have provided a demonstration of long-term protection against the two types that are in the vaccine—100 per cent protection against HPV 16 and 18—as well as the cross-protection that Danielle referred to earlier against infection types 45 and 31.

**Ms Moore**—I would add to that that we do have ongoing clinical trials happening in Australia, both in South Australia and Perth, for our vaccine, which is terrific.

**Senator ALLISON**—What are those trials looking at?

**Dr Streeton**—We have trials looking at co-administration of our HPV vaccine with other standard adolescent vaccines, such as hepatitis B Boostrix, currently used on the adolescent

immunisation schedule. We are also doing a study looking at the use of this vaccine from a protection point of view against older women in that 25- to 55-year-old cohort.

**Senator HUMPHRIES**—I want to ask a couple of questions about comments made in the inquiry about issues associated, firstly, with clinical trials. There have been quite a few comments made by people that we have not run clinical trials in this country very well, not just in association with the rollout of new drugs but just generally processes to do with the treatment of people with gynaecological cancer. I do not know how heavily a company like yours would be involved in trials not related to a drug, but as far as ones related to drugs are concerned are you happy with the process? Do you think that we could improve that process of trialling drugs and rolling out the information available from them?

**Mr Gosman**—At any point in time there would be up to 80 trials being undertaken for different drugs and different vaccines in Australia. Because of the nature of the population we find Australia is a good place to do trials because it is not a homogeneous population. For example, there have been experiences where, say, if you are wanting to do a trial with a focus on how Korean people will respond you can recruit faster in Australia than you can in the US. We also have the only phase 1 clinical trial unit in Australia, which is based in Randwick. I think the issue we find with clinical trials is that you have to go to each university and get the ethics approval and there is quite a degree of variation in the process that each university does. I know the NHMRC has been doing a lot of work in that area trying to get much more consistency, but you will find some places might potentially take 12 months while others could take three months.

**Senator HUMPHRIES**—To give approval?

**Mr Gosman**—Yes, and then you cannot start the process until you get the ethics approval.

**Senator HUMPHRIES**—It is hard to understand why there would be differences in different universities.

**Mr Gosman**—The trouble is that they all follow different processes. There is probably a historical perspective; it is what they have done in the past. That is why I think the NHMRC is doing some valuable work trying to get consistency. It is not only in trials. There are plenty of other areas where you can have evidence of universities following different approaches to the same issue.

**Senator HUMPHRIES**—The other issue raised related to the question of rolling out education programs in conjunction with new drugs, for example the one that you are talking about today. Is GlaxoSmithKline involved in that sort of process usually? If not, should it be? Are there any defects in that process from your point of view?

**Mr Gosman**—For a number of our medications we work with patient groups. For example, with asthma medications we will work with some of the asthma organisations. We have worked with Diabetes Australia. We are upfront and quite transparent about what we do and we provide that information on our website so there can be no claims that anything is being done underhand, and it is usually in response to requests from those organisations. We focus very much on particular activities which usually are of an awareness nature. For example, with the asthma



organisations we have done work in schools to make people aware. If you look at asthma generally, it is considered to be underdiagnosed by 50 per cent, so it is quite important to do some of those information programs. Similarly, diabetes is again very much underdiagnosed.

**Senator HUMPHRIES**—Will you be advertising Cervarix when it comes onto the market, and do you need to?

**Mr Gosman**—We are prohibited from advertising any of our medications in Australia. Only over-the-counter medications can be advertised.

**Senator ADAMS**—I am from rural Western Australia and I was just wondering about the Aboriginal areas. What work have you done with trials in those areas?

**Dr Streeton**—To date we have not conducted any specific trials in Indigenous female populations but we are collecting epidemiological data to get an understanding about the burden of HPV infection in these women and the types of HPV that infect them. There have been discussions internally about exploring the idea of perhaps looking at doing a trial or some sort of demonstration project in Indigenous women with the vaccine.

**Senator ADAMS**—What about non-English-speaking background populations? Have you done anything there?

**Dr Streeton**—The clinical development of our HPV vaccine has been very much of a global development. For instance, Australia is one of many countries that have provided subjects to be part of the trials conducted on this vaccine. In fact, a great proportion of subjects have been recruited from women who reside in less developed areas of the world. With that sort of breadth of participation in the trials we get a feeling of how well the vaccine works in different types of populations. Is that answering your question?

**Senator ADAMS**—It sort of is, but not really. Coming back to the education side of it, if this vaccine is approved and everything goes ahead, how are you going to deal with educating people? It is fine for people who understand what it is all about but there are an awful lot of people, as we have just said, who think pap smears are supposed to diagnose ovarian cancer. We know it is not right but a lot of the community think they do. How are you going to reach these people to really be able to deal with the issues?

**Ms Moore**—At the moment the groups that we know have a lot of experience in this area are the pap screen organisations. As a company we are very conscious that cervical cancer is the leading cause of cancer deaths amongst women in our Indigenous communities, and that there are several groups in Australia that have traditionally low rates of screening. They include Indigenous women and women from culturally and linguistically diverse backgrounds. There are also issues with trying to improve the rates of screening amongst women with disabilities, mental illness et cetera. As I said, the groups that have the most experience in that area of making sure that these women present for their paps and are appropriately treated are the pap screening organisations. We have been talking to them and getting as much information and education as possible from them at the moment.

**Mr Gosman**—I will go back to the question Senator Humphries asked. In terms of the support we have given in the area of, say, mental illness—again a lot of the issues are to do with people who cannot speak English, who do not know where to go and so on— we have actually provided support to mental health councils to publish information in up to 20 different languages which is then provided through some of the community health resources and so on to help give that awareness. I think they would be some of the areas where we would be looking at working with other organisations.

**Senator ADAMS**—If more Aboriginal health workers are needed—they are very poorly paid—does the company sponsor any training of people or anything like that as far as getting the right result?

**Mr Gosman**—Not specifically in that area. GSK as a company supports a number of activities and a lot of those are being done industry wide—for example, we are supporting the training of people in Papua New Guinea on HIV—but not specifically in Australia with the Aborigines.

**Senator FERRIS**—Can you give us some comments more generally, and perhaps from a slightly more broadly based perspective, about the difficulty of raising funds for research in clinical trials in Australia. You may not have been here this morning when some of our witnesses made comments about this, and certainly we had evidence in Sydney about the need for more money to be made available for trials. Does your organisation sponsor commercial trials? Could you give us a bit of an overview of the philanthropic approach, or perhaps even the philosophical approach, that you have to this sort of more broadly based research effort?

**Mr Gosman**—We are highly supportive of what the government has done over the last five years in terms of increasing the amount of research funding that goes into the medical area. We do trials—I do not know if you would call them commercial trials—in Australia for commercial products and we do find it, as I was saying before, a very conducive environment in which to do that. It is a well thought out regulatory environment, other than the issue around the ethics, and it is a good population. We are always looking to do more research. As an organisation one of the issues we always face is making people aware of the capabilities that we have within Australia.

**Senator FERRIS**—How about funding basic research?

**Mr Gosman**—We do about \$32 million a year in R&D and a lot of that is in clinical trials—probably \$20 million of that would go into clinical trials. We then fund a range of postgraduate research, university related research. We are not talking huge amounts of money—it could be a \$25,000 project here, a \$50,000 project there. We fund a myriad of those kinds of projects. We also have a number of commercial relationships with some small Australian biotech research focused organisations. As a company we are always looking to do more research in Australia. The more funding that is put into research, the more opportunity and time there will be to establish those partnerships.

**Senator FERRIS**—Do either of the other witnesses want to make a comment?

**Ms Moore**—I think Alex covered it very well.

**Senator FERRIS**—That was my only question. The submission is very self-explanatory.

**Senator HUMPHRIES**—The HPV virus obviously afflicts women but because it is sexually transmitted I assume it is transmitted by men. Does it affect men?

**Dr Streeton**—The HPV virus is a very large family of viruses—in fact, there are many hundreds. But only about 40 have a tendency to infect genital mucosa but that can infect both male and female genital mucosa. Then they are divided into low and high risk types. Genital warts would be a clinical outcome of the low risk types and we know that genital warts occur both in males and females. The high risk types are oncogenical cancer-causing, so they cause the cancers that we see in the female genital tract. They can also cause penile cancers and anal cancers. GSK has been putting efforts at this point in time to develop a vaccine that is initially targeted for women to provide the best possible protection against cervical cancers for women. We are, however, looking at undertaking trials in boys as well to understand the effect of the vaccine in boys.

**Senator HUMPHRIES**—It would be a decision for health authorities quite a long way down the track as to whether such vaccines would be made available on some sort of whole of population basis for males.

**Dr Streeton**—That is right.

**Senator ALLISON**—What does happen if males take it? Is it ineffective?

**Dr Streeton**—With the vaccine we are developing, which is the bivalent HPV 16 and 18 vaccine, if you were to give it to boys you would probably induce an immune response, so you would see an antibody response to those antigens. But there is no clinical endpoint that it would be protecting in the boys.

**Senator HUMPHRIES**—So nothing would happen apart from that reaction?

**Dr Streeton**—I am wrong. The clinical endpoints in the boys I am not so familiar with but it could provide some protection against anal cancer.

**Mr Gosman**—Perhaps we could—

**Dr Streeton**—Come back to that.

**CHAIR**—You can take that on notice.

**Senator ALLISON**—In your talks with government so far has there been any agreement reached about this new vaccinated group of women who will come through and the frequency with which they will need to have smears?

**Ms Moore**—Not from within GSK. That would certainly be left up to the department's own guidelines on when smears occur. We are aware that there is consideration of some changes but that is not a charge that would be led by GSK in any way.

**Senator ALLISON**—Even if your vaccine covers 80 per cent of the prevalence there is still that other 10 per cent, and we have to now consider how best to identify those still at risk and how frequently they need to be checked. You are not involved in that discussion or you do not have a view about it?

**Ms Moore**—Our view is that, for the foreseeable future, women should absolutely still continue to get their pap smears and vaccinations.

**Senator ALLISON**—I am talking about the new generation, the soon to be vaccinated ones, as they come through—for the rest of their lives or until they are 55 or whatever the coverage is.

**Ms Moore**—Until the vaccines are able to cover 95 per cent to 100 per cent of cervical cancers and HPV strains, then absolutely you will need to continue to have your paps. So it includes even that next generation.

**Senator ALLISON**—That refers to the new generation, not just to the current one.

**Ms Moore**—Yes.

**CHAIR**—I think that is it, unless you have any other comments you would like to add.

**Ms Moore**—Just to thank the committee for allowing us to present further. I also put on record our thanks to Margaret Heffernan for getting all this started. She is an amazing campaigner.

**Mr Gosman**—We have some issues to come back with, and we are happy to take any other questions that may arise over time.

[1.32 pm]

**DAVID, Dr Rachel, Director of Public Affairs, CSL Ltd**

**LEONG, Dr Jane, Medical Director, CSL Pharmaceuticals Ltd**

**WAIN, Dr Gerard, Consultant, CSL Ltd**

**CHAIR**—We welcome witnesses from CSL. You have been provided with information about parliamentary privilege, protection of witnesses and privacy provisions. Would anyone like to make an opening comment?

**Dr Wain**—I am a gynaecological oncologist. I have had a long involvement with cervical screening in Australia . I have been the director of the New South Wales cervical screening program for the last 10 years. About a year ago CSL asked me to work with them because of the imminent release of the vaccine. That is the explanation of my position with CSL today.

Cervical cancer prevention programs based on the pap test have been amongst the most successful public health achievements in modern history. Since the implementation of organised cervical screening in Australia in the early 1990s, the incidence and mortality of cervical cancer have halved. Australia has now the lowest mortality from and the second lowest incidence of cervical cancer of any developed country in the world. These successes have relied on the careful implementation of the cervical screening pathway from recruitment of women to the program, the world's highest quality laboratory services, the establishment of pap test registers and the expert clinical management of women with screen-detected abnormalities.

In relation to this last aspect of the pathway, Australia has recently adopted new management guidelines for the management of women with screen-detected abnormalities. The guidelines were developed by a multidisciplinary committee of 22 national experts, including Professor Ian Frazer, the current Australian of the Year. The committee also included four of Australia's leading gynaecological oncologists. In developing the guidelines the committee looked at all of the available evidence about cervical screening and, after widespread public consultation, produced evidence based guidelines for the optimal management of women with screen-detected abnormalities.

These guidelines have been endorsed by the NHMRC and by the College of General Practitioners and the College of Obstetricians and Gynaecologists. These guidelines draw upon the latest available evidence on the human papilloma virus, or HPV, which is the cause of cervical cancer. I would like to table a copy of the new guidelines in case the committee has not had the opportunity to review them yet. Most importantly, there is a chapter in the guidelines that summarises the role of HPV in relation to the natural history of cervical cancer. I would commend this discussion to the senators as a very useful summary of this very detailed science. The implementation of these guidelines has been associated with a broad education program for GPs and women. I would like to table some of the literature that has been developed by the national program about these new guidelines and particularly about the role of HPV in relation to cervical cancer.

This program is also being taken around to GPs across the nation. In New South Wales, for example, we are conducting a series of workshops amongst all 35 divisions of general practitioners. I have been giving these symposiums to GPs—two or three a week. The seminars consist of about a two- or three-hour discussion group with advice to GPs about how to explain HPV, its role in cervical cancer and the role of the new guidelines to women.

**CHAIR**—Dr Wain, how recent is all that?

**Dr Wain**—These booklets arrived in my mail just yesterday.

**CHAIR**—They are that recent? So those booklets are brand-new. And your seminar series?

**Dr Wain**—The seminar series started about two or three months ago and they are scheduled to run over the next few weeks.

**CHAIR**—That just gives me a focus for the time.

**Dr Wain**—Because these guidelines have just come into force from 1 July, the educational program has been timed to match that program. That is what is happening: the brochures are national, the workshops are in New South Wales and each of the states is responsible in turn for the implementation. I know that similar workshops are happening in all states around the country.

I have started my presentation with a discussion of HPV because we are now in a very exciting new era of cervical cancer prevention. As all senators will be aware, the HPV vaccine is now available in Australia. Gardasil was developed in Australia and will be available for use through GP prescriptions in the next few weeks. It is currently the only vaccine registered in Australia. I have available for the committee the product information brochure that is being attached to this vaccine and that will be widely distributed to general practitioners.

The vaccine is listed in Australia for use in males and females and there are more details about that listing in the brochure. I am happy to table that for the committee's interest. CSL has submitted an application to the Australian government for public funding of this vaccine through the national immunisation program. This application is currently being considered by the Pharmaceutical Benefits Advisory Committee and a result of this application is expected in November this year. The vaccine will add a primary prevention strategy to the already successful secondary prevention strategy. It does not replace cervical screening but the addition of the vaccine to the existing program is extremely cost-effective.

On Monday this week I presented data to the Public Health Association's 10th National Immunisation Conference showing that the addition of vaccination with Gardasil will further reduce cervical cancer incidence and mortality, and will dramatically reduce the number of screen-detected abnormalities. A universal mass immunisation program in 12-year-old girls will come at a cost per QALY of approximately \$19,000—a figure which is well below national benchmarks that would normally be considered good value for money by government. The research in drawing it together has brought together many of Australia's experts in this area in developing the model upon which the pricing is based. It accurately reflects Australian data and

will be a very reliable model for predicting the impact of the vaccine on the Australian population. I am happy to discuss that further if the committee wishes.

There are very important issues of awareness about HPV. The National Cervical Screening Program is promoting the role of HPV in its new management guidelines. The company is launching a broad campaign directed at GPs and women to explain the relationship between HPV, cervical cancer and the vaccine. The campaign aims to empower women to take this extra precaution to additionally protect against cervical cancer. The message will strongly reinforce the message that the vaccination will complement the existing screening program rather than replace the existing screening program. CSL is very proud to be part of this new, exciting era for further improvements in women's health care and for the capacity to further reduce the incidence and mortality from cervical cancer. We urge this inquiry to endorse the rapid implementation of a mass immunisation program for Australian women.

**Dr David**—That basically summarises the combined work that CSL Limited and Dr Wain, through our advisory committee, has achieved over the last year. CSL Limited, as you know, is a wholly Australian pharmaceutical company. We are very excited, as this is the first large-scale vaccine and pharmaceutical product that we have brought fully from the discovery process through, with our partner, Merck & Co in the US, to market. We are very proud that this will be launched in Australia in four weeks.

**Senator ADAMS**—You heard me asking questions about the divisions of general practice and the information they were able to disseminate. You are doing New South Wales. Who is doing the other states?

**Dr Wain**—The implementation for this is really felt to be a local issue. The messages were developed nationally but the implementation has been developed in each state. I cannot tell you in detail how they are doing it in each of the other states, but I know that each of the state programs are launching education programs about these issues. We have found in the past in New South Wales, because of its diversity, that one to one educational sessions with GPs in the division setting is the most productive and useful technique. It is time-consuming, labour intensive and expensive but it is the best way to explain these very complicated messages.

**Senator ADAMS**—What about videoconferencing? Have you been thinking about that further out?

**Dr Wain**—The national program organised a satellite broadcast a little bit earlier in the year with Professor Hammond from Perth. Ian Frazer was involved in that process and several other doctors. That was sent out by rural satellite broadcast. I cannot off the top of my head recall the attendance, but it was massively well received. It is now available on the National Cervical Screening Program website.

**Senator ADAMS**—We will be receiving evidence from Professor Hammond tomorrow. You probably heard me ask the question about getting the vaccine to Indigenous and non-English-speaking women. How are you going to deal with those issues of being able to screen them in the appropriate way?

**Dr Wain**—For cervical screening?

**Senator ADAMS**—Having their pap smears and the administration of this.

**Dr Wain**—The national program has always had Indigenous women as one of their highest priorities throughout the entire history of the screening program. There has been a national forum for Indigenous women. Working in this area is an incredibly complex area. As a male, I have not been closely involved in this area. Each of the state programs and the federal program has funded very intensive campaigns with women down to their local communities, organising the communities to assist with these programs. I recently reviewed an article for the *Medical Journal of Australia* that I believe will be published shortly. Professor Condon is presenting evidence to this inquiry about the success of local programs in the Northern Territory. We have seen quite unheralded but dramatic improvements in terms of screening services for Aboriginal women across the country. It is variable from area to area, but it has certainly always been a high priority for the Cervical Screening Program.

**Senator ADAMS**—I was wondering if there was a role there for the Aboriginal health workers.

**Dr Wain**—For taking pap smears? There certainly is and they do take those.

**Senator ADAMS**—There has been some criticism about it. I did ask if there was any funding anywhere for extra dollars to go into training.

**Dr Wain**—In my experience this is often a very sensitive discussion. Much of it has to be done at the local level amongst the local health workers. It is not something that needs to be broadcast widely around that this is regarded as women's business and largely inappropriate that some of us be involved in it at all. I know that the efforts at a local level across the country have been quite intensive.

**Senator ALLISON**—A naive question about how it is that two pharmaceutical companies have the same, or is it the same, vaccine?

**Dr Wain**—I will answer the science. It is not the same vaccine. The vaccine that CSL are bringing to market this week contains vaccines against four types of HPV, 16 and 18, which are the two commonly associated with cervical cancer, but it also contains vaccines against 6 and 11, those associated with genital infections, genital warts, condyloma and many low grade lesions on the cervix.

**Dr David**—The virus-like particle technology which is contained in both vaccines is a completely new technology and it is one that has been worked on in centres all over the world. The actual intellectual property associated with that is complex and not relevant to the discussion here. Both companies, GSK and CSL Ltd, were fortunate enough, in a similar window of time, to develop a research direction which enabled them to produce products which were highly successful in humans. As Professor Wain has stated, they are not the same. The CSL product is a quadrivalent product, that is, it contains the four strains. The GSK product is a bivalent product which contains the two strains, so we have taken a different approach in the construction of those products.



**Dr Leong**—I think, more importantly, is that it recognises that boys and men suffer disease from HPV and the inclusion of 6 and 11 is actually on a more public health perspective, so that when you vaccinate both men and women can benefit from vaccination with this quadrivalent vaccine.

**Senator ALLISON**—Your proposal to PBAC was for this to be available to boys and girls of the same age?

**Dr David**—Initially, no. We have an indication from the Therapeutic Goods Administration for women aged 9 to 26 and for boys aged 9 to 15. The data in men is such that we need some more information before we can show cost-effectiveness in that population for the purposes of a national immunisation program. That clinical trial is currently under way. Because anal and penile cancers and male genital warts combined are less of an issue for the health system than cervical cancer, if we were to bring that to the government for funding now it would be most unlikely to fund boys at the moment. We are hoping that the data we gain will show that what we call ‘herd immunity’ will be improved if boys are vaccinated in a universal program so that we have a chance of totally eliminating from the whole community those strains in the vaccine that cause cervical cancer. Jane might be able to advise when that trial will be complete.

**Dr Leong**—The male efficacy study is under way and will be completed in 2008.

**Dr David**—So in that year we might look forward towards bringing a totally universal program to the government.

**Senator ALLISON**—Assuming both vaccines are approved for subsidies under the PBAC process, who decides which one to use?

**Dr David**—The state government immunisation coordinators decide.

**Senator ALLISON**—I see. It is not up to the GP or—

**Dr David**—If it is a funded program then the state government immunisation departments make the decision on a tender basis, and they take a wide variety of factors into account. Obviously in the private market where the patient pays the full cost, the GP will advise them as to which product best meets their needs.

**Senator ALLISON**—If I get this right, the federal government will decide the age group for which this will be subsidised; is that right?

**Dr David**—Yes, based on the data provided to them by CSL.

**Senator ALLISON**—It possibly will not be 9 to 26 for girls—it will be 9 to 13 or something of that sort?

**Dr David**—I might clarify this by detailing what we have submitted to PBAC. In the next few weeks we will be making the vaccine on the private market. However, the cohort that we have sought funding for in the November submission is women aged between 9 and 26. The way that it will work is that we have a single cohort, which will be the ongoing cohort of girls at the end

of primary school, whenever that will be in their respective states. So girls aged 11 or 12 will receive that vaccine on an ongoing basis. In the initial phases there will be a catch-up program for high school girls which will also be delivered in schools. For the remaining cohort, which is women aged 18 to 26, we are also applying for national immunisation program funding for those women to receive the vaccine from their GP. That means they go to the GP and they receive the vaccine free of charge, unlike a PBS product where they have to go to the pharmacy and get a script filled and then return to the doctor. That is what we have submitted for funding. It will be up to the government as to whether they accept all or some of the CSL proposal.

**Senator ALLISON**—The decision making of the state government then is about their spending on the distribution of this drug to schools? I am not sure what the states have to do with it. The Commonwealth subsidises it; what do the states do?

**Dr David**—The Commonwealth will also subsidise the states for some of that distribution—that is part of what takes place through the COAG and Medicare agreement process. There is a public health funding agreement under which that is remunerated from the Commonwealth to the states. At the moment the question is, I suppose, how will the schools program be undertaken? The reality is that it is directly administered by the state government and they coordinate that with schools. However, there is also a role for the federal government in how that takes place and a role for the companies as well in terms of assisting with the provision of education to school principals. It is quite a difficult thing to get up and running, but there are good precedents in Australia with rubella and hepatitis B and it is quite an effective way of delivering vaccines.

**Senator ALLISON**—Is cost a factor for the state government or not?

**Dr David**—In the tender process?

**Senator ALLISON**—I am just wondering on what basis the state government makes a decision about whether it is this one or that one.

**Dr David**—At the moment that question is academic because there is only one vaccine registered. However, if the other vaccine was to become registered in the time frame in which they would make the decision, a number of variables would be taken into account, not the least of which is that these vaccines are different and they cover different strains. That would be part of the process as well as certain other aspects as to what value the companies can add.

**Senator ALLISON**—But yours covers the same ones that theirs covers; is that right?

**Dr Wain**—CSL covers additional ones and that would in turn affect the cost-effectiveness of the vaccine.

**Dr David**—That feeds into the cost-effectiveness so they would need to take that into account as well as a number of other aspects about the product: ease of delivery, adverse events and what they call a value add, or what the company can help with in terms of delivery of the program.

**Senator ALLISON**—You say in four weeks time this will be available to doctors for private prescription?

**Dr David**—Yes.

**Senator ALLISON**—Can you tell the committee what the cost of the dose will be?

**Dr David**—This vaccine is delivered in three doses: an initial dose, then one two months later and then one about three or four months after that, so we are looking at the three doses over a six-month period. When a vaccine is available on a private script, there are a number of mark-ups that apply to the final retail price. There is a wholesaler mark-up, a pharmacy mark-up and a thing called the cold chain mark-up, which means people charge for keeping it in the fridge. Taking into account all of those mark-ups, we are estimating that the final retail price will be in the order of \$150 to \$155 per dose. That will vary because particularly in some—

**Senator ALLISON**—Sorry, per dose or per set of doses?

**Dr David**—Per dose, so you are looking at a total cost of about \$450 to \$460 for the course. That will vary as, particularly in rural and remote locations, the pharmacists charge more to dispense vaccines. That is one of the reasons—because for some families the cost will put it out of reach; even though that cost is spread over six months it is a big ask for some families—CSL has invested so much time, money and effort into producing an economic model for the PBAC that has taken account of the best available economic advice, both internationally and locally. It has put a lot of effort into the model to show cost-effectiveness. We really rushed that through to the government because we are aware that the private market price will put it out of the reach of some families.

**Senator HUMPHRIES**—I assume the dose is administered subcutaneously rather than orally.

**Dr Leong**—It is an intramuscular injection.

**Dr Wain**—It is an injection.

**Senator HUMPHRIES**—You have mentioned that, ideally, it is delivered under an immunisation program to girls in years 11 and 12. Is that what you said?

**Dr David**—At the end of primary school. That will be grade 6 in some states and grade 7 in others. We will use a catch-up for the high school girls initially.

**Dr Wain**—The explanation for that is partly immunological and partly logistic. The immunological response is that it is better the younger you are—under the age of 12. The logistic response relates to the fact that they are getting rubella and hepatitis vaccines at age 12. The clinical aspect is that the more people who get it before the onset of sexual activity and the likely contraction of HPV infection at some point the better the vaccine is going to work. So the 12-year-old is really our concentration for a number of reasons.

**Senator HUMPHRIES**—But it is still possible for a 40-year-old woman to be prescribed and have the vaccine; there is still potential benefit?

**Dr Wain**—The drug is licensed in Australia for use up to the age of 26 because the data showing effectiveness in the older age group is not yet available. From a clinician's point of

view it is not going to do any harm to the woman at the age of 40 but she is clinically probably well beyond the point at which she is going to get maximum benefit. She will not get no benefit and she will not get any harm, but the amount of benefit to that woman is difficult to estimate.

**Dr Leong**—There are ongoing studies in adult women up to 45. Those results will be available in 2008 as well. We will certainly be tracking, recognising that the risk continues throughout one's life. There will be data coming through in 2008 on this.

**Dr Wain**—The message for those women is clearly to continue having pap screening because that is the best protection against cervical cancer in that age group.

**Senator HUMPHRIES**—There is a section in your submission headed 'Summary of recommendation to the inquiry'. I am not quite clear what the recommendation actually is. Can you summarise it for us?

**Dr David**—We are seeking endorsement of the fact that we will be seeking funding from the government for a national immunisation program from November of this year. The committee itself cannot decide on or recommend funding but we are seeking an acceptance that adding this primary prevention strategy to the screening program offers Australians the best chance of eliminating cervical cancer and the majority of abnormal pap smears and genital warts in future.

**Senator FERRIS**—I have a more general question. You might have heard it when you first arrived as it was my question of the previous witness. It is always considered that the drug companies have plenty of money. When anyone wants to do research on anything, they head for the drug companies if the government rejects any application. Can you tell me what the policy of your company is in relation to approaches for more general clinical trials, in a wider community sense, and can you outline any collaborative work that you are sponsoring in Australia at present.

**Dr David**—CSL puts probably in the order of \$200 million every year into medical research in Australia. We are the biggest funder of medical research in Australia. We have a number of programs, which range from basic research programs right through to post-marketing surveillance studies for drugs that are already on the market but we are checking that they are working properly and that their side effects are what we expect. Encompassed in that are partnerships with block funded medical research institutes, small to medium biotech companies and even individual researchers who have linkages with CSL. We are not indiscriminate in the way we fund things. Obviously there is a critical evaluation process. At CSL that is called PharmaPlan and it takes place on a twice-yearly basis where we do review R&D plans globally, and that includes the Australian business. We do look very carefully at what the risks and benefits are. Particularly in the biopharmaceutical industry where CSL comes from we are looking at very high risk and the prospect of 10 to 15 years before any return is realised. So that is quite a complex process. Certainly, when we embark on a project we are not necessarily expecting that there will be a return—most of the time there is not. However, there must be some synergy with our core business, which is biopharmaceuticals, plasma products and vaccines.

**Senator FERRIS**—Are there any examples of that research that you could outline for us that fit into the gynaecological cancer aspect of our inquiry that come to your mind?

**Dr Leong**—We currently have a collaboration with Professor Suzanne Garland looking at the prevalence of HPV in women in Australia—remote, rural and urban. It includes a significant number of Aboriginal candidates as well in this particular research. That is certainly ongoing. Another example is the model that Dr Wain talked about where we did significantly fund a group of experts to put together a model that is very robust using the latest data from Australian women to inform the model so that it is completely relevant to Australia.

**Dr Wain**—This cost-effective modelling has never really been achieved before in Australia and a cervical screening program has never been able to do anything as sophisticated as this. It has been done by the support of CSL. The ‘herd immunity’ effects that are being modelled is groundbreaking epidemiological research and that has also been funded by CSL. And that is not mentioning the development of this vaccine itself which is some years back.

**Senator FERRIS**—I asked the question because the witnesses we have had in Sydney and here have all talked about competition for funding. It must be very difficult for companies such as yours that are seen as being very wealthy multinationals to constantly be getting submissions from individuals or teams of people looking for funding for their particular work. Do you have any in-principle views on the way in which research is funded in Australia?

**Dr Wain**—Can I answer that as a completely independent clinician? I would expect CSL to look after their shareholders in terms of what they are interested in. If they do not have drugs that are particularly relevant to gynaecological cancer then I think it would be quite inappropriate to be funding research in that area. I think the company in turn has responsibilities and that it has to be a collaboration between all of the groups. Each group has different interests and different stakeholders. I think with this example here, of a drug that has great relevance to the gynaecological community and that is taking research into the community now, the interaction between the clinical community, me, the company, has been an extraordinary example of collaboration.

**Dr David**—I add that when you are beginning a project, or you are beginning to work with someone who may have quite a small NHMRC grant or may not have anything but just some very good contacts, you do not know necessarily what that is going to turn into 20 years down the track. As I said, it is very high risk. For example, we do a lot of basic research and we work with people in the area of the immune system on some research targets that are actually very general in terms of their applications. Basically, we are very hopeful that in years to come we will have another Gardasil, but you can never guarantee that. You have to keep an open mind and talk to as many people as possible about what they are doing and what you are prepared to fund.

**CHAIR**—Thank you very much. If there is any supplementary information you want to give to the committee, please do so because we do not report until October.

**Dr Wain**—Could I make one last comment? As a clinician who treats women and watches them die from cervical cancer, I think it is an absolute ethical demand that this vaccine be incorporated into our system as soon as possible. It is not a commercial obligation, it is an ethical obligation on the part of people like me. We are talking about a vaccine that is going to halve the incidence of cervical cancer in women. But there is the notion that we are going to have to ask women to pay for this vaccine shortly and that means potential inequities are introduced into the system through poor women not having access to the vaccine. It is just

beyond my belief that we could allow that to happen. The women who most need this vaccine need it through a mass universal vaccination program.

**CHAIR**—Thank you very much.

[2.06 pm]

**NIKOLOVSKI, Ms Connie, Private capacity**

**CHAIR**—Welcome, and thank you for giving your time and coming to share your experiences with us. I know that you have received information about the process, about how it works and the protections and so on. If you have any questions along those lines, just ask us as you go along.

**Ms Nikolovski**—I am here to tell you my story about my ovarian cancer experience.

**CHAIR**—We would like you to tell us your story and then we will go into questions.

**Ms Nikolovski**—I am a little nervous. I have written it out and I am going to use that as my guide. Ladies and gentlemen, thank you for responding to my submission and inviting me here today to share with you my story about my life with ovarian cancer. My battle was, and continues to be, fought not alone but with the ongoing support and dedication of a medical team led by Professor Michael Quinn, Mr Robert Rome and the medical staff at the Royal Women's Hospital. It is because of them, and because they made me feel important and that my life was worth fighting for, that I am here today.

I am Connie Nikolovski—that is the name that everyone knows me by—and I am 51 years old. I am proud to tell you my age because 13 years ago I did not think I would be around to say that. In 1993 I was sentenced to death when I was told that I had third stage ovarian cancer. I am sorry, I am finding it hard to continue.

**Senator FERRIS**—Would it help the witness if Margaret Heffernan reads the statement for you?

**Ms Nikolovski**—Yes.

**Ms Heffernan**—I will read this on behalf of Connie Nikolovski. As you heard, Connie is 51 and in 1993 she was diagnosed with stage 3 ovarian cancer. Third stage meant that the cancer had spread from the primary source—the ovaries—to other parts of the body. In Connie's case it travelled upwards through her stomach to the diaphragm. Surgery was not going to capture all the cancer cells as the diaphragm is inoperable. Therefore chemotherapy was required. Sixteen months after chemotherapy Connie was diagnosed with cancer in a secondary organ, the spleen. Fortunately, testing proved that it was the same type of ovarian cancer but this time her doctors offered taxol and cisplatin as her chemotherapy and this saved her life.

Connie's cancer is a reoccurring type of ovarian cancer and she has a genetic disposition labelled BRC1. This makes her susceptible to ovarian cancer and breast cancer. It also means that Connie's siblings and Connie's mother's side of the family are carriers and may develop ovarian cancer, breast cancer or prostate cancer. So not only is Connie a survivor of ovarian cancer but, at the age of 21, she cared for her 42-year-old mother for three years while she fought and lost her life to ovarian cancer.

Today Connie gives unconditional support and guidance to her younger sister who is 40 years of age and who recently had her ovaries removed as a preventative measure, and to Connie's daughter, who is 28 years of age and who several years ago commenced her journey with ovarian cancer and preventative measures against it. Connie hopes that very soon the early detection screening test will be available in time for her and for her daughter and other younger Australians. Connie is living proof that cancer can be beaten if treated in time with the right medication and a dedicated, caring medical team.

So why has Connie chosen to present to the committee today? Because she firmly believes she is meant to be here to make a difference—the time is right. She wants to make a difference; she was ignorant about cancer and especially about gynaecological cancer. To Connie, like everyone else in the community, the word cancer terrified her and she saw it as a death sentence. Connie is here to tell you and to tell everyone who wants to listen to her that that is not always the case—it does not have to be a death sentence. Connie wants to help those people who are frightened, who do not know how to ask or where to seek information, and let them know they are not alone.

So in Connie's experience her enemy was not cancer but fear. Several times she wanted to give up as it seemed too hard to deal with. She was stripped of her dignity, the chemotherapy depleted her energy levels and the fear of the unknown did not seem worth the effort. Connie's mood swings caused conflict at home with the family and at times she did not want to share her emotions with anyone but wanted to leave and die on her own. She had suffered by experiencing the cruel death of her mother and the sadness it left in her heart. So Connie reflected on that sadness and that turned her around. She did not want her husband, daughter and loved ones to experience the same sadness. She wants people to know that it is okay to feel this way and that it is normal; it is part of the rollercoaster ride but help is available for dealing with these emotions. It also needs to be seen that these emotions are entirely normal.

She wants to comfort and inspire them the way the Royal Women's Hospital oncology team helped her. She wants to help make it easier for others to seek appropriate preventative measures that will increase their chances of survival and to minimise the fear they may have to endure if the diagnosis is left too late. Connie wants people to discuss ovarian cancer the way they talk about diabetes.

We all know of the fight and success stories of breast cancer through celebrities such as Kylie Minogue, Geri Halliwell, Olivia Newton-John and others who are everyday reminders to young and old that early detection and preventative measures can beat cancer. But how often do we hear on radio or television about celebrities with ovarian cancer? How many people on the street can quote you the name of a famous survivor? And it is perceived that ovarian cancer is no longer targeting mature age women although they are in the high risk group.

Connie believes there is not enough information available to the community warning people about the dangers of ovarian cancer. Despite the efforts of established ovarian cancer organisations that are attempting to get this information out it does not get high media profile, and if it is available it is not being communicated effectively. The information needs to be in a language that can be understood by every Australian, and in Connie's initial submission she talked about people from middle European background and their perceptions about the term 'cancer'. People should learn from a young age that cancer is a word that should not be avoided



but must be discussed but, most importantly, that there are many types of cancers each with their own symptoms, their own method of testing and their own treatment.

In addition, Connie considers we also need to better educate GPs, nurses and pharmacists as these are the people the community turns to when they are sick. If they do not have the answers, they should be able to confidently refer to a central repository of ovarian cancer information: a library that tells them who the specialists are, where the hospitals are, what the medications are, where the support groups are. and who the psychologists, the social workers and the financial advisors are who are supporting patients and families. We have to stop assuming that the GP has all the answers about cancer and we have to help the GP help the community.

When Connie started experiencing changes in her body, she decided to bypass her GP. Because of her mother's experience, she did not feel confident that she would be diagnosed in a timely and correct manner. It had taken three months to diagnose that her mother had a gynaecological condition. Connie booked herself for a check-up at the gynaecological department in the Royal Women's Hospital, which is a self-referral unit—one of the few of its kind in Australia. That means that you do not need a GP's referral to attend for a gynaecological examination. Often GPs will not refer you on, so this is a very important facility. Most people do not have Connie's experience. People need to know what to look out for, how to listen to their bodies. It is still believed that the pap smear will detect ovarian cancer, and that is a constant reminder of the ignorance that is out there in the community.

Last year at work, Connie raised over \$1,200 for ovarian cancer research. The amazing thing was the number of people, both male and female, who told her of their experience with ovarian cancer. It is out there, it is killing women and no-one is talking about it. Yet early detection could have saved many lives.

Something else that came out of these conversations was the pressure placed on the cancer patient and their family, particularly their partner, from the workplace. The emotional strain on the patient and family is enormous. People need financial support as much as medical support during this time. If you have to go to hospital with your partner for tests or treatment, you should not have to worry about what the boss is going to say because you have to take another day off. The government should either help subsidise a small business employer or support the employee directly. The bureaucracy surrounding Centrelink is painstaking and interferes with the healing process.

Connie's personal experience is that a single group of experts in the field managing this disease from all the right angles offers the greatest chance of survival to women. She owes her life to a team of doctors and support staff who made it their mission to fight ovarian cancer for her and with her. Their sole purpose was to focus on this disease and to make her feel important and valued. Connie hopes that you, as a Senate committee, can do the same for cancer patients.

**CHAIR**—Thank you. We will go to questions and see if there are some more things we can find out, but what we need to know from you is what you want us to do. You have told us your story with great honesty and through generations of your family, but what we need is for you, with experience, to tell us what you would like us to do. I will go to questions from the other senators.

**Senator ADAMS**—As far as spreading the word about ovarian cancer is concerned, you have all the expertise there as to what has happened to you. How do you think that the organisations that you are involved with can get the word out there about the dangers of ovarian cancer, or how can we do that?

**Ms Nikolovski**—I did not realise how silent people were about their experiences. I was very open about the way I felt. I share my feelings. I took opportunities. I know there are people out there who just do not come forward—who are not very open at all. They often withdraw, and that withdrawal prevents them from accessing information. If the information is more readily available for them by way of GPs and pharmacists and in normal community places, that would make it a lot easier. There are information booths in hospitals. I found a lot more information in the Royal Women's Hospital than in a clinic. This is the normal everyday person who does not have access to this information.

**Senator ADAMS**—You have a lot of case studies of people speaking different languages and people with different understandings and different upbringings.

**Ms Nikolovski**—Yes.

**Senator ADAMS**—What would you suggest that we do to improve the situation for them so that they are fully aware of what is going on?

**Ms Nikolovski**—Definitely more television, because everybody watches TV—and communicating. And radio, in people's own language—not just in the Australian language. We are a multicultural society, so we should cater for that. I know that people stick in their own little groups. As soon as you have a representative of one community, that flourishes throughout that whole community.

I believe the Chilean community do not have the knowledge. It was only after I talked about my experience that a coworker shared her experience with me and then she said, 'Oh'. I said, 'I know the Italian community is probably a little bit more knowledgeable, because I am of Italian background.' She said, 'I still know that with the Chilean community it is nowhere there.' This sort of information tells me that we are still a long way away from communicating effectively to everybody about cancer—cancer as a divided disease, not just one cancer is one disease—and them understanding that.

**Senator ADAMS**—So we need peers in all of those groups, and probably doctors, because we have a terrific lot of medical students now coming through from different cultures. Those are the people that should be spreading the story to their people so that we can move it forward.

**Ms Nikolovski**—Absolutely.

**Senator ADAMS**—Thanks very much. What you have done is very good.

**Senator ALLISON**—I am interested in your relationship with your GP. Obviously you knew what the symptoms were through your family and your mother's cancer. Did you instinctively say, 'I know what this is about, I recognise the symptoms,' or did you tell your GP what you were going to do?

**Ms Nikolovski**—I didn't tell my GP what I was going to do. I monitored my own body because of the experience I had with my mother. First of all there was my age; I started feeling these different symptoms and I thought, 'Oh, that is unusual'—my mother was diagnosed very close to that age. It was a very slow process. It took me about six months to monitor myself and equip myself with a lot of information to tell the person that I saw in the clinic. With all that information I was geared up ready to tell my story. I felt, from the experience of watching my mother be cared for, that it was really important that the communication comes from the patient as well. Medical people do not extract enough information; maybe they are not educated to. So perhaps there is the need for more education about people skills; I understand that they are skilled at what they do, but that is just another area I noticed when my mother was being cared for that needed to improve.

**Senator ALLISON**—A lot of other women would nonetheless still go to their GP and say, 'I think this is what's happening for me.' What was different in your case? Perhaps you have answered the question by saying it was so close to what was going on with your mother. The challenge it seems is to get the 50 per cent of women who we have been told for the last three days do not receive adequate care through a multiskilled team or from gynaecological oncologists, such as are available at the Royal Women's Hospital. Does your GP now know?

**Ms Nikolovski**—Definitely. There has always been constant communication from the Royal Women's Hospital to my GP. He was quite alarmed that this had actually happened. I had been going to my GP previously for a lot of symptoms and he sent me off to different tests. When I say 'previously', it was probably about a year before. I was having these symptoms and he sent me off from one test to another test and I was getting sick and tired of seeing no results. It was like I was disappointed they could not find anything wrong with me but it is not that. It is just that when you are feeling pains and you know there is something wrong, there was no answer. I was ultimately disappointed and I gave up on the GP and said, 'I'm just going to check myself out.' I more or less dismissed it, I even talked to myself and said, 'I'm not sick any more, there's nothing wrong with me,' but lo and behold there was something wrong.

**Senator ALLISON**—When did it start to dawn on you that this might in fact be an inherited tendency, or a genetic predisposition I think is the right word?

**Ms Nikolovski**—I did not really know; I did not really want it to be. My grandmother had breast cancer and passed away when she was in her late seventies. I did not really see the connection. I thought, 'Oh, gosh, you never know. It could be something to do with my gynaecological make-up.' I did not really think it was genetic. It was only after I had been treated. Mr Robert Rome was doing genetic research at the time. I spoke to him about it and then together we worked on having genetic testing. I had counselling for that. I agreed that I would go and have genetic testing. I thought it was a case of damned if I did and damned if I didn't. I thought, 'What else can I do?'

**Senator ALLISON**—Did that show you that you have the gene that makes you susceptible?

**Ms Nikolovski**—Absolutely. It was proven.

**Senator ALLISON**—Do you find yourself being a kind of counsellor for other women who have been in this position? Do people who have been diagnosed like to talk with you?

**Ms Nikolovski**—Yes, they do—men and women.

**Senator ALLISON**—What is that like for you?

**Ms Nikolovski**—I quite find that I like helping people. It is also draining at times, but I now know how much I can give. Basically it is at the initial stages when someone comes to me. It is just little things. Recently a family friend of mine was diagnosed with breast cancer. She rang me and said, ‘I don’t know who to turn to, Connie. I know you have experienced cancer. Can I spend some time talking with you about myself?’ I said, ‘Sure, no problem.’ We sat and we talked. I gave her information like ‘When you go to the doctor, ask questions. Tell them everything. Don’t just sit there and assume that they are just going to extract this and diagnose you perfectly. You will need to communicate very effectively with them and you must not turn away. If you have a question, get it answered—whether it is the answer you want to hear or not: there are no guarantees.’

I explain that you just do this bit by bit—without overwhelming the person, of course. As a support person and a carer, you have to be very careful; you do not want to give them daunting information—just enough for them to feel satisfied that they have been heard and they are not alone. And you just remind them to do it one stage at a time, one step at a time. It is a long journey—though not for everybody: for some people it might be short-lived. People may have the operation, have chemo or not. It depends on the extent and how advanced the disease is at the time. My friend is having her last chemo today. It was only recently. She has breast cancer. They removed one breast; they have given her the treatment. It was all contained. It was removed in the operation. Now she is at the end of her journey with the chemo. Hopefully things will get better. It is nice to be there to give the comfort and inspire people, but it is also draining at times.

**Senator ALLISON**—You may not want to answer this question, but earlier today we had a sexologist, a sex therapy person, who talked at length about the difficulties for women who have gynaecological cancers—in their relationships and in dealing with a whole range of things. Did you have access to a sexologist and if so was that useful to you?

**Ms Nikolovski**—I do not have access to a sexologist, but when I had emotional or psychological problems I would go into my clinic and break down, just like I broke down reading my statement. I was fortunate that there was a head nurse there who picked me up and offered me the service at the right time. That is great, but it would have been good if I had known a bit more beforehand—that this was available. It was just that they were there for me. I went searching, but how many people go searching for help? How many people will break down? Maybe they do; maybe they do not. I did not have any control; it just happened.

I was then referred to a psychologist. That was great, but my husband, being of ethnic background, did not agree. He did not think there was anything wrong with me. He thought this was just normal and said, ‘You’ll be fine.’ I said, ‘How come I’m breaking down and crying? How come all this?’ It was a bit of a task trying to encourage him to come along to counselling with me. The first appointment was booked on his birthday, of all days. He did not want to go, so I had to cancel it. The next thing I know the nurse rings me and says, ‘Connie, you didn’t make it to the appointment.’ I did not know what to say, so I just told her it was his birthday and asked how I could do that to him. She goes, ‘You’re only thinking about him; you’re not thinking about

you.’ So, yes, we did talk about how I felt—there was no drive. Having my ovaries removed I went through clinical PMT—post, premenstrual—what is it?

**Senator ALLISON**—Something like that—secret women’s business!

**Ms Nikolovski**—I went through all that—the flushes and so on. People would say to me, ‘How come you have got that? You are not that old, you are not supposed to.’ You see, women do not even understand; I did not understand. Today, even telling others, they say, ‘Well, how come you went through all of that, how come you had that?’ ‘Because I have had my ovaries removed—part of my mechanism is not working anymore.’ There was all that to deal with and with my husband and not needing him because I was going through all this. He was very good. He came along to the counselling session. We went once, we went twice—he said, ‘I told you there was nothing wrong with you.’ But it was nice to have a counsellor there saying, ‘Connie, understandably after what you have been through it is okay to feel like that. There is medication available’—which I tried. In my case I did have hormone replacement therapy once, but I got the reoccurrence and because of my genetic make-up it was better for me not to take it anymore. I had to deal with creams, medication tablet first—that was no good because it used to make me sick. Now today it is all self-managed; it is all up here. It is really hard, but it is working okay. But it is hard work, it is not easy I have to say.

**Senator FERRIS**—We congratulate you.

**Ms Nikolovski**—Thank you.

**Senator FERRIS**—We have had evidence from a number of witnesses suggesting that the best way of dealing with the lack of understanding about gynaecological cancers is to establish a national gynaecological cancer centre, which would work in the same way as the National Breast Cancer Centre. Some people in Sydney suggested that we could broaden the base of the National Breast Cancer Centre and make it a women’s cancer centre. When you went searching for information, did it occur to you to go to the National Breast Cancer Centre for that information?

**Ms Nikolovski**—No, not at all. What was made available was the Peter MacCallum Cancer Centre—everyone knows about Peter MacCallum—but to me that was too broad. I had ovarian cancer, why would I be going there?

**Senator FERRIS**—How did you go about finding the information that you said was so useful for you?

**Ms Nikolovski**—There were some people who were very passionate within the nursing staff and who were not compensated or paid but who felt personally passionate about alternative therapies and anything to do with cancer. They helped just one on one. They knew I was very receptive about wanting to know more, wanting to help myself more, getting better, and so they provided a lot of information to me.

**Senator FERRIS**—So they acted as a personal resource?

**Ms Nikolovski**—Yes.

**Senator FERRIS**—Do you think it would have been more helpful if you had known that there was a national gynaecological cancer centre?

**Ms Nikolovski**—Absolutely. It is like when I went to the Royal Women's Hospital—why did I go there? It was because it was gynaecological. I did not go to my GP because I could not trust that he could tell me. He was not geared up enough to get me treated in time. Something in there was telling me that was not good enough, so I went to the gynaecological centre because I thought women's problems needed to go there. And that was because of my experience with my mother. It would certainly help the community—definitely.

**Senator FERRIS**—Thank you very much.

**CHAIR**—I have only got one question and it is, what are you talking to your daughter about?

**Ms Nikolovski**—What am I talking to my daughter—

**CHAIR**—Yes, on these issues.

**Ms Nikolovski**—She is involved. She is active. She is at the moment under the careful eye of Mr Rome. Actually Mr Rome's father was the person who treated my mother.

**CHAIR**—When you mentioned the surname I thought it would have to be the same—

**Ms Nikolovski**—Yes. The file was at the hospital. I felt, 'Who else can I turn to? They know all the history. They are there for me. I just need to ask for the support.' I was there, I asked, it was offered, and she is being taken care of. Because she was so young, there was really nothing they could do for her at the time until she got to an older age. At the moment, as a preventative measure they have put her on a pill—with ovarian cancer apparently there is an overstimulation—which will control that. Hopefully in time some sort of testing will be there for her, if the need arises, so at least she can have peace of mind. At the moment, she is taking that type of precaution.

**CHAIR**—And working in the system.

**Ms Nikolovski**—Yes.

**CHAIR**—Thank you very much. Thank you for sharing your experience with us. It makes the whole situation much more real. Thank you again, Ms Heffernan.

**Proceedings suspended from 2.35 pm to 2.48 pm**

[2.45 pm]

**ALLEN, Associate Professor David Gordon, Chair, Gynaecological Cancer Committee, Cancer Council of Victoria and Chair, Victorian Cooperative Oncology Group**

**BROUN, Ms Kate, Manager, PapScreen Victoria, Communications and Recruitment Program, Cancer Council Victoria**

**POWELL, Mr Michael, Vice Chair, Cancer Voices Victoria**

**ROOS, Dr Ian Albert George, Chair, Cancer Voices Victoria**

**CHAIR**—I appreciate your patience and your time in coming to see us. Have any of you given evidence to an inquiry before? I note that you have information on parliamentary privilege, the protection of witnesses and also the in camera process if you choose to use it. It is very straightforward. If any or all of you would like to make an opening statement, that is how the process operates, and then we go to questions. Does anyone want to make an opening statement?

**Mr Roos**—I am chair of Cancer Voices Victoria and Michael is vice chair. It may seem strange that two males are appearing before an inquiry into gynaecological cancer.

**CHAIR**—Not at all.

**Mr Roos**—That arises from the time and availability of other people. In our constituency we have people who are affected by gynaecological cancer whom we have consulted. One of the points we want to make is that the psychosocial needs of people affected by gynaecological cancer are similar for all those people affected by cancers of the reproductive system. Cancer Voices Victoria was formed 12 months ago at a public meeting. One of our briefs was advocacy for greater psychosocial support and affordable psychosocial support. That links with our submission to this inquiry.

**CHAIR**—Mr Powell, do you want to augment that statement?

**Mr Powell**—No, not for the moment.

**CHAIR**—Ms Broun or Professor Allen, did you want to make a statement on behalf of Cancer Council Victoria?

**Professor Allen**—Yes, I am happy to make a statement. I am a gynaecological oncologist working in Melbourne, mostly in public hospital practice at the Mercy Hospital for Women and at Peter MacCallum Cancer Centre. I have been involved with several of the submissions to this committee and was cosignatory to two of them, one being from the Cancer Council Victoria and the other one from the Peter MacCallum centre. I also had some input to the RANZCOG and gynaecological oncology department at the Mercy, which Peter Grant put in, as well as the ASGO one, which I think Tony Proietto may have spoken to already.

**CHAIR**—Yesterday, yes.

**Professor Allen**—I am here with Kate Broun, who is also from the Cancer Council Victoria. The Cancer Council Victoria is an independent volunteer based charity which is a member organisation of the Cancer Council Australia. The council conducts and funds research and funds prevention programs, data collection and information services.

With regard to research funding, we believe that clinical and basic research is underresourced around Victoria, especially in the gynaecological oncology units, of which there are three major ones. I am sure from this morning you have met most of my other colleagues. You are probably going to hear a very similar story from me, and I apologise for that.

The clinical workload in public hospital units is heavy and time for research is restricted and often not funded. Funding for research fellows and nurses would be of enormous help and benefit. For example, clinical research of treatments and investigations utilising emerging cancer technologies could greatly improve patient outcomes. This could include areas of genetic testing, targeted drug therapies, vaccine therapies, gene therapies, intraoperative and image-guided radiation therapy and improving scanning techniques like PET scans and MRI scanning. All this needs further research.

We believe that screening for cervix cancer has been very well organised and has been quite successful in reaching all women in Victoria. The Cancer Council and PapScreen Victoria, which Kate represents, and the pap smear registry have played an important role in this area. The result is that the incidence of cervix cancer in Victoria has halved in the last 10 years. This is a remarkable achievement. However, the screening programs for other gynaecological cancers lag well behind. Much research is necessary in these areas—for example, the use of biomarkers or MRI scanning.

We believe that a national gynaecological cancer body is needed in some shape or form to coordinate the research, data collection and treatment protocols which are required in the area of gynaecological cancer. What we really need is consistent, good management of women with gynaecological cancers. We should be able to improve patient survival by measuring agreed outcomes, reducing variations in the provision of care—that is a very important point—and supporting quality initiatives and multidisciplinary care. But this all needs adequate coordination and funding. National protocols or guidelines should also be available, and they are not.

All women diagnosed with a gynaecological malignancy should also have the opportunity of an opinion from a certified gynaecological oncologist early on in their management planning. The care of women in remote and regional areas must also be considered.

Support to get either the doctor to the patient or alternatively supporting the patient to travel to an accommodation in the metropolitan areas should be very much considered and improved. At the moment I know a lot of gynaecological oncologists who move into rural areas without any funding or payment at all and this should be addressed. The other point there is that women living in remote and regional areas have poorer outcomes in terms of survival when compared to women in metropolitan areas and it is just a very important point to address.



Cancer Council Victoria also provides a cancer information and support service which is also detailed in the submission. The provision of information and support to the community on the education of primary care doctors and nurses, and indeed some of our specialist colleagues, should remain a priority. However, education of the public should be carefully considered and messages and advice must always be properly formulated and tested prior to being disseminated; we think that is an important point as well.

**CHAIR**—Ms Broun, do you want to make any comment? I know you are here from the Cancer Council, but particularly from your PapScreen position.

**Ms Broun**—Yes. As David said, I am the program manager for PapScreen's communications and recruitment program, which is a program of the Cancer Council Victoria. We have been funded by the Victorian Department of Human Services through the National Cervical Screening Program for about the last 16 years. So obviously, we have had a long history and a lot of experience in developing communication messages for women and working with health professionals as well.

**CHAIR**—We will go to questions.

**Senator ADAMS**—And wonderful results too—that is very good. Thank you, Professor Allen, for all those comments. I am from rural Western Australia and the comments that you have made about rural women not being as fortunate in being able to access services the way they should. For anyone who has gynaecological cancer it is great that people are out to visit, but for their actual treatment and support they must be given access to a multidisciplinary team, for all the reasons that we have heard today. We have had some very good evidence today on the practical issues about these things and that is what this committee is all about—to get some practical issues out and to get practical solutions: how do we actually fix the problem? I am very keen to have some information about the Patient Assisted Travel Scheme in Victoria as to how accessible it is, how well it is advertised for rural women and the way they can access it. Do you call it PATS here?

**Prof. Allen**—Yes.

**Senator ADAMS**—Ours is called the Patient Assisted Travel Scheme in Western Australia. Is it successful? Does it have to improve?

**Prof. Allen**—I could not give you the actual details of how that works and how successful it is. I do know that I fill in quite a few of the forms, but that is as far as my involvement goes. It is something that is appreciated by the women I see, but whether it goes far enough I am not sure. It only funds in many cases some travel and assistance for a support person. If we are really serious about bringing multidisciplinary care and the best possible care to these women, and if we are going to bring them to a metropolitan area for that care we really need to fund them fully for transport, meals and accommodation for them and their support people. As you say, if you are moving a doctor—a gynaecological oncologist for example—out to a remote area there is only so much they can do outside of the multidisciplinary team and the supports that they use every day in a big hospital. So they are still not going to get the full benefit of the treatment that is given in a metropolitan area or big city. But it is a trade-off. Is it more disruptive to have them come down to a city or to stay in the remote area? But if they are going to come down I think we

need to support them a lot more than we are at the moment. There is support, but I do not think it is enough. I cannot really comment on how successfully this system is working—I think it is run by the Department of Health.

**Senator ADAMS**—I want to ask one more question. As far as the escort goes, in Victoria does that person have to have some medical expertise or are they prepared to let the psychosocial aspect of it go, because in some states you have to have a medical reason for that support person. Some sort of medical something has to be provided. None of us really know, but psychosocial support, no, they will not let them.

**Prof. Allen**—Our system is that there is a box you can tick which asks: ‘Is a support person necessary?’ That can be a partner, family member or anyone else. Usually we will tick that, because obviously someone travelling down does need that support.

**Senator ADAMS**—In WA they have to be able to offer some medical support; psychosocial is not taken into account.

**Prof. Allen**—I think that is a little tough.

**Senator ADAMS**—In the Northern Territory, the Indigenous people are allowed an escort, the other people are not, so we have all sorts of problems. Can any of you help me with that question?

**Dr Roos**—Yes. One of the difficulties for all people with cancer in rural areas is the availability of psychosocial support. In rural areas there are very few practising psychologists who understand the difficulties of cancer, particularly reproductive cancer. There is a paucity of them in metropolitan areas. The community support in some areas is good, but because you are dealing with cancers of the private parts of the body, people have difficulty talking about them, particularly in small communities. There is not the availability of people to whom you can unburden your emotional distress at some of the things that have happened to you. There is a heightened need for people with cancer of the reproductive system for emotional and psychological support in rural areas. That has to be addressed.

**Senator ADAMS**—Do either of you have any experience with the travel?

**Mr Powell**—No, I have no experience with the travel. I think Victoria is probably set out a little bit better than some of the other states.

**Senator ADAMS**—You have some larger regional centres.

**Mr Powell**—But there is still a distance problem.

**Senator HUMPHRIES**—I have a question to the Cancer Council. You fudged the question in your submission of representation on bodies like Cancer Australia. You are in good company because most of the submissions do, actually. What specifically do you think we should say about this in our report? It would be easy to say yes, let us have representation from people with gynaecological cancer experiences, either as consumers, clinicians or something, but specifically what do you think we could do about that?

**Prof. Allen**—I think most people have fudged it because people do not know a lot about Cancer Australia just yet. There is an outline of how it would function. I know that there is a committee appointed, and I believe that imminently a CEO will be as well. But if you look at that committee, which I have done only briefly—I think it is called an advisory committee—it has no real gynaecological representation. I do not know if the idea is to try to represent most of the cancer entities on that committee or not. It seems to have a lot of breast input and interests. Certainly we believe, and I know that ASGO, the Australian Society of Gynaecologic Oncologists, believes as well that we should have some sort of voice or connection with that, even if it is in the form of a subcommittee, or whether some national gynaecological body should be aligned to the Cancer Australia. But we believe that sitting in or around councils like that is very important.

**Senator HUMPHRIES**—Would there be a dozen different areas of cancer specialisation? I do not know how many—

**Prof. Allen**—It may be reasonable. At the moment in Victoria we are organising our cancer into different tumour streams, and there are 10 tumour streams, as you may have heard from the local government here. On the Cancer Council Victoria we have, I think, 14 or 15 tumour streams that we work with. It could be that a body like that or some representation in those tumour streams could be aligned to Cancer Australia. I do not think it is unreasonable for everyone to have a voice so that their importance, if you like, as a cancer group can be heard.

**Dr Roos**—Just to comment about Cancer Voices Australia and the advisory group, we note that there is nobody representing a consumer organisation on that body and we have supported Cancer Voices Australia in their efforts to get a consumer representative on that body.

**Senator HUMPHRIES**—That is a fair point. I want to ask a question I have posed to a number of other witnesses. When we present our report, for argument's sake let us say that we recommend that we spend a lot more on research into gynaecological cancer and that we spend a lot more on establishing a national gynaecological cancer centre and all these other things that have been urged on us in these submissions. People then say to us, 'Okay, you are focusing on gynaecological cancer but there are other indicators of problems in other areas of the community, for example, more men than women die each year from cancer in Australia. There are serious problems in Indigenous health with respect to cancer and other things.' So as this scenario goes, people may say to us: 'Why do we focus on gynaecological cancer? What is the area of priority that it attracts by virtue of this report?' What would your answer to that question be?

**Dr Roos**—The answer would be a focus on cancers of the reproductive system—that 10 per cent of the cancers of females and 30 per cent of the cancers of males. That would widen that out because they have similar psychosocial issues related to the nature of the cancers and the side-effects of the treatment.

**Senator HUMPHRIES**—So you would say a focus at the same time on prostate cancer among men would be a reasonable—

**Dr Roos**—As an organisation representing general cancer rather than specific cancers, I think we would be concerned about having multiple organisations at the government level

representing different cancer types. But there are groupings of cancer that have similar problems. As I said, our brief for this hearing is psychosocial issues. The psychosocial issues arising from cancers of the reproductive system are very similar for males and females.

**Mr Powell**—The psychosocial issues are, up to a certain age, a lot about sexual performance and that does put a lot of pressure on relationships. Anecdotal figures say that more marriages or relationships break up than is the norm with other cancers because the implied pressure is there—maybe in older life some people do not put that much pressure or concern on it. I feel, from people I have spoken to and my own experience, that education to the partner is also a very important issue. Allowing the practitioners to step out of the boundaries—which obviously have to be very tight on privacy—to recommend counselling and to recommend different aspects might help each partner understand the relationship issues better. Some partners switch off and expect their partner to get back to being active in every function more quickly than is practical. There is a lot of pressure. And of course as soon as it creates a relationship problem, down the line it goes to other government departments with divorces, support, all that sort of thing. As we are saying, psychosocial help in this area specifically may arrest some of the alarming trend in relationship break-ups.

**Senator HUMPHRIES**—That is an interesting perspective. Thank you.

**Prof. Allen**—The only thing I want to add is that some of the gynaecological cancers, especially ovarian cancer, are pretty lethal. I have some of the figures in front of me. In 2003 in Victoria the incidence of breast cancer was 2,868, with 721 deaths from that disease—about one in four—whereas for ovarian cancer there were 310 with 247 deaths. It is one of the more lethal cancers and I think it does need a lot of effort to reverse that.

Focusing on cervical cancer, for example, has led to an enormous drop in its incidence, whereas the figures in Victoria show that the incidence of ovarian cancer is still rising. The incidence of cervical cancer has absolutely plummeted, with the proper organisation of screening methods. It is very fortunate that in cervical cancer there is a precursor lesion that you can treat, and prevent the cancer. That is unique when it comes to cancers. Usually we focus on just treating them early. That is what we need to be looking for in gynaecological cancers—the lethal ones like ovarian cancer. We need some early warning system, or some way of picking them up early, so we can treat them with good success, and we just do not have that. I think it is not unreasonable to be focussing on these cancers at this time.

**Senator ALLISON**—The Breast Cancer Council currently has the ovarian program. Do you recommend a continuation of that arrangement?

**Professor Allen**—No. We were not recommending that in our submission. We acknowledge that structure at the moment, but we were recommending a national gynaecological body. The main reason for that is that the breast cancers and gynaecological cancers in Australia are treated by totally different sets of doctors, who have no relationship with each other, with different multi-disciplinary teams, et cetera. Personally, I would not want to see gynaecology generally put under the same umbrella as breast, or calling it a women's centre, purely because I think you need the focus squarely on gynaecology at this time. We were not supporting that structure.

**Senator ALLISON**—On the subject of psycho-social support—I do not think you were here—we had earlier today a sex therapist who works at the Austin. She said she is one only of a tiny handful of such therapists around Victoria. All of them are in Melbourne, I think. She pointed to the very grave difficulties that women experience with their treatment and their diagnosis, even in an ongoing sense. You would presumably support the greater use of such people?

**Dr Roos**—Yes, very much. You are dealing with a range of cancers where some of them have direct outcomes on the ability to have a sexual relationship. Others will be severely limiting and people will need help to be able to maintain a reasonable relationship, and with others there are some more psychological underpinnings that affect that relationship. So the availability of therapists in this area is the long-term wellbeing of survivors of cancer. A lot of the psychological issues and emotional issues are not expressed in the treatment phase—they are expressed often quite long afterwards. So if you have a young person whose fertility has been compromised, the real issues from that may not arise for some years. Later on, when they are out of the treatment phase, people expect them to be living a normal life and these issues are affecting them.

There needs to be available those specific sorts of support and emotional support in areas where people have difficulty discussing them. It is not like some of the other cancers where you can discuss the outcomes, or they are visible. Often the disfigurement arising from intervention, or these sorts of things, is going to be very private. It is not visible, it is hidden. Continence problems are hidden—you do not talk about them. Yet there are services to assist people, but often people do not know about them. So it is the availability of that information and the resources. We would like to see more being done in that area but also, to start with, an audit and directory of what is available in the community in these areas that is also available to clinicians so that they can refer to it. Often we find that clinicians are not aware of some of the services that are out there that could help their patients.

**Senator ALLISON**—Should patients be told that their best chance of effective treatment is through a multi-disciplinary approach?

**Dr Roos**—Yes, undoubtedly.

**Senator ALLISON**—Do you advise people about this?

**Dr Roos**—We are not qualified to advise people. We are patients who have survived cancer and we are advocating on behalf of others. So we are not technically qualified but we strongly support, for instance, the Victorian government's initiatives on multi-disciplinary care and care coordination.

**Senator ALLISON**—Professor Allen, how can we get it across to women that, when their GP wants to send them off to an oncologist or a gynaecologist, or says he will do it himself—which we have heard about in New South Wales—they be encouraged to say, 'No; I need to go and see the specialist sub-group of gynaecological oncologists'?

**Professor Allen**—Again, that needs a lot of coordination and education in the community. This is something which some centralised body could do. With the initiative of forming these

integrated cancer centres or services in Victoria, we are aiming to overcome that very problem. It is not uncommon that you might get a general surgeon or general gynaecological person who is performing surgery finding an ovarian cancer and referring it straight off to a medical oncologist without any input from the gynaecological oncologist and their multi-disciplinary team. That is a very important point. I mentioned in the opening statement getting rid of a lot of the variation in the current practice. Only state-wide or national protocols and expectations and outcomes that can be written into practice are going to get rid of those variations and get people to the right centres. I strongly believe that every woman with gynaecological cancer should have the opportunity, at least, of consulting with a gynaecological oncologist. I am not trying to corner any market. Just having the opportunity to talk to someone who has trained specifically in those areas is important.

**Senator ALLISON**—Rather than trying to educate 10 million Australian women, is there not a quicker and more effective way through the medical profession of doing this?

**Professor Allen**—We have tried very hard in a number of areas, and we do have national guidelines, but getting them out there and getting people to heed them is a difficult process. Again, I am sorry to harp on this but a national body would raise the profile of those very issues. We believe they are important if we are going to get the best practice of care for women with gynaecological cancers.

**Senator ALLISON**—Would you agree with evidence given earlier this afternoon to the effect that we have very little data on what treatment works? I think it is part of this argument, isn't it, if you cannot say, 'A gynaecologist oncologist has a much higher success rate than just going along to Joe Blow, and here's the data to prove that'?

**Prof. Allen**—Yes, there is not a lot of data—that is exactly right. That is the sort of data that needs to be collected as well. Could I just add that the psychosexual issues are profound and there is not enough support for those in any of the hospitals I have worked in or any of the systems, and that really needs to be addressed very strongly. I support the views of Dr Roos.

**Senator ALLISON**—About the funding for that: is it a hospital decision whether there is such a person or is there state funding for it? How does that work?

**Prof. Allen**—It is a hospital decision. In any busy hospital clinic, it takes a long time to start those sorts of discussions and to work through those issues. You know they are there, but you often do not address them because there is just no time and no specific people to do that. But, if you do open that sort of discussion with every single patient, they have all got an issue that needs addressing, and it is impacting on their lives quite profoundly.

**Senator ALLISON**—In fact we heard some nurses do not even broach the subject because they know that there is no-one to refer people to, so it is better not to ask the question.

**Prof. Allen**—I think that is absolutely right, which is rather sad.

**Dr Roos**—But sometimes there are people to refer to and the nurses do not know about it.

**Senator ALLISON**—Hence the directory.

**Dr Roos**—That is another problem, and that was actually highlighted in the guidelines for psychosocial care of adults with cancer. Some of their focus groups brought out that particular issue—that, even when there were referral sources available, people dealing with the patients did not know about them, so patients did not get referred to them.

There is another problem where you do need education of women. They have been very, very good with cervical cancer, in pap smear education and getting people to undergo pap smears, but there is an area of difficulty, because of the private nature of where the irritation et cetera may be, in even getting a GP to examine. It is an area where euphemisms are used, so one of our people talked about how she had had a general irritation for 15 years and had difficulty getting more than a cursory examination ‘down under’. Because it is embarrassing for all parties involved to be having thorough examinations, and particularly for people from different ethnic backgrounds, there can be added difficulties there. Some of the emotional distress can actually come before adequate diagnosis and there needs to be education in some of those areas, and that is the same for men as well with testicular and penile cancer.

**Senator FERRIS**—I really do not have too much to add other than to say that I think the last three days have made all of us understand what a minefield this is and how confusing it can be for somebody who finds themselves at the gateway for the first time. They step into the paddock, if you like, and they are confronted by this plethora of organisations, advice and information—or the lack of it in some areas. Do you think a national gynaecological cancer centre would help address those sorts of fundamentals? My biggest concern is that if you have a gynaecological cancer you are unlikely to google ‘breast cancer’ to get the information, so that puts you in another part of the paddock, I suppose. I am also worried about putting another overlay, if you like. Do you feel confident that this would serve a role sufficiently important to justify its formation as yet another agency?

**Prof. Allen**—Yes, I do. I do understand the extra layer when you have the machinery in place with the breast centre, but I do think it is a worthwhile way forward.

**Dr Roos**—Certainly many of the members on our committee are also trained volunteer counsellors with organisations such as Hopeline and Cancer Connect, so we are dealing often with people who are newly diagnosed and seeking information. I have to say, the information that is available on the internet through the National Breast Cancer Centre is really good. If you know of somebody who has an inquiry or of a relative who has breast cancer et cetera, you can refer them to that and they can get good, reliable information, with the consumer guidelines available and so on. If you could repeat that sort of availability of and accessibility to information for other cancers, you would be doing a great service to those who are newly diagnosed.

**Mr Powell**—I think the major issue is setting a minimum standard of information available to patients with any reproductive cancer, because you can go to one hospital and be overwhelmed with what they give you and go to another and get virtually nothing. If we could nationally set a standard, an organisation like that could possibly have that as a main target. Set a minimum, set a protocol and everyone has to be given this minimum information, which gives them the guidelines of where to go and is structured in such a way that country people have the phone numbers, toll free numbers, to talk to somebody, because they cannot go down to the corner and find someone. It has to be structured to suit all Australians. That is where the big problem is now,

even with a city like Melbourne. There is no minimum. The guidelines for the practitioners also vary from hospital to hospital, and very often, because of the private nature of the issue, the practitioners clam up and wait for someone to complain before they offer any information in advance.

**CHAIR**—Thank you very much. If there is any information you think we should have at a further time, we do not report until October. I love the daffodil on the top of the building. I think that is just wonderful. I have never seen that anywhere else and it just makes it stand out. That is just very visual and I love it. Thank you very much.



[3.28 pm]

**LEE, Mr Simon, Chair and Founding Director, National Ovarian Cancer Network Australia**

**LIVINGSTONE, Ms Karen Maree, Founding Director and Chief Operating Officer, National Ovarian Cancer Network Australia**

**LIVINGSTONE, Ms Nicole Dawn, OAM, Founding Director, National Ovarian Cancer Network Australia**

**WALKER, Ms Carolyn, Director, National Ovarian Cancer Network Australia**

**CHAIR**—Welcome. You have received information on giving evidence and parliamentary privilege. If you have any questions, just let us know. I know at least two of you have been listening to evidence all day, so you have the system down pat, I would expect. If any or all of you would like to make an opening statement, that is fine, and then we will go to questions.

**Mr Lee**—I would like to start by thanking the senators for this opportunity to meet with you and to discuss these matters today, and I would also like to commend Margaret Heffernan for the work that she did in triggering this inquiry. We much appreciate her efforts. One of the reasons I am here, and why I am glad to be here, is that my wife was diagnosed with ovarian cancer in 1999, and she died in the year 2000. Around August 2000, which was just a few months before she finally passed away, she was determined to ensure that her own life or death was not going to be in vain. She was absolutely convinced that something needed to be done to ensure that other women did not go through the experience that she had. You have heard many experiences about the diagnosis and the journey of women with ovarian cancer, so I do not need to repeat any of that. What she did do was to hold a press conference; it was more or less a statement from her deathbed. She was very sick at the time and she was determined that this was going to be the real last ditch effort to try and draw attention to a disease that we all felt was not receiving sufficient attention at this time.

There was no ability to detect it earlier. There was no apparent interest in investing in detection tests, or screening tests, or even promoting and providing women with sufficient information to protect themselves. That was the one thing that Sheila clearly believed in—that in the short term information was an absolute key, and the more women knew about the disease, the more chance they would have to protect themselves. At that press conference I promised on national media to continue Sheila's campaign, and that is one of the primary reasons that I am here today.

**Ms N Livingstone**—I first became aware of ovarian cancer in 1993, when my mother's sister Dawn was opened up by a general surgeon, diagnosed with ovarian cancer, and very quickly closed up, and referred then to a gynaecological oncologist at another hospital for de-bulking surgery. I remember doing some brief investigation—as much as you could back in 1993—and I remember thinking that there is not a lot known about this type of cancer. What I did not know at that time is that ovarian cancer can run in families, and that my own mother, Elsie, would be

diagnosed some five years later with the same disease. I now know that there is a hereditary risk that makes up about 4 per cent to 7 per cent of ovarian cancer cases.

My sister and I both watched two women whom we loved very much try hard to defeat ovarian cancer. Unfortunately, ovarian cancer ended up defeating them. There were the constant rounds of chemotherapy, the anticipated wait for the CA125 marker to see whether it was low enough, the nausea, the constipation and the hope, diminished, only by then dashed by the reality of another failed chemotherapy treatment. It was once described to us as a roller-coaster ride. I think it is a pretty apt description. It has also been described to me, and to the other board members, by our former director, Denise Hinds, who was in remission at the time, as waiting to be hit by a bus—again. Through all of it, I never saw my mum's or my aunty's spirit defeated. My mum lost her battle with ovarian cancer on 28 July 2001. I was away overseas covering the world swimming championships in Japan. My aunt, Dawn Weymouth, lost her battle on 18 December 2003. Mum was two years and 10 months from her diagnosis when she died, and my aunt was nearly 11 years. My aunt was one of the lucky ones, if you want to call it that, living past five years.

A decision to form a national consumer group, OvCaAustralia, was driven by the need to make a change, to actually save some women's lives, so no more women would die in vain. The national ovarian cancer network, OvCaAustralia, was incorporated in July 2001. I was joined by Karen, my sister, and Simon Lee, and our original other two directors, Linda Gibson and Denise Hinds. We had all been directly touched by ovarian cancer. When we first began our awareness program there was no readily available information about ovarian cancer for women in the community. Incidentally, for your information, Linda Gibson died in January 2005 of ovarian cancer, stage I; and Denise has resigned as a board member because she continues her roller-coaster ride and her fight for survival.

OvCaAustralia has worked hard to change this, initially by producing awareness brochures, which I have just given to you, incorporating symptoms, risks and preventions. We established a 1300 toll free information service and set up our website [www.ovca.org](http://www.ovca.org), which Simon created in the first place. The sceptics told us that we would be creating anxiety amongst well women by releasing ovarian cancer symptoms publicly. As a women, I would rather know. OvCaAustralia could not stand back while 800 women die each and every year, our Australian women.

We did all of this by fundraising ourselves and volunteering extreme amounts of time on our own. We all took turns of having the 1300 number hooked through to our homes, and we answered the calls. OvCaAustralia has relied heavily on fundraising and on corporate and individual donors. Unfortunately, the majority of individual donations have been through bequests over the past five years.

Following the disappointment of being rejected for a \$25,000 grant to run a national awareness campaign by the Office of the status of Women's development program, OvCaAustralia realised that we had to do it ourselves. So, thankfully, through an advertising agency and through some pro bono work, we made our own TVCs—community service announcements—and they are still currently airing on Channel 9. OvCaAustralia was late last year successful in securing a patient services grant from the Department of Health and Ageing for cancer support. With these funds OvCaAustralia has begun to produce resources to support and inform patients. These initiatives to date include our DVD *Ovarian cancer: the journey*. It is

a very informative DVD for patients who already have ovarian cancer. We have patient postcards designed to inform women of OvCaAustralia and our resources and the support and information we can offer them. A series of both hard copy and pdf files has been written by a professional health writer and are currently readily available for patients. With the continued funds from the Department of Health and Ageing, initiatives planned in the future include patient organisers—similar to those of our sister organisation, the national Breast Cancer Network—which we are researching at the moment to make sure we include what patients need and want. We will be undertaking that in 2007.

As worthwhile as it has been to help women who already have ovarian cancer, we desperately need to educate our community about ovarian cancer before it destroys more lives. We need to get it early. OvCaAustralia has identified some areas of concern in relation to ovarian cancer and patient care which we would like to bring to your attention today. Despite the solid work done by agencies to ensure the release of clinical management guidelines, we are yet to see changes in referral patterns or an improvement in GPs' understanding of, and interest in, this disease. My sister Karen can speak later of an alarming conversation she had with a GP about ovarian cancer and his lack of knowledge.

OvCaAustralia believes there are shortfalls in treatment of ovarian cancer patients, especially in areas which have already been covered today such as psychosocial support services in both treatment and post-treatment phases. OvCaAustralia is gravely concerned that within the community there is a misconception that a pap smear will detect all gynaecological cancers. I speak to a lot of women. I say to them, 'Put your hand up if you think a pap smear covers ovarian cancer.' I am yet to find anyone who does not put their hand up to that question. Another misconception is that ovarian cancer is an older women's disease. The youngest case in Australia that we know of is of an eight-year-old girl, and OvCaAustralia has a number of young women patients.

OvCaAustralia would like to see more specific information for patients relating to genetic and familial predisposition. Karen and I are both BRCA2 positive. My mother left blood before she died. Thankfully, the blood was tested by Peter MacCallum. All of our extended family now have the ability to be tested for BRCA2. That has taken place with our family. We would like to see more specific information available for patients with that predisposition, especially ovarian, breast and bowel cancer. We would like to see a greater emphasis on family history taken by GPs as part of general health checks.

Finally, OvCaAustralia would like to see a consolidated, collaborative effort to develop and implement an early diagnostic test and subsequent potential screening program. When I think about the collaborative effort we need—and I come from a swimming background, having gone to three Olympic Games—I think about the results of the swimming team compared to the results of the athletics team. The swimming team work cohesively, they have a lot of passion about being a team and therefore the success and results are there. The athletics team do not quite have that same spirit; therefore they do not have the same results. We need to work for a common goal. The initiatives we have raised impact on the health and wellbeing of all Australian women and their families—the blokes too. They transcend state borders; therefore we need a significant contribution from the federal government to fix this problem.

**Ms Walker**—As well as being a director, I am an ovarian cancer survivor. I was diagnosed with stage 3 ovarian cancer in March 1998. I had experienced symptoms which I did not know then, but now know, are very common symptoms of ovarian cancer. In 1998 there was no information available, so I had no idea how sick I really was. I was tired and emotional—I teach teenage boys—I put on weight around my abdomen, but I thought because I was tired and not exercising I was just putting on weight. I was trying to diagnose myself because there was just no information around. What I now know is that these are common symptoms of ovarian cancer. In hindsight I had been experiencing these symptoms for quite a few months, but had nowhere to go for basic information.

I finally went to my doctor who, luckily for me, was fantastic, and sent me for an ultrasound straight away. I had the ultrasound on the Saturday morning, and my doctor waited for me to go back to her at about one o'clock. She found the Mercy hospital then and there and made an appointment for me at 9 o'clock on the Monday morning. I went to the oncology ward at the Mercy hospital and I remember having to sign all these forms. I had absolutely no idea what was going on. They said to me that there was a mass attached to my left ovary and that I needed to sign forms to say that they could remove it. It is still a bit of a blur as to how many forms I signed, but I just seemed to be signing body parts away saying that they could take more and more and more. That was on the Monday morning. On the Wednesday I went into surgery. I was in surgery for 7½ hours, where I was diagnosed with stage 3 ovarian cancer.

I then spent the next eight months here at Peter MacCallum, taking part in a high dose trial of chemotherapy. That involved three conventional doses and three high doses, which is about seven times the conventional dose. I then had three stem cell transplants where they took my own stem cells, froze them and then gave them back to me at the end of each week of chemotherapy. That was the only time in the trial that I could not pull out, because without the stem cell transplants I would not have survived. It was tough. It was brutal. I certainly went through all the symptoms that other people went through—the mouth ulcers, the vomiting, the aching bones and so on—but it worked and I am very grateful.

I do not want other women to go through what I went through, and that is why I am a volunteer with OVCA Australia. Women, men and doctors need to be aware of the symptoms. They need information. They need to ask questions. They need an organisation like ours to phone for information, or just to come in and meet with other women who are experiencing the same thing. I believe very strongly that knowledge is power, and it is important that we work together to get this vital and life-saving information out into the community. I have lost a number of friends through ovarian cancer. We went through our treatment together. Two of us that I know have survived. I certainly do not want to lose any more friends. If they had been able to access information they might well be here with me now and be able to speak to you as well.

The statistics you have heard already, but they still blow me away: 1,300 women will be diagnosed with ovarian cancer this year and, of that, 800 will not survive. Having been through it, I think it is an appalling statistic and one of which we be ashamed. It is lack of awareness, it is lack of information. Early detection would mean that we would have a completely opposite statistic, where 90 per cent would survive. At present there is no early detection test for ovarian cancer, so I think it is absolutely essential that we have access to information and awareness of the symptoms. We cannot let any more women die simply because they did not have information. Thank you.

**Ms K Livingstone**—I would like to firstly acknowledge the presence of June Smith in audience. June is an ovarian cancer survivor of nearly 20 years. I would like to relay a conversation I had. I was asked to speak at a Rotary function out of Melbourne approximately two months ago. The setup was that I would be speaking followed by a local GP in this area. After a long time in the car to get to this particular point, I arrived and was asked if I would ring the GP because he would like to speak to me. I got him on the phone, at which point he asked me who I was. I told him and who I represented.

He asked me what I would be presenting at the function, and I said to him, ‘the signs, symptoms, risks, preventions of ovarian cancer,’ at which time he asked me what the symptoms were of ovarian cancer. At first, I was taken back but I gave him the benefit of the doubt thinking that perhaps he was checking my credibility and I asked him did he want me to read off the symptoms, at which time he said to me, ‘Yes, please.’ And I proceeded to do so. At the end of it, he asked me what the guideline is for a woman who is suspected of ovarian cancer. By this time I obviously realised that this gentleman had no idea what ovarian cancer was, yet he was a community GP. I explained to him that the clinical guideline is for women to be referred to a gynaecology oncologist, and that a gynae-oncologist actually did the frontline surgery was critical for survival. At that point his comment was, ‘Why not refer them to just a local gynaecologist?’ At that point, shaking all over with anger and frustration, I referred him to the Ovarian Cancer Program and suggested that if he was coming to speak after me, it would be advisable that he perhaps downloaded some information from that particular site. He commented that he did not have time to do that. Subsequently I informed him that I was going to read my own presentation before presenting, to make sure that the women got a comprehensive session, and understood the information with regards to ovarian cancer. I can tell you that the GP did not turn up on that night to present. In my experience, this is indicative of a lot of GPs. They have the belief that perhaps they will never see a case of ovarian cancer in their practising career. Our response to that, on regular occasions, is that perhaps they already have seen a case but they did not know. That is my opening statement.

**CHAIR**—It is pretty scary. I am sure Senator Adams will want to get into that.

**Senator ADAMS**—Thanks you all very much. You all have very personal stories to tell, and this whole session is about—as you heard me say—the practical issues. As you know, I come from a rural background. I have been trying to get information about the Patient Assisted Travel Scheme. I am very pleased to hear you say that people must go to a gynae-oncologist because with the Patient Assisted Travel Scheme it states you go to the nearest specialist, and unfortunately often—and I am not saying anything against specialists who practice in regional areas—they are not gynae-oncologists. They are normally general surgeons who will remove a tumour, and they are very good at what they do, but that is not what our people should be being subjected to. They should be given the best possible care and, as I said, with the backup of the multi-disciplinary team. If we can get that message across here it will certainly help.

As far as the GPs go, yesterday I was probably rather harsh in Sydney and I was pulled up. I am saying we should be kind to the GPs because often in a year they may not ever see someone with ovarian cancer. We do have information out there. If a lot of information were put out, every single woman of child-bearing age would be coming in saying, ‘I have all these obscure pains, and this and that.’ GPs would be inundated with women coming to see them. I do not see

that as a bad thing because at least they could check through and eliminate factors. This is the whole trouble. And that is where the research is so important.

**Ms K Livingstone**—I think one of the problems is that it is always considered last, not first. GPs need to actively consider that this could be ovarian cancer and send patients to diagnostic tests. In our experience, a lot of women are being misdiagnosed, and more than twice, before they are correctly diagnosed, and valuable time is passing before they are correctly diagnosed.

**Senator ADAMS**—That is absolutely right.

**Ms N Livingstone**—I want to point out too that a transvaginal ultrasound is quite expensive. It is something that needs to be considered. It cannot be used as a general population screening test, but there are a series of things to do to eliminate the possibility of ovarian cancer and CA-125 and TVU are two of them, but a transvaginal ultrasound is expensive.

**Mr Lee**—I would like to put things in perspective from the GP's point of view. There is perhaps this view that GPs are seeing cancers every day. Unfortunately nobody from the Cancer Council is here now. If you look at the total number of cancer diagnoses each year, you see that we have 25,000 GPs but only a few will see cases of cancers of any sort, even breast cancer, in a year. That, in a sense, makes ovarian cancer not as rare. It is not like they are seeing cancers every single day and then maybe once every couple of years an ovarian cancer may pop up. It is something that they need to keep on their radar all the time in looking for cancers. Ovarian cancer needs to be considered as one of those.

**Ms K Livingstone**—Obviously there are cases of younger women as well. There is a perception that it is older women, or post-menopausal women. As we said, we know of an eight-year-old girl who is now, I am happy to say, 12 and doing well.

**Senator ADAMS**—I know of a six-year-old girl. Ms Walker, do you have any comment? It is the rural access that I am looking at.

**Ms Walker**—When I was here at Peter MacCallum, I became very good friends with two people. One was coming from Hamilton and it was incredibly difficult for her to get here with her husband for the week. She wanted her husband to stay as well but he had to rent a place. It was really difficult and extremely expensive for them to come as a family to have the support.

**Mr Lee**—With regard to travel assistance—it varies from state to state, which I think is one issue—certainly in Victoria it is really only a subsidy. It does not cover anything like the full cost. For example, you have to travel at least 100 kilometres in one direction to get assistance for travel. If you need to stay over and have to stay in commercial accommodation, the allowance is \$30 a night. I do not know where you are going to find accommodation for \$30 a night in Melbourne. You claim it back afterwards, once you have receipts, but there are big issues for people involved.

**Ms K Livingstone**—And you have to rely on your GP to tell you about the scheme in the first place.

**Senator ADAMS**—That is right. A lot of people have no idea what I am talking about.

**Ms K Livingstone**—Absolutely.

**Senator ALLISON**—Ms Walker, this looks to me to be a really useful leaflet, but can you explain to the committee how different your situation might have been had you had this from the beginning.

**Ms Walker**—In hindsight, now I know what the symptoms are. I was experiencing abdominal pain, and I was really tired and emotional. I basically had all the symptoms, but I had no idea what it was. Looking back I probably was experiencing those symptoms for about three or four months before I got to the stage where I was in so much pain that I could hardly move. That is when I thought I had better go to the doctor. I am a teacher, I take sport. There are always things, as women, that we have to do, and we tend to put ourselves last. Deep down I probably knew that there was something not right, that I was sick, but there seemed to be a lot of other things that I had to do. If I had had that information, I would have gone to the doctor a lot earlier and not been diagnosed as late as I was. I am one of the lucky ones who survived it, but I believe I would have made the effort to go to the doctor earlier.

**Senator ALLISON**—I think you said you had a female GP. Is that correct?

**Ms Walker**—Yes.

**Senator ALLISON**—Did that make a difference?

**Ms Walker**—I think it made a difference that I trusted her. I do not think it would make a difference to me whether it was a male or female, but just that I could go to someone that I trusted and I could lay it on the table and say, ‘This is what’s happened.’ I trusted that she would do the right thing. I trusted her advice. I am not sure; for me, I do not know that it would have made much difference had it been a male doctor, so long as I felt that I could trust him with what he was doing.

**Senator ALLISON**—I wonder whether—and this has not come up at all in our inquiry so far—of the women you have been speaking with, those who have gone to female GPs might have had a greater level of awareness than male GPs.

**Ms K Livingstone**—I guess it is fair to say that women GPs possibly have more of an empathy as to how a woman is presenting and the symptoms she is experiencing. I do not think there is any data to say that it is one way or the other at this point in time. Part of the message we give women is that we are instinctive, that we know when something is wrong and that we should trust our instincts. I guess sitting before another female, you would hope they have the same intuition.

**Senator ALLISON**—Do you ever have the women who make contact with you, if they are in a position to afford it, seriously consider the private hospital option, rather than public? How do you deal with that?

**Ms K Livingstone**—We had a patient forum which we cohosted with the National Breast Cancer Centre’s ovarian cancer program here in Melbourne in February. One of the things that was quite disturbing, particularly for private patients, was the perception that, as a private

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

**Senator ALLISON**—The committee has had submissions from a wide range of organisations, including organisations like yours, although not exactly like yours. If there were in place a national gynaecological cancer centre, institute or whatever we call it, and there were groups funded to do awareness raising, or that simply dealt with awareness raising, would you be happy to pack up, go home and get on with your lives; or do you think there is a role for groups like yours that have really been formed out of necessity?

**Ms N Livingstone**—In hearing the continued suggestion, which we well and truly support, of a gynaecological centre, we would hope that well and truly entrenched in there is an area dedicated to awareness and education. Research is vitally important but we fight for a detection test. As we have pointed out, as has everybody, there are 800 women dying every year. So we have to make sure that there is awareness by and education of the medical fraternity in there as well.

Probably speaking on behalf of my sister and myself, we are somehow hopefully saving lives. We know we have saved lives because we have received correspondence from women saying, ‘Thank you very much for your information and for being able to find information. I was diagnosed with ovarian cancer, thanks to your help.’ We have had numerous items of correspondence like that. We hope it was in an early stage; we do not know. But if we can save a life, then somehow it makes mum’s death okay and somehow better. If there is continued education and awareness out there, then we are really at the forefront of battling it.

**Ms K Livingstone**—We would also like to continue with regard to patient resources and support. We find that an extremely important factor of what we do. Our charter is solely awareness—raising the profile of the disease—and also patient support and resources. We do not do research. We believe there should be more investment into research, and we are very supportive with regard to that. But there are already people doing that and certainly that is not our charter. Our charter is to support patients and also to raise awareness throughout the community of these symptoms, preventions and risks.

**Ms N Livingstone**—I know Simon will want to speak about this too but I would just point out that where we reside here in Melbourne—we are a national organisation—we are upstairs in a two-storey office. Downstairs we have turned into a girlfriends gallery to try and raise funds, as a charity, to fund the organisation. But we are actually running a drop-in centre for women. Unfortunately, ovarian cancer patients are often not well enough to go out. We started at once a fortnight but now we have spread it out to once a month because we are finding that women are not well enough to come as frequently as we would hope they would. So once a month we have women with ovarian cancer come over and have a very long cup of tea.

**Mr Lee**—I would like to add to that. In terms of a national centrally funded organisation, which is a great idea, to be effective, an organisation like that is going to have to have good consumer representation and advocates. To get that, that has to be external to that organisation.



There is still a role very much for an organisation like ours to keep in close contact with patients, families and other community representatives throughout the nation in order to adequately collect that information and to relay information back to them and to make sure that their interests are being represented appropriately for the national organisation's sake.

**Senator ALLISON**—In order words, you have become good at what you are doing and you would like to keep doing it? That is what I am hearing.

**Mr Lee**—Yes.

**Senator ALLISON**—Ms Livingstone, your stint at Rotary. Is this one of the many that you do, and do they give you money at the end of your performance?

**Ms K Livingstone**—Not always. We do not ask for that. But we do take along some of our bell key rings and teal ribbons—Carolyn has one on today. Teal is the international colour of ovarian cancer. We have changed our brand to a bell. The reason for that is we say that we do not want it to be silent any more. We want to ring the bell.

**Ms N Livingstone**—The other one is, 'If there are symptoms, ring a bell'.

**CHAIR**—It is very clever.

**Ms K Livingstone**—In answer to your question, we do not ask for payment to come out. That is a service that we provide, as is our 1300 information line, which we man. If women are looking for information they can call us. We can send out brochures. If they are patients, we can send out the DVDs. But women, generally, are looking for people to tell them what they need to do, and what the correct procedure is. We get a lot of women ringing. In fact, I had one last week where a woman had lost her mother to ovarian cancer and there was some breast cancer in the family. She had not been put into a high-risk clinic. Nicole and I participate in the Peter MacCallum Cancer Centre familial high-risk clinic. This particular woman was trying to do her surveillance on her own, as a high-risk woman. She had identified herself as a high-risk woman. She had changed GPs and she was trying to get a system of tests that she could have so that if there were any changes in symptoms she could be diagnosed quicker. The GP said to her: 'Don't worry about the CA-125. You don't need to have a blood test.' Whereas, we know that the guidelines for high-risk women is a CA125 marker, as well as a transvaginal ultrasound once a year. In addition to that, Nicole and I have mammograms every year, and we are about to begin an MRI test, which Professor David Bowtell referred to this morning.

**Senator ALLISON**—So you do not get money from Rotary. You have put a lot of money into this yourself. You got knocked back for \$25,000 from the Office of the Status of Women. What ideally would you like to see by way of funding for your organisation?

**Ms N Livingstone**—Funding for awareness. We receive funding for patient services and support at the moment.

**Senator ALLISON**—Is that state government funding or federal government?

**Ms N Livingstone**—Federal government.

**Senator ALLISON**—What program does that come out of?

**Ms K Livingstone**—The cancer support program.

**Mr Lee**—It is about strengthening cancer care in Australia.

**Ms N Livingstone**—That is how we have done the DVD, and will continue to do the diaries, the kits for women, for 2007. We will continue to do those programs and projects. As I said, it is a great satisfaction to help women that have ovarian cancer, but we really need to get out to women. Women in the early stages of ovarian cancer or women who do not have ovarian cancer need to know about it, not only for themselves but for their daughters, their sisters and their female loved ones. Awareness for us is imperative.

**Ms K Livingstone**—Part of what we have identified is that we do not have the funds to do our own awareness campaign, so we have enlisted the support of an international award-winning advertising agency by the name of M&C Saatchi. They have developed a campaign for us, which I would like to share with you, if that is okay.

**Ms N Livingstone**—They came to us, which was lovely.

**Ms K Livingstone**—Yes.

**CHAIR**—But you are not going to lose your bell, are you?

**Ms K Livingstone**—No.

**CHAIR**—That is beautiful.

**Ms K Livingstone**—You would have to say that it is far more striking, and certainly there is no doubt as to what we are talking about with regards to putting it into women's psyches.

**CHAIR**—Yes, visually.

**Ms K Livingstone**—Yes, it is very strong visually.

**CHAIR**—How long is your funding for?

**Ms K Livingstone**—Four years.

**CHAIR**—Four years from when?

**Ms K Livingstone**—May 2008 is the last instalment.

**Senator FERRIS**—I think you have pretty much covered it. I was just saying to my colleague here, Senator Adams, that I would really like to see your application for the funding. How long ago did you put that in?

**Ms K Livingstone**—It was in 2004. It came under the responsibility of Senator Kay Patterson.

**Ms N Livingstone**—Whom I spoke to at a function, about the rejection of the funding.

**Senator FERRIS**—What was the explanation? Are you able to tell us?

**Ms N Livingstone**—One of our past directors—whose mother died of ovarian cancer, and who has since had a child and resigned, for maternal duties—called the office and was told that we qualified in all areas for the grant, however it was not seen as a women's issue. It was seen as a health issue, so we should contact the health department.

**Ms K Livingstone**—We contacted the health department at that time, and unfortunately there was nothing that we could apply for to carry out an awareness campaign. There was only something available for research.

**CHAIR**—So you fell in between the two departments.

**Ms K Livingstone**—Yes. We learnt to lobby, because not long after we were rejected there was a federal election announced. So we had a baptism of fire with regards to lobbying to get something, and that resulted in OvCaAustralia being included in both the ALP's policy and the Liberal Party's policy.

**CHAIR**—So in many ways, you are lobbyists, now amongst all the other roles.

**Ms N Livingstone**—We need to be.

**CHAIR**—You carry out all the other roles, but it is a good thing to have positive lobbying. Would you include that as part of your function?

**Mr Lee**—Yes.

**Ms K Livingstone**—It is part of our function.

**Mr Lee**—It is not a prime function.

**Ms K Livingstone**—Our prime functions are patient support and services, and also awareness. Five years ago, when we first started, there was not a lot of information in the market place about ovarian cancer at all. We were probably the pioneers in getting that information out. Subsequently, a lot of the research groups have associated awareness with the promotion of their research. We found we were getting a lot of phone calls, which were generated by these campaigns, to our 1300 number. Our organisation employs two part-time people. I am one of those, and I am paid for 13 hours per week.

**Ms N Livingstone**—She works about 35 hours to 40 hours per week.

**Ms K Livingstone**—And we also have another lady who works 16 hours, and that is the extent of our paid resources.

**CHAIR**—That is the paid staff—two part-time positions?

**Ms K Livingstone**—Correct—and a lot of passion.

**Senator ADAMS**—While you are talking about your advocacy role, I was just going to ask: do you have anything to do with the Breast Cancer Network Australia? Do you talk to them?

**Ms K Livingstone**—Yes, we do. We believe that the Breast Cancer Network is our sister organisation, and certainly Lyn Swinburn feels that we are a sister organisation. We seek advice from them with regards to some of the initiatives that we undertake.

**Ms N Livingstone**—Part of that connection is that we are supported through the National Australia Bank and MLC, their superannuation arm. National Breast Cancer Network Australia has a relationship with Raelene Boyle. So, too, do we, through the National Australia Bank. Raelene is a survivor of ovarian and breast cancer. We know Lyn Swinburn and Raelene very well. It is more of a mentoring thing for us.

**Senator ADAMS**—I have been a consumer rep of theirs for quite some time. I still do it a little bit. I think that they have done the hard yards, so it is really important for you to get that partnership with them, and use what they want you to use. I know that they have offered their My Journey Kit to Margaret, so that it is there to be utilised.

**Ms N Livingstone**—I think the thing that we realise with Lyn Swinburne's organisation is that she is very supportive of us. She does not feel threatened by us in any way, shape or form, because she understands it is for the greater good, so she is not protective in any way. She is very sharing with us, which is wonderful for us. You just mentioned Margaret. I just had a brief head-bumping conversation with her a moment ago in talking about, 'How do we get the message out about ovarian cancer, about the multidisciplinary team, and even just something so simple as that pap smears do not cover ovarian cancer?' I know, as a young woman, I receive every 12 months a reminder for my pap smear in the mail from my doctor because I am registered for that. I am sure there are many, many women right around Australia that are registered for that so perhaps there would be a way to include a message on that to women about ovarian cancer, about it not being detected by pap smears, and even a simple message about the symptoms. And if they are lasting for more than two weeks and they are not normal, then please see a doctor about ovarian cancer.

**Senator ADAMS**—That would be great.

**CHAIR**—Can I just ask one question, because we are getting close to time. How national are you? One of the things that we have found out is how many organisations there are around the place that have been stimulated in very similar ways to yours—that someone has experienced the pain or the loss of a family member, and there has been nothing for them and that has got them going. So there are a few. How do you fit nationally? I am from Queensland, by the way.

**Ms K Livingstone**—I guess when we founded, it was a very quick transition for us to actually meet other women, or other women were contacting us that actually wanted to be involved because they had been directly affected. We actually have representatives all the way around Australia, with the exception of the Northern Territory, at this point in time. The best way to put

it is that we find a lot of women patients are not looking to undertake that kind of advocacy role, so we are limited with regard to patients being able to speak. We understand that, because we understand that part of their role is to get better and the need to concentrate on that. What we actually have nationally are representatives who actually go out to the community to speak, and most of them have been affected directly by ovarian cancer, not necessarily patients themselves.

**CHAIR**—Yesterday we had evidence from John Gower, whom I know quite well. That organisation is quite small. It is has been working in Queensland for many years. How does your group and that group interact?

**Mr Lee**—We talk a lot—we just had lunch.

**CHAIR**—He likes lunch.

**Mr Lee**—At the moment we are discussing how we can, in fact, better work together with the sorts of things we are exploring. For example, with regard to the DVDs and the patient postcards, John said to me, ‘Send up a whole package to me, and I will send them out to our database.’ We basically are offering the same sorts of things. We will put together patient information packages based on the resources that he has got and the ones that we have got, so we are going to combine those sorts of efforts.

**CHAIR**—So his group—not him personally—would refer to you, you would refer to them, that kind of joint thing?

**Mr Lee**—Yes. We definitely have had dialogues going for many years. We have avoided treading on each other’s turf from a fundraising perspective. In fact, we have done shared things, and we do not have any issues with that. It is a very good working relationship. I think it has been a bit of a struggle for us as well in terms of the fact that this is a big country. Each state has its own rules and regulations that we have to conform to in order to act as a charitable organisation in those states. We do feel it is worth going to that effort because we have a telephone information line and we have a website. People contact us; they want information. We cannot discriminate on the basis that you live more than 150 kilometres or something from us. It does not matter where you are, we know—

**CHAIR**—Unlike the patient travel scheme.

**Mr Lee**—That is right. We know that some states do not have really any support infrastructure at all, so those are the women who most need it. It has been very important to us that our whole charter is based on providing services across the country.

**Ms N Livingstone**—On our website, which we are just upgrading at the moment, we launched a patients’ forum, so patients can actually get onto the website together and talk. Senator Adams, you were talking about rural women feeling a little bit isolated and perhaps not having the medical attention that they need. Sometimes the emotional support and network of other women are not quite there for rural women as well. So we have a patient forum that women can get on and actually communicate with each other and post messages.

**Senator ADAMS**—Would you like to put a question on there about the travel scheme and how they cope with it?

**Ms N Livingstone**—Absolutely.

**Senator FERRIS**—Can you perhaps tell us three things that you would like to have had available to you when you were diagnosed that you did not have and that maybe are still not available or are available now?

**Ms Walker**—Gosh, that is a tough one.

**CHAIR**—It was a question without notice.

**Ms Walker**—I was really lucky in that my doctor diagnosed me straight away, and she was very easy to talk to. I will bring up some of the things that some of my friends went through.

**Senator FERRIS**—Yes.

**Ms Walker**—I was speaking to you about this earlier. One of the girls that I went through with was 18 years old, and it was not diagnosed until she went to the fifth doctor. She went to four different doctors and she was told, ‘It’s period trouble, and here’s some more pills,’ and ‘Try this one, and try that one, and take a Panadol and lie down.’ She took her mum to the fifth doctor because she was so distraught. And her mum said, ‘We’re not leaving this office until you refer us for an ultrasound. So, we’ll sit here as long as it takes but you need to write a referral.’ And when she went to have the ultrasound and then went to another doctor, he said, ‘Gee, we wish we’d got you a bit earlier; it’s stage 3 ovarian cancer.’ Those are the sorts of things that I really would like to see addressed.

My story is a good story. It is really good because I was lucky that my doctor was fantastic. She was straight onto it. She did not say, ‘It could be this or that.’ She said, ‘I’m going to send you for an ultrasound. Don’t panic. Just because I’m sending you to oncology doesn’t mean that it’s cancer.’ It was lunchtime on Saturday. I could not get to the hospital until Monday morning. I think she knew but she thought there was no point stressing me for the rest of the weekend thinking, ‘I’ve got cancer, I’ve got cancer.’

So I think having a doctor that you trust, who is aware of the symptoms but whom you feel that you can talk to, is really important. It is obviously important to have family members who are aware of the symptoms who can just be there for you. Or, if you do not have family members—and a lot of women do not have family, or do not feel that they cannot speak to their partner or their family about it—it is important that there be services available where you can just get on the phone.

The person on the other end of the phone does not even need to say anything, but it is just important that you have someone there listening to you and saying, ‘Yes, I’m still here,’ so that you can get rid of the anxiety or whatever. It is important that you just have someone to listen to you. I think that is really important.

The other thing that was vital for me when I went to the Mercy Hospital was that I had my aunty come with me—because my mum and dad could not come. My dad had just had a stroke, so mum was having tests with him. But my aunty came with me, and that was absolutely essential because there was so much information. You just have to have another person because you cannot take it all in. In having someone with you who can absorb maybe a third or half the information while you get a third or half the information, together you almost get the full story. It is just so overwhelming. You go from knowing nothing and thinking, ‘I’m a bit sick’—cancer was not something that I had even thought of—to being told, ‘There’s a mass attached to your left ovary. We’re going to do surgery.’

And then within two days I was spending 7½ hours in surgery. Within 3½ to four days of that I was going through early menopause. They came in and put pamphlets on my side table and said, ‘You’re going to go through early menopause.’ And I thought, ‘Well, that’ll happen when I leave hospital.’ They do not tell you that it is going to happen right away. And all of a sudden I had the hot flushes and I thought, ‘My God, what is happening?’

So it is important to have someone there, so that when they bring the pamphlet in they just do not put it by your bedside, but you have someone there saying, ‘I’ll read the pamphlet and then we’ll have a talk about it.’ It does not have to be someone who is directly affected, but just someone who can absorb half the information and whom you can talk to about what is going on—because you definitely need someone to talk to.

All the boys at Melbourne Grammar know that I have had ovarian cancer. I actually did a talk to the 200 boys in Year 10 last year about ovarian cancer. I think talking about it is really important. It is part of the therapy. I hope that answers the question.

**Senator FERRIS**—Good answer.

**CHAIR**—Does anyone have any comments they would like to make? Sometimes at the end you think of something you really want to say.

**Ms N Livingstone**—I wanted to let you know that we had a fundraising event last Sunday night, which we have run twice now, called the Linda Gibson Memorial Comedy Night. We had 470 people turn up on a rainy Sunday night. We have raised money from that and we are now in pre-production for an awareness video. So we will move ahead with that in the coming months.

**Ms K Livingstone**—One of the reasons for having an awareness DVD is that a lot of people are not comfortable with public speaking. So they will be able to put the DVD on and let the women see the information. It is the correct information. Women also worry that they might miss something or that they are not covering all the bases. Having a DVD means that women are getting the correct information, and they are getting it from us. We believe we are a pretty good source to disseminate that sort of information.

**Ms N Livingstone**—Again, just to put it in capitals, and in inverted commas: we are funding it ourselves.

**CHAIR**—Linda would have enjoyed that. Thank you so much, and thank you for your patience. I know you have sat through this committee nearly all day. Can I just add one thing

before you go. The evidence that we had this morning is that in the speciality that we all rely on in this area there are no trainees coming on this year. So the talks are so very valuable that you are doing encouraging people to go into the field. For young people who are looking to make careers that could be one other thing to add: that we just do not have the professionals. We did not know that until this morning.

**Ms N Livingstone**—Can we leave you with something Linda would say? ‘If in doubt, check your ovaries out.’

**CHAIR**—It is a shame we cannot just pop them in and out. Thank you so very much.



[4.22 pm]

**NALL, Ms Catherine Marjorie, National President, Australian Physiotherapy Association**

**SHARPE, Mrs Robyn Margery, Senior Clinician in Lymphoedema and Women's Health, and Representative, National Continence and Women's Health Group, Australian Physiotherapy Association**

**CHAIR**—Thank you for joining us. As you have given evidence before, you know the system and you have got the information about the protection of parliamentary witnesses, privileges and in camera, if you choose. Would either, or both of you, like to make a statement to begin?

**Ms Nall**—I would like to start and then I will hand over to Robyn. Firstly, thank you very much for the opportunity to be able to present to you on the position held by the APA on matters related to gynaecological cancer. While I know you have our submission, we have also prepared a brief handout outlining today's presentation. We have also given you some important supporting documentation, on palliative care, physiotherapy services and equity in the provision of lymphoedema garments.

As you know, the Australian Physiotherapy Association is the only body which solely represents the perspective of Australian physiotherapists and their patients. We have 11,000 members representing over 80 per cent of Australian physiotherapists. Within this group we have got a range of members with specialist expertise in the physiotherapy management of gynaecological cancer and the conditions that are associated with it. While I have some expertise in this area, as director of physiotherapy at Austin Health here in Melbourne, which has a very large cancer service, I am very pleased to be able to be joined by Robyn, who has extensive experience in this area and, in particular, in the management of lymphoedema. As you know, Robyn is a senior clinical physiotherapist at the Royal Brisbane and Women's Hospital, and she is also a member of the Australian Lymphology Association and the Continence and Women's Health Group of the Australian Physiotherapy Association, as she said. That is our equivalent of a specialist society or a college within the medical profession that you would perhaps be more familiar with. I will now ask Robyn to speak to our submission, and I will then at the end just speak very briefly further to funding issues associated with the provision of physiotherapy services.

**Mrs Sharpe**—You can see from the presentation that we have put together here that I would like to start by saying who is affected by gynaecological cancer. You have probably heard these statistics several times already in the last couple of days, but one in 70 women gets some form of gynaecological cancer and at least 18 per cent of women who undergo treatment for these cancers develop lymphoedema post treatment.

To put a face to what I experience in my day-to-day practice this is a briefing of a 30-year-old woman patient of mine who was diagnosed with cervical cancer, treated with surgery, pelvic lymph node dissection and radiotherapy in 2002. The age of 30 is quite significant because what we are noticing in practice, and you have probably already heard, is that the age is lowering.

Where once these cancers were found more in the 35 years of age and upwards group, we are seeing a lot more in the 20- to 35-year age group.

This particular patient of mine developed lymphoedema 12 months after her surgery and was seen by me at clinic at an appointment for follow-up at the regular clinics we hold for medical follow-up. I gave her a self-management program and her first garment as she lived 600 kilometres north of Brisbane and was not able to come back for a follow-up appointment to me—to a major regional centre and not a country town either. Her lymphoedema continued to worsen because of the distance and the lack of services between Brisbane and her hometown. Part of her social history that has evolved over the course of time is that her husband left her 12 months ago and she questions her condition of having a very fat left leg and lower abdomen as part of the cause. She needs garments every four months and needs regular treatment to control this condition. At the moment we manage with her coming down to Brisbane for two weeks at a time on a yearly basis for intensive treatment. There is no maintenance treatment available where she lives and there are no health professionals in her city who have the relevant skills.

Her annual cost of living with lymphoedema, which we totted up together, is about \$3,000 a year. This is because she actually makes do with off-the-shelf garments not made-to-measure garments, which would have doubled that amount. Loss of income to her is not included in this figure. The effects on her four young children, who are currently aged between six and 12 years, unlike the ad that says 'priceless' are just not able to be calculated. When I told her that I was preparing for this hearing her words to me were: 'My surgeon said lymphoedema is not life-threatening and my cancer is fixed. From my point of view it is worse than the cancer. At least that was cut out. This is permanent and has ruined my life.'

I wanted to present that to you to put a human face to it rather than just give you facts and figures. What we do know about gynaecological cancers and lymphoedema is that early detection and intervention of lymphoedema reduces the impact and the severity, and that is backed up by some solid research. We have no rationale for what is provided for these women with lymphoedema. It differs not only between states but also between hospitals, between the public and private sectors and between health insurance companies. The incidence of lymphoedema following gynaecological cancer is not insignificant—18 per cent is a conservative estimate. If you look at the figures for vulval cancers, which I grant you are only five per cent of the total number of cancers, you will find that if they have radiotherapy as well as surgery you are looking at close to 100 per cent. It is a very high risk.

If treatment is not successful and palliative care becomes necessary, the care for these patients is ad hoc and underfunded. Appropriate physiotherapy treatment can reduce hospital admissions and improve quality of life for these patients, but it is not available to most of them. The worst fear for patients after breast cancer was found to be recurrence and the second biggest fear was developing lymphoedema, and you can say the same for these gynaecological patients. Lymphoedema causes a great deal of distress and expense for the 20 per cent or so, and probably more, of these women who have had gynaecological cancer.

What I would like to see done as a result of this inquiry and further investigation into the treatment of lymphoedema following gynaecological cancer is to allow better access to physiotherapists who have expertise in treating lymphoedema and that an equitable solution be

found to allow women with lymphoedema to be able to afford the necessary garments and treatment on an ongoing basis. Lymphoedema is chronic, it is long term and it does not go away.

Clinical education for physiotherapists to ensure a skilled workforce that can provide these services needs to be appropriately funded. The introduction of Medicare rebates for physiotherapy services proven to be effective—for example, for lymphoedema and for pelvic floor treatment, which is another side effect of these treatments—will reduce the burden of cost to patients unfortunate enough to have developed a gynaecological cancer.

We need to ensure that health insurance rebates are at least close to the actual cost of what is needed and that there is some equity between health funds in how much is rebated, and to establish or improve funding for physiotherapy services for palliative care patients, thus improving their quality of life and reducing their hospital admissions.

I just want to add a couple more points that are not on there. Continence is still a really big issue for these patients. I did not go into a lot of detail because I think there is a lot more information around about continence and its side effects compared with lymphoedema. But when you consider that the treatment for gynaecological cancer invariably involves hysterectomy for almost all of them and radiotherapy for a large proportion, the effects on the bladder and bowel are significant. The continence management is not quite the same as from other causes, as a lot of the damage is irreparable.

I would also like to make a comment about multidisciplinary teams for the treatment of gynaecological cancer: that it is more than just three different types of doctors, which is often the definition you hear in many circles about what multidisciplinary means. And I want to acknowledge that Professor Alex Crandon—who for a long time was director of gynaecological services at the Royal Women's Hospital in Brisbane—actually had the foresight to employ a full-time physiotherapist and social worker back in 1996, and for that we thank him because a lot of our work has come out of those positions.

**CHAIR**—Mrs Sharpe, I just want to ask one question there. We have had significant evidence from various very well-credentialed units and they have not all claimed to have had a physiotherapist and a social worker. From your experience around the country how many of those organisations would have those services?

**Mrs Sharpe**—Most of the very major gynaecological oncology centres do. There are a couple of notable exceptions, but in four out of six states there are.

**CHAIR**—I hoped that would be a basic requirement. Ms Nall, you want to talk about funding.

**Ms Nall**—I will start with public sector funding first. Whereas there are physiotherapy services attached to the gynaecological units, I think all of the physiotherapists involved in the area would talk about the very severe limitations there are on the resources available to them. There is no doubt that if there were more resourcing available to support staff, the staff would be very fully utilised. As it is they have to prioritise very severely in order to meet the needs of new patients coming in and therefore cannot provide the ongoing service that they would like to be able to provide. That I guess moves us on to how outpatient services are funded. Again,

outpatient services in the public sector are very limited. They vary from state to state and territory as to how much resourcing is able to be provided. As you know, physiotherapy is almost entirely reliant on state and territory based funding rather than Medicare funding.

One of the hopes we had with the recent Productivity Commission recommendations was that—while we acknowledge that Medicare is not a perfect system and that the fee-for-service funding model could be improved, that is what we have at the moment for dealing with most health services—there would be some recognition that there needed to be broadening out of Medicare funding to recognise the role of the multidisciplinary team in the management of so many different conditions. One of its recommendations in fact was to allow evidence based access to services rather than just the very strong focus on medical services that currently exists.

Unfortunately, while there has been some recognition of the need to broaden Medicare, the recommendation has been very much watered down in terms of the response by COAG, and, as we understand it, that is essentially due to the position of the federal government rather than the states and territories.

To have Medicare funding available based on evidence would have a significant impact on the sorts of services physiotherapists could provide to people with lymphoedema and other conditions associated with gynaecological cancer because it would allow all of the advantages that we have been able to see, from the limited public sector funding that exists, to be extended to patients more widely in the outpatient areas. It would also allow a more critical mass of services to be developed because of an alternative funding stream. That would deal with some of the rural and remote access issues that have been identified, and it would also allow more specialisation to occur in this particular area among a range of physiotherapists.

Moving to the private area, the extent to which private services are often not as well developed as services in the public sector has already been discussed. I have personal experience of this through a close friend and colleague who died from ovarian cancer 18 months ago and who was in the private system. I come from the public system so I was aware of what we are able to offer our patients. I was quite concerned at the lack of coordination and the lack of access to a multidisciplinary team; it was all done on a very piecemeal basis. Part of the lack of access is due to the lack of funding to support the services, other than just the medical services that are supported on a fee-for-service basis. I think there is also a lack of awareness of what a properly functioning multidisciplinary team can contribute. That also opens up the issue about the very low rebates that come back from private health insurance for physiotherapy. They are often capped and they are certainly only a small proportion of what is required.

Moving very briefly to palliative care services, again there are some very limited physiotherapy services available in palliative care. They are more the exception than the rule, yet often patients in palliative care can benefit enormously from physiotherapy services, both to help them maximise their quality of life and to address specific musculoskeletal, continence and other issues they might have. I am happy to take questions.

**Senator ADAMS**—It is really good to have lymphoedema up there because it has taken a while. I have been to see the minister a couple of times about it. I really feel that, getting back to the rural people, there is the problem of firstly—you have heard me before—trying to get an appointment and, secondly, trying to get multiple appointments, which is just not possible. There

are a number of physiotherapists who are not prepared to do lymphoedema or even go away and do courses on it, simply because they can see four or five patients to one lymphoedema patient—it is such a long-term issue. Then there is the cost, of course. I am lucky, I suppose, that I have an upper arm lymphoedema, but there is just the cost of these garments—\$400 twice every six months. I can do it but other people cannot. I have friends working on farms with arms just like this. They are going to cost the health system so much in the future. I am really looking at this as a health prevention thing. Somehow we have to get the EPC items increased to the number of sessions that can be done.

In Perth there is one area now where we can have lymphoedema treatment. One of our specialist people has since retired, so another person has gone out of the system. It is very difficult for people to be treated. I do not know what you can do with your association. There has to be better remuneration for them to be able to even consider taking up that particular area of expertise.

**Ms Nall**—We have been working very hard to try to get that understanding among decision makers. That is something we regularly raise with the minister and his advisers, as well as individual politicians, when we have the opportunity. Even the issues around EPC are not straightforward. Whilst that was a very welcome first step, it is totally dependent on the GP being amenable to doing the paperwork. Even though they are well remunerated for doing it, we still have significant opposition from many of them to undertake that.

The other problem is that it has to be a GP referral—because so many of these conditions are identified by specialists rather than GPs. We see health services as having multiple entry points. Therefore, there should be able to be referral from anywhere within the health-care team. So, in the same way that, for instance, optometrists can refer directly to ophthalmologists and vice versa, we also believe it is important that specialists can refer directly to physiotherapists for evidence based interventions and the patient receive an appropriate rebate.

**Senator ADAMS**—Have you taken that to the minister?

**Ms Nall**—Absolutely. We have been talking about it until we are blue in the face.

**Mrs Sharpe**—It is a subject that is very dear to my heart. I have been working in this field for the last 12 years and my entire goal in life is to do something to improve equity of access to services for lymphoedema. We get away with it in a fairly side-door manner in Brisbane at the moment because we have five gynaecological oncologists who operate in both the private and public sector. When the private sector patients get lymphoedema, because they have not seen a physiotherapist in the private sector for any of their treatment for their cancer they get referred to me in the public sector, usually because they have had radiation services on our campus. So they come in legitimately but by a side door, which then loads up the public sector. I sometimes jokingly say I have a 100 per cent management role and a 50 per cent clinical role. I keep expanding what I can because we are basically the last-stop shop for these patients to get some kind of treatment.

In the private sector there are probably half a dozen physiotherapists who are willing to take the considerable drop in income to see lymphoedema patients on a regular basis. Even a standard treatment not involving complex physical therapy involving massaging and bandaging still takes

three-quarters of an hour, whereas if it were a musculoskeletal condition they would be seeing three or four patients in that same time.

Then there is the problem of charging adequately to remunerate them. With a rebate of something like \$28 regardless of length or complexity of consultation, a lot of them are charging their patients \$75, and that is still well short of what it is actually costing them to provide that service. It would be really good if an awareness of the lack of access and complete lack of equity in what people are able to achieve in their treatment could be raised at more and more levels. One of the things we offer in the public sector is a complete service from pre-admission and ongoing. I have some patients who have been on my books for my entire 12 years. With those patients, we have known that the early detection and early monitoring process significantly reduces the severity of their lymphoedema, and, instead of requiring four weeks bandaging before a garment, we can usually get by with self-management programs, off-the-shelf garments and really vigilant monitoring, and keep it under control.

**Senator ALLISON**—I do not know a great deal about lymphoedema. What difference does it make to an individual to have both ongoing and early access to lymphoedema treatment from physios? In terms that we would understand, can you describe how this physically makes a difference?

**Mrs Sharpe**—When they come to see us, by having careful monitoring through measurement programs—mostly we use circumferential measurements around the limb and several points and do a total volumetric calculation—we can fairly quickly detect—

**Senator ALLISON**—You are calculating the amount of liquid?

**Mrs Sharpe**—Yes, extracellular fluid in the limb. Unchecked, that limb can develop three, four or five kilos of fluid. That is quite often unilateral, which creates a raft of other problems—musculoskeletal difficulties with the back and hip pain from the subsequent swelling and lack of mobility. If we have consistent measuring and calculation of volume and keep an eye on it, when we start to see a drift upwards we can institute some measures such as home massage programs. We can put them in a garment and on a careful exercise program. Skin care is vital.

**Senator ALLISON**—By a garment, do you mean an elasticised sheath?

**Mrs Sharpe**—An elasticised compression sheath, like that one on the leg. They are not comfortable. In Brisbane, and presumably in Western Australia too, they are damned uncomfortable in the heat. But it is a lot worse without them, because the fluid just goes out into the periphery and has no way back because of the impaired lymphatic drainage as a result of the treatment. Vulval cancer is often used as the equivalent to breast cancer, and people think that lymphoedema is not such a problem because the numbers are low. But with uterine cancer, cervical cancer and a lot of ovarian cancers we now take out lymph nodes from the pelvic region, which are where the nodes in the groin drain up to. So we are removing the drainage a little higher up, but we are still impairing and impeding that drainage flow significantly for these women.

**Senator ALLISON**—And the ones who have both lymph nodes removed would be at the highest risk, I suppose?

**Mrs Sharpe**—You do not usually have groin nodes and pelvic nodes taken. Groin nodes, because they are a regional block, like the auxiliary nodes, do have a higher risk. With the pelvic nodes the problem is that the risk is bilateral. One of the issues on the agenda at the University of Queensland at the moment is developing a better bioimpedance measurement form to detect the bilateral lymphoedema, because there is no control limb. Both limbs are equally at risk, and we do not know why one limb develops lymphoedema and the other does not. In some cases both do develop lymphoedema. In other cases only one does, and then we have this gut feeling that probably there is a subclinical level of lymphoedema in the opposite limb as well.

To my way of thinking, the measurement before any of the treatment is instituted is vital, because that is the only control you have. Once the treatment has been done, you do not know what has been changing already in that lymphatic system. One of the things we would like to see across the board is some kind of standardisation at a national level of what is done for these patients for their lymphoedema management as well. So if there is some thought to forming a national body, as I have been listening to this afternoon, we would like it to include more than just medical staff. We would like it to include people like physiotherapists, social workers and clinical psychologists, who all have a very large role in this field.

**Ms Nall**—It is probably also worth mentioning that uncontrolled lymphoedema is life-threatening, as you may not have already heard. The more swollen a limb gets and the poorer the drainage is, the more at risk that limb is of developing infection as a result of just a very simple knock or bump. Of course, once the draining of that limb is not good, it is much more difficult to then manage that infection. So, at very worst, it is a life-threatening condition, not just one that is functionally difficult and certainly aesthetically difficult.

**Senator ALLISON**—Is there still some progress to be made in the effectiveness of treatment, and is there enough research into that? We heard this morning how little research there is in surgical techniques and practices. What about for this area?

**Mrs Sharpe**—There is a whole open field on research in this area. There are bits and pieces of it being done. Professor Neville Hacker is doing quite a bit of work at the Royal Hospital for Women in Sydney. He has a couple of staff specifically for research there. There is also a great deal of research being done worldwide on surgical treatment for lymphoedema and on gene therapy. In fact, Dr Marc Achen from Melbourne is part of that international trial looking at the possibility of being able to grow lymph vessels. The last I heard they were still on rat tails and rabbit ears, but it is a huge step forward that they accidentally identified the gene that stimulates the growth of lymph vessels. You would have to talk to him for further progress on that.

**Senator ALLISON**—Is this stem cell research?

**Mrs Sharpe**—No, they are actually looking at research on what gene stimulated blood vessel growth to try to stop it, as some tumours have an overenriched blood supply, and they accidentally found two factors that stimulated lymphatic vessel growth alone. So, instead of wanting to stop that, we are now looking to enhance that and to see whether that can be promoted. I have not heard the update on his research in the last 12 months, but it is going on at five centres around the world at the moment.

At this time, the gold standard for treatment is called complex physical therapy. This treatment evolved in Europe mainly, under Dr Michael Foeldi in the clinics in Germany. It involves daily massage, the wearing of a compression garment, skin care and exercise. That is still the gold standard. As far as trying to find better treatments is concerned, there are myriad pieces of equipment on the market, from things called ‘wobblers’ to different types of massage machines. The use of laser is still being investigated, but a huge amount needs to be done on the use of low-level laser. Anecdotally, we think it works significantly in reducing the very hard, fibrotic swelling. In fact, there are some people in WA who are doing the trial at the moment.

**Senator ADAMS**—Yes, I have been on that trial.

**Mrs Sharpe**—That is progressing, but at this stage we have no gold standard other than the complex physical therapy, which is costly and very time intensive for the therapist and certainly ongoing for the patient, because this then becomes a daily routine for them for the rest of their lives.

**Senator ALLISON**—I do not think we have heard about skin condition before as a symptom.

**Mrs Sharpe**—Because the lymphatic drainage on the surface is impaired because more and more is going out into the tissues and cannot get back because of the more proximal blockage then, as Cathy mentioned, the breakages on that skin can very easily develop into an infection. Even without a breakage, because we have the normal bugs on our skin every day, if you use heavy soaps or do not keep the area moisturised and the skin dries out and cracks, particularly on feet—and particularly in Queensland on our thonged feet—the potential for entry for bugs through those cracks in the skin can then lead to quite a significant infection that can put people in hospital. I have had a couple of patients who developed cellulitis which had progressed to septicaemia because they had not been aware of the significance. They just thought they had the flu and a high temperature and did not notice the red spot on their skin. So maintaining skin integrity is vital to maintaining care of the limb.

**Senator ADAMS**—Can you explain about the damage that can be caused with radiotherapy?

**Mrs Sharpe**—Most of the radiotherapy that we see for the uterine and cervical cancer patients is external beam radiation to the pelvis. It basically fries the lymph vessels. It singes them to the point where they can no longer drain, so that impedes the drainage even further than from the vessels that are already taken. There are a varying number of lymph glands in the pelvis, anywhere from 30 to 70, and the number taken in surgery varies enormously.

Unfortunately, at this point there is no equivalent to a sentinel node biopsy that can be done. Research is being done on that with the groin nodes, but at the moment, with the pelvic nodes, it has not developed any further. Dr Jim Nicklin in Queensland has done some work on looking at the iliac vessels and has been able to find that there is a bit of a tendency for there to be more external than internal iliac vessels, but again that has not gone far enough to alter management on a long-term basis. But once those vessels are removed—and at this stage they cannot be regrown—and then a radiation occurs to remaining vessels, the chances of lymphoedema go up significantly.

**Senator ADAMS**—Right, that is exactly what happened to me.



**CHAIR**—Mrs Sharpe, in terms of getting people to take on the specialty, there is a workforce shortage in just about every form of medical or quasimedical field at the moment, but I have actually had lobbying about places for physiotherapists at various universities. But just getting people into the field and then that extra step towards doing the kind of specialisation that you have talked about, can I get some general information about it? I know your submission mentions that, but I would just like to get some general information. Also, quite selfishly from my point of view, as you are located in Brisbane, are there services similar to yours in other parts of Queensland? If I were in Mount Isa, for instance.

**Mrs Sharpe**—No, there are very few. I will answer the second part first. This patient I am talking about came from Yeppoon, and I have also—

**CHAIR**—Yeppoon is close to Rockhampton general hospital, but they had to come to Brisbane?

**Mrs Sharpe**—There was an occupational therapist there who had training, but she has been moved to another area so they no longer have any staff trained. Mackay, which is another few hours further north again, has two registered nurses working in community services who can do brief monitoring because of the breadth of their duties, but there is nobody to do complex therapy. We are hoping now, with Nambour establishing a new oncology service—and they do have a half-time physio and occupational therapist there—that that will start to address some of the pressure that we are experiencing on our services.

From the training point of view, we have an acute shortage of physiotherapists. I do not think there is one establishment I can think of that is fully staffed or not operating on a lot of locums—if one can find them—at any point in time. Once we do have them through and qualified, the breadth of physiotherapy is vast. Having people specialise into the area of cancer care services and lymphoedema in particular requires a couple of years of experience generally, followed by a basic training course that most states run once a year, some every 18 months. They are usually the equivalent of seven days full-time training. That then needs funding for the person to do the course—in most places it is around \$1,200 to do that—and then the backfilling so they can attend.

Then one relies on the ability of the hospital or the service it employs to be able to afford for them to treat lymphoedema patients. There are practitioners up and down the coast of Queensland who have the skills but who are not permitted to provide the service because they are so limited by what they have in their hospitals that they have to ration what they can do. They do not do it lightly, and I feel for the directors of physiotherapy services across this nation when they are faced with a situation of whether they see the person who has just had their hip replaced and who has to go home tomorrow or they see the lymphoedema patient in the cancer care unit who will be there for another few weeks. That happens on a daily basis, so the person in the cancer care unit never gets seen. But until we have full staffing I cannot see an imminent solution to that problem.

**CHAIR**—Is the Queensland experience shared across the country?

**Ms Nall**—Very much so. Although we have moved from having only five to having 18 physiotherapy programs within the last 10 years around the country, our big problem is currently

a constraint on the capacity to deliver clinical education. That is because the funding levels provided for physiotherapy education are so low. According to the relative funding model the cluster we are in is below science, and we are currently arguing with the minister that we should be funded in the same cluster as medicine per student per year. The needs are identical in terms of the biomedical sciences base, and then in terms of the intensity of supervision that is required in order to produce someone who is safe and effective and ready to practice at day one, because we do not have an intern year.

**CHAIR**—So it is straight into practice?

**Ms Nall**—Yes.

**CHAIR**—At 21 years of age, if you go straight after uni.

**Ms Nall**—Yes. In fact when the Department of Education, Science and Training last year put out a call to universities to say, ‘We’ve got another 2,800 allied health places we would like you to allocate and we are prepared to fund them,’ not one university responded because all had problems with clinical capacity constraints. The minister is only just starting to become aware of this problem, despite our intensive advocacy on the issue.

**Senator ALLISON**—The health minister or the education minister?

**Ms Nall**—The education minister. We have also spoken to the health minister. Of course the problem is that it falls between the cracks so it is really hard to even get to first base. Or it is a case of: ‘Oh, that’s a state responsibility. Oh, that’s a Commonwealth responsibility.’ I know there was some discussion at the recent COAG meeting and we are hopeful that there might possibly be some change in this, but it has to happen right now. We have physiotherapists in Queensland and in Victoria who will not be able to graduate this year because they cannot complete their clinical education. This is despite the country crying out for more physiotherapists.

**CHAIR**—Can you give the committee some more information on that so that we can use it and take it up through our various networks. To the best of my knowledge I have not had that particular information. The situation is just wrong.

**Ms Nall**—Yes.

**CHAIR**—Thank you so much for coming. It is such an important element for everyone, but in this inquiry the extra pain of patients with lymphoedema is something that we need to consider.

**Mrs Sharpe**—Thank you for the opportunity.

**Committee adjourned at 4.58 pm**