COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Gynaecological cancer in Australia

FRIDAY, 4 AUGUST 2006

PERTH

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Friday, 4 August 2006

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

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

Senators in attendance: Senators Adams, Ferris, Moore and Webber

Terms of reference for the inquiry:

To inquire into and report on:

Gynaecological cancer in Australia, and in particular the:

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

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

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

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

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

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

WITNESSES

Committee met at 11.04 am

KATRIS, Mr Paul, Executive Officer, Western Australian Clinical Oncology Group, Cancer Council Western Australia

ROONEY, Ms Susan Hannah, Chief Executive Officer, Cancer Council Western Australia

SLEVIN, Mr Terry, Director, Education and Research, Cancer Council Western Australia

SHARMA, Mrs Sushama, Consumer Representative and Advocate, Cancer Council Western Australia

CHAIR (Senator Moore)—I always begin by acknowledging the traditional owners. Perth is a particularly wonderful place with a strong history. We are the Senate Community Affairs References Committee and the people you are going to be talking to are Senator Ruth Webber, who is from Western Australia; Senator Jeannie Ferris, from South Australia, who has been very active in getting this committee active on this topic; and Senator Judith Adams from Western Australia. She will be joining us soon and has a long history with this hospital.

I welcome representatives from the Cancer Council Western Australia and the Western Australia Clinical Oncology Group. I know that you have all received information on parliamentary privilege, the protection of witnesses and the capacity to give in camera evidence, if you choose. If you have questions on any of those things, please ask us as we go along. We thank you for your submission. We also thank you for the time given and effort made to share with us today your own experience. I would invite any or all of you to make an opening statement and then we will go to questions.

Ms Rooney—Thank you for the opportunity to talk to you this morning. First, I want to say that we have contributed to and also support the joint submission from the CCA, COSA and NACCHO. Today we would like to give you more of a local perspective on some of the Western Australian issues that pertain to the subject of the inquiry. We also make the point that a number of the recommendations in the previous Senate inquiry into certain treatment options for persons with cancer are directly relevant to this inquiry. We are greatly disappointed about the lack of meaningful response to and action on these recommendations. We are very hopeful that this will not be the case in relation to any recommendations out of this inquiry. We welcome this inquiry.

Mr Slevin—Thank you for the opportunity to come along. I will give a brief rundown and hopefully lead in to what others have to say. We put the submission in when the 2003 Cancer Registry data was available. Now the 2004 data is available. In quick summary, it is a story that you will hear elsewhere. That is, gynaecological cancers—cervical, ovarian, uterine, vulval and vaginal—collectively account for about 10 per cent of cancer incidence in women—that is, new cases in Western Australia—and about 10 per cent of deaths from the disease or roughly four per cent of the total cancer burden both of incidence and of mortality.

In general terms, the summary and conclusions from our proposals are very much about strengthening research in the area and also providing support and assistance for people diagnosed with the disease. There are specific recommendations in there, but many of them relate particularly to the Senate inquiry which reported in June 2005. Obviously, there is a lot of overlap. The particular things that we would like to focus upon relate to areas in which we have done well in respect of gynaecological cancers. There has been substantial progress in relation to cervical cancer. The pap screening program for cervical cancer, which has a 60 per cent participation rate in eligible women, has been operating in Australia since 1991 and has resulted in a reduction in incidence and mortality from the disease. So that is a great success.

There is even more success on the horizon in relation to the potential for vaccination against cervical cancer, which is another exciting opportunity. It needs to be further explored but certainly is very good news when it comes to gynaecological cancers and their management and prevention in Australia. There is also a dark side, a less successful side when it comes to gynaecological cancers. Perhaps the most common example used is ovarian cancer. This is a disease that is generally diagnosed at an advanced stage. We do not have good means by which we can prevent the disease. We do not have good means by which we can detect it early in a successful way which will result in better prognosis for those women diagnosed with the disease. Therefore the outcomes are poor for that disease. The frustrating thing is that there is not anything that is immediately on the horizon that might better guide us as far as early detection of ovarian cancer is concerned. There are trials under way, but we really do need to await the outcome of those trials before we can confidently go forward when it comes to finding a solution for ovarian cancer.

There is clearly a challenge in relation to Aboriginal women. We know that Aboriginal women in Australia are less commonly encompassed in cervical cancer screening programs. We suspect, although the data is hard to get, that Aboriginal women are doing more poorly across the spectrum in relation to gynaecological cancers. There is a lot more I could say, but I will wind up my opening comments in that way.

Mr Katris—I would like to start by letting the community know that the NHMRC has produced guidelines for the management of particular gynaecological malignancies, especially ovarian cancer. These are internationally recognised and well-held systematic reviews of the literature. At the same time, as Terry pointed out, the survival figures are somewhat poorer for a particular range of the gynaecological malignancies. There is yet to be any evidence that the Australian lot is any worse than anywhere else internationally, but what we do not have are systematic patterns of care studies. We have really well-designed clinical guidelines but we have very little Australian literature or research evidence to determine how well the Australian clinical community is adhering to those guidelines.

I will bring everyone’s attention—I will table it—to data published in 2002. It is from a Victorian data set which reviewed all ovarian cancers diagnosed in 1993, 1994 and 1995. That data is now approximately 10 years old, but it is still the best, well-held Australian figures we have for how well we are complying with particular guidelines. If possible, we urge the government and state health jurisdictions to look carefully at more updated patterns of care studies that at least reflect the situation in the first decade of this century. We also strongly promote where possible clinical trial participation for Australian women with gynaecological malignancies. We feel that we do have fairly good levels of participation but it could always be better. Given the rarity of these cancers, we probably will not have clinical trials that are specific and unique to Australia, but where possible Australian women should have every opportunity to participate in international and well peer reviewed studies.

At the same time there has been a series of cancer related reforms that have come from the Commonwealth looking at the value of multidisciplinary team opinions and management. We urge everyone to consider that it is the basic right of every woman with a gynaecological malignancy to receive a comprehensive multidisciplinary opinion. I think they are the main areas I would like to highlight today.

Mrs Sharma—I would like to start with the positives. I represent women who have had ovarian cancer as I am a survivor of ovarian cancer. On behalf of these women and their families, I would like to say how grateful we are for the level of expertise and the abilities of the medical people who have taken care of us, thanks to which many of us are still alive. One of the things that I come across often in the support group that I am part of is that King Edward has done a great job of handling multidisciplinary care. I have experienced that with the menopause clinic as well. They are really thorough, they get back to you and they do not forget about you after you are gone. What I and a lot of patients find very puzzling is that, if this system can work in public hospitals, why doesn’t it work in private hospitals? Often the doctors are the same in both setups. Are they not exerting enough pressure on private hospitals to take it up more seriously? It does not just help the patient; it helps the doctors as well because there is not just one person responsible for the welfare of the patient. There is a lot more security knowing that you are getting this care within the hospital system when you first come in. All in all, I think it does affect the outcome, how well the patient lives for whatever time they live for.

With ovarian cancer a lot of women come in very late and sometimes the tumour is not removable because it involves so many organs they cannot really get rid of it all. Other times the chemo does not work either, so these women are left with virtually no options. It is not very easy because it is not like they are going to be dead in a week. It is a few years of a slow-growing, or even a fast-growing, cancer which affects their ability to function. At that time a lot of them turn to the community for alternative or complementary therapies which will ease their suffering.

At the moment, in Australia, there is no credentialling or accreditation of people who offer alternative or complementary therapies. Obviously, a lot of these cancer patients end up with charlatans who steal not only their valuable time but their money as well. I do not see why this should be happening in a country like ours. We should really be providing secure, updated information for these cancer patients and telling them where they can go, instead of just offloading them and saying, ‘Sorry, we can’t do anything more for you.’

I have lost at least half a dozen people in the last year who have had nowhere to turn to. And it is a really sad way to die. It is a very bad cancer. Especially if you meet someone who is in the end days, you see that it is just terrible. So I think we need to do something about this. I am sorry; I have just lost a friend a few days ago.

My last point is that there is no integrated medicine institute in Australia. There are clinics in Europe, like Paracelsus and Dr Issel’s clinic. There is one in Switzerland and one in Germany but in Australia we do not have an approach like that and I do not see why not.

Senator FERRIS—Thank you, Mrs Sharma. I am interested in hearing a little more about your final comment—that is, about the overseas clinics that you just mentioned, such as the one in Germany. I wonder if you could tell us a little bit more about those clinics and what they do.

Mrs Sharma—What I know about it is that two of my friends from the support group have been there—people who had ovarian cancer. Paracelsus is a clinic which is in Switzerland. It is a mainstream, traditional medicine clinic but it also uses alternative sources—not just complementary but alternative sources and other forms of medicine. The idea is that the patient is the most important entity there, not that you have a disagreement with that philosophy. They try to incorporate everything into doing the best for the person.

I think that is the way we should be going as well because we do not have all the answers in chemotherapy and radiotherapy, and there are a lot of other traditional medicines in the world. In US, for instance, a lot of research on heart disease and cancer involves traditional Chinese herbal medicines, Ayurveda and homeopathy, but we do not have anything here which combines everything into one system and offers the best for the patient.

Senator FERRIS—Do you see this from the hospital perspective or do think it should be a private enterprise operation?

Mrs Sharma—I do not think it should be a private enterprise because I think somebody should be looking over their shoulder. I think the government has to be responsible for what they are doing, because there are a lot of private things happening here—people who offer cures and say, ‘My treatment will cure you no matter what stage you are at’—but nobody is really checking on them carefully enough. They are often charlatans, so we need some government body to oversee this.

Senator FERRIS—Thank you. We have had a lot of evidence that suggests that, whilst the National Breast Cancer Centre has done some wonderful work on breast cancer and ovarian cancer, it is somewhat confusing to have the two in one body, which has no reference to ovarian cancer—or gynaecological cancers in general—in its title. Does anybody have a view on that, that they would like to express?

Ms Rooney—I certainly think that it would be useful to look at the name. If you are suggesting that you have separate entities, there are issues around economies of scale and cost. So it may be useful to look at a more inclusive name which reflects more of the work that the centre does. It is certainly an excellent centre.

Senator FERRIS—We have had that evidence. One of the comments that was made was about the difficulties of removing the words ‘breast cancer’ from the title because they are so closely identified with what they do. It was felt that that would in some ways perhaps blur the focus. But there have been a number of individuals who have suggested a national gynaecological cancer centre which would work along the same lines as the existing NBCC. So if any of you have any comments to make on that, we would appreciate it.

Mr Katris—The existing Ovarian Cancer Program underneath the banner of the National Breast Cancer Centre amongst clinical circles definitely does have a profile. Its efforts in producing guidelines regarding early detection and symptomology within general practice have come out of that group. The expertise of the National Breast Cancer Centre is second to none. It is internationally recognised as a very well organised, systematic group that produces great evidence based guidelines. There is no doubt that the existing Ovarian Cancer Program is a move forward. I am personally unclear about how much that needs to be separated from the current level of expertise. But, definitely in general practice circles and guideline implementation dissemination, some of the work that has recently come out from the Ovarian Cancer Program in a very short time—I think it is approximately four years since the program has been up and running—is well regarded in clinical circles. But, as for public perception, that is probably another debate.

Ms Rooney—If you do separate into separate organisations or centres, it necessitates extra money being spent on administrative costs. Given that costs are certainly an important aspect of that, I think that needs to be taken into account. You can also get a critical mass of people in terms of the level of expertise when an organisation has different centres under the one banner. But certainly I think there is a problem with people recognising the name.

Senator FERRIS—As a consumer, Mrs Sharma, did you or any of your colleagues and friends have any difficulty accessing information when you were diagnosed?

Mrs Sharma—I personally did not but there are many people who have had difficulty. We do have very good professionals looking after us, there is no doubt about that, and they do provide information. But, as I said, for complementary or alternative paths to take when there is nothing in traditional medicine, there is nothing.

Senator WEBBER—Obviously, we have had evidence from the NBCC and other people. One of the discussions we have had is about public awareness and where the effort should go, whether effort should continue to go into GP education or whether we should look at making women as a whole more aware of the signs to look out for and then the risks associated with that in terms of the very vague and generic symptoms. You do not want to frighten every woman in Australia into thinking she has ovarian cancer but you do not want them to wait too long. What are your views about where that effort should go? Should we try and do both or is it a matter of either/or? Also, I notice there has been a bit of GP education over here. It looks like 2003 was a busy year. What does the Cancer Council have in the pipeline for this year?

Mr Slevin—It is something we wrestle with. It is not an easy issue. As far as public education in cancer goes—which is one of the things that cancer councils are best known for—we do have to strike a balance between getting a profile and getting the attention. The notions of cut-through, as you will know from your own careers as politicians, of reaching your target audience, is an immediate challenge. Sometimes the way some organisations can achieve that is through hyperbole, if you like, so that it is a clear and dramatic statement of a problem. We have a clear and dramatic statement of a problem, but what we do not have is a clear and constructive solution to that problem.

The difficulty with vague symptoms, which we currently have to draw upon in relation to gynaecological cancers, in particular ovarian cancer, means it is a very difficult line for us to walk. We do not want to scare every woman into thinking she has ovarian cancer at a certain stage in the normal monthly menstrual cycle. We think that would be an irresponsible thing to do. In answer to your question, we do work as much as we can with general practitioners and we try and provide the best information we can, but that information is still very vague. So I guess the answer to your question is: both of those as constructively and sensibly as we can. But the next stage is a greater investment in research that helps us to more acutely define that information we provide—exactly what are the types of symptoms or the kinds of steps that women can constructively take to get clearer and more helpful guidance as to whether they need to take the next step to see their general practitioner to have potential symptoms investigated.

Unfortunately, we do not have a magical answer to that. I wish we did, but from where I sit, and from the experience of watching this over the period of 12 years that I have been at the Cancer Council, the best solution that I have seen is research that provides us with better guidance as to the information that we provide both to general practitioners and to women so they can know more specifically what it is that they are looking for. That will help to guide a pathway to an earlier detection outcome.

Mr Katris—Particularly on ovarian cancer, it is important to remind everyone that unfortunately we do not have high levels of evidence anywhere internationally for a screening program, and the routine screening of asymptomatic women for ovarian cancer is not recommended by any official body in the world.

Highlighting the issues that Terry has pointed out, there is probably a horse that has already bolted in this nation—and this is unique to Australia—and that is the unnecessary removal of a lot of benign pigmented lesions for suspicion of melanoma. There has been a huge initiative of the Australian government to try to arrest and correct that problem. Clinically, removing a lesion for the suspicion of melanoma is a hell of a lot easier than investigating through very invasive procedures to determine whether or not we have an endometrial, ovarian or gynaecological malignancy. It is important to remind ourselves of that.

But there is evidence that, for those at high risk, surveillance programs are worthwhile. We are talking about families with women who tend to have cancers that are discovered or that develop earlier, and they tend to cluster in families with ovarian and breast cancer. I am pretty certain that the National Breast Cancer Centre, in national initiatives that are funded by the charities and the government, have been able to grab those family cohorts. I suppose one lasting message there is to ensure that we continue that effort in tracking those families and having surveillance programs so that, if we are going to have invasive procedures, at least we are doing it to the right families and the right women.

Mrs Sharma—I would like to say that, as we were talking earlier, women or young girls are really very ignorant about gynaecological facts, and I think maybe a review of sex education in schools is called for, because eventually the person themselves is responsible for their health. If they knew that a certain symptom was not normal and after a particular period of time it should be looked into and a doctor should be contacted, then I think a lot more women would feel comfortable going to a doctor about something instead of first of all not knowing what their bodies are made up of, not knowing what is normal and hesitating to go and see somebody. Maybe the information should start in high school, not about cancer as such but so they at least know what is normal about their bodies and what is not and, if something is abnormal, they should feel free to contact a doctor or get themselves checked up.

Senator WEBBER—I guess an extension of that is about the way we are conducting GP education at the moment. Is the effort and the manner good enough? It seems to me from some of the evidence we have had that, yes, it is an unusual cancer but, picking up on Mrs Sharma’s point, it is still something that women have to be reasonably assertive about to ultimately get the treatment that they need. Therefore, if you do not know what is normal you are not necessarily going to know to be assertive about taking the next step. Is there more we can do and what should we do to make GPs more aware of what to look out for?

Mr Slevin—We have had a GP education program partly funded by the Department of Health of Western Australia for about six years, and our experience is that we get good GPs through the door to come to education and the GPs who are perhaps less enthusiastic about investing time to stay up to date are inevitably the harder ones to reach. Again, I do not know that we necessarily have a magic answer to that. There is a system in place, which is run by the Royal Australian College of General Practitioners, that requires updating through continuing medical education and similar point type systems. We very much engage in that to maximise access and I think we have a pretty good penetration in the general practice community in Western Australia. But it is an ongoing challenge. It is an ongoing effort. Like any workforce, people come into and out of the general practice workforce.

Particularly in relation to the ovarian cancer issue, there is a frustration. Just as it is hard for us to know what the precise advice to provide women is, it is also difficult to provide that advice to general practitioners. We can push the communication line and being open to a persistent concern raised by a woman in relation to a gynaecological problem, but it is almost an attitudinal thing, and it is kind of hard to teach an attitude. We have programs in place where we try and bring people in and weave in communication skills, listening skills, as part of the more technical training that we offer. Certainly, it is the technical training that is generally more attractive to general practitioners. Those who are interested in communication skills training tend to be the ones who are at the higher end of that skill spectrum anyway.

I suppose the way to tackle that really is to keep on keeping on. We just have to keep ploughing away at offering those kinds of programs and find as many constructive ways as we can to do that. One of the more recent constructive experiences we have had was using RACGP Online Learning, which is a web based learning tool. We ran a program specifically in palliative care, and we had a very high uptake—because it was on the web, it was a national program—particularly of remote GPs, who engaged in online discussion in relation to a particularly challenging palliative care case study. That is something that we want to investigate further and build more modules in relation to these kinds of issues to encourage that kind of discussion. So we are using old technologies, face to face; we are using new technologies, particularly web based; and we are finding that more GPs are prepared to engaged in that kind of methodology. Again, I wish I could offer you a magic answer but we have not found one yet.

Senator WEBBER—I will leave the rural and regional questions to my friend Senator Adams. I have a final question: on the issue of clinical trials, we have received evidence about women’s access to them and about general support—that there should be much greater involvement. There is the issue of ensuring that women from diverse backgrounds, including remote and Indigenous, are involved in or have access to them. Do you have any thoughts on that?

Mr Katris—It is internationally recognised that the best predictor of your getting onto a clinical trial, regardless of any tumour type, is a white, educated, young woman with breast cancer. That is where the highest level of participation internationally is at. In Australia, through the Genital and Urinary Group of Australia and also the gynaecological group, I am certain that we have high levels of participation. In WA, because we have one centre, which you will probably hear about later—the service may well be fragmented but there are only one or two places where you can receive chemotherapy—most of these trials are chemotherapy regimens. They are giving chemotherapy in different ways, often in combination. They use words such as ‘doublets’, ‘triplets’ and ‘quadruplets’ because of the outcomes of those particular cancers. Those cancers tend to need a whole range of different arms.

In Western Australia, I think there has been an overdependence upon the charity—the Cancer Council—to fund clinical trial participation. It is definitely a barrier. Clinicians will report that if they had more data management support—which does not come at such a high cost, really—they would be able to randomise more women onto trials. Of the last few large international trials, we would say, anecdotally and objectively, because we see the figures in terms of the league tables of entry into these trials, that in Western Australia, particularly in ovarian, we are quite happy with our participation rates in some of those major trials. But we could always do more. We are also concerned that if there is an internationally recognised trial in Europe or the USA that is accruing people and that is exciting and interesting, Australian women should have the opportunity to participate where possible.

Mr Slevin—While clinical trials were not a big part of our submission, we very much support the position put by Cancer Council Australia in relation to support of clinical trials as being a very important way forward. We do fund a chair in clinical cancer research at the University of Western Australia—and you will be hearing later from Professor Michael Millward. We also fund Cancer Council Clinical Trials WA and have established collaboration with the Western Australian Institute for Medical Research, which is about boosting the entire capacity for clinical trials conduct in Western Australia. It is a slow building process to improve that, and there are a number of ways in which it can be done. One is about educating and promoting clinicians to participate in clinical trials; another is about removing the barriers, and removing the paperwork and a lot of the background work—ethics approvals, a lot of the systematic background work looked after by clinicians—so that clinicians can focus on what they are good at, that is, dealing with patients. There is also the matter of the statistical support behind them, and so on. We are trying to put more infrastructure in place to do that.

But there is another side of that, because that is the service delivery end. There is also the push end—the consumer demand end. We are putting work into trying to communicate with consumers about whether clinical trials are a good thing to ask treating clinicians about and to investigate whether there is a clinical trial that is suitable for their circumstances. But, of course, within that there are also ethical issues about ensuring that people understand what the nature of a clinical trial is. It is a research project where they could get either best current practice or the experimental treatment, and people go into that in an informed way. We are reiterating what Paul said to an extent. Unfortunately, we think many clinicians feel more confident to offer that to people with a more thorough educational background than perhaps someone who they feel might not be as well equipped to wrestle with some of those questions. We are trying to avoid some of those biases, but it is part of the work that we do to promote clinical trials to all of the stakeholders.

Ms Rooney—I would add—Paul mentioned this—that there certainly is need for an injection of more funds from the state governments as well as the Commonwealth government into the area of clinical trials. As the Cancer Council WA is not a large organisation and has a limited amount of funding we have certainly applied it to areas where we think it has the most leverage, but it certainly needs more resources. Some of those resources can perhaps deal with some of the more difficult areas that you identify, because often that is about a resource issue, in order to then address that.

Senator ADAMS—Thank you all for coming. I am absolutely delighted that we managed to get the inquiry over to Perth. It is very important and I am thrilled to see some of the people I approached for submissions. They are here and they have put their submissions in, so that is great. Before I get onto rural and regional issues, on the issue of clinical trials, I am a rural breast cancer survivor and I have found myself that it is quite frustrating when you want to be in a research project—as I do, because I am really keen to make things better for somebody else coming along later on. It is very hard. The minute they know that you live in the country, forget it, you are not included. I think we are missing out. I know that funds are very limited, but rural women are missing out so much. There are some great people out there who would love to be involved, but we are just not given the opportunity. It has been pretty difficult. As soon as I say I would like to be involved, especially in the activity one—putting on weight and all that sort of thing; I thought that would be great—‘No, you’re not here, you can’t be here Monday, Wednesday, Friday so, sorry, that’s it.’ So that is probably something to think about.

During the evidence, I have become quite concerned as we have gone along that a number of gynae-oncologists—though we have one here who is a lot younger—are saying, ‘We’ll be retiring perhaps in 10 years time.’ The lack of younger registrars coming up behind them is quite worrying. So I would like Mr Katris to tell us what is happening in Western Australia to promote that specialty.

Mr Katris—I know a little bit about the issues because the workforce issues have been a concern to us as a charity for quite a while now. There are well-held evaluations that have been undertaken by AHMAC, and the medical workforce issues for medical specialities have been around for a while. There are documents from 1995 through to 2000 referring to the specialty shortage. I know there are questions also in general practice, but Sushama pointed this out to me only a couple of days ago—I forget the actual quotes we were looking at—and we feel in Western Australia that we are short at least one full-time specialist for the workload that is required per capita. The figures are usually US based, because they have modelled things a little differently. You could argue the same also in medical oncology that we think we are about four or five specialists short in Western Australia. The figure that is quoted from the American Society of Clinical Oncology is one haematologist and one medical oncologist per 100,000 persons. It is not quite the same for gynae-oncologists. I think the figure that has been quoted is 400,000 persons per gynae-oncologist, the superspecialty of a surgeon with a declared and dedicated interest to that anatomical region of women.

I do have a point that I could quickly mention on clinical trials in rural and regional areas. Here in Western Australia we have had some experiences where we tried to set up clinical trial activities in Bunbury. When we have an enthusiastic clinical community located in rural and regional locations, the biggest frustration we come across is the coordinating centres, which usually are international or eastern states based. They quite often restrict participation to a centre according to volume, so it has been a long, hard and tortuous path for us to get clinical trials running in Bunbury. Again I remind the inquiry that this has occurred in the absence of any state injection. The charity have really pushed this to ensure that we get at least a little more clinical trial participation in rural and regional Australia. At the moment it is biased towards breast cancer. Where we can get women onto trials, it is only breast cancer. But you are right, because women with ovarian and gynaecological malignancies live in the south-west and all around the state as well.

Mrs Sharma—You mentioned the numbers of gynaecological oncologists. Since the recommended norm is one to 400,000 and we are nearly two million here, we are two short.

Senator ADAMS—I think we have another group coming up that might be able to help with that question. I notice that in your evidence you have given quite a good presentation on the Patient Assisted Travel Scheme. But because you are the people we all look to for accommodation, help and all the rest of the relevant issues, would you like to give a brief overview of the Patient Assisted Travel Scheme and how patients are made aware of it being available to them, the facility you have with Crawford Lodge, how you deal with rural patients and what Western Australia needs to do?

Ms Rooney—Patients generally find out about PATS through not only us trying to educate them but also their local service provider. There are some real issues with PATS in this state. For example, one of the things you certainly would have noticed is that your flight would be paid for only if you travel for more than 16 hours. If you travel for less than 16 hours—say, for 15½ hours—you have to go by car or bus and, if you are unwell, that is really inadequate.

There are also real problems with people who fall outside of the 100-kilometre radius. If you are within 100 kilometres you are not eligible for PATS overnight. If that is the case and you are ill, you will have to travel home every night. You certainly do not get subsidisation. With increasing issues, such as petrol prices, we find that really adds to people’s financial burden. For example, we provide financial support for people and last year our budget was about $65,000, but this year it is up to $150,000 because so many people come to us needing financial support for their petrol bills, power bills et cetera. So it is very basic things for which we provide a small amount of support.

The Cancer Council has a lodge, called the H Crawford Lodge, in Nedlands where people can stay for around the price of PATS. PATS is $35 a night, which we then use to provide that service for people so they are not out of pocket. If people are not eligible for PATS then our charge is $35 a night. But if the person is unable to pay that charge we then either subsidise it to a certain extent or sometimes just provide it. However, we do not have enough accommodation. We turn away about 50 country people a month seeking accommodation from us. To address that shortage, we have a building site in Shenton Park that we are in the process of looking at converting. In the meantime it is housing some country people, but its size only allows us to house 14 at the moment and we want to increase that to about 28.

The issues around PATS are really concerning. My concluding statement is that, for some people, cancer makes you poor—and for rural and regional people it is even worse because they are not covered well in terms of the recompense they get.

Senator ADAMS—Mr Slevin, do you have anything to add to that?

Mr Slevin—That is not my area of responsibility within the Cancer Council, but certainly my experience has been that those who do get access to our services are extraordinarily grateful for them. I know, in talking to my colleagues who run that service, it is very much a tug on them to have to say no to anybody. They are unfortunately having to say that more and more frequently. We are working to redress that problem by increasing our capacity. It seems to me that the administration of PATS at a local level is a real issue as well—those people who actually learn about it—so we certainly try to address that through our cancer helpline by making sure that people who do call us from the country are aware of that. We have also increased our provision of service in the country through our Cancer Council support staff. Susan can probably update you on that.

Ms Rooney—We have what we call cancer support coordinators who are basically there to provide support for people in the country. We had six; we have just increased that to 13 people around the state. Part of their role is to inform people of those things and also to advocate on behalf of patients. Sometimes the responses to PATS are quite contrary, depending on who you get dealing with your issues. So we have had to advocate on behalf of people at quite senior levels when someone has not been granted PATS for no evident reason or when the guidelines have been applied quite harshly.

One of the other things that we have seen happen is that somebody is given PATS but the instant that the patient is too ill to stay in their lodge and has to go into hospital, the carer’s PATS is cut off. The view is that, because they no longer have to care for that person, there is no longer any need to provide them with PATS support. Sometimes that is not the case. It depends, again, on who is making the decisions around the PATS subsidisation.

Senator ADAMS—That seems to be one of the biggest issues and, with hospital budgets blowing out, PATS is always the one that they try to say, ‘No, there is no more money and you can afford to drive up.’ Some of my constituents have issues with this. That is the reason I wanted to raise it. It is a huge problem. The way I look at it, as far as rural people go, is the specialist area for this is in Perth and no-one should be denied having a multidisciplinary team behind them. Why should countrywomen have to suffer and be denied that service because they live somewhere else? I am very strong on that and it is something that has been coming out from the other witnesses. We have had very good evidence on it.

As far as the escorts go, unless your referring GP ticks the box that says your escort is someone who can provide you with medical help, your escort does not get paid for. Psychosocial help is not considered, so somewhere those guidelines have to be changed. I would like you to pick up on that, particularly with your organisation. It is just so important because of the number of people who are being denied it. It is exactly what you are talking about—the patient becomes so sick that they have to be admitted to hospital, therefore their carer and escort, who has been with them all the time, has to pay their own way. It is absolutely unfair.

Senator FERRIS—It costs more anyway.

CHAIR—We have run out of time. Does anyone have any other comments they would like to put on record? Remember, of course, that we do not present our report until October, so if there is other information you want to send to us in the next few months that would be very useful. Do you have any comments?

Mr Slevin—I have a very quick one for Senator Adams. The Cancer Council has run a rural specialist breast nurse program—putting part-time nurses in Albany, Bunbury and Geraldton over the last four or five years—which was funded by the Commonwealth department of health through the state department of health. It has proved a very successful model, specifically in the area of breast cancer, and to an extent it has shown the way in which those services can be provided. That program is due to wind up at the end of this current financial year, but, with our support, on the basis that an ongoing service provision should be provided by the state, they are putting in place state funded cancer support nurses. We are doing a report on that program and we are very happy to provide a copy of that final report to the inquiry—particularly to you, Senator Adams.

Senator ADAMS—That would be great because what has come up in discussion at our other hearings is whether with breast nurses in the rural area who have had that training there is a way of having gynae nurses, even if the roles have to be combined, though there are two thoughts on that, because gynae-oncology is very different to breast cancer. But really and truly, when it gets to menopause and a lot of issues like that, if you have one person who can combine the two roles, because there is quite a lot of duplication, it may be a way forward.

Mr Slevin—We are expanding the training of those nurses at the moment.

Senator ADAMS—That is great. Thank you very much.

Mrs Sharma—We hear about the dollars being spent on these services. They are really an investment and not a loss to the country, because the end result is that fewer man-hours are lost—and not only from the patient returning to work sooner but also from the family getting back to normal sooner and the partner and carer returning to work sooner. Government money being spent on these services does not represent a dead loss. The country really needs to look into this because eventually, with people being able to return to work sooner, it will save dollars.

Mr Katris—I have one final point. Most of the community and we are aware that, approximately a year ago, there was another Senate inquiry into cancer, which was a legacy of the late Senator Peter Cook. Observers of the group and you will be hearing a lot of recurring themes. We were notified recently by Cancer Voices WA, a prominent consumer group in that state. I will table a letter that group has sent to Minister Abbott expressing frustration and unhappiness regarding the adequacy of some of the responses to the recommendations made by the Senate—and I know that this committee will be aware of and familiar with that. However, we should remind ourselves that a number of major initiatives in this nation of ours are moving towards cancer reform. This should be plug into that and, hopefully, we will see some major improvements in the outcomes.

[11.53 am]

BANCROFT, Mrs Ann Veronica, Private capacity

WHITE, Mrs Barbara, President, Lymphoedema Association of Western Australia

CHAIR—Welcome. Do you have any comments to make on the capacity in which you appear?

Mrs White—I am actually wearing two hats. I am here also as a consumer—and I hate that name. I am very nervous as I am new at this, so please bear with me if I make any mistakes.

Mrs Bancroft—I am a member of the Lymphoedema Association and a long-term lymphoedema sufferer.

CHAIR—We have received a submission from the Lymphoedema Association and we have a private submission from Mrs Bancroft. Mrs White, I know that you are going to give us a statement and I think Mrs Bancroft may also give one. We will start with your statement, Mrs White.

Mrs White—I have had lymphoedema since 1996. It was caused by the removal of my lymph nodes during cancer surgery and that has caused considerable problems with my life physically and mentally. I have suffered cellulitis, which has meant I have had to be hospitalised at least four times. The first time I had cellulitis, it was very traumatic, as I had no idea what was happening. By the time my husband got me to the doctor, I could barely walk. My doctor had no idea what was happening to me and sent me to King Edward hospital to be admitted. Also, due to fibrosing, which prevents the lymphoedema from draining correctly, I suffer increased swelling and hardness in the leg, which has meant longer management treatment every four months. This is why I have bandaging and taping. The manual lymph drainage, on its own, does not reduce the swelling and hardness in my leg.

Because of the lack of information and awareness that I experienced, I joined the Lymphoedema Association of Western Australia, and I have been president since 1997. This gives me the opportunity to provide information to others so that they may be able to avoid getting lymphoedema. I realised it was too late for me, because once you get lymphoedema you have it for the rest of your life. As President of the Lymphoedema Association of Western Australia, I feel that the government needs to provide funding and assistance in these areas: screening for and evaluating risks of acquiring lymphoedema prior to surgery and preventative treatment postoperatively. Also, government hospitals need to provide adequate physiotherapy staff to enable comprehensive treatment and care for lymphoedema patients, and the government should encourage private health insurers to provide extended treatment rebates specific to lymphoedema—that is, with no life limit.

Funding to the Lymphoedema Association of Western Australia is required. It currently costs the Lymphoedema Association of Western Australia approximately $5,000 a year to cover costs to supply information to and obtain it from people who seek us out. Government funding would allow for education to be delivered to sufferers and for medical staff to understand that lymphoedema requires constant treatment. Additional funding is required for the March 2008 lymphoedema seminar for the public, as it is the state's responsibility to fund this event. The amount of $30,000 is required for disposable costs—that is, advertising, registration, brochures, printing, postage, venue et cetera. Additional funding is required to hire staff. This event will raise awareness in Western Australia within the medical profession and in women, Indigenous people, other cultural groups and remote region groups. Without funding, it will be impossible for this event to occur. In addition, funding needs to cover the cost of full-time and part-time staff being employed to cater for the progress and development required for such a public event and for the dissemination of information.

The ALA does not fund the seminar for the public, and the Victorian association received from their government $94,000 to fund consumer advocacy and GP awareness. The Lymphoedema Association of Western Australia is currently existing through the work and efforts of a few retirees. This is no longer sustainable. Unless funding can be acquired for some paid, younger staff, the association will fold and Western Australians will have no point at which to find out information. Further funding is needed to the Lymphoedema Association of Western Australia in order for it to be able to provide information to women, Indigenous people, people of other cultural backgrounds, people in remote regions and the broader community. Instead of waiting for the people to contact the Lymphoedema Association, it would allow for education to the people. For this to be carried out effectively and efficiently, the association would require paid staff in full-time and part-time capacities. Government funding to help individual sufferers with the cost of treatment and bandaging and compression garments is also needed.

CHAIR—Thank you, Mrs White. I know you had that prepared. Is there any comment you personally would like to add at this stage?

Mrs White—With regard to ovarian cancer, I find that there is not enough awareness about it. If people are like me, they will not have awareness. I had always been a very active person, I had never been sick and I had only been to hospital when I had my children. I knew nothing about ovarian cancer or about any other types of cancer that affected women. When you are told that you have this, it is a big shock to the system. Then, when you go into hospital, psychologically you do not know what questions to ask your doctors and things like that. I think that needs to be improved upon as well.

CHAIR—Mrs Bancroft, thank you for your very short and direct demands but, nonetheless, would you like to make a comment?

Mrs Bancroft—When I was hearing before about the PAT scheme, and my operation was 17 years ago, so it was a long time ago, I had forgotten that part of it but it appears that it has not improved in that time. I remember feeling dreadful. I virtually had to come up to Perth for the treatment, and had all the complications and the worry about finance and so on. Then, really, we had to relocate from the country to Perth to access further treatment.

Anyway, this is fresh in my mind, so this is what you are getting. A week ago I had an infection—the usual cellulitis. When the rash appeared, I knew it was not the flu and reached for the antibiotics and was on the path to recovery. It takes a while to feel normal again. It had been only three months since the last attack—a shorter gap than usual. My feverish brain wondered whether, if I had had more intensive treatment in the early days of developing lymphoedema, I would have avoided these occurrences that arise, suddenly and unannounced, and disrupt life. It makes me feel vulnerable and I am not a reliable asset on committees. Travel insurance is another difficulty.

As I grow older, other conditions interact with the lymphoedema. Osteoporosis has caused fractures in the lower spine and, with less mobility, makes putting on compression garments difficult. Once I went to hospital with a suspect deep vein thrombosis. It was not—just an unexpected lymph swelling in the good leg. On two previous occasions the symptoms I thought were of lymphoedema were, in fact, of clots.

I find it all somewhat confusing, and I am sure others do too. So I would recommend sufficient funding to hospitals for initial and continuing therapy, with enough physiotherapists trained in manual lymph drainage techniques. Perhaps support staff, working under the professionals, could be used for routine procedures. I would also welcome a service where I could access medical advice from someone having more experience and knowledge of lymphoedema than the average GP. For instance, I know from hearsay that some people are on long-term, low-dosage antibiotics. Is this an option for me? I do not know the pros and cons; the idea has not been suggested.

I have been recommended to go for laser treatment. There was no appointment available for four months. I presume some of the clients’ need for this treatment would be from the results of surgery and radiation after gynaecological cancer. This would be private treatment, involving cost. If it is an effective treatment, a machine should be available in the public hospital. I believe studies, possibly inconclusive at this stage, have been done on breast cancer patients.

In previous years, I swallowed expensive pills from the University of Adelaide. We were told they helped the condition, but they were withdrawn when somebody died. I think that person might have been on tamoxifen, which complicated things. Another treatment which came and went was the sequential compression pump; useless—even counterproductive. So, more research, please.

CHAIR—Thank you, Mrs Bancroft. I know Senator Adams will get deeply into the questions but, before I go to questions, Mrs White, you have brought along your evidence to show us, so I feel it would be very useful to get that on record. I know that we do not have film, so *Hansard* cannot give graphic coverage, but you could just talk us through the amount of bandaging and so forth; I know that you are going to talk about the cost. So if you would like to give us some comment on that on record, before I go to questions, that would be very useful.

Mrs White—I have here six padding and nine compression bandages. These are what you have to wear—all of these bandages. You have to buy all these things; they have to be provided. I would normally just have bandaging but, because my leg will not react to normal bandaging, I have to have sports taping as well. So two lots of tape go on, then all this padding goes on, and then all these compression garments go on. That is all added cost. To offset the cost of these, we have to wash and reuse them, which is not as perfect as it could be, but there is just no way that you can manage to do it otherwise. I usually have to have this done about every four months, and I only have it on one leg. I have it in the groin, but only on one leg. If I had to have two legs done, it would be twice that.

CHAIR—Forgive my ignorance. We have had professional evidence, but I have not actually had the bandages in front of me before. How many of those go on your one leg?

Mrs White—There are six there of the padding bandages and then there are nine of the compression bandages.

CHAIR—On each leg?

Mrs White—On each leg.

CHAIR—Mrs Bancroft, you would have double that?

Mrs Bancroft—In previous years I have had, but it has funnily happened that one leg has improved and the other one has got worse. In fact, when I have had bandaging treatment and have gone to bed overnight with the bandages and the other leg has not had a compression garment on it, the fluid does seem to transfer, despite all the war scars on my abdomen.

Senator ADAMS—It all looks very familiar to me.

Senator FERRIS—Declare an interest!

Senator ADAMS—Yes, I have to just about declare an interest in this. I had eight weeks of bandaging for my arm, with cellulitis as well, so I certainly fully appreciate what both of you have gone through. I think probably the legs are worse than the arms, so well done and I thank you both for appearing. It is terribly important. We have had very good hearings throughout the inquiry with people talking about lymphoedema, so I think you will both be very happy to hear that. The issue has been raised in Sydney, in Melbourne and also in Canberra, and I am very happy that it has been highlighted. Would you like to tell me how many lymphoedema specialists we have left in Western Australia to actually help people with lymphoedema?

Mrs White—There is none.

Senator ADAMS—There is none?

Mrs White—No, apart from physiotherapists who do courses. There is no specialist. There is no specialist in Australia. There is a professor in South Australia, at Flinders University. He is a professor of lymphology, but there is no specialist doctor.

Senator ADAMS—Do you know how many physiotherapists are taking up lymphoedema treatment?

Mrs White—Not very many, for the fact it is very time consuming costwise and they do not make any money out of it, so they are not taking it up. The physiotherapists who are in public hospitals have been cut back with their treatment. I am an outpatient of King Edward Memorial Hospital for Women, and I could not obtain the bandaging, which I pay for privately, at King Edward unless I had cellulitis and they had to admit me into hospitalisation.

Senator ADAMS—So you have to be an acute patient before you can be treated in a public hospital?

Mrs White—If I get cellulitis, I have to go straight to the emergency department and they admit me and put me on a drip for antibiotics.

Senator ADAMS—And how do those rural women get on?

Mrs White—They do not. The services in the rural areas have been cut down. At Bunbury they had two full-time physiotherapists who were helping with lymphoedema. The association helped to fund them to do a course, because normal physiotherapy is different from physiotherapy doing manual lymph drainage for lymphoedema. It is totally different. So we paid for that, which was about $800, and about two to three months afterwards they cut that service down and now there is only one operative in Bunbury, working 2½ days a week. They also have to attend to the wards, so you can imagine what time is left for lymphoedema. Lymphoedema takes at least three-quarters of an hour to an hour for a massage and manual lymph drainage, and then you are looking at three-quarters of an hour to an hour afterwards to do bandaging, if you have to have bandaging. All the other regional places are exactly the same. They just do not have enough people to care for lymphoedema.

Senator ADAMS—Mrs Bancroft, you said you had to relocate from Bunbury, which is in a rural area, to Perth for treatment.

Mrs Bancroft—This was a long time ago, and it was a combination. We had retired, so we re-retired to Perth and I do have access to the hospital. I do not like it that much, so I do not go that often—about every six months.

Senator ADAMS—So, unfortunately, it is an insidious problem that sneaks up on people: you may be all right at the start but then it creeps along and, unless you are educated and really understand what is going on, you can end up in a lot of trouble.

Mrs White—There is more awareness in the public hospitals now; there is not enough in private hospitals. I man a helpline. I get repeated calls from people who have had operations in private hospitals, and they have not been told enough about lymphoedema. If you can get onto lymphoedema very early, you do have a chance of controlling it far better. It is a case of the government being penny-wise and pound-foolish, if you like that old saying. This is what it amounts to. It costs a lot more money in the long run to look after lymphoedema. It would cost me and my husband at least over $1,000 a year for my treatments.

Senator ADAMS—How about you, Mrs Bancroft?

Mrs Bancroft—I access a private masseur because, at the time I thought I needed it, there were not the facilities in the public hospital. I have continued going there, so that is an ongoing cost. Once a month I have a full body massage.

Mrs White—I would also like to point out that, because I am an outpatient at King Edward's, and I am a heath card holder, they do provide me with my garments, which you would have seen in there. Because of my build I have to have a custom-made stocking. I have two a year, which are pantihose, where I should really by rights have four because the compression is not sufficient. But I do not have to bear the cost of that—which is fortunate because, if I had to buy those privately, it would cost me double.

Senator ADAMS—How much would that be?

Mrs White—My stockings cost $400. If I had to buy it outside the hospital, it would cost me $800 for one pantihose. The mind boggles, doesn't it. It is a very serious thing. I know it is not relevant to the gynaecological aspects, but lymphoedema is such a big problem, not only with surgical; it is primary as well—and men.

CHAIR—We consider that it is very much relevant to this inquiry because of the high percentage of people who are suffering this element as well. So you can feel confident that the issues will be raised in the report.

Senator WEBBER—I want to expand a bit on those from outside of Perth. I first became aware of lymphoedema when travelling up in the north-west with a lot of the Indigenous women. They will have surgery and there is absolutely no knowledge, then years later they deal with the consequences. To your knowledge, when women are diagnosed these days with some of the health issues that may lead to surgery, as one of the ways of contracting lymphoedema, is it now openly discussed that this is a possible consequence or is this just something where we still wait for it to eventuate? Do medical staff in this hospital and elsewhere know enough about it as a consequence these days, or do we need to do more?

Mrs White—In the public hospitals, they have improved the information. I would not say that so much about the private hospitals, judging from the phone calls that I receive wanting information. I am getting some GPs now who are referring people to the association. We are very particular about who we refer people to so that they get the right information, the right treatment, because it can do a lot more harm if they receive the wrong treatment. Unfortunately, this can happen.

Senator WEBBER—This is for the record and the information of others, rather than something that I expect you to know: if it is a condition that is left untreated, can you give us a bit of a description of what that is like.

Mrs White—It is like elephantitis with your legs. If it is left untreated, you can end up with badly ulcerated legs. Your weight balloons. This is the frustration of a lot of people who have lymphoedema with their legs. They put on weight, they cannot exercise. They go to their GP, whose comment is, 'Go home and lose weight and your lymphoedema will get better.' A lot of people are older and if they have very bad legs they cannot put their compression stockings on themselves. They are not easy to put on.

Mrs Bancroft—These would be the people whom we probably do not see very much. They are hidden away in the community. Do we even know what the numbers are? I do not think we do.

Mrs White—You can get a little more help in the suburbs, but it is hard in the country if you have to travel distances. I would like to make a comment about the pap screen. When I first had lymphoedema, my leg and my abdomen were getting worse, and I heard indirectly that if you applied to the public health department you could get some funding. So I had a copy of what my complaint was—due to an operation at King Edward—from my physiotherapist and from my local GP. Then I wrote to the public health department. They funded me to go to South Australia because that was where the best treatment was at the time, and they had a laser machine. They funded my airfares and my accommodation but they would not fund the treatment or the cost of bandaging and things like that. That was back in about 1997 or 1998.

Senator WEBBER—Mrs White, you talk about the work you do on the helpline. How do you publicise that and how many calls would you get?

Mrs White—We have to rely upon word of mouth—them being referred to us. We send out newsletters four times a year to members to keep people abreast of what is happening. This is why we have tried very hard to get the Australian lymphology conference here in Western Australia for the very first time, to promote awareness of lymphoedema. It is a really serious problem.

Senator WEBBER—Absolutely. Thank you.

Senator FERRIS—How long would it take to do all that bandaging? Do you have to do it twice a day?

Mrs White—No. You have to have massage first because you have to clear the lymph nodes on your body before they start doing any compression to your legs. That has to have somewhere to move up. You do not have enough drainage. Therefore, if you are not moving that up here first, there is nowhere for it to go. You have to have a half-hour massage first, and then you have the bandaging. That is left on. The next day I go back again, in the morning, and I take it off. My leg is measured, I have a shower, another massage and it is re-bandaged. This is what happens. The first time I had it done, I had it done for four weeks in a row. I had to front up there every morning for bandaging. I looked like Michelin lady when I got my legs bandaged. You have to try to do the things you would normally do in your life as well.

Senator FERRIS—And you only have one leg affected?

Mrs White—I have only one leg affected. My left leg has been good. I had a lymphosyntigraphy, which is another means of seeing how bad the lymphoedema is and the problem spots in your body so they can concentrate on that particular portion that needs more massage. That showed my left leg was finding its own passage up and draining over to my right leg, which was creating more problems. That was covered—because I was a health card owner—by the government. I did not pay for that. It is about $200 to have a lymphosyntigraphy. It does show where the problems are. It does not help it to go, but it does help to show the massage therapist what they have to try to counteract. Unless you are doing this continuously, you are never going to have a decent life with lymphoedema. I have always been an outdoor person. It makes a big difference to your life. You are conscious of lymphoedema every day of your life. It is always there with you.

Senator FERRIS—In a practical sense, what difference has it made to your life?

Mrs White—Physically and mentally it is a big problem—and sexually with my husband. And I have had to curtail what I do. As I said to you before, I have always been an outdoor person and I have to choose what I can do. I cannot do it in the summer months, because in the summer months the blood drains out of the blood vessels more and that causes more swelling. So it is a very big problem.

Senator FERRIS—You just touched on the issue of psychosocial support. Do you have available to you any psychosocial counselling?

Mrs White—I did not when I had my operation after the ovarian cancer. I had no problem whatsoever with my operation—because it was a very bad, radical operation—but there was no discussion about lymphoedema. I would not have refused to have the operation if I had known of the after effects, because it saved my life. They had given me two to three months to live but I am still here.

Senator FERRIS—Was that 10 years ago?

Mrs White—No, I had it in 1991, and when I go back to King Edward and I see the surgeons there they all look at me in amazement and think, ‘How did you survive?’ But you do what you have to do. This is why I am with the Lymphoedema Association and not with the ovarian association—because I cannot do both.

Senator FERRIS—Yes. We did have some very good evidence from a psychosocial counsellor in Melbourne yesterday. I am just wondering whether you are aware of psychosocial services in Western Australia and whether, as an association, you have ever tried to avail yourself of that for the association members?

Mrs White—No, not really, because, as I said, we are a very small association. We are only funded by our membership. Because there are a lot of older people, we cannot get people to involve themselves in the association. I am 75 years of age and I am still trying to do it. It is just impossible.

Senator FERRIS—I suppose it surprises me that the service is not available as readily as it could be.

Mrs White—Well, it is just not made known. It is the same with ovarian cancer; there is not a lot of information out there. I read an article in the paper the other day about something which I thought was a very good idea. It was that when women who are over 40, at least, have a pap smear they should have an internal examination, because when you have an internal examination—as was the case with me—it may show that the uterus is all misshapen, and things like that. They could pick that up a lot earlier. Before that internal examination my only symptom was a stitch, like when you run too far or something like that, and no other signs. I am sorry if I have waffled on a bit.

Senator WEBBER—No, it has been great.

CHAIR—Would either of you like to add anything on the record? Of course, as you know, we have about another month before we have to pull the report together, so if you think of things we should know in that time please get in contact with us. But, for the sake of the record today, is there anything you would like to add?

Mrs White—I think I have probably said enough. I would just like to see a lot more help out there for people. A lot of these things could possibly be avoided or, if they cannot be entirely avoided, it would make it a lot easier for them to be managed. And that is what it is all about, because you have to manage a lot yourself. It is not always possible, because a lot of people do not have a partner and so they do not have help with massage or bandaging at home.

CHAIR—Mrs Bancroft, do you want to add anything?

Mrs Bancroft—No, I agree with everything Mrs White has said.

CHAIR—We heard very strong evidence yesterday afternoon, from the Australian College of Physiotherapists, about the role of physiotherapy and the need for resources. The *Hansard* transcript of that evidence will be available publicly next week. You may like to have a look at that and see whether there is anything in their evidence that might make you think of something you want to add. It was very strong commentary.

Mrs White—I have attended ALA conferences in the eastern states. Six years ago the cancer foundation made the point that, besides breast cancer, there were other primary and secondary lymphoedemas. That was a very good conference. Two years down the track we had a second conference to set up a steering committee, and that is as far as it went. So we do need to carry things through and not just talk about them. We need deeds, not just words.

CHAIR—That is a very useful way to end your contribution. Thank you very much.

[12.26 pm]

COLLINS, Ms Robyn Patricia, Acting Executive Director, Midwifery and Nursing, King Edward Memorial Hospital for Women

GREGSON, Ms Jane Anne, Clinical Nurse Coordinator, Menopausal Symptoms After Cancer Clinic, King Edward Memorial Hospital for Women

McCALL, Ms Yvonne, Honorary Coordinator, Mid-life and Menopause Support Group Inc., King Edward Memorial Hospital for Women

SAUNDERS, Professor Christobel, Acting Director, Cancer and Palliative Care Network

CHAIR—Welcome. Ms Collins, we thank you for your hospitality today. When we are having an inquiry of this type, it is particularly valuable to have it in a hospital for women because it brings much more focus to all our discussions. You have been given information on the way the process operates—the protection of witnesses and giving evidence in camera if you choose to do so. Professor Saunders, I know that you have given evidence to a previous inquiry. Would you like to comment on the capacity in which you appear today?

Prof. Saunders—I am the Acting Director of the statewide Cancer and Palliative Care Network, Professor of Surgery at the University of Western Australia and Vice-President of the Cancer Council of Western Australia.

CHAIR—I now invite you to make an opening statement and then we will go to questions. We received a document this morning from the MSAC Clinic.

Prof. Saunders—Thank you for giving me the opportunity to talk to you. I thank Senator Ferris for asking me to come along; I had not planned to come along today. I have contributed to some of the other statements that have been presented to you today, in particular those from the Cancer Council of Western Australia and the Western Australian Clinical Oncology Group. One of the reasons I wanted to talk to you today was to give you the opportunity to ask me questions in my capacity as Acting Director of the statewide Cancer and Palliative Care Network. This is an organisation which has been set up in only the last year—and I have brought some reports to submit to you—following this document we produced last year, which is WA Health’s cancer services framework. The idea—much as it is throughout the rest of Australia and the world—is to look at better ways we can deliver health care to patients with cancer. After all, we are aware that if you completely ignore all the fantastic new research that is going on and just deliver the very best care to every patient with cancer, you can improve their survival by at least 20 per cent.

That is a remarkable thing. If we just think about that then we know we can improve health care outcomes. For me as a doctor taking that on, that is the thing that motivated me. I am a doctor and a researcher but nevertheless I can probably do more for the health of my patients by changing the way we deliver health care.

The other thing that is important to remember is that there are only two outcomes if you have got cancer: the length of survival and quality of survival. There is nothing else. Everything else is a surrogate outcome. We need to look at improving the length of survival but also the quality of survival, and I think that has really changed recently for the management of cancer patients, as in other diseases as well. Jane is going to talk to you in a minute about one of those initiatives that we are doing here. We are looking at managing the long-term problems that cancer patients have, whether it be gynaecological malignancies or other cancers—and menopausal symptoms are of course one of the major factors in both breast cancer and gynaecological malignancies—and we are very excited to be able to look at that.

There are a whole host of other ways of doing it. So what we have tried to do in this state over the last year is really look at how we could improve those two things from the point of view of putting better systems in place. The idea of the network is not a service delivery. Service continues to be delivered in the public and private sector—it is about fifty-fifty in cancer. It is really about influencing the way that things are done by developing guidelines, protocols, standards accreditation and new ways of doing things and using things like multidisciplinary care and putting the patient at the centre of the model.

We have also been involved with palliative care, which is certainly not my area of expertise. I have brought along a final report on palliative care in Western Australia on what our plans are. We have been busy since I have been acting director—which is a volunteer role—for the last few months in trying to put some of the initiatives that we want to introduce, and fortunately we have some state funding for that. I have brought for you a draft progress report, which is literally hot off the press this morning, of what we have been doing to give you some idea.

We have also tried to have a plan over the next year of what we really want to do. It is obviously not specifically for gynaecological malignancies but they are a major part of it. We are looking at making these changes by dividing cancer into 11 or so specific areas and bringing together both clinicians and other stakeholders involved with those areas and letting them, as the people who manage the disease and are involved in it, identify what they need to do to make improvements and then trying to support those. This Senate inquiry is very timely because it has encouraged the gynaecological oncology community to realise that they can do better. Your recommendations will be very important for us.

One of the key areas is looking at some things like improved nursing—and what Jane is doing in the MSAC Clinic is one example of that. Another good example is how we can try to improve coordination of patients through better nursing care coordinators in both metropolitan and, importantly, in both rural and regional Australia. That is one of the big problems that we have: outcomes are not as good as they could be in rural and regional Australia. Quality of life and length of life are not as good as they could be for a woman who lives in the country. A good example of what has happened is the breast cancer scanning program, a federal funded initiative for which funding is running out next June. There will be no more money; that will be the end of it; we will not have it anymore. Wouldn’t it be marvellous if we could and if we could have scans in other things such as gynaecological cancer? That is one thing that you can think about, and I want to put on record that federal funding for that initiative is running out.

We could have perhaps a women’s cancer nurse in the country. There are a lot of things that are similar to breast and gynaecological conditions and indeed other things as well. Cancer could be assisted by putting some rural cancer nurse coordinators in position through the initiatives that we have, and those positions have been advertised and are being filled at the moment. I wanted to tell you what we were doing in this state and make a plea for your recommendations so that we can continue the work both with state and with federal help. Another position that I hold is on the advisory group of Cancer Australia, which, as you know, has been a federally funded initiative. Our first meeting is, I think, on 1 September, and I will be interested to see what other jobs you give us to do on Cancer Australia.

CHAIR—Thank you, Professor. We will try to struggle through the responsibility you have given us about our recommendations. Ms Collins, do you wish to make an opening statement?

Ms Collins—No. I just want to say further to what Jane will say very shortly that this initiative that King Edward took up, we believe, is probably unique in Australia and, if nothing else, make a recommendation that other organisations take on this service. Jane will tell you about her sojourn in other places in the world where they were very impressed. I am really here to support Jane and to answer any questions about how we went through that process, if you wish.

CHAIR—Thank you, Ms Collins. Ms Gregson, we have been told about your evidence all the way through—now you have your chance!

Ms Gregson—Thank you very much. I appreciate the opportunity to present evidence on behalf of the Menopausal Symptoms after Cancer Clinic. I have already given you some background information, but there are some points about the clinic that I would like to emphasise. I think one of the strengths of this clinic is its multidisciplinary approach to patient care. As menopausal symptoms after cancer is an emerging issue, there is not a large body of evidence on which to base care. All the patients that we see in this clinic are discussed at multidisciplinary meetings held once a month. These meetings are unique in that they are not intra hospital, which is common for a lot of multidisciplinary meetings; they are interhospital meetings. We have doctors from all the teaching hospitals in Perth come. Professor Saunders comes. This provides the opportunity to give women quality care and for the doctors themselves to learn as we go. It also allows different medical specialties to collaborate, which might not necessarily occur.

The Menopausal Symptoms after Cancer Clinic also has a research profile. We have been able to develop appropriate material for patient education. There is not a lot of patient education material regarding menopause after cancer—in actual fact, there isn’t any. There is currently a booklet that we have written and we are evaluating at present. We have also developed management guidelines for menopause after cancer. This will help standardise the management of these women.

The actual support nurse role, which I am currently undertaking, provides women with access. I am a specialist breast nurse. I have gained experience in menopausal management since I arrived here over 18 months ago. This provides women with care and support not just for menopausal management but also for other management issues relating to their cancer diagnosis. At the stage at which we see women in the menopause after cancer there are often survivorship issues—they have gone through their treatment and they have come out the other end of the treatment program. They can have issues like those being discussed earlier, such as lymphoedema. It is the opportunity to perhaps identify those issues early. Women might not necessarily recognise it as something they should be doing something about, and that has occurred in our clinic. Also, for women who may have had a bilateral mastectomy, it might be 18 months or two years afterwards and now they are thinking, ‘I wouldn’t mind a reconstruction.’ We can provide information on how to go about getting that.

It is also about recognising women who are suffering from depression or other issues relating to their cancer diagnosis. We have a very good clinical psychology service here at Royal Perth, which is now going to be extended not just to breast cancer but to all cancers. That part of the role is very useful for the women who come here. The role is also utilised by other specialist breast nurses in rural areas who often ring me with patients whom they want to discuss. I have been asked to present the model of care to nurses here in WA, nationally and internationally in a breast course in Malaysia.

I think at a patient level, as this is a survivorship issue, the women come to this clinic often seeking care and relief from their symptoms. They are also seeking information and support, and the opportunity to discuss their symptoms in a way that they can feel validated and supported is of great benefit.

As Robyn has already said, to our knowledge this is the only clinic of its kind in the world. Professor Hickey is recognised as the leader in the field. We have seen women from ages ranging from 17 to 70-plus. We have had women mostly with breast cancer come to the clinic. Women with gynaecological cancers, lung cancer and leukaemia have also been to the clinic. That is all I would like to say, thank you.

Senator FERRIS—I am aware that Professor Saunders has a one o’clock appointment, so can I quickly ask you a couple of questions rolled in together. Jane, perhaps later you might also like to comment on this. The suggestion has been made by a number of our nursing witnesses that we might be able to combine breast nurses with gynaecological training, not so that we could diminish the value of a breast nurse in any way but rather perhaps value-add their personal development and the ability they would then have to counsel a broader range of health issues.

The second is that we discussed earlier more informally the multidisciplinary team and, as you said, nobody argues with that idea now. What about the idea of having a gynaecological cancer peak body along the lines of the National Breast Cancer Centre and underneath the Cancer Australia banner, or do you think that this plethora of individual organisations is going to blur the impact of each of them? Sorry about all the questions. I am just trying to be efficient.

Prof. Saunders—On the first point, on cancer nurse coordinators for gynaecological cancer: yes, I do think they would have an extremely important role. Breast nurses were first in the UK in the 1970s and a randomised controlled trial showed them to be extremely effective. Almost any patient who has been through the process and had a breast cancer nurse will realise how valuable they are. Whether they should be rolled together so they can treat other women’s malignancies as well is difficult, because often women are treated in different areas and, as you can see, different hospitals. That occurs in the case of this and in very different specialities as well. From a practical point of view, it would be extraordinarily difficult for them to be running between clinics. From a philosophical point of view, however, I think it would be a reasonable thing to do and it may be more practical in some areas than in others. For example, in rural areas it would be practically quite difficult to do. That would certainly be the case in WA, but it may be possible in some areas and in some smaller hospitals, for example.

On encouraging the idea of a gynaecological specialist nurse coordinator, there has been a lot of work done in the last few years and a lot of interest in what a nurse coordinator is and what a specialist nurse is. There are around the country a number of good academic nurses—like Patsy Yates, in Queensland—whom you may have spoken to and who have been very involved with developing what their role is. Indeed, we have done a lot of work here, because we are appointing these people, to see what their role is. Their role is different. For some of them it may be to almost individually hold each patient's hand and take them through a care plan. In other cases, there is far too much cancer for them to do that. Breast nurses cannot do that and they have more of an information role. I think the idea of them is important, but exactly how they work physically will depend on where they are.

The second point you raised was the idea of a peak body for gynaecological malignancies. I do think it is a good idea. I think it is an excellent idea. As you say, you could get a proliferation. You could get one for every organ specific cancer, and maybe that is not a bad plan. The idea of having something at a national level to look at standards, at the development of guidelines and at pushing through those improvements in care is good. Also, it could ensure you have an excellent service so that you would have the translation of clinical research into clinical practice as soon as possible. It would be a very good idea for it to advocate to the federal government and the state governments, via Cancer Australia quite possibly, what is needed in those cancers. It would bring together a critical body of massive expertise. Gynae cancer is relatively rare, fortunately. Australia is a big country, spread out, but with not very many people. Each place has actually only got a pretty small amount of expertise in it. If you could bring together people in a country the size of Australia, I think that would be a very good idea.

Senator FERRIS—I will let others see if they have any questions for you.

Senator WEBBER—I am more than happy for Professor Saunders and the others to have some input on this. As part of this inquiry, we have spent a bit of time looking not only at that structure and at how to bring together the energy, the focus and the coordination but also at the gaps, at what is missing, and at what the priorities need to be. We have had lots of evidence about the need for psychosocial support. We know we need that. We are focused on the multidisciplinary team, and that was a key recommendation of the cancer inquiry that Senator Moore was on. My question is this. Do we know enough about the kinds of support these women need or do we actually need to look at putting in some more research first? We have had evidence saying, 'Yes, we know it; we've just got to do it,' versus other evidence saying, 'No, we're still grappling with it.'

Prof. Saunders—Like everything, I think it is a bit of both. We know undoubtedly that more psychosocial support is useful, but always there is research that can be done to look at how we identify which patients are in need of support and which are not and at how we get the message out and teach people. A lot of it is an educative role as well.

The thing I am going to at one o'clock is a meeting on a communication skills workshop for young women with cancer and the specific needs that they have, which the National Breast Cancer Centre is running. So it is running those kinds of things for gynaecological malignancies.

But there is never such a thing as knowing everything; we are always learning and putting research into it.

I think that is a really important point, though: whenever you have a good service, it is always based on research, whether that is laboratory research, research in communications skills—‘research’ means a whole range of things. If you look at the best cancer services in the world, Canada is a very good example. Canada has some of the best cancer services in the world and the best outcomes; they are all based on a research model. If you look at cancer services in British Columbia, their signature, if you like, is care and research. I think that is how we should always base a good model of care.

Senator WEBBER—Does anyone else have some comments on that?

Ms Collins—I would like to talk about the coordination type role. I think that, with any type of specialisation in medicine today, there is so much subspecialisation. Whilst in the rural sector it is too hard to sometimes break the body up into a thousand pieces, to have at least somebody available so that the woman can access one named person quite readily, from eight to five, is so important. From a personal perspective, one of my very best friends is going through Christobel’s unit at the moment. She said to me: ‘Do you know how good it is? I know how busy Christobel is. I can pick up the phone and ring that breast nurse.’ Whilst the breast nurse may not know the answer, she is the conduit to finding that answer. I think that is terribly important. Here at King Edward, Fiona Logan—I think Fiona is in the audience—manages our gynae-oncology service as the liaison nurse, and I know that the women appreciate that so much, as Jane does from the Menopausal Symptoms after Cancer Clinic. I think in big centres like this it is absolutely essential—or, indeed, wherever. Women also get bowel cancer. I do not know whether the breast nurse would be the expert for bowel cancer.

Ms Gregson—But she would find where to go.

Ms Collins—Absolutely.

Senator ADAMS—I would like Ms Collins to give us a little bit of history as to why the menopause after cancer clinic started.

Ms Collins—I think that is thanks to two terribly proactive physicians, namely Professors Martha Hickey and Christobel Saunders. It was their foresight to lobby the executive for funds to appoint this position. We were very lucky to have the expertise of Jane Gregson, so it got off to a flying start. But I have to say, for the investment for the women of this state, it is outstanding. Whilst I do not say it is a cheap investment, it is a very worthwhile investment, certainly for the organisation, but for the women. We are here for the women; we are not here for each other. We were just lucky that we had a very supportive executive but we also had the seed sown by two proactive physicians.

Prof. Saunders—I have to tell you, Senator Adams, that the first money actually came from industry—me asking the drug company to support Jane initially, to convince the health department, if you like, that it was worthwhile; but we easily did that.

Senator ADAMS—The menopause support group has been here for quite some time. Where will they fit in in the future? Once again, like the lymphoedema foundation, you have volunteers. I have been involved with both organisations. Those people have given so much, but there is a limit. Is there any possibility of obtaining funding for the role of the menopause support group? Is it an important role?

Ms Collins—It is an important role. Ms Yvonne McCall is, I believe, an outstanding contributor to that service for Western Australia who should be noted. Sadly, she is not 21. We are in the process of looking at how to sort out the future services. The knowledge base that Yvonne has is second to none. It is through sharing that information and keeping information up to date that the women get the right information. How we do that is really yet to be sorted. But I think the menopause support group most certainly will continue.

CHAIR—I have just one question. I think the initiative of the clinic is superb. It just reinforces for me this. Through this inquiry we have had evidence from so many people who work in the field. I think just about everyone who works in gynaecological oncology has been involved, which is wonderful. There seems to be a very strong sense of collegiate behaviour. That has been the evidence—that is, that people share their knowledge. In their own evidence they state that there are limited turf wars that go on. I am interested to know this, in terms of the sharing of initiatives that work. If this initiative in Perth has been as successful as people say it has been, why is it that it is still the only one? That is my understanding. For something that is working so well, and the need for it has been identified so clearly—and I am sure this happens all over the place—why is this the case? I would like to get something on record, some opinion, as to why it is not being replicated elsewhere.

Prof. Saunders—I suppose, when you look first at the medical side of it, we treat mainly patients who have breast cancer, although we do treat some with gynaecological malignancies. The real nugget there is that gynaecologists have very little to do with people who manage breast cancer. The strength of this initiative has been, I guess, the fact that this is a small place and we have managed to get together. It has been very satisfying, from a professional point of view, to learn so much from one’s colleagues. But actually getting together a group of doctors who normally have very little in common—remarkably, you would think they would have a lot, but they do not—is quite significant. That I suspect is the case in a lot of places.

Then also, I suppose, traditionally gynaecological oncology has not had the experience of multidisciplinary care that breast cancer has had over the last 20 years. Breast cancer has had that experience of multidisciplinary care because of two things: breast screening programs, which have introduced the concept of it to surgeons—and, as a surgeon, I can criticise what surgeons were like and remain like in some fields—and consumer pressure. It has been the case, right back since the seventies, that breast cancer has affected many women who are middle aged, are middle class and have a loud voice, whereas other malignancies do not. People with lung cancer and oesophageal cancer are much worse off than those with breast cancer and probably worse off than people with gynaecological cancers. That is the honest truth.

For it to work, you need to get a whole shift of ideas into the gynaecological oncology community. They need to know that actually you can listen to a whole range of other people—endocrinologists, bone experts, psychologists and nurses. Nurses actually have valid medical opinions. Some doctors still find that difficult to work with. It is changing here. There is that and there is the fact that they are looked after by people on different sites. That makes it very awkward. You just do not work with each other.

Ms Gregson—I think other clinics are going to be set up. I was speaking to Professor Kate White this morning, and they are looking at doing a similar clinic in, I think, Prince Alfred. When I have spoken in Sydney, other nurses have come up to me and said: ‘This is a great idea. We want to do it in our hospital.’ But it is going to take some time. We in Perth obviously were very lucky that we had Martha and Christobel and a lot of energy, which moved it along very quickly. If you have that at the top, it happens more quickly.

Ms Collins—I will just add to that. One other thing we are doing is this. Jane’s paper has been accepted to the Women’s Hospitals Australasia meeting in Launceston in November. I think that one of the things is spreading the word, and maybe no-one else has thought of it. Once they know the outcomes of it, I am quite sure it will not take much.

CHAIR—It would seem obvious to have it with the women’s hospital network. I have just been subtly passed a note from Senator Adams, which says: ‘Can we have Yvonne McCall at the table? She is from the menopause support group, is wearing a blue jacket and is at the back.’ Professor, if you have to rush away, that is fine.

Prof. Saunders—Thank you so much for having us.

Senator FERRIS—We have really appreciated you making your points.

CHAIR—Thank you very much, Professor, for sharing your time. Ms McCall, I do appreciate your coming forward. I know your name was mentioned earlier and we welcome your contribution, naturally.

Senator ADAMS—What is the role of the Mid-life and Menopause Support Group for people with gynaecological cancer? Just before you walked into the room, I had asked Ms Collins about where the menopause support group was going to end up and she had some fairly positive comments to make, but you missed those.

Ms Collins—I also said you were not 21, equally sadly.

Senator ADAMS—Yes, unfortunately.

CHAIR—Yes, Ms McCall, that is on the record.

Ms McCall—Just add 15 years! I joined the group in 1990 and I have been the coordinator since 1991. That was a very fast learning curve for me, and since then I have gone to all the conferences, medical meetings and things to keep up to date, to keep my knowledge base up to date. I get hundreds and hundreds of calls from women. Their need is to understand about menopause, to understand about HRT and to understand why they need it if they do, what happens if they do not take it or what happens if they do take it. Conflict can come from the media and from doctors—and doctors do not always understand or keep right up to date either—so it fills a huge gap for most of those women.

I compiled a dossier for Robyn with some of the thankyou letters, and over and over again they said, ‘Thank you for understanding,’ ‘Thank you for listening,’ and: ‘Thank you for helping me to understand. Now I know where I’m going.’ So I think once women do understand these issues—whether it is related to cancer, whether it is related to menopause and not cancer or whether it is related to menopause and any other thing like epilepsy or whatever—they are confused about medication interactions and about why they perhaps need to worry about bone density. They want you to explain all that, so that is what I have been trying to do, and I have kept going because of the response from the women. They are so grateful to have somebody there who is independent.

I do need to close the support group and I want King Edward Memorial Hospital for Women or somebody to take up the issue that I have maintained all this time. So finding someone with the necessary background knowledge and keen enough to keep up to date and answer the phone to talk to these women I think is vital. I have certainly passed on a lot of menopausal women who have had previous history of breast cancer or other cancers to Jane, so it is good to have this interaction. It is good to be on the site where we can confer and we can tell each other about meetings we have heard of. If some of the representatives of drug companies come along and they are going to talk about new medications, they let me know or I let them know, and that interaction, that site value, is really good.

Senator ADAMS—How can you help rural women?

Ms McCall—We often have public meetings, which are very well attended. We have had between 60 and 160 people come. It takes a lot of work. And for the last couple of years I have had them videoed, and the hospital has helped with that. Then I go on to global email—and I need a bit of help with that too. But if I can get to the rural women then they can know these videos are available. If I can get to their community nurses, they can let them know, and the community nurses could use the videos to hold a meeting of their own in their own area and use their local papers to let women know about it.

So that is what I have been trying to do for rural women. I have maintained this stance for a long time that they should not be left out. It has been difficult with the self-funded support group to advertise to rural women. We are in the country phone books—again I think courtesy of King Edward. I do not think many women find us there. They find us in the *White Pages* of our local metro book, but I do not think many of the country women find us that way, so it is hard to know how to get to them except through the global email system, but there are quite a few people I have talked to from country areas, and sometimes they have mothers in the city who have let them know that we exist.

CHAIR—We are getting close to time and there is only so much we can talk about because of the nature of the questions. I just want to ask one question of you, Ms McCall, and I also invite Ms Collins and Ms Gregson to jump in. My question concerns the fact that so many of these wonderful initiatives are stimulated and supported by volunteer networks. You have streams of funding which are always inadequate. It does not matter which stream it is or where it is from, it is always inadequate. But the heart seems to be the ongoing passion and dedication of volunteers. I am just wondering whether any of you would like to make some comment about how we continue that, because there are always questions about whether the volunteering generations have gone and whether volunteers in the next generation will be around. Your story is so indicative of so many organisations—we had the lymphoma women here before—that I would really like to have something on record from all of you, from your professional points of view, about that dynamic.

Ms McCall—I have never been able to find another volunteer who has been interested in getting up to date with menopause and having that knowledge. You find a lot of people who espouse the alternative type of approach, who are really keen on acupuncture or whatever—and it is probably because they are hoping to find patients—but to follow the medical model and to be really up to date takes a fair bit of commitment. And, yes, my family have thought I have been mad and my friends, if I have any friends left, think I am mad, because it is very time-consuming. But even finding volunteers to do some secretarial work is getting very difficult. Most women are working and when they stop they want to relax. And, of course, if they have not already contracted something that will force them to stop, they do not seem to want to work voluntarily. I think Princess Margaret does not have as much trouble because they have little children and there is a great appeal in that.

CHAIR—I take it that that is Princess Margaret Hospital?

Ms McCall—Yes, the children’s hospital.

CHAIR—I am not from here. I am sorry—

Senator WEBBER—She’s from Queensland.

CHAIR—I am from Queensland; we do not have one of those.

Ms McCall—King Edward Memorial Hospital has babies, but volunteers are not allowed to look after little babies of postnatal age. But, yes, it is now terribly hard to find volunteers with commitment. They might come for three months work experience to do some work on the computer or answer the phone for me, but that is about all.

Ms Gregson—I think it is very useful having a volunteer organisation associated with our clinic—perhaps not so much for the women who have had cancer, because the HRT issue is often denied to them—and generally it is very useful for women to be able to ring up and get information and know where to go if they need any further support. But I agree with Yvonne: I think there are a lot of women who might be of volunteering age but who are still working, and they do not have time to volunteer. That is where we are, at the moment.

Ms Collins—Having said all of that, I think women’s health is somewhat more fortunate than many other disciplines in medicine, as is evident from the Women and Infants Research Foundation shop that is predominantly run by volunteers. Yvonne, as I said previously—and I am sorry that you were not here to hear it, but it is on record—with technology and information changing so much, your knowledge is second to none. To replicate that would be very difficult, and maybe you have to change how you do things. You still need to be able to offer the professional knowledge, but the support group is what we can really continue to support here.

CHAIR— Thank you, Ms Collins, Ms Gregson and Ms McCall. Again, Ms Collins, thank you very much for your hospitality. If any of you have supplementary comments you would like to give the committee, please do so, because this committee is important. Senator Adams is now going to grab another witness from the floor.

[1.04 pm]

NEWNHAM, Professor John, Professor of Obstetrics and Gynaecology (Maternal Fetal Medicine), University of Western Australia

CHAIR—Professor, in what capacity are you appearing before the committee?

Prof. Newnham—I am professor of obstetrics on this campus but I came to say hello to Senator Adams at lunchtime.

CHAIR—I feel certain that Senator Adams will make you earn that conversation at lunchtime by getting some comment from you on a question she is about to ask.

Senator ADAMS—Thank you very much for coming to see me. It is great to be back. Research dollars: this was really what was leading from Ms Collins's comment. We have already looked at the shop. I have explained a little bit about the Women and Infants Research Foundation. I have showcased the new research model that may be coming up for Western Australia. I have suggested that it may be a way that we can get through the New South Wales-Victorian divide with an overarching centre for gynaecological cancer. I did explain about the two hubs of research that may happen here in Western Australia. I wondered whether you could give an overview of the researchers here, coming back to the gynaecological oncology side.

Prof. Newnham—I have not come here to talk about that, but I am delighted to. We are not very active in gynaecological oncology research on this campus. We are primarily obstetric, foetal, newborn and menopause dysfunction or bleeding type researchers. So oncology has been our weakest link. It is a tragedy that that is the case, because we have outstanding clinical services here and outstanding surgeons in oncology. But the research world of molecular biology and gynaecological oncology is elsewhere in the town. One of the many reasons we want to move this campus to Sir Charles Gairdner Hospital is to bring our clinical oncology service together with the basic scientists who work in this field. At the moment they are not well connected.

The reasons for doing that are to increase the critical mass and to bridge the gap between the bedside and the laboratory bench. We have done that in all our other fields; we have yet to do it in oncology. The funding of research benefits from that. The funding of research in Australia primarily comes through NHMRC. We aim to be competitive with NHMRC in our various areas of strength, and we are with obstetrics and newborn medicine, and with other areas of gynaecology, but we are not with oncology. So if we were to bring these together, that would hopefully result in us becoming competitive at an NHMRC level.

But funding for research comes from many areas. The key to running an academic program and successful research is to have a diversified income base. No one researcher can live by NHMRC alone; you need a diversified income base. On this campus, we do that by having international grants—we hold three grants from NIH in the United States; we hold grants from the Canadian Institutes for Health Research—and we hold NHMRC grants; then we have local funding, which, on this campus, comes heavily through the Women and Infants Research

Foundation. We run businesses in the form of a cafe and gift shop, a baby photography business; we have invested moneys; we have donations from the public. All of those things add to our ability to provide the infrastructure on top of which our scientists and clinicians can thrive and be competitive. So that is a little party political speech on how we fund research on this campus, which may have been what you asked me, Senator Adams.

Senator ADAMS—Yes, that was it. We are very lucky to have you here and I am sure, over lunch, my colleagues will enjoy discussing issues with you.

CHAIR—Thank you for coming, Professor Newnham. If you have supplementary comments you would like to give the committee, please do so.

Proceedings suspended from 1.09 pm to 1.32 pm

FLAHERTY, Mrs Kylie Maree, Committee Member, Marketing and Events, Gynaecological Awareness Information Network

JENKINS, Ms Natalie Jane, Chairperson, Gynaecological Awareness Information Network

MAZZELLA, Mrs Kathleen, Founder, Gynaecological Awareness Information Network

WHITE, Mrs Barbara, President, Lymphoedema Association of Western Australia

CHAIR—I welcome you all, and particularly Mrs Mazzella. It is lovely to see you again. I know how much effort you have put into getting this inquiry going, and I do want that noted for the record. I would expect that all of you may have an opening statement to make, which we get on the record, and thank you for your submission. We did have the previous submission that you put to the roundtable. After your statements we will go to questions. Does anyone wish to make an opening statement?

Ms Jenkins—I have an opening statement on behalf of the group. Firstly, GAIN would like to thank the Senate Community Affairs References Committee for conducting this important inquiry into the gynaecological health of Australian women. Secondly, we would like to thank you for inviting us here today. Thirdly, we would like to acknowledge the authors and initiators of the petition that was presented to the Senate in conjunction with GAIN’s National Gynaecological Day 2005, that being Ms Margaret Heffernan and Ms Alexa Rosengarten.

GAIN is here today representing the views of women in our community. GAIN is a national organisation driving awareness and education of the importance of gynaecological health. We aim to ensure that women’s voices are heard at community, clinical and government levels and to decrease the emotional trauma that is endured by women who have been diagnosed with a serious or ongoing gynaecological condition. To do this, GAIN works with the community sector, the health sector, academics and government. We are, though, essentially a consumer group. GAIN has affiliations nationally and internationally and has a strong network of supporters throughout the health and women’s sectors.

In responding to the Senate inquiry, GAIN wishes to move the importance of gynaecological health up the government’s agenda. We and a number of other individuals and organisations around Australia want to see gynae health treated as prominently and importantly as the very successful breast cancer movement. Importantly, GAIN considers gynaecological health to be much more than cancers alone. This does not mean at all that we downplay the severity of gynae cancers, as indeed many of the women we support have endured the spectrum of them. However, it is crucial to recognise that some conditions are, and may be, linked to some cancers. An important example of this is the relatively recent discovery that some strains of the human papilloma virus lead to cervical cancer. In short, we do not know yet what we do not know.

GAIN understands that many women suffer multiple gynae conditions and many of these are present either pre cancer diagnosis or arise post cancer treatment. We do not yet have the knowledge as to whether other gynae conditions are related to gynae cancers. For this reason gynae cancers should not be treated in isolation. In addition, there are a number of severe and debilitating gynaecological conditions that have a major impact on women’s lives. Endometriosis, polycystic ovary syndrome, vulva vestibulitis and fibroids are just a few examples of an increasing number of gynae conditions.

In Western Australia recent research has shown that we have some of the highest rates of hysterectomies in the world, similar to that reported for the USA. The majority of these are undertaken to deal with persistent gynae conditions, such as fibroids, menstrual disorders, endometriosis and prolapse. As such, we urge the inquiry to consider gynaecological health as being broader than gynae cancers alone.

Gynaecological cancers and conditions are a very sensitive issue for the great majority of Australians. Unlike other illnesses and conditions, gynaecology is shrouded in secrecy and bound by societal taboos that suggest we should not talk about these things. Women are often our own worst enemy, chastising other women when gynae problems are mentioned and encouraging them to keep quiet about it. On the flipside, many men feel extremely uncomfortable with the subject and often pass it off as women’s business. How many of us have been in a position of trying to talk to our male partners about a concern and being told they do not want to know about it, and how many of us have tried to confide in a female relative or friend and seen that look of distaste or discomfort glaze over their face? I know I can now talk about vulvas and vaginas over the dinner table without a second thought, but I suspect I am the anomaly rather than the norm.

Women in Australia are suffering and some are dying from this unnecessary veil of silence. It may sound dramatic, because it actually is. The emotional side effects of gynae conditions can be extremely isolating and that is why GAIN was formed, so that women could share with other women and break down the silence. Many people do not understand that women with gynae conditions face both pre- and post diagnosis. In the first instance, we know that many women will simply go undiagnosed due to the embarrassment of having to tell their GP their symptoms and undergo a physical examination. Some women feel the mere mention of gynae symptoms will raise accusations and questions about their sexual practices. The reality is that many gynae conditions are not even related to sex.

This is where GAIN believes that knowledge and education is the key. Once we have knowledge, some of these feelings of embarrassment, guilt and fear will dissipate. Post diagnosis does not necessarily provide any relief. Some gynae conditions are easily treatable whereas others are an ongoing routine of tablets, creams, operations and physical examinations. In many cases, sexual activity becomes painful if not impossible, therefore affecting a women’s sexuality, her femininity and relationship with her partner. Physical effects can include loss of hair, skin conditions, and the inability to walk, work or participate in sporting activities or even light exercise. Body image can be severely affected and, for some, even carrying out day-to-day activities can be painful. All of this adds up to a life of extreme stress, fragility and an emotional rollercoaster of fear, guilt, embarrassment, anger, panic and uncertainty. This in turn has a ripple effect into all aspects of a woman’s life and therefore her partner, children, family and friends. GAIN understands that gynae conditions are not just a woman’s problem but can affect the whole family. These psychosocial outcomes are not easily captured in facts and figures and this is why GAIN believes that they are often overlooked when research, treatment and support programs are being designed.

GAIN has four key issues that it would like the inquiry to consider as a priority. The first is research and reporting. GAIN understands that there is a need, or we believe that there is a need, to fully capture cancer incidences by recording and including precancerous conditions and treatments undertaken in the cancer statistics. This would include capturing HPV and CIN treatments, giving a true reflection of how widespread gynae cancers actually are in Australia. GAIN understands this is not currently happening.

The second is screening and preventative measures. We believe it is essential to fast-track the new human papilloma virus vaccine into a school inoculation program. This vaccine is one of the most important breakthroughs in women's health that we have seen in many years. It has been said that it has the potential to virtually eradicate cervical cancer and thus will save hundreds of Australian lives and significant amounts of ongoing emotional trauma. The vaccine must be made available to girls at presexual ages and widely available throughout remote Indigenous and multicultural communities, where cervical cancer mortality and incident rates are unnecessarily high.

GAIN strongly advocates that the implementation of the inoculation program not be linked to a misleading discussion around sexual promiscuity. It will be a tragedy if this debate is allowed to damage the potential for early vaccination. But as a caution, even with the introduction of the vaccination, the highly effective pap screening program should not be subject to funding cuts, as this is sending the wrong message about preventative health to the community. Similarly, research and funds must be applied to finding a suitable screen tool for ovarian cancer. With an 85 per cent mortality rate, increasing incident rates and symptoms that can easily be passed off as more related to common health issues, this must be a priority for the Australian government.

The third is psychosocial support. This is the least understood effect of gynae cancers and conditions and therefore probably the least supported. GAIN believes that increased research needs to be undertaken on the long-lasting psychosocial side effects of gynae conditions and integrated programs established alongside medical treatments. GAIN is very pleased to see the psychosocial support project for gynaecological cancer patients in New South Wales, and recommends that this should be an Australia-wide program. Psychosocial support must also extend to the partners and families of women affected. The ripple effect must be understood and managed. The fourth is awareness and education. Most importantly, GAIN recommends that increased awareness and education campaigns be implemented Australia-wide. Awareness is the key to prevention and even cure, as women can take care of their own gynae health.

GAIN continues to be surprised and dismayed at the lack of knowledge and awareness of gynae conditions amongst the general populace. We believe this is the result of the social taboo surrounding the subject. Further, GAIN believes education and awareness is a two-way street. The public need to be better informed, and health clinicians, particularly the all-important GPs, need greater education on how to diagnose, treat and manage gynae patients. We desire to see a culture of working with your doctor for a better outcome overall.

In summary, GAIN supports the notion of a coordinated approach to awareness, education, research, treatment and ongoing management of gynaecological patients. A powerful voice is required to implement national campaigns and programs similar to that of the successful breast cancer movement, which has achieved a great deal for the Australian community.

Finally, I would like to leave you with a quote that I believe sums up the ongoing fear and isolation that a women with gynae cancer endures. When I bring up any concern about cancer or reoccurrence, my husband rolls his eyes and my children just ignore anything I say. I have come up against something that could have, or could eventually, take my life. I have faced something that has shaken my very being with fear. My family acts like, 'Oh, it was a scare but it all came out okay, so be thankful and forget about it.' If only they could understand how badly I want to forget about it and never have to think or face that monster again. But that is not my reality. My family does not have to live with those thoughts every day; I do. They block it out; if only that was doable. Thank you for your time and support.

CHAIR—Thank you, Ms Jenkins. Ms Flaherty, were you wanting to make an opening comment?

Mrs Flaherty—Natalie has done that on behalf of our group.

Mrs Mazzella—I would like to note that I took the day off work today because I did not want to miss a minute of what the committee is doing here, so I am really pleased that it has all come together as it has. Twelve years ago I was a broken shell, and I placed an advertisement in the *Woman's Day*. From the stories that came back from there, I just could not believe that women have to endure what they do. The more we can perhaps follow what GAIN and Natalie have said today the better it will be for women's health in Australia.

CHAIR—Thank you very much. We will now go to questions.

Senator WEBBER—First, I offer apologies for missing the beginning of your statement. As is often the case with these things, we tend to run a little behind time and cram in as much as we possibly can to inform ourselves. Thank you for all the work you have done as an organisation, between the work that you have done and Senate Ferris's personal passion and commitment. They are the reasons we are here today, so I thank you for that.

I want to turn initially to some of your final comments about public awareness and public education. We have had some conflicting evidence along the way about where the priorities need to be, because, as with all things that require money, there are priorities. Some say, 'Well, we don't want to put too much effort into a public awareness campaign for women themselves, because a lot of the symptoms for these cancers are very generic and we do not want to convince every woman that she has, say, ovarian cancer; the effort needs to go instead into GPs.' I was wondering if you could expand a bit more on what your organisation thinks needs to happen and what the priorities should be.

Ms Jenkins—We think it is a two-way thing. It has been suggested to us many times before that we should not generate too much awareness and education because all we will do is scare women. That is possibly underestimating the ability of women to be able to gain knowledge and use it in a way that is for their benefit. Our experience as a support organisation, from people that contact us on a daily basis, is that their lack of knowledge and awareness has contributed to whatever problem they have had, in that they often do not know how to describe their symptoms or indeed their gynaecological parts correctly; that they did not know that these things existed and how they could prevent transmission of them or how they could look after themselves; and that they feel ignorant when they go to their GP or gynaecologist, which no woman needs to feel about her body. We believe it has to be two-way. The flipside is that GPs are the most important link, because that is where women need to go and will go first. They need to also feel that their GP understands them, understands what to look for in their diagnosis and can help them through what can be a really embarrassing and problematic scenario. Definitely I think there should be priority at both ends of the scale.

Senator WEBBER—That leads well on to my next question. You talk in your submission about misdiagnosis of women. What has also come across has been very late diagnosis because, as I say, of those very generic symptoms. From the women that you deal with, how much of that misdiagnosis do you think is actually attached to the fact that they are not assertive enough about getting adequate treatment, because women are not all as well educated and assertive as perhaps people in this room are? The flipside of it is very late diagnosis and therefore crisis diagnosis.

Ms Jenkins—Anecdotally, of course—we do not have statistics on this—I would say that in the beginning it would probably be fifty-fifty, but as it progresses it will come up to about 75 per cent. That is my sense. We have a lot of women who say that they kept going back and back, and in the meantime they will start to generate their own knowledge and awareness. It is often following repeat visits or changing their practitioner before they actually get a diagnosis that they believe is correct and they are happy with and is suitable. I think as it goes along possibly it is higher in terms of the right diagnosis not being made early enough. Kylie may want to add to that.

Mrs Flaherty—I can add to that also from a personal view, in that I am a long-term endometriosis sufferer. I came on board to run the national day last year, but GAIN has given me a very big insight into my own health. I changed practitioners three times until I was actually diagnosed correctly, but I had been suffering since practically the age of about 15. It was not until I was 26 that I was diagnosed with very severe endometriosis. I was on track for a hysterectomy this year, but I have a very healthy three-year-old boy, thankfully in the hands of two very good doctors. It is very important to be able to understand yourself what is happening and also to make sure you are comfortable with your doctor, and not be afraid to change. It is really hard if you get a doctor who is not a specialist in the gynaecological area. Do not be afraid to maybe even get a second opinion from a different doctor. That is an important message that we take forward.

Mrs Mazzella—Personally, I left a lot of the responsibility up to the doctor, because I was a busy working mother and did not have time to worry about these things. I thought, ‘I will go to my doctor and he will sort it out for me.’ But I think that we as women need to take on board a lot more than we do. Because of doctors’ time restraints in this day and age, they do not have the time. I do not think they are supposed to be educating us. Other people should be educating us as well and through the schools.

Senator WEBBER—That naturally leads on to the next one. The whole issue of discussing our gynaecological health still has a bit of a stigma attached to it. As you have said, young women do not know enough about it. I have raised with some of my colleagues that I think I know more about prostate cancer than they know about any cancers that any woman can get. How do we get around that taboo? A cancer is a cancer is a cancer. We are more comfortable now talking about breast cancer than we have been. How do you think we have reached that point and what do we need to do about all these others?

Mrs Mazzella—I think we need to face it. I have had vulval cancer. I go to sexual educators and they say, ‘Oh, it’s the vagina,’ and I would say, ‘But this is the vagina and this is the vulva.’ They would say, ‘But, you know, women aren’t comfortable with using the correct terminology,’ so they use pet names. Some of the educators need to learn to use the direct name so that we can become confident to go to the doctor and use the correct terminology. Even the word ‘endometriosis’, the more we hear about endometriosis it just rolls off your tongue and it makes you feel like you are empowered. But if you have to use wrong words, it is taking the empowerment out of us when we go to the doctors.

Ms Jenkins—These sorts of discussions are clearly doing that. The fact that we are now having this inquiry around Australia—it is being talked about and it is being recorded in *Hansard*—actually seeks to change those attitudes. It has to be a bottom-up approach as well as a top-down approach. One of the things GAIN said that was fantastic was Professor Ian Frazer winning Australian of the Year, because now he has put a major spotlight on the human papilloma virus, which most of us, two, five or 10 years ago did not even know about. Again, Mrs Mazzella, in terms of terminology, is saying that those of us who may have had it—and I suspect most of us have; in fact, the statistics show that about 70 per cent of women will have it at least once, maybe not the high-grade but the low-grade strains—will have had it described to us as the ‘warts virus.’ The terminology is not even being used correctly. I really believe it has to happen at all levels. It has to happen in schools and we have to be up-front about terminology and using it for the different types of gynaecological cancers. Using ‘gynae cancers’ in itself as a catch-all is not providing the right levels of education. The media has to be on to it. We have to be talking about it in public forums and again at all levels—community, clinical and also government.

Senator ADAMS—Thank you for coming—it is really good that you are here. Firstly, perhaps you could tell us about your Great Gynae Day Out that is coming up. I think that is really important, so we will get that on the record. Would one of you like to do that?

Mrs Flaherty—The Great Gynae Day Out is on 10 September this year at the Hyatt from 10 am till 4 pm. We have a very jam-packed day this year. One of the things that, since I came on board last year, we have been trying to do is to spread the knowledge and education out to the communities by trying to incorporate all community members, and also trying to encourage the male community to come in as well.

We have a few different things happening this year. In particular, we have three very important information sessions on gynaecological health. We do have a cancer session, which Professor Ian Hammond is heading up for us. He will be speaking on gynae cancers in general—the stats and facts. He is giving the clinical perspective on that. Then we have Jenny McCloskey speaking on HPV and where the vaccine is to date. GSK is one of our sponsors for the day. It is very important where the vaccine is at. Thirdly, we have a lady from the WA cancer prevention program speaking on the importance of pap smears. This year I have asked her to address what a pap smear does and does not pick up, because that is really important. She is going to focus on that and say more about the screening program. There will be lots of literature as well. We have a great little gynae showbag for everybody to take away. We have lots of pamphlets in there as well—some little goodies for all ladies.

There will be a lot happening, so excuse me if I forget something. In the second session we will have talks on endometriosis, polycystic ovaries and a talk on infertility from a personal perspective. We have clinical as well as some personal experiences in there, which we feel is a good way of getting the message out. We also start the day with the Perth Playback Theatre Company, which was a very successful part of our day last year. They are absolutely amazing. They ask questions of the audience and re-enact somebody's story. Hopefully you can come along; it is an amazing thing to watch. Then we have something on continence—how to keep it that way. We have some pelvic floor exercises. We also have some multicultural dancers and performers as well as the lovely lady from Shemoves—a bit of pole dancing as well—who will show us how to move like a goddess. We have a few fun things. We will have some henna tattooing, hair braiding and a wellbeing room, so we are really trying to bring in a full circle of treatments as well.

Mrs Mazzella—I believe we have an Aboriginal group coming as well; is that correct?

Mrs Flaherty—We do. We have a booth on Aboriginal health—Derbal Yerrigan is going to provide a booth. We will have some information booths as well. Gosnells Women's Health Service is going to be there assisting on the counselling side and with services available for women with health problems. The Cancer Council of course will be there. There are a few others things. We are still trying to build our schedule.

Senator ADAMS—It is a wonderful initiative.

Mrs Flaherty—The flyers will be out this week.

Senator FERRIS—What sort of money would you raise with something like that?

Mrs Flaherty—This year's event is actually not a fundraiser. Our fundraiser is next Thursday evening, when Professor Ian Frazer is speaking. We decided to put our sponsorship money into the community, and that is our contribution as GAIN, to drive awareness and education on gynaecological health.

Mrs Mazzella—The fifth year of our celebration is coming up. We had the Great Gynae Debate a few years ago. One man and his wife came along the first year and enjoyed it so much that he brought his daughter and her boyfriend along; he shouts them a ticket every year so that they can come along. There is a family environment and it is fantastic that the men and women can come together. I think the work we are doing is tremendous.

Senator ADAMS—Do you have many inquiries from rural women for help or for information?

Ms Jenkins—We do. Most of our support is via email. We find that women find that is the best way to do it, although Mrs Mazzella does do a lot of phone support as well. I think a lot of women like the anonymity, and email obviously is cheap and accessible. We do get a lot of rural women and remote women from all around Australia and even internationally as well, because we are quite unique in what we do. One of the things that we are implementing with the Cancer Council is a new online support group that we are partnering with Cancer Council WA. We are going to set up a function where women can talk online at designated times monthly to start with and hopefully it will become weekly, so that it is accessible. I know that there are some issues with technology in some remote areas of Australia, but it is a very accessible format for people to get support and talk to other women.

Mrs Flaherty—That will be launched on 10 September.

Mrs Mazzella—As much as the internet is out there, in terms of woman-to-woman contact and bonding, such as that among the breast cancer women, there is so much that you can learn from each other in a support environment. There is a huge gap in that. The more that we can do that, the more we can heal. Sharing is healing. We need to address the issue of bringing women together who do want to connect with others. When you come up from the country and you are here on your own, it would be good if you could go to some other women's organisations or women to speak with about it who understand. That needs to be addressed as well.

Ms Jenkins—On that note, GAIN is a totally voluntary organisation. We do not have any money. We find it very difficult to provide the services that we would really like to in terms of one-on-one contact in rural areas for that reason. There is a real gap in that service provision in Australia.

Senator FERRIS—From a personal perspective, Ms Jenkins, when you were diagnosed with whatever your problem was, can you tell me the first three things that came into your head, how you dealt with them and whether you think that those gaps, if you like, in the system still exist.

Ms Jenkins—I probably need to clarify that I am not actually involved with GAIN because I have been diagnosed with a gynaecological condition. I come from a very different perspective so I will pass that on to Mrs Flaherty, if that is okay, because that is her experience.

Mrs Flaherty—I will answer your questions in order, if you like. How did I feel when I first was diagnosed? I was afraid but also relieved. At the same time, I had suffered for so many years—I was an active teenager and young adult—and it is quite debilitating. I was in bed while a lot of my other friends were out and about doing stuff. I was scared, not knowing what it was and having never heard of it, but also relieved that it looked like there was an answer to it. The next path for me was, if I look back now, six laparoscopies; so six surgeries, one at Christmas time just about every year. That certainly put a lot of strain on family life and on my work life as well. I had never had a sick day in my life until then. Your second question?

Senator FERRIS—What the three things were that you felt on diagnosis. You have given two. Was the third one an information related one?

Mrs Flaherty—Yes, the gap, absolutely. I will give you a good example. I have just been in touch recently through a work colleague whose daughter, aged 26, has just been diagnosed with endometriosis. Again, she had been a sufferer for about five years. She blacked out and was taken to hospital. She had severe endometriosis. I was quite surprised that more than 10 years on she had not heard of endometriosis. She is in Sydney, which has a much bigger population than we have here. I was amazed that she had never heard of it. Ten years ago I had not heard of it and yet someone still today did not know anything about it. I am in touch with her quite regularly now and she has been on the GAIN website looking up all the information that she did not have access to.

Mrs Mazzella—I find that very interesting, because I believe there are 600,000 women with endometriosis in Australia. I know a young 32-year-old who had 19 operations for endometriosis. She was not getting her answer, she went over east to have an operation, and still did not get her answer. She is now infertile, she is left alone, she cannot work and she lives with her mother. How many other girls are there out there like her? I want to take this opportunity to talk about the sexual health side of things as well, apart from the psychosocial things. As to sexual health, to get support I think it is very expensive to be able to go to a psychologist but there is also the embarrassment and everything else that goes with it. That is a huge issue that needs to be addressed as well.

Senator FERRIS—We have been looking at how we can best address some of the issues that you have just talked about. Obviously, training is one of the ones for the general practitioners and nursing staff and all the rest of it. Then there is the issue of reassurance. Networks like yours obviously perform a really important role in addressing that. The third one is how to best get people to know how to go about accessing information. You have talked about the fact that 10 years on you still have gaps in that information system. Do any of you have any thoughts on how that could be addressed in a cost-effective way?

Ms Jenkins—I think a coordinated approach is the way to go, somewhere that is highly visible and highly accessible all across Australia for information. The internet is a fabulous tool, but we all know we put something into Google and it is mind-boggling what comes up. Often we do not get to the right places or we get to so many places and we get conflicting information. That is great as a start. We even found, doing some research ourselves about what is out there, that there is a huge amount of networks out there. A coordinated and very visible approach, such as that the breast cancer movement has had, which has been very successful, would be fantastic for gynae conditions.

Mrs Flaherty—In addition, just to strength what Ms Jenkins said, I am rebuilding the GAIN website. Importantly, we facilitate information; we are not going to recreate it. I am looking for centres and websites that women can go to. I am coordinating access to those through our portal. I have found a number of things where I have said, ‘Wow, I did not know that existed,’ or, ‘Is that really the centre or did they say they are the centre?’ I am trying to be very careful with what we are putting out there, too, and making sure that we link women correctly to the right centres. I am looking at all the major centres for all the major gynae health conditions and cancers. Something coordinated is definitely the approach that we would like to see.

Senator FERRIS—One of the things that we found in the last few days is that there is an enormous amount of information around. The difficulty is knowing how to search for it.

Mrs Flaherty—That is right.

Ms Jenkins—That comes back to having that knowledge in your very early formative years, that is, knowing of endometriosis and what the symptoms are when you are a young woman so that, if it does come up in your life, you know what terms to ask for, put in and to search on. As Mrs Mazzella pointed out, the internet is just a start. It is not the be-all and end-all. We use it a lot because it is so accessible, cheap and gives us immediate access. Any coordinated approach must have personal one-on-one. Picking up Mrs Mazzella’s point, it is so important that people know where to start—and the internet is a good way to do that—or where to phone or who they can go and see. That needs to be very clear.

Senator FERRIS—One of the difficulties—and we were discussing this at lunchtime with some of our friends from the lymphoedema group—is that they are not computer literate. A lot of the complications from some of these diseases that are now affecting women in Australia involve older women who are not computer literate, who do not have access to the computer and do not feel confident with it. They might get some scary stories about it, anyway. The telephone is still a preferred method of communication for a lot of those women, and face-to-face is even better, which is where organisations like yours, the Great Gynae Day Out, and all those things are so much more important. I take it from what you have just told us that you would support a national gynaecological cancer group, association or function of some sort in the same way as the breast cancer organisation?

Ms Jenkins—Yes, we would. GAIN would very much support that. We would, however, say that it should be broader than cancers and be conditions as well. The point about a coordinator is that women, if they have multiple different conditions or they suffer conditions after being treated for cancer, they need to know one place to go to and not 15. I think that, again, there needs to be a coordinated approach. GAIN does advocate and we do support a coordinated national centre for gynaecological health.

Senator FERRIS—This is normally Ruth’s question but as she did not ask it I will: do you have much contact from women of a non-English-speaking background or Indigenous women?

Ms Jenkins—Yes, we do. We have a little and we have had a couple of recent examples where we have had women contacting us via our website. We have spoken at a number of events for multicultural and Indigenous women, but not as much as we would like to, and I think that is part of the problem. One of the things that we are doing is putting a focus and a target on multicultural and Indigenous women for our Great Gynae Day Out this year.

Mrs Flaherty—That is hopefully going to be the start of what we want to look at for the next 12 months, working with them to set some programs up. We are hoping that their coming along and being part of our day will encourage them and our relationship further on that.

Mrs Mazzella—I also spoke with a New South Wales Aboriginal women’s group. When I came home, the head lady said, ‘Kath, when I heard you speak, you allowed me to speak more openly to the next group of women and we were able to save one of the women’s lives.’ I also spoke at an Aboriginal women’s group in Fairbridge Farm on a retreat. Even though sometimes my story is not very nice, it sometimes makes women think, ‘Where am I in the picture?’ If you say ‘cervical cancer’ people think, ‘Oh, yes, my doctor takes care of me.’ I think that I have a tool that I can offer. Yvonne McCall from the Menopause Clinic is a wealth of information. With the information that she has gathered over the years so many women can learn from her. She needs to be out in the public, doing the work that she does and sharing her knowledge. Perhaps I could share my knowledge, and not everybody perhaps wants my knowledge. I think that I have a tool, but I just do not how to get there.

Senator FERRIS—That comment leads me into my final question, which is: can you give me some idea of how much it costs you to run your little group? Everybody seems to run on the smell of an oily rag. As we said before lunch, this is very much a heart thing, where people volunteer and do this work for nothing because they care. Your organisation would be typical of a number that do this sort of work. Can you give me some idea of the sorts of costs? I guess you raise most of the money yourselves?

Ms Jenkins—We do. We run on a smellier smell of an oil rag. Our operational budget is about $10,000, and that is raised through membership, donations and money that we raise from our fundraiser the previous year. That is big, by the way; that has increased about tenfold over the last few years. If I were to make a true estimation of all the work that the volunteers put in, I would be saying that we would be at least four full-time salaries running that organisation. It comes at a cost to our personal lives, because we spend a lot of time doing volunteer work, which we do because we are passionate, at quite a cost to our own work. I would say that there is at least those salaries in there.

The other thing that we have is our Great Gynae Day Out, and that is a more sizeable budget, but that is sponsored by a corporate pharmaceutical, GlaxoSmithKline. Also, the Office of Women's Policy in Western Australia contributes to that, as does the Cancer Council. That is a discrete activity. But $10,000 for us is a big budget.

Senator FERRIS—Are all the staff volunteers or do you have a permanent staff member?

Ms Jenkins—We have no permanent staff member. Only in the last two years we were able to bring on via our major sponsorship someone to coordinate our national day, and that is purely for that purpose. They do not get paid as well as we should be paying someone, but that is the reality of our circumstance. We do not have any full-time staff.

Mrs Mazzella—I wish that we could, as a health consumer group, be more accepted by and included in some of the academic issues that are going on in the university. We have so much to offer. It is not just about gynaecology, it is psychological and so on. I think we could be utilised a lot better within the university. Do you know what I am saying?

Ms Jenkins—There is a network of people out there who have a huge amount of knowledge and support to give that could be utilised by other networks that have already been funded. I think this comes down to this issue that we are doing it out of passion, we are volunteers and we have a lot to give. We do not necessarily have the resources but others do have the resources and could use us, if that is the right term. I think that is replicated Australia-wide and internationally, I would suggest, as well.

Senator WEBBER—Would you see that that is therefore something that perhaps a national centre could then look at coordinating?

Ms Jenkins—Absolutely, yes.

Senator WEBBER—And making sure you all talk to one another?

Ms Jenkins—Absolutely. I am very aware of the recent study that *Business Review Weekly* did about the not-for-profit and charity sector and the replication going on. I know it is slightly controversial, but I think there is some merit in this. There is a huge number of people driven by passion and who are limited by resources and often to their own geographical area. If we could bring all of them together in a coordinated way without losing that passion and losing that network of people, I think that would be a huge benefit for Australia and for what we are trying to achieve.

Mrs White—Could I just say something?

CHAIR—We are very informal today. Normally, you would not be able to, but please come to the microphone if you want it on record. We are women; we can do it.

Mrs White—At the Australian Lymphology Conference in Queensland last year there was a group from all the states. We met informally on the Sunday morning and tossed around what we thought was the best way for us to go forward. We thought that a national consumer voice only would be a good thing so that we had more clout. With respect to bodies such as GAIN and others, such as breast cancer, if we had a whole big picture with just one consumer voice, we would have some more clout with government.

CHAIR—I know Senator Webber has another question.

Senator WEBBER—This is probably a good one to wrap it up with. It follows on from something that Senator Ferris was saying. The committee has had two different views about what kind of structure should be recommended and the way forward. I notice you support the priority of a national network. Can I just get you to say on record whether you think that does absolutely have to be separate? I did not learn until we started this inquiry that the National Breast Cancer Centre deals with ovarian cancer, too, so it has been an educational experience for me. I am probably a bit odd in that I think breast cancer means breast cancer, but there you go. You learn something new every day. Do you think it absolutely has to be separate or should we look at a more holistic national women's—

Ms Jenkins—Yes. We are aware that there are two quite separate views on that. Probably our view can be summarised by saying that we would advocate for a separate organisation, mainly because we have to get gynaecology and its very specific issues out there. If it was going to be part of another organisation, such as the Breast Cancer Network, then the name needs to be changed and the priority needs to be equal. Breasts are much more acceptable now, which is fantastic—and I know they always were not. We have to get our gynaecological regions acceptable as well.

CHAIR—Senator Humphries could not be with us today but he had a question that was on his mind. I think it is a very good question. I would like to have it on record for your response. It is a bit similar to Senator Webber's. When this inquiry is finalised, there will be a series of recommendations that we hope will be very positive about gynaecological cancer, and questions will come back, such as, 'Well, it still is a very small percentage of the overall Australian population. In fact, more men die of cancer than women,' which is in the current statistical base. The health dollar is stretched so far. Why should the community expend more money in this area? What is the justification for doing it?' I would really like to have, from your organisation's perspective, a rationale for why more money should be spent in this area.

Ms Jenkins—A couple of things come to my mind. Firstly, I do not think we actually do have the full picture, and that comes back to our discussion about the precancerous, the statistics and other conditions. Secondly, the statistics we have seen show that gynaecological cancers are on the increase, as are other gynaecological conditions. Thirdly, the emotional cost to our community is not measured and we do not know the extent of it. We do know that women, in whatever networks they have, their family makeup, their partner's relationships, are generally those that are dealing with the emotional and nurturing of others. The ripple effect is that, if women are not able to handle their own trauma, that comes at a cost to their wider network and their families. I think it is a bigger picture than actually looking at counting cancer incidences.

Mrs Flaherty—If you have a gynae cancer or condition there are lot of post treatments that you have to go under, and they also have side-effects or they can lead to another condition. You may get captured once for having one thing, yet you may pick up other conditions or you may have a condition that could lead to cancer that is not yet related. That is another important issue.

Mrs Mazzella—I would just like to focus on the precancerous issue. How many women are having hysterectomies, or parts of their bodies taken out as a hysterectomy, as contrasted to what men are having removed? Maybe we would have to have the hysterectomies, but I do not think we understand fully why we are having hysterectomies. If we could do the research and have a better understanding of that, perhaps we could answer that question a bit more. I think women are having lots more operations than men are. If we looked at that a bit more closely, we might be able to give you a proper answer to that. I know there is precancer of the vulva and they are just cut out, but they are not on the statistics. You cut a little bit out of the vulva and it is astronomical, but what are the numbers or statistics on precancer? Is anybody keeping stats on precancerous conditions? We do not know; let us start asking.

Ms Jenkins—For us it is not a woman versus man thing, it is about the bigger picture. Unfortunately, they are the things that, as we said, are not measured so we really do not know the true cost and true extent.

CHAIR—Thank you very much and good luck with your fundraiser next week and with your information days. We would very much like to get some feedback before this committee concludes about how they went, because both of those things will happen before we have to report.

Ms Jenkins—Thank you very much for your time and support.

Proceedings suspended from 2.20 pm to 2.34 pm

SMITH, Ms Tanya Maree, Private Capacity

CHAIR—Welcome. Do you have any comments to make on the capacity in which you appear?

Ms Smith—I am undergoing treatment for ovarian cancer.

CHAIR—Thank you very much. You have received information about the way we operate, parliamentary privilege, the protection of witnesses and so on. If you have any questions as we go through, we will address those. Just so you know, everything will be recorded in *Hansard*, which is a public record. Your information will be shared by the whole group, not just by those who are here today. We have your submission—thank you very much. It was a very personal discussion about what you are going through. We appreciate your effort and we would like to hear more from you. Would you like to make an opening statement and then go to questions or go straight to questions?

Ms Smith—I would like to make an opening statement.

CHAIR—Go ahead.

Ms Smith—Firstly, I would like to thank the committee for the opportunity to present to you today. Each year over 1,300 women are diagnosed with ovarian cancer and over 850 die. Many of these deaths could be prevented if they were diagnosed early. How can we diagnose early? We need to increase public awareness about these cancers and about the importance and implications of family cancer history. I was diagnosed with ovarian cancer and I did not even know it existed. We need to educate general practitioners about all aspects of these cancers and about the importance of a patient’s family cancer history. We need to educate them to investigate the possibility of gynaecological cancer. We need to develop predictive tests where there are none currently available and we need to ensure that genetic and familial cancer centres around Australia put in place a mechanism by which they advise all members of the families they are counselling of their cancer risk. Two years before I was diagnosed, the BRCA1 gene fault was discovered in my family. However, I was not given the information. Had I had the information I could have had risk-reducing surgery and I might not have ovarian cancer today.

Many deaths could be prevented by improved treatments. How do we improve treatments? We need to fund much-needed clinical trials through ANZGOG. The clinical trial I took part in may help redefine the standard of treatment for ovarian cancer patients. Clinical trials are critically important to determine new and better treatments, and we are fortunate to have a dedicated group of specialists at ANZGOG with the skills and expertise in place now to make a difference.

We need to ensure that all women have access to gynaecological cancer centres with specialist medical and psychological staff who can provide the multidisciplinary care needed. This is the minimum standard of care required. My experience is that attending one of these centres has made a huge difference to maintaining my quality of life and in assisting my fight against ovarian cancer. We need to ensure that there are enough highly trained specialists to meet the demands now and in the future in the gynaecological cancer area.

How do we achieve these initiatives? Through Commonwealth funding. There is not nearly enough Commonwealth funding to support these initiatives. In an effort to keep the doors open, many organisations undertake fundraising activities. I have been involved in fundraising activities to support ANZGOG and ovarian cancer. One event in particular, comedy for cancer, was held in 2004. The public support for this event was fantastic, and we are running another event again in November this year in Sydney. While helpful, these activities are still not enough to sustain the ongoing vital work of organisations such as ANZGOG. Apart from funding, we need Commonwealth leadership, leadership in encouraging the many gynaecological cancer organisations to work together and, indeed, to lift the representation and profile of gynaecological cancer in all key cancer agencies.

Finally, when do we need to put these initiatives in place? Now. If it takes two years to fund a public awareness campaign and clinical trials through ANZGOG, 2,600 women will be diagnosed with ovarian cancer and 1,700 will die. If it takes five years to develop a predictive test for ovarian cancer, 6,500 women will be diagnosed and 4,250 will die. It is my hope that I will soon see these initiatives in place and saving the lives of Australian women.

CHAIR—Thank you very much.

Senator WEBBER—Certainly those statistics that you finished your statement with give us the sharp focus we need in terms of recommendations that this committee and others might make. Thank you for sharing a very personal story with the committee. Usually the personal is political or does become political in inquiries like this. I first want to talk about some of the points you make about the lack of consistency in approach and care. You say in your submission that you have been down to the Brownes Cancer Support Centre at Sir Charles Gardiner, which I think is a great centre. Can you tell me how you found out about the care that you are now getting in Western Australia?

Ms Smith—Actually, I have not yet attended the Brownes centre, but I am aware of it. I was given the information from somebody who works at Sir Charles Gardiner. I was very impressed with it and I did some research about it. The point that I wish to make about the Brownes centre is that essentially it is being funded by private enterprise and people are donating their time. To me, it seems like an ideal example of something we could duplicate in every state, connected to every major gynaecological cancer centre, to benefit all cancer patients and their partners. It does not seem to take a lot of government funds and seems to be pretty much self-sufficient. It provides excellent facilities.

Senator WEBBER—You have told us about your treatment in Sydney. In terms of one of the issues that the committee is grappling with, it has been suggested that what we need is some sort of national structure—and perhaps the development of a best-practice model, to use a term that is in vogue these days—that would allow greater collaboration and greater coordination, and therefore some consistency, not just in the treatment but also between treatment, research and so on. As a patient who has travelled the nation, do you think that would be the right way to go? To your mind, if we decided to do that, would it need to be a specialist gynaecological service or should we look at a more overall, collaborative, say, women's health umbrella organisation?

Ms Smith—It would be difficult for me to determine which would be the best way to go, from my experience. However, I would say that I think it is critically important that women have access to a specialist gynaecological cancer centre. Because the medical needs are so multidisciplinary, you need a full team of people through every aspect of your treatment and through every aspect of the disease. All I could really say is that it is very important that each capital city at least have that centre available and, further, that there is some way to ensure that, within each state, major regional centres have access to or are linked to those centres so that the expertise can flow through. Again, I am not sure how that could be done. That probably would be better answered by those more medically expert than I am, but that would be my recommendation.

Senator WEBBER—It would be better answered by people other than me, too, I can assure you. It is more ‘what’ rather than ‘how’. In terms of the diagnosis of conditions such as yours, again, obviously, the first step in this process is increased education. We have two schools of thought about which should be the priority—that is, whether the priority should be public education so that women are more aware of what is going on in their bodies and the signs to look out for or whether the priority needs to be given to GP education, because they are the people that need to pick up the first signs and try and prevent some of those deaths that you have talked about. As someone who has battled her way through the system, from your point of view, should it be an either/or, should it be both? If we do decide to go down the path of an education campaign amongst women, should we be concerned, as has been put to us, that if we do that we will scare most women into thinking that they have ovarian cancer? I would appreciate your views on that.

Ms Smith—To answer the first part of that, I personally believe it should be a dual approach—that, yes, there needs to be an effort in public education but also it is very important to educate the general practitioners. My thought is that they really need to have gynaecological cancer more at the top of their mind than they currently do and, in many cases, they need to be prepared to discount it in the patients that they are treating. Would you mind repeating the second part of your question?

Senator WEBBER—You have answered, probably, the first two of them, in that it should be a dual approach.

Ms Smith—Yes.

Senator WEBBER—As someone who has had this experience, are there any concerns about running a public education campaign amongst women in particular?

Ms Smith—I can well imagine there would be and I think there probably was when we started at the very beginning with awareness of breast cancer, perhaps prostate cancer and many other diseases. There is often a lot of fear at the very beginning of public information about them. However, it is vitally important to do it. I understand that there may be some fear. It is very fearful having cancer. If you have the opportunity to prevent it then it is much better to be a little afraid at that point than to find out later that you have it. That would be my recommendation.

Senator WEBBER—Thank you.

Senator FERRIS—I congratulate you on your submission. It is a very powerful story that you have told. One of the things that I would like to raise with you is the extent of, shall we say, information post surgery. Did someone come into your hospital room and explain to you what is available and what has happened, or has this been something that you have found out for yourself as you have gone along the way? I noted that you say on page 2 of your submission:

> I knew about cervical cancer and the need to have pap smears, I knew about breast cancer, the need to have examinations and mammograms, but I did not know cancer of the ovary even existed.

I think that is a common view. Can you tell us what happened after your surgery? How did you go about finding that you were on a long pathway and who helped you along the way? If nobody did or if it was limited, can you tell us what you would like to see for the people who find themselves in your situation?

Ms Smith—Initially, my surgeon sat with me and explained what had happened during surgery and then I was referred to the Royal Women's Hospital at Randwick under the care of Professor Michael Friedlander for my oncology and chemotherapy treatment. From there, I found the information quite good. Perhaps I needed a little more time. I got a lot of information very quickly. It was in many ways hard to digest everything, but over the ensuing months I got a lot of excellent information about the treatment and the disease and felt very comfortable with being able to ask any of the nursing staff and the oncologists any questions that I might have had and felt quite comfortable with the amount of information that I had. In that instance, I feel I was quite lucky. I was also referred to the genetic counselling clinic at the Prince of Wales Hospital, because it was suspected, and later confirmed, that I had the BRCA1 gene fault. Again, at that counselling service I was given quite a deal of information. It is an excellent counselling service. From there, I did a lot of my own research as well. I can only say that my experience is that the information given to me has been very good.

Senator FERRIS—Do other people you have come across since then have the same view that you have?

Ms Smith—Most of the people that I met while I was having treatment at the Royal Women's Hospital felt very much the same. I certainly cannot speak completely on their behalf, but that was the impression that I got. I think at a hospital like that, with its connection to the Prince of Wales Hospital, it seemed to me that we were able to draw upon any of the services within the campus, and that was a huge benefit. If there was something specific that we needed, in my case the genetic counselling service, I could simply go to the other hospital and draw upon that, and it was very close by. It certainly was a very positive experience, if you can put it that way.

Senator FERRIS—To what extent do you think the social support groups, some of whom have given evidence today, have helped you and do you think that they perform a valuable role in a general sense in supporting people? Do you belong to one? Have they sustained you?

Ms Smith—I do not personally belong to one. I certainly would consider belonging to one but, having moved from New South Wales to WA in the past 12 months and done some travelling, it has not really been suitable for me at this time. I believe they offer an excellent service. While I was in Sydney I relied upon some of the psychological and counselling services that were available at the Royal Women's Hospital, as opposed to joining a group. I felt that I really preferred one-on-one type assistance to being in a group. As you move through this process, your needs change. It is certainly a good thing to be able to sit down with a group of other people who can support you. But, on that point, I would say that it is very important to have that psychological counselling opportunity. It is critically important, because the needs of women with gynaecological cancers are quite unique, and there are a number of areas where psychological counselling can certainly help.

Senator ADAMS—Thanks for your submission. It is very good. You went through the public system; is that correct?

Ms Smith—Yes, I did.

Senator ADAMS—Do you have any friends who have gone through the system? We are trying to identify the difference between public and private, because we have had quite a lot of evidence that has shown there is quite a difference. Have you had any friends who have gone through the private system for gynaecological cancer?

Ms Smith— I am actually in the private system now in WA. I am being treated at a private hospital. The main differences are that I cannot access all of the services that I was able to access when I was in Sydney in the one location on the one day, if you like. My trips to the hospital are more frequent. I sometimes travel to different hospitals for different testing, whether it be blood tests or scans. This all takes time and is difficult sometimes when you are not well. It is more of a strain on my partner and my partner's work commitments. When I was in Sydney, as I explained before, I was able to access on the Prince of Wales campus, whether it be at the Royal Women's Hospital, at Prince of Wales Private or at the Prince of Wales Hospital itself, any of the facilities that were there when I needed to relatively quickly. The system was very well organised in that, typically, a cancer patient could go into the Royal Women's Hospital in the morning, have their blood test, see their doctor, the results would tend to come back very soon after, and you would know whether you were having treatment or your treatment was delayed. If you were having treatment, the treatment was ordered and organised, your medication was sent up to you while you were having treatment so it was ready for you before you went home, and then off you went. It is a much more complex system now. I tend to get my own medication. I do not necessarily always get to see my doctor before I have treatment, although sometimes I do. Tests are done at other hospitals and then sent to the hospital where I am having treatment. Scans are done at other hospitals. I might get them a few days later rather than on the day and then I have another appointment. It is not as compact and as efficient as it was.

Senator WEBBER—You talked about all the support, counselling and so on. Do you think enough emphasis was put on actually providing information and support to your partner and your extended family, or was that job left to you?

Ms Smith—I would have to say that my partner had access to the same support that I had. We were encouraged as a couple and individually to take advantage of that and it was always open to my partner to attend any counselling session that was required. It was very good.

CHAIR—I would like to ask some questions about the identification of the gene, because we have had some strong evidence about that being one of the areas where there needs to be much more research, that that is one of the great breakthroughs. Consistently, in this area there is a discussion around issues of privacy. In your submission you alluded to the fact that you have now got the identification, but for you it would have been better to find out earlier. I would like to get something on record from your perspective. How do you think that should be done, now that we do have the two genes that have been identified? They are not foolproof and everyone knows that, but just how do you think that kind of information should be shared and what should be done with it?

Ms Smith—I think it is very important that the information flow is not left to the family. There are many reasons for that. Families are often geographically separated, they are often not close, and there are many reasons why families do not communicate. For that reason, the responsibility or the initiative needs to be taken by the genetic counselling centres or the familial counselling centres that are available. They are the people who have the information about the gene fault, they are the people who have the information about the families and are in fact studying and counselling the families. I know that there are probably many privacy and legal issues around that, but I think we have to find a way. I do not know if I know how we can do that, but I think we need to sit down and talk about it and talk to the genetic counselling centres about those issues. I am sure they have feelings about this themselves and what they would like to do. This is too important an issue not to discuss it and not have the opportunity to try and work out a way to do it. As I say, I do not know that I have the answer. I wish I did. I am sure there are a lot of legal and privacy issues that will need to be covered, but I think we can find a way to do it.

CHAIR—How did you find out?

Ms Smith—I finally found out after I had my first operation and I was sent some information from a family member.

CHAIR—After the event?

Ms Smith—After the event, yes.

CHAIR—I have one other question about clinical trials and then I will go to other members. There has been significant evidence given to this inquiry and to a previous one about the importance of clinical trials. You mentioned that you were part of one and you raised the point about the inadequacy of funding and how that is an essential element of your proposition that came before us. Can you tell us a bit about your experience in the trial? What benefit was it to you to be involved in the trial?

Ms Smith—The benefit of being involved in a trial is not always one that is obvious while you are going through it and, in my case, it certainly was a harder road because the treatment was a longer treatment and had some more side effects.

CHAIR—Was that at Prince of Wales?

Ms Smith—It was at the Royal Women’s at Randwick. But on the other hand, the level of follow-up was much greatly increased because I was on a trial. I was given basically weekly follow-up and had a weekly involvement with nursing staff, research staff and, of course, the oncologists. Every little aspect of what you are going through and feeling is noted, recorded and dealt with. There is very focussed attention, which can be quite beneficial for you. But long term, I think anyone who has been in a trial realises that you do so not only to try to benefit yourself, which is probably unlikely in the short term; in the long term it is benefiting everybody who has ovarian cancer. The information is invaluable. As I stated in my submission, it may change the way in which standard treatment is given or what standard treatment is given. That is critically important. We need that. It is crucial. In Australia we are lagging way behind in those kinds of trials. They are the only trials that are really going to make a difference to treatment. I guess my real point is that, if we have to wait five years for a predictive test, what are we going to do in the meantime? We have to treat this disease. We cannot put all of our eggs in the predictive test basket. We have to be able to treat it and we must be able to develop better and more effective ways of treating it. The only way to really do that in the correct scientific way is through a clinical trial.

Senator WEBBER—At the beginning of your submission you outline your personal experience. Unfortunately, it seems from the evidence we have had that it is all too common; that it was your insistence that got you to where you needed to be. Can you perhaps share with us what led you to be that insistent? What was the process you went through that got you to that point? To what extent do you think that it was that initial insistence that means you are where you are today? What would have happened if you had not been that adamant at the beginning?

Ms Smith—Because the symptoms of ovarian cancer are so vague, when we are busy, are working long hours and have a very busy working life, we tend to gloss over what is going on. It is very easy for someone like a medical practitioner to almost back that up. But I got to a point where I thought, ‘Something is really wrong and I need to do something about this,’ and at that point I launched into action. That action meant going to a doctor and insisting on some tests. While I was waiting for those to come about, I was able to talk to some friends who were in the medical area who gave me probably the most valuable recommendation I could have, and that was: make sure you insist on seeing a gynaecological oncologist. At the point where I was getting a referral that is what I insisted on. That was reason I did insist on that. That was the most important piece of information that I got. They were not able to diagnose me before they operated. At the point of the operation, the best person to have on my team was a gynaecological oncologist, who could remove as much of the cancer as possible, which is what happened and which gave me my best chance for survival. That is why I think that is critically important.

Senator WEBBER—At the moment it is patient insistence that gets you there?

Ms Smith—Yes, I think so.

CHAIR—Do your friends know that that advice was so important? It is a critical piece of advice through a friendship.

Ms Smith—That was from a friend who had some medical experience. I do not know whether she knew how important that was for me, but she just knew that it was important for surgical reasons from her experience working in hospitals. I think her view was that, if you were going to be operated on, you needed to be operated on by a gynaecological oncologist.

CHAIR—And you were fortunate enough to be in Sydney, where there were very good ones.

Ms Smith—That is right. That was the other key point. There are not very many of them, and I was—

CHAIR—Thirty-five. That is the best; we have got the list. In terms of the process, it is knowing that and having the strength, through all those networks now, for that advice to be given to women. Ms Smith, is there anything you would like to add? You have given us a lot of information—a double-whammy: your written submission and a thought-out presentation this afternoon. Is there anything else you would like to leave us with this afternoon?

Ms Smith—No, not at this point. Thank you.

CHAIR—If there is something that you think of that we need to know in the next couple of months, please forward it to us. As I have said before, this is an important inquiry. Thank you for your time.

Ms Smith—Thank you.

Proceedings suspended from 3.09 pm to 3.32 pm

KOSKY, Ms Michele, Executive Director, Health Consumers Council, Western Australia

CHAIR—Thank you very much for your time and your submission. I know you have done this kind of thing before, so you know all about the processes. From having read it, I know you have discussed your submission with at least Senator Adams. Do you have an opening statement to make? Then we will go into questions.

Ms Kosky—The Health Consumers Council is a unique organisation in Australia. It is the only funded patient advocacy organisation in the country in the sense that we provide a public service. We provide telephone and personal support and advice to consumers who ring us. We go with people to their medical practitioner or their health provider and we provide them with, I suppose, a very direct service and very direct assistance. That gives us a unique opportunity to comment about what consumers have reported to us regarding the issue of gynaecological cancer.

Senator ADAMS—Thanks for coming. I note you have written a very good submission on my favourite topic, PATS. We will start with PATS and go to the access for women with gynaecological cancer in Western Australia, the problems you have had as a council, and the issues that have been raised with you.

Ms Kosky—The issues are around what in a way could be a metaphor for the whole of health: the lack of integration, the lack of coordination, and I think a view by the West Australian government, regardless of its political complexion, that PATS is a treasure that is known to the Department of Health but ‘we certainly would not want rural communities to know about it because then they might use it, and then we might have to seriously fund it in an appropriate way’. It is fragmented; it is not promoted; it is made very difficult for people to access. It does not provide a sufficient range of choices in areas, I think, for women’s health, although I am conscious I am making a generalisation in this way. I just think that women with gynaecological cancer, like women with breast cancer, develop a relationship with their treating physician. If you are a woman from the country, you are unable to do that because you have to go to the nearest specialist service, which may be in Perth, in Port Hedland, in Esperance or whatever. So your capacity, I suppose, to work in partnership with your treating physician is limited because of the reduction of choice and because PATS only subsidises under certain criteria. We think that is very regrettable. We think, in fact, the problems with both the Patient Assisted Travel Scheme in Western Australia and the Isolated Patient Scheme in other states and territories is probably worthy of its own Senate inquiry.

Senator ADAMS—We do have it, of course?

Ms Kosky—No, not at all. No, we have not. I am just looking at a submission we did some years ago where consumers reported back to us that PATS can only be accessed through a general practitioner, and patients find that problematic. We are hoping that, with the reform of health services in Australia, when nurse practitioners might have much of the role of general practices, then that might make it easier for women to access PATS services. PATS forms are difficult and complex to complete. I would have to say we have been talking with Western Australian country health services about PATS for about 10 years, but in a more serious way in the last two years, and they have agreed that they have a problem. We are currently redesigning all of the information around PATS but also thinking in a novel way to encourage PATS clerks to understand that they are in fact providing a service to the community as service providers and they are not in charge of Aladdin’s Cave and not allowed to let anyone in. So we are very pleased that a service mentality will be adopted by PATS clerks in country services in Western Australia. We think that is a very good move.

In addition, women with cancer and patients generally report that public transport and transport is a health issue for country people and it is something this committee could well note. The whole lack of availability of public transport within country towns, between country towns and then between country towns and regional centres is something that is raised with us often. I understand this is not a Senate inquiry into rural transport, but I think it is important to note that for country people it is a very major issue. There is a great deal of reliance, in addition, on the Royal Flying Doctor Service that women have reported and they are always concerned that the Royal Flying Doctor Service may not be available for their emergency transfers. I am sure if the RFDS is speaking with you they will raise their own issues. That was a very long opening statement; I even got tired.

CHAIR—We seem to be surrounded by Western Australians. I am sure they have very good questions.

Ms Kosky—Good.

Senator ADAMS—Can you comment on the multidisciplinary team for women with cancer, and specifically gynaecological cancer, from your consumers’ point of view?

Ms Kosky—Only that people welcome the involvement of a multidisciplinary team, but they would like to have someone that is coordinating their care. They do not want to tell their story to eight different people with no sense of coordination or integration. Case management is a bit of a popular cliché at the moment, taken from mental health, and it seems that cancer is going to take a bit of a case management approach in the acute sector. We would say that care coordination is absolutely critical to the effective use of multidisciplinary teams. People certainly appreciate the availability of people beyond medical practitioners.

There is also often a desire for people to in some way control their own health destiny by the use of complementary therapies, which I think is highly evident from the Senate inquiry into cancer services.

Senator ADAMS—Something that has come up quite often is the difference between the treatment for women with gynaecological cancer in the public sector and the support with a multidisciplinary team as at Royal Perth. When you go there for breast cancer, as I have been, you have all the different disciplines looking at you specifically. With gynaecological cancer we have found that the private hospitals have a very ad hoc approach, whereas the public hospitals have the team there. Have you had anything coming back to you from the—

Ms Kosky—Dissatisfaction with private hospital care?

Senator ADAMS—Just as to the difference between the two, as to where the better care appears to be, and focusing on the team approach?

Ms Kosky—The public system, yes, without a doubt. People think that they are going to get a different and better level of care in the private system, but often they report back that they are very disappointed because they seem to be limited just to their medical practitioner and no-one else meets with them, talks with them, discusses their issues or provides any additional treatment for them.

Senator WEBBER—We will continue on with the Western Australian flavour. Accepting what you said earlier about your organisation being unique and highly valued, in looking at the development and the evolution of treatments like the discussion of the approach we think we should take to gynaecological cancer in the previous cancer inquiry, is there enough recognition of the consumer voice? Is that coming across loud and clear? Do we need to perhaps look at making that a bit more formal in the way we approach things?

Ms Kosky—I understand that the Australian government are establishing something called Cancer Australia. I understand that the chief executive has not yet been appointed, although you may know more about this than I.

CHAIR—Imminently.

Ms Kosky—Imminently? Good. That has been quite a long search for this person, I have to say, and I am not sure what level of people with cancer are involved in the decision-making in that organisation. Cancer organisations have come late to consumer participation, but they are well ahead of diabetes and arthritis, certainly in this state. Nationally, women with breast cancer have been great advocates for improved treatment, care and research. I think that the greater consumer involvement the better, but there could be great improvement.

Senator WEBBER—From a consumer point of view, obviously being diagnosed with any form of gynaecological cancer would be what I presume is a very traumatic experience. I personally have been fortunate enough not to experience that. From your point of view, do we put enough effort into, and do we know enough about, the psycho-social support that these women need? We have met and heard extensively from the medical experts and we have heard about the research, but do we know enough about how to look after the woman, as such, and what other supports she needs?

Ms Kosky—It is difficult to privilege gynaecological cancer in the body as against breast cancer, ovarian cancer or whatever. I just realised that ovarian cancer probably is under gynaecological cancer.

Senator WEBBER—You will find it in the National Breast Cancer Centre, apparently.

Ms Kosky—The NHMRC passed a very good evidence-based document two years ago on the psycho-social management of people with cancer which absolutely understood that psychological support was critical to both people’s treatment and being able to monitor their illness effectively. I would never use the word ‘cure’ anymore, but I think there is a real opportunity for better psycho-social integration in cancer care generally, particularly for women with gynaecological cancer, just because I think it is very private and often viewed with some degree of shame and guilt. We do not have very healthy attitudes to sexuality and genitals and all of that stuff in Western society, and I am not sure that we have it anywhere in the world.

I am just about to say the last thing I was thinking on my way here, which is a really stupid approach to being intellectual. I was thinking how interesting it is that we do not even consider the whole breast self-examination. We do not even think: should we be promoting some self-examination in gynaecological care? Should we be adopting a better ‘Women, know your bodies a bit better’? Do we need to understand how our bodies work better so that when things go wrong we have the capacity to understand that something has gone wrong and not be entirely reliant on medical practitioners, who also I think often find the examination of women quite problematic.

Senator WEBBER—Indeed, we had evidence of that just before you came here, and other evidence we have had is of the women that seem to get through this intriguing journey from starting to feel ill to some form of medical intervention and medical treatment. Certainly the message I am getting loud and clear is their access to that has more to do with their insistence that something is wrong than medical knowledge that something is wrong. Some of that seems to be the generic symptoms, the initial symptoms, you will have of bloating, tiredness and just knowing it is not quite right. So, yes, it seems to rely on assertive and therefore probably well-educated consumers rather than anything else.

Ms Kosky—So there might be a recommendation considered from this inquiry that there be a consumer-led mapping exercise to develop both a program and a resource that assists women to understand the likely pathway of gynaecological cancer. I just think it is going to drift unless this inquiry takes some control. I think it is a very fragmented area of health and, unless someone becomes the gynaecological champion in the Australian government, then once again it will just drift.

Senator WEBBER—When looking at those kinds of supports, we have had evidence saying that we know what the support is that we need to give women, we just need to get on with it and do it, versus other evidence that says, well, you look at the diverse backgrounds and therefore cultural issues that we have in the Australian community now and perhaps we do not know enough about the language in which we need to communicate with these women and therefore what cultural support they are going to need. What would be your view? Do we know enough, do you think? Is it just matter of taking those guidelines and doing it?

Ms Kosky—I do not know what we know. I think the evidence you have received could well have come from researchers, which would surprise none of us, so let us do some more research. I am more interested in practical services on the ground. We are not going to have a ‘one size fits all’ psychological support service for all people with cancer in Australia, we are going to have some sensitive delivery of housing and support that recognises that we are a multicultural society and includes Aboriginal people as well. I would be reluctant to do the floor research, let the researchers take six years, then we will develop something, so that 10 years down the track we might actually have something.

I think the work that was done two or three years ago was very good work that could be built on pretty quickly to find out what people from non-English speaking backgrounds wish, what women with gynaecological cancer wish, what kinds of supports they would like around them and how sensitively that needs to be managed, especially in cultures that are very different to our own. That should not take too long at all.

Senator FERRIS—My questions relate very much to the issues you have already covered. One of the difficulties that women facing gynaecological cancers discover is that they frequently know nothing about it, even though they are well-informed health consumers and well-informed about their own health. They suddenly find themselves at the start of a pathway that leads them into the unknown. Yet, by numbers this is a very serious type of disease. Do you have any comment on the extent to which starting off with girls at school with sex education and learning to understand that, just as we now know about pap smears and we know about breast cancer, we also need to know about some other forms of gynaecological cancer and how early we should start these messages.

Ms Kosky—Oh wow! I suppose I have a kind of 60-year-old's resistance to starting off scary stuff at school. I think that within a broad sexual health program you could certainly talk about gynaecological cancer, but we do not want—

Senator FERRIS—Gynaecological health.

Ms Kosky—Gynaecological health, sure. I think within a broad sexual health framework that would be extremely useful. In fact, I think sexual health has ignored gynaecological health at its peril for a very long time. It probably needs to be firmly placed on the sexual health agenda in Australia. It is very similar in some ways to the way breast cancer was managed in the 19th century. It was a disease of shame; people did not go forward; they died without any treatment whatsoever. It seems to me that where gynaecological cancer is now breast cancer was 80 to 100 years ago.

Senator FERRIS—Or even 20 years ago.

Ms Kosky—Yes.

CHAIR—I want to ask one last question about the argument about positioning in the community the issue about focusing on gynaecological health amidst all the competing causes and issues that are seeking acknowledgment and funding. Why should gynaecological health be prioritised?

Ms Kosky—Because we have made very considerable advances in breast cancer and it is a very serious issue for women. We do make up 50 per cent of the population so I just think on the grounds of equity it would not be unreasonable to say that, as part of the fight against cancer, we should be looking at gynaecological cancer as well as all other forms of cancer, and we should persuade the powers that be that this should be a health priority worthy of investment for three to five years, with a proper evaluation, and we could see if we have made any difference whatsoever. But I think it should be prioritised just on the grounds of equity.

I talk in my submission about the piece that Kath Mazzella, who is present today, wrote in the *Woman's Day* about the terrible isolation felt by those women who wrote back to her. She showed me some of the letters, and they were heartbreaking. So I think it should be prioritised on those grounds too. I think particularly for marginalised communities, for women in rural and remote Australia, this is a very, very serious matter and it is a matter that needs the leadership of the Australian government. I am hoping this Senate inquiry will provide that.

CHAIR—Thank you very much, Ms Kosky.

[3.55 pm]

CASSIDY, Dr Barry, Visiting Radiation Oncologist, Western Australian Gynaecologic Cancer Service

DUFFIELD, Mrs Valda, Social Worker, Western Australian Gynaecologic Oncology Service

LEUNG, Dr Yee, Gynaecological Oncologist, Western Australian Gynaecologic Cancer Service

MILLWARD, Professor Michael John, Cancer Council Professor of Clinical Cancer Research and Chairman, Western Australian Clinical Oncology Group

PICKSTOCK, Dr Sarah, Palliative Care Physician, Western Australian Gynaecologic Cancer Service

CHAIR—Good afternoon, and thank you for giving us your time, as well as your venue. We ask any or all of you to make an opening statement on record and then we will go into a discussion process with the senators. Does anyone want to make an opening statement?

Dr Leung—I have been asked to do so on behalf of the group here. I will start by presenting a statement. Each of us is very prepared to answer any particular questions. Some of us will have particular expertise in a question you may have for us, and we would delegate it to that particular person.

We believe that in Western Australia we currently deliver world-class care for women with gynaecological cancers. Despite this, we recognise that there are aspects of the delivery of our care to the women of Western Australia that can be improved. We also see a role in raising the awareness of gynaecological cancers in Western Australia to the women in this state, as well as to our fellow healthcare providers, through educational programs. So we do welcome the Senate inquiry into gynaecological health as a mechanism that will hopefully allow us to achieve these goals through the provision of funds and other initiatives. We speak only for gynaecological cancers, because that is our area of expertise, rather than other gynaecologic health issues.

Care for women with gynaecological cancer is best delivered in a multidisciplinary fashion. This is achieved for the majority of women with gynaecological cancer in Western Australia. Members of the multidisciplinary team in Western Australia include the patient’s family doctor, the gynaecologist, gynaecologic oncologist, radiation oncologist, medical oncologist, pathologist, anaesthetist and palliative care physicians, as well as our allied health professionals including nurses, physiotherapists, dieticians, social workers and psychologists. The patients also have access to special interest clinics. We do have a clinic at King Edward and you have met with the ‘menopause symptoms after cancer’ clinic, so there are those special clinics as well.

In Western Australia, we have a centralised Western Australian gynaecologic cancer service based at King Edward for uninsured public patients. This hospital, you will have seen, is a freestanding women’s and neo-natal institution. Consultative services for gynaecologic, radiation and medical oncology are provided, along with palliative care, anaesthetic and pathology services. Our colleagues are very supportive of this centralised service and refer the majority of patients with gynaecologic cancer to our service. For privately insured patients, three certified gynaecologic oncologists—that is myself, Dr Ian Hammond and Dr Tony McCartney—manage women with gynaecologic cancers in large metropolitan private hospitals in conjunction with visiting medical oncologists and radiation oncologists, as well as palliative care physicians and pathologists.

There are proposed changes to the delivery of health care for the women of this state. The state government is committed to a relocation of this hospital to Sir Charles Gairdner Hospital, which is an established large metropolitan hospital. In our submission, we propose that the establishment of a National Gynaecologic Cancer Centre similar to the National Breast Cancer Centre concept would help address some of these issues that we see are lacking or may be improved with our health delivery. This centre would be critical in coordinating the following functions, and I will just outline six major ones. Much has been said about screening, and we do have a very well-established cervical cancer screening program. It is mature, and this has been reflected by a decreasing incidence of cervical cancer. So that is a very mature and well-established screening program.

Endometrial cancer presents as an early stage in 75 per cent of cases. There is not really a precursor natural history in this cancer, so it is not really amenable to screening. Much has been said about ovarian cancer screening; however, the majority of these cases present late, at an advanced stage. Until a novel screening tool is available, current methods are handicapped by the high incidence of false positive tests. In other words, they will pick up things which are not really cancer and cause undue anxiety. A National Gynaecologic Cancer Centre may help coordinate ongoing updates in the latest in these screening programs. The other cancers, such as cancer of the vulva and vaginal cancer, are quite low in incidence and therefore a screening program is probably not effective, given the low incidence and prevalence of these cancers.

The second aspect of a gynae cancer centre could be an involvement in education. Education comes in many different levels. Our cancer service in Western Australia provides subspecialty training of gynaecologic oncology for fellows or, in other words, gynaecologists with a special interest to pursue a career in a subspecialty of gynaecologic oncology. The position here is very popular for both local and overseas doctors. It is very competitive and they look at coming to spend a year with us for training in gynaecologic oncology. Dr Farrell, who is in the audience, is one of our fellows. She is from Sydney. Three gynaecologic oncologists are available to gynaecologists for consultation and advice. We also help train our colleagues in surgical techniques. We have always been available for emergencies. We provide telephone advice for our colleagues.

We have also been involved in updating general practitioners, allied health workers and the public through lectures, workshops and seminars. As you can imagine, our workload is pretty tight. Our clinical workload is very heavy. Perhaps a national gynaecologic centre may assist us in streamlining educational programs and provision of resources that would help us with our current workload.

Provision of medical care is the third aspect of the cancer centre that may help. In Western Australia, patients are referred to the Western Australian Gynaecological Cancer Service or to our private consulting rooms, depending on whether they are public patients or privately insured patients. Following assessment, various investigations may be required, including very complex imaging studies or blood tests. In an ideal world, you could have this as a one-stop shop, but that is not really feasible. So in reality this is an area where significant improvement could be seen and would be welcomed by both us and our patients, whether they are public or privately insured. Hopefully, the Senate inquiry will see this as an area of need and make appropriate recommendations to address this, not only for patients with gynaecologic cancers but also other patients with cancers.

The treatment guidelines are available in various states. With available evidence based medicine, it would be ideal to have a uniform guideline throughout the nation. A national gynae cancer centre would go a long way towards providing such guidelines and would be available free to both health professionals as well as members of the public via the internet, if that is what they wish. Each gynaecologic cancer unit at present has some sort of a database on patients. A national gynae cancer centre could potentially ensure adequate funding of all units to maintain an up-to-date and accurate database that would also be centralised and allow us to do studies, such as patterns-of-care studies, to improve our delivery of health care.

In Western Australia, provision of the treatment is fragmented, with patients receiving surgical intervention at King Edward. They may need to go to either Fremantle Hospital, Sir Charles Gairdner Hospital or Royal Perth Hospital for the chemotherapy. Radiation is sometimes delivered at different sites, such as Royal Perth Hospital and Sir Charles Gairdner Hospital, and we hope that this can be addressed with proposed changes to the delivery of health care in the state as the relocation process of King Edward to Sir Charles Gairdner occurs.

With our population base of two million, we are unable to provide care in regional areas because most of the population are clustered in certain towns and cities. Only four cities outside Perth have gynaecologists, although other towns have visiting specialists from time to time. We do provide consultative support to our colleagues. They can either fax us or telephone us. Perhaps a telemedicine type approach at prearranged times during the week may be of help where, as a multidisciplinary team, we can actually provide expert advice for some of the complex patients that go back to their rural community. It is something again the inquiry may help assist in identifying and working on.

For the allied health services in Western Australia, there is a discrepancy between what is available for public and private patients in accessing allied health care. Public patients at King Edward are very fortunate to have ready access to a wide variety of these services, such as stomal therapy, pharmacy, physiotherapy and the others I mentioned such as social work, dietetics and psychological medicine. In the private sector, the provision of these services is very fragmented and at times costly to the patient. A gynaecologic cancer coordinating program of some sort, comprising a team of nurses, social workers and clerical staff as well as doctor input, would allow both public and privately insured patients to access these various services as again a one-stop shop concept.

The funding of these provisions as well as funding for a private gynaecologic cancer centre for private patients to access these services could be considered, and a national gynae cancer centre may help coordinate these teams and identify where patients can access these services and make sure that they do not slip through the gaps in terms of accessing physiotherapy, dietetics or whatever as necessary.

We have also identified a special needs group, and a gynae cancer coordinator could ensure that outpatients from remote areas or new immigrants are not disadvantaged by ensuring an uncomplicated journey from their diagnosis in the hometown to the investigation, some treatment and follow-up that is undertaken in the metropolitan centres such as King Edward.

Another area that needs to be urgently reviewed is the PATS system, or Patients Travel Assistance Scheme. This is a very unwieldy process for our patients in country areas. Rural patients have to go through a very convoluted process of applying for travel assistance through rural administrative staff that sometimes makes them feel like second-rate citizens. I think that is wrong. A national gynae cancer centre could help streamline such a process and administer assistance to our rural population as they require it, without them having to go through all these hoops.

I turn finally to research. Whilst we have been involved in research as an institution, both basic science with an ovarian cancer study and currently an endometrial cancer study, and also been involved in multicentre clinical trials with the Australian and New Zealand Gynaecological Oncology Group as well as the United States Gynaecologic Oncology Group, the population base in Western Australia alone restricts independent research activities, only because of our small size. So, if we were to be effective in our research, something like a gynae cancer service centre could help because currently individual units have to apply to be involved in multicentre trials. If we had a gynaecologic cancer centre, they would be able to coordinate all the gynae cancer units in Australia and allow more participation in international trials from the United States, Europe and elsewhere. That would be of great benefit to our patients.

I am going to stop there because I am sure you do have lots of questions and it is late in the day. The other members of my team are waiting to speak, I can assure you.

CHAIR—Is any other member of the panel wanting to make a general contribution at this stage on behalf of the medical oncologists, the palliative care people, social work, or radiology?

Mrs Duffield—Can I clarify something that has been said on our Patient Assisted Travel Scheme. Dr Leung is right. Sometimes, because it is a subspecialty area of gynae-oncology, patients have to jump through the hoop of, ‘Why can’t you just see the gynaecologist up here,’ and often if they are quite symptomatic and looking like perhaps they have ovarian cancer or something like that, they really want a support person to come with them, but they may not be able to afford for that person to fly independently. The PATS system has capacity for an escort to come, but I have had the experience of a patient being told, ‘But you don’t need your husband to carry your bags,’ which is really frustrating for us. We have really distressed women here whose partners are quite remote. They could be from Broome or Kununurra or Esperance, in the south. That is something I would definitely support in that submission.

CHAIR—It is just more stress in the whole process.

Mrs Duffield—Then they just do not recover well after their surgery because they are here on their own.

CHAIR—Professor, were you wishing to speak?

Prof. Millward—I was going to make a statement a little bit on behalf of medical oncology, perhaps to back up what Dr Leung has said regarding the critical importance of care coordination for women with gynaecologic cancers, and, indeed, all patients with cancer. We have a problem in Western Australia in that the gynaecologic cancer hospital is separate from the centres where women receive chemotherapy or radiation therapy for their cancer if they need it. This undoubtedly makes the journey for the women more difficult and coordinating that journey more difficult. We do hope that the plan that the state government has announced to relocate King Edward Hospital will improve that, but it will not fix the problem by itself. We find patients with other cancers, even if they are getting all their treatment in one place, not infrequently saying they feel it is not very well coordinated.

Coordination of cancer care is not just a matter of physically bringing treatment facilities close to each other or having one-stop shops; it involves the important role of the care coordinator that Dr Leung has outlined. This is particularly important also if some of the women are going to have some of their care delivered in major regional centres. There are some facilities for medical oncology in regional centres, but they do not operate on a subspecialist model and they will rely on coordinating care between people practising in that community and a gynaecologic cancer major treatment centre in Perth. So we do need to be aware of that, and the role of coordination will be more important as care gets more complex and survival from cancers improves. So, women may experience longer survival but require more episodes of treatment and more episodes of care. Again, coordination of care is crucially important.

CHAIR—Are you wishing to say something about palliative care or radiology, Dr Cassidy, at this stage?

Dr Cassidy—Not really, no.

CHAIR—I know that Senator Adams will have questions. I am sure all senators will, but I will go to Senator Adams first as this is her home base.

Senator ADAMS—I am also a rural breast cancer survivor and I went through the public system, so I was going to ask you about how your private patients got on, but you have already told me that. This inquiry has been coming up. We have had two days of hearings in Sydney and one day in Melbourne yesterday and the marked difference between someone as a private patient or a public patient with multidisciplinary teams is just coming through loud and clear. So thank you for that particular statement because it saved a little bit of time for the questions I was going to ask.

PATS is one of my big problems, having been involved with that for many years as a member of the hospital board, the Metropolitan Health Service Board and all the other things that go with it. It is a nightmare. You have said this might be something that a national gynaecological cancer centre could actually have as a review. I know Michele Kosky said the same thing in her submission. Really and truly, we have had a terrific amount of evidence from the other states with the same problems. You have mentioned the person travelling as an escort. Unless it can be signed that the person travelling as an escort can do something medically for the patient, forget it. It is just absolutely crazy. In the Northern Territory the Indigenous patients may have an escort and anyone else may not. Of course, for any oncology or major surgery there they have to go out of the Territory, anyway. So there are huge issues right throughout the nation, but I think Western Australia is probably one area where we can really demonstrate it.

The other thing is the referral to the nearest specialist. I do not want to sound disparaging about some of our general surgeons who are still remaining in rural areas. There are not many of them, and they do tend to do whatever they can do. But how does a GP, when referring a patient, bypass a regional centre, such as the southern area where I am, where there is a general surgeon and someone who could probably take out a tumour or take this out or do this, and get them to Perth, to an area where they can be treated in a specialist area? It is very difficult. A number of constituents ring me and say, ‘Can you help?’ I suppose, with my medical contacts, they think I can do something. But it is just so hard. I do not see why any rural person should have to go and fight a PATS clerk in a rural hospital because they have run out dollars. I know when I was first treated they said, ‘PATS is available,’ and I said, ‘You have to be joking. Me, as a member of the Metropolitan Health Service Board, asking for PATS in my community town? Goodness me. No way.’ But there is a lot of discrimination, which is just not fair. Someone who is newly diagnosed with a gynaecological cancer has to come to Perth—that is, if they can get in. Then they are told, ‘But you can afford to drive up.’ There are so many issues. This is where your psychosocial consideration comes into it. You are diagnosed; you have no-one to go with you; you have one car. You might be able to drive to Perth. You get to Armadale; then where do you go? You are not game. Where do you park your car? That was the first question I asked, actually, ‘Where do I park my car when I come in for all my tests?’

There are lots of little issues like that. They might seem small, but they are pretty big when you are faced with all this. You have kids; you have shearing; you have all these other things going on in the background and you forget about yourself. You have three people here who have had cancer so you are talking probably to the converted. A lot of what has come up has just given us a lot of support in that people are thinking the same way we are. Because of that we can really force a lot of the issues forward that have come up in the inquiry. As to clinical trials for rural people, the attitude is, ‘If you live outside the city, we don’t want you.’ When you are putting yourself forward to be in a clinical trial to help someone else, that in itself can be just a slap in the face. It has really frustrated me. I have managed to do one for lymphoedema.

CHAIR—I was wondering when you were going to ask a question.

Senator ADAMS—I am coming to the question. I was just going to ask you to consider including rural patients in clinical trials.

Prof. Millward—I can address that question to some extent because one of my hats to wear is as a clinical trialist. Personally, I go out of my way not to exclude people from outside Perth from clinical trials, but it is undoubtedly more difficult for them if the trial demands additional tests, additional appointments or additional time away from home. Patients who live in the metropolitan area will find that easier than patients who do not. That is not an absolute reason why clinical trials should not be offered to people from outside Perth. However, I have had experience where patients on clinical trials who have been required to come to Perth for their trial have been knocked back from the PAT scheme. The PAT scheme will not support patients who travel for clinical trials and it will not support people who come for clinical trials as opposed to normal care. So there is discrimination against the participation of regional and rural patients in trials from the system, not necessarily from the trial itself.

Senator ADAMS—Could you give us an indication of the number of your patients, either with radiation oncology or with the surgery, that get lymphoedema, because this is a problem that also has raised its head right throughout our evidence, and we have had the Lymphoedema Foundation here today giving evidence as well?

Dr Leung—Just by way of explanation, lymphoedema occurs only if we do a lymph node dissection. The number of patients that we actually need to do an extensive lymph node dissection on is not great in the overall scheme of things. Of the people that we do perform lymph node dissections on, perhaps 10 per cent will have troublesome lymphoedema, and that is probably the same regardless of where the lymph node dissection is performed. I am not trying to demean or minimise what you have, but for a patient to drag along a very heavy leg is a little bit different, I think, from somebody with an arm type problem. For our rural patients particularly, or even for some of our private patients, access to lymphoedema clinics is difficult. If they are from the rural country areas they may depend on what physiotherapists are available in that town who may or may not be trained in lymphoedema care. For private patients, they have to be seen privately, which can be very costly, especially if they do have troublesome lymphoedema, to go back repeatedly for care. Another alternative is to go to a lymphoedema clinic at Crawford Lodge, which not only looks after our patients but other cancer patients, so they are overloaded in terms of what they can manage.

CHAIR—Does anybody want to comment from the radiation side on that?

Dr Cassidy—Only that if radiation is added on following a lymph node dissection, the rate of lymphoedema goes up, but the other problems are similar, of course.

Prof. Millward—I make just one comment on the subject of lymphoedema which is going to be completely separate to the purpose of this inquiry, but one of the most distressing things that I have noticed in patients with lymphoedema has been men with lymphoedema. Men get lymphoedema the same as women if they have dissections of lymph nodes under their arm or in the groin. If they do, they can have just as bad problems, if not worse. Men’s arms are sweatier and hairier and they may need to do more heavy manual work or, at least, may not be able to stop doing that type of work. Some men have found that if they do access support for this they are a bit of a freak, because these services are set up for breast cancer women, and men with lymphoedema are treated a little bit differently.

CHAIR—It is good to have that information.

Senator WEBBER—I am another local, absolutely. It is not often you get to say I am the lucky one because I have not had cancer, but I am the one of the four of us that is, at least, healthy in that respect, if not in lots of the rest of my life. I want to return initially to your comments about the screening processes we have for lots of other cancers, breast cancer, cervical cancer and whatever. One of the challenges we have in Australia, and in Western Australia, is getting that screening process out to the Indigenous community. Therefore, we obviously have an increased incidence then of having to treat the cancer. Do you have any recommendations on what we need to do to actually increase that?

Dr Leung—Some of our colleagues actually go to those communities and offer a service. I really am very proud that they actually do that, and it is often out of their own time. To provide more support for them is what we need to do, to encourage them and to support them in that whole process, because the service that they provide to those communities cannot be underestimated. Furthermore, if they have more time and more support they can probably train some of the local Indigenous people to be nurse practitioners, to take pap smears, to do those things and to go out because, as you are aware, in some of those communities the women are very shy and do not want to be looked after by somebody who is not of their community. Sometimes it is the opposite: they prefer not to be looked after by someone of their community. So each community will be a little bit different in what they need, but to provide ongoing support for those of our colleagues who do that would be great.

Senator WEBBER—As I say, I am lucky, I have not had this experience, but I am learning a lot about it along the way. If I end up being diagnosed with one of these cancers, it is my very clear impression from the last few days that for me to access the kind of team approach and to be looked after as a whole person, I need to be a public patient rather than a private patient, that that is where I would get that overall coordination rather than having to find my way through the myriad systems. First, is that perception right? Second, we have all these incentives built in saying we should take out private health insurance, so what do we then need to do to make sure that the private system can look after people as well?

Dr Leung—I think you are almost spot-on in your assessment in that, if you are a public patient in a tertiary institution such as King Edward or perhaps the institutions that you have been to, you will find that access to those ancillary or allied health services is a lot easier because they are centralised and they are freely available. We are very fortunate in this state that the services that support us are fantastic. We do not underestimate that at all. As a private patient it is much more fragmented. It is dependent, I guess, on us as individual gynaecologic oncologists to be cognisant of and to be aware that there may be other issues, but it is uncommon for me to say to a patient that I look after in my private hospital, ‘Would you like to see the social worker,’ whereas here they are offered that service almost without having to ask for it. It is similar with physiotherapy. There are private physiotherapy clinics that will come up and see my patients to provide them lymphoedema care and advice but, again, that can be costly. Dieticians: again, it depends on which institution you are in. So, yes, it is a little bit harder. It is not impossible but it is a little bit harder; I am sure it is costlier. A coordinating cancer system of some sort could actually make sure that those gaps are not missed—that patients do not fall through any of those gaps—by saying, ‘Regardless of what your insurance status is, this is a card and we are going to tick off the boxes along this card to make sure that all the facets of your care, be it medical, be it dietary, be it physiotherapy, have been attended to at minimum cost and with ease of access.’

Dr Pickstock—I agree with you that, certainly, it becomes more difficult for patients who go through the private sector to access all those allied health things. But I would say that sometimes having private insurance is still a benefit and, certainly, for the ladies I see who eventually end up needing palliative care one of the problems clearly is adequate community funding of palliative care. What a lot of ladies—a lot of patients—would like to do is to have as much care as possible at home and, very often, choose not to come in to hospital. But if people do need to come back into in-patient care towards the end of their life, one of the big problems we have in Western Australia is inadequate in-patient palliative care beds. Currently, all the palliative care beds in this state are really outside the major hospitals. We have consulting services at Royal Perth and Charles Gairdner but the palliative care beds are largely in private hospitals or not-for-profit hospitals. There are beds for public patients, but it is certainly the case that, if you have private insurance and you need a bed, you are much more likely to get a bed in some situations. So, despite people often struggling when they have had cancer for a long period of time and have spent a lot of money, we really encourage people to keep up their private insurance, just because we know we can always get them admitted.

Senator WEBBER—One of the other issues coming across, as it does with everything to do with health care, is the challenges of the medical workforce. To put it bluntly, particularly with this inquiry, Dr Leung, we are told we do not have enough of you. Not you personally, but apparently as a profession you are getting too old. So what do we need to do to get more people like you?

Dr Leung—We are addressing that problem. In the past, we have admitted only one person each year to the training program. With our rising population we have looked at that, and the number of my colleagues over the age of 55 is quite high. So in the next 10 years we will need to replace them and we are addressing that by increasing the number of trainees going through the gynae-oncology program. There will be a lag, and our population base of one gynae-oncologist per 400,000 to 500,000 should be addressed in the next five years if we maintain what we are doing. I think you are probably getting the same message elsewhere. No? You are not getting the same message?

Senator ADAMS—No.

Senator WEBBER—I was going to say, you seem to be a step ahead of some of your colleagues on the east coast.

Dr Leung—Yes. It takes three years to train a gynae-oncologist, so that is why there will be that lag, but we are addressing that. Some overseas doctors who have trained here have applied to take up some of the positions which are lacking. South Australia, for instance, is very short on gynae-oncologists and they have looked at a couple of our overseas trainees staying on, so there are ways around it.

Senator WEBBER—But we seem to then have the overall shortage of allied health. If we are looking at that team approach, we seem to be struggling.

CHAIR—How about your medical operators, Professor Millward?

Prof. Millward—I would not be as confident as Dr Leung that we will have an adequate workforce in medical oncology. One of the reasons is that, as I have said before, as improvements in cancer treatments and in cancer survival occur, the experience will be that women will require care for longer for gynaecologic cancer so they can live longer, and that will mean that they will be under the care of oncologists for longer. And whereas in gynaecologic oncology there is often the need for major specialty surgery at the beginning and sometimes after that, it tends not to be a repetitive process. So the need for gynaecologic oncologists is going to be based on the population and the aging of the population, whereas the need for medical and radiation oncologists will be based on those factors plus the improvements in those treatments, which will mean patients will be under the care of those doctors for longer. That will filter through to the need for nurses and other staff to run units that deliver chemotherapy and radiation oncology. Patients in the future will require more time from those resources, so the space to accommodate new patients will get less.

I hope we can solve the workforce issues. We have made advances in Western Australia in terms of admitting more medical students over the last few years. But that will take a long time, 10 years plus, to filter through to specialists that are needed. The other issue, particularly for regional and rural patients, is whether they will have access to general practitioner services. That is going to be a major challenge for patients outside of Perth and even in some places within the metropolitan area, because it is nice to talk about coordinating care between specialty teams and the patient's general practitioner but, if we are having major shortages of general practitioners, that is going to be less and less feasible for more and more patients. Perhaps even more critical, because I do not think we have made nearly enough moves to try and fix it, is the workforce shortage in nurses, who are not individually but as a group aging quickly. We are going to lose an awful lot of staff over the next 10 years.

CHAIR—Dr Pickstock, in your specialty?

Dr Pickstock—Clearly there is an expanding role for palliative care, and we are taking on a much more supportive care role as well as our terminal care. We have been very lucky in Western Australia in that we have got lots of keen, enthusiastic doctors training in palliative care. I think the important thing for us is to realise that much of our work is not just in teaching hospitals but also in the community. For example, in metropolitan Perth we might have 40 in-patient palliative care beds but we have well over 500 patients being looked after at any one time within metropolitan Perth in their own homes with the Silver Chain Hospice Care Service. One of the ways we have got around issues for rural patients at the moment is that the palliative care specialists of Western Australia run an outreach service, a 1300 number, so that rural GPs and nurses can ring a palliative care specialist on a 24-hour number to get advice and information, and we send people home with that number.

In terms of training, as I say, we have lots of keen trainees. Interestingly, despite palliative care being quite a community based specialty, there is not any funding in Western Australia for a single registrar training position in the community. We have lobbied for that for the last five years and we have still failed to get any funding for it. We are going to run a community registrar position as of next year, but only because the Cancer Council is prepared to fund that for us in the short term.

CHAIR—Is this positive attraction to trainees that you describe in Western Australia reflected in other states?

Dr Pickstock—Not to the same extent, I believe. Just talking to my colleagues elsewhere, we certainly have more trainees in Western Australia, for example, than they have either in Victoria or in New South Wales at the moment.

CHAIR—That is interesting when you look at the demographic.

Dr Pickstock—I think some of it has been partly from my colleagues, such as Doug Bridge and Kirsten Auret, who have worked very hard with the university. All of the medical students now do a full week of palliative care. We managed to get it increased from one day to five days. Every medical student now does an attachment to a hospice for the whole week and every single medical student goes out and visits a patient in their own home. Since we have been running that, we have seen a lot more people apply to do junior jobs in palliative care, which hopefully will increase the skills that they take back to general practice, general medicine or other specialties. That has increased our trainee numbers as well.

CHAIR—Ms Duffield, social work is an integral area but it is often overlooked. In terms of your work force issues—

Mrs Duffield— I think there will be always be social workers.

CHAIR—Always?

Mrs Duffield—Always. We may have a new name. We have three training schools of social work in Western Australia: one in Bunbury and two in Perth. There are always social workers being trained.

Senator WEBBER—But do they go on and work as social workers? One of the challenges we are having, say, with nursing is that we are chock full with people in training but we do not actually end up with them as nurses in hospitals.

Mrs Duffield—Yes.

Senator WEBBER—They go off and become health workers or educators.

Mrs Duffield—People will go off, but it is usually after two or three years. The people who are committed, particularly to medical social work, will stay. I have been out 20 years and I have done just about 20 years in medical. We have good ‘stickability’, I think.

CHAIR—Dr Cassidy, please, get on record the issue with radiology.

Dr Cassidy—Our workload is enormous. We train our own people here. We have a combined training course. We are in a terrible situation now, because we just trained our two latest guys and they are both going to Ontario to do their fellowships. We are all working twice as hard now. What we have had to do in the interim is to get a locum over from Victoria. We still are not quite there. We are not catching up, really. But the good thing is that I am the dinosaur; I am the only one over 55 in my particular group. All of the others are fairly junior, so that is good for the future.

CHAIR—But you do reflect the national position on the shortage of radiologists?

Dr Cassidy—I think it is getting better, but what has happened, I think, is that the intensity and the technology has increased. I am still seeing 500 or 600 new patients a year, whereas the national recommendation is 200. That has to change. We are used to having these large workloads to cover that.

Senator ADAMS—How are the waiting times for gynaecological patients for radio-oncology work?

Dr Cassidy—It is variable. At the moment, our unit at Royal Perth Hospital is doing the public patients from King Edward, and the waiting time varies as anything from three to six or even eight weeks. We have been taking the overflow from Charles Gairdner Hospital to try and cope with their six-month waiting list. That is a bit artificial.

Senator FERRIS—I would like to explore the issue of research. One of the issues raised by previous witnesses has been the question of the early screening test for ovarian cancer. There is a suggestion that, because it is so far away—some people say 10 years—we may be better off to put more funds into research for treatment and treatment options in the short term. Do you believe that there should be a high priority given to work to develop the early test or should the subsequent issues that I covered get priority equally?

Dr Leung—I think development of a new test for screening for ovarian cancer is probably best done in a small number of institutions with large population bases that are able to access the numbers required to test that test. For instance, in this city, if we wanted to test something for ovarian cancer screening, it would be very difficult and it would just be a waste of money and time unless we were able to piggyback onto a multi-institutional-type situation. There are a number of centres around the world that are looking at ovarian cancer screening, either using a battery of tests or looking at profiles of blood tests, to try to come up with something that is going a lot better than we have at the moment. They should continue to do that, with our support. We could, in the fullness of time, perhaps recruit our patients into those types of situations and studies, and I think that is where we would have our value.

In terms of putting money into treatment, again, if we were able to lift our profile enough, then the Europeans and the Americans would be more interested to say, ‘Well, you are a national unit and we will recognise you as a national unit; your patients will be recruited into all the clinical trials that we have currently running in the United States, Europe or elsewhere, even South-East Asia, and therefore we can get the numbers up quickly to get an answer to the questions we are trying to answer.’

Senator FERRIS—Professor Millward, would you like to make a comment?

Prof. Millward—I think it is a mistake to try and say we should favour one type of research over another type of research. The answer is that we should support, encourage and increase funding for all types of research, because if we are trying to guess what might be the most likely to succeed or try and guess what might be the most important, we are very likely to be wrong. Science and medical research does not work that way. What we can say, though, is that to develop a screening test for ovarian cancer is a very major undertaking indeed. One of the leading people in this area in the world is actually a Western Australian, whom we had out here recently, who is a statistician in the US. He is helping coordinate trials of literally hundreds of thousands of women in the US and the UK to try and test screening blood tests for ovarian cancer. These are the sorts of numbers that we need to try and prove that a screening test works.

To undertake that in Australia is really not a feasible option. We may be able to do preliminary work to try and develop the blood test, but to actually test whether it works as a screening thing involves, as I have said, hundreds of thousands of women.

Trials of treatment are important but, again, trials to prove a new treatment is superior to existing treatment may involve large numbers of patients—sometimes hundreds, sometimes thousands, but not usually much more than that. Again, that requires collaboration. It requires collaboration around the country and with international science. That is certainly something that could be coordinated through the type of national gynaecologic cancer centre that is envisaged in our submission. We do have quite an active Australia-New Zealand gynaecologic cancer trials group, which has not been in existence all that long but has succeeded in linking some Australian centres with overseas trials. The work of that group would be complemented very much by the type of national centre that is outlined.

Senator FERRIS—Are you satisfied that there is enough collaboration between research agencies in Australia? This is another issue that was raised by previous witnesses earlier in the week—the need to ensure that there is not duplication, overlapping and so on. In fact, a witness from Brisbane gave evidence about the possibility of some national agency defining what sort of work Australia could do in gynaecological cancer research and then using a large pot of money nationally to work out which team should do the work, rather than having individual teams running around themselves trying to get money to do work and maybe not being able to do it as well as they would like because of the shortage of resources. Do you have any comments to make on that?

Prof. Millward—I think it is undoubtedly true that science and medical research nowadays has to be a lot more cooperative than it used to be. It takes a lot more money to do, it requires a lot more people and it requires the involvement of people with very different backgrounds. It is a little bit like multidisciplinary care for cancer patients. If you are going to do scientific research, you may need many different scientists with different backgrounds and different skills all working on a problem to have the best chance of being successful.

Whether that is best done through a process of formation of research institutes that delegate tasks or through the sort of competitive model that we currently have for funding I am not sure I can definitively answer for you. There is certainly something to be said for competition to ensure excellence, but there is also a need for coordination to prevent duplication and time wasting on writing grants that could be spent on more productive areas of science. I think this is not a specific problem for gynaecologic cancer or perhaps even cancer, I think it is a medical research priority issue.

Dr Leung—I totally concur with what Professor Millward has said. I guess from your point of view it seems fragmented, that individual units are doing their little bit here, there and everywhere. There could well be duplication, because one unit may not be aware what another unit is doing. That is where a national centre would help coordinate all of that to say: ‘Look, this is what is available. Yes, your unit may be in a better position; therefore, go for it,’ as against just spreading it out everywhere and everybody doing a little bit. We will come to answers much faster because of the volume of people that will be recruited into those trials; that will give us a faster answer rather than having 10 patients here, 15 patients there, and not knowing what is going on. I think your idea, what you picked up, is quite correct. I think something like that would be helpful for research.

Senator FERRIS—One of the other comments that was made by those witnesses was on the issue of the NHMRC's capacity to fund trials. There was a suggestion made by one of the witnesses this week that perhaps the NHMRC is currently not so generous of spirit, shall we say, towards applications being made for funding for clinical trials as distinct from basic research. Do you have any comment on that or have you had any practical experience in that area? Or do you know of anybody who has?

Prof. Millward—I think there is certainly a perception, which I think is at least partly factual, that the NHMRC is more prone to fund basic and translational scientific work rather than clinical trials. It has made changes and funding has been made specifically available for clinical trial infrastructure and clinical trial coordination. We do not have the system that is present in the US or Canada, where there is a national cancer-type institute that has a specific budget for running cooperative clinical trials—not just the infrastructure for trials but running the trials themselves

To give an analogy: we have a system that will fund a little bit of the work but not all of it. Doing trials is expensive and requires different things to doing laboratory experiments. We are not as well set up in that area through the NHMRC as we are for applications for laboratory research. But I do think there have been some improvements in this area and I do hope it continues.

Senator FERRIS—Perhaps what we need is some American philanthropists to relocate to Australia. There does seem to be a lot more privately funded philanthropic work coming out of the United States in some of these important research areas than we seem to have achieved in Australia thus far.

Prof. Millward—I think that is very true. It has certainly been commented on for quite some time and in many fora that there is a greater culture of philanthropy in the US than there is in Australia. I guess that is something that we need to work on. Unfortunately, I doubt any of us here will be in a sufficient position to make our own large philanthropic donation to rectify the problem.

Senator FERRIS—Interestingly enough, though, it was suggested that the model for the Australian film industry—and somebody also suggested the model for, dare I say it, the thoroughbred industry—where there are more than 100 per cent tax benefits, or have been in the past, could be used as a model for some of the research that has a high priority, which again might come back to what you are suggesting in the sense of a national body defining national goals and seeing whether they would qualify for this particular, perhaps more appropriate, taxation treatment. Do you want to make any comment on that?

Dr Leung—No; I do not know anything about thoroughbreds!

Prof. Millward—I do not know anything about thoroughbreds or indeed about the film industry!

Senator FERRIS—They have generous treatments, or they have had in the past—more than 100 per cent.

Prof. Millward—I guess any approach that may encourage philanthropy would be worth working at. I believe there are some incentives. For example, if you donate a major work of heritage or art to the nation there is some taxation or other thing as well. Maybe that should apply to donations for medical research.

Senator FERRIS—That is what I was getting at, in a light-hearted way. Thank you very much for that.

Dr Pickstock—Just changing topics slightly, about the issue of research: from the palliative care point of view of research certainly it has been quite difficult for people sometimes to access money through NHMRC-type grants. Many of the palliative care things we are researching are quite hard to get a handle on and probably fall more into that area of psychosocial care and multidisciplinary care. But the sorts of issues that palliative care have been researching are very much about things like caregiver needs and issues like fatigue, which has been very poorly researched, for people living with cancer. As Professor Millward said, as more people have successful treatment and live longer with cancer, long-term survivors and fatigue and so on become a bigger issue. Funding for the palliative care part of cancer research is also a problem.

Senator WEBBER—Do we know as much as we need to know about the support that people with these diseases need? We have had some evidence that says: ‘Yes, we know about all of the support we need. We know all about the psychosocial things. We know everything. It is just a matter of doing it.’

Dr Cassidy—One of my colleagues, Yvonne Zissiadis, is actually looking—I think it is a first in Australia—at patient satisfaction and asking the patients themselves whether they are getting enough information and whether the information is correct. There is a small group of people where it is deleterious to give them too much information. That is only one of the things that have just come out of her work.

Senator FERRIS—It would also be interesting to know how much they actually retain of what they are told.

Dr Pickstock—Clearly, we are never going to know all of the answers. I think we need to remember that we are all unique with all our decisions in life and health decisions. We all have unique coping styles. The challenge for us as healthcare workers is to try to pick the right style for the right person. Interestingly, with cancer we talk so much about ‘suffering’ from cancer and ‘survival’ with cancer. They are really loaded terms. What I would like to see us do—and perhaps an overarching gynae cancer centre could do this—is encourage all sorts of things, like patient health records; that might improve communication from specialist services back to GPs. One idea might be to have a formalised role, I guess, for multidisciplinary teams, making sure that women have been offered the opportunity of referral to everyone on that team, with an explanation of what that person could do and knowing that if they choose not to have the referral at this stage they could come back and do it in the future. A big issue I hear about is fragmentation of care. We have to be very careful to support GPs in the country areas, and in particular those picking up very difficult patients. The gynae cancer centre could support a whole lot of initiatives, such as telemedicine, patient held records, et cetera.

CHAIR—A couple of questions have been raised in other places and I would like to get your comment. I will leave my favourite till last. My favourite is the data registry. Senator Adams asks about patient assisted travel; I ask about data registry. The other two are to do with referrals and also waiting times.

We have had evidence from your comrades in other states about significant waiting times for surgery. A situation described in *Hansard* was of people being bumped because of closing operating times and things like that. We had quite disturbing evidence from New South Wales and Queensland. The Victorians yesterday said it was not as bad in Victoria. I would like to get a sense, in Western Australia, of the waiting times from when a woman is told that she needs surgery to the surgery occurring.

Dr Leung—I might take this opportunity to clarify about manpower, because it is to do with manpower and the provision of care. Just to clarify my comments earlier about manpower, we currently have 34 certified gynaecologic oncologists in Australia. We probably need 40 to 50 for our population base. If I do not say the following, my fellow, Dr Farrell, is going to stab me in the back when I leave this room, so I have to say it.

CHAIR—And then we would have 33.

Dr Leung—Very good. The interesting thing about manpower issues is that every time you ask about or do a survey on manpower the type of week you have had will determine whether you say, ‘I’m going retire tomorrow’ or ‘I’m going to retire in 10 years time.’ That is true for my colleagues who are in their 50s or 60s. We have a proportion of people who are in their early 60s who will probably be retiring in the next few years. There are a number in their 50s who would say, ‘Yes, I would retire tomorrow if I could.’ In terms of replacing those people, if we maintain our current intake and increase our current intake, then we would meet those manpower needs without any problems. The problem is actually getting people into the training program. Last year we only had one person applying for the position. Partly that is because of the lack of funding in a lot of institutions for those fellows in training. Institutions just do not have enough money in their budget, because as you know, these days in hospitals, a particular department will be given a certain amount of money and they have to divvy out that money to wherever. If they do not have enough money to pay for a fellow in gynaecologic oncology in that unit, then that person has to be self-funded or look at getting assistance and fees or some other way of getting their income for that year as they train in that unit. I think looking at individual units and making sure they have enough funding for fellows in those units should be a priority to ensure that we do attract high-quality trainees into those programs and not waste those positions.

CHAIR—For the discussion here, King Edwards’s budget would have to cover the funding for someone to be trained in that specialty?

Dr Leung—Yes, that is right.

CHAIR—And that would be competing with other priorities in the budget?

Dr Leung—That would certainly be competing with other aspects of the budget, whatever that department requires. Having said that regarding the medical manpower, the other issue which has already been identified is that there are issues of anaesthetic manpower, operating nurse manpower and nurses on the ward manpower—person power. The issue there is that we can put in so much, but if we are allowed to operate on so many cases on a particular list, it would be foolhardy for us to try to extend the goodwill of our colleagues and the hospital by putting on more than we should.

You asked about specifics. I go through the referrals for the public patients in this hospital and I try to allocate appropriate appointment times for those patients. Certainly for the country patients, what I try to do is streamline the process by identifying that they are from the country: they may need a particular procedure, they should be seen on such and such a day, within three days rather than having to go back home and come back again to stay the weekend and have their surgery the following week. That takes a bit of time to coordinate. It does not always work properly, because I do not have enough backing to do that properly. At the moment, if a general practitioner sends in a referral, I will look at that within a week, I will allocate a time, which is at the moment about three to four weeks, and they will probably be on an operating list within three to four weeks.

CHAIR—That is significantly better than we heard about from Queensland and New South Wales.

Dr Leung—It does fluctuate. There are times when I am inundated with a manila folder full of referrals. In that case it stretches out to six weeks, but that is not usually the norm; it is three to four weeks. It should be within three to four weeks. Occasionally somebody comes in urgently and somebody else will need to be bumped from the theatre list so that they can be operated on.

CHAIR—Who tells them they have been bumped? The registrar?

Dr Leung—Yes, our hospital staff do.

CHAIR—The other question that Senator Allison has been asking about regularly—she could not be here today because she is unwell—is the quite confronting evidence we have had that some 50 per cent of women are inappropriately referred. Even after they have gone through the trauma of finding the condition, which sometimes can be quite difficult, the evidence we have had indicates that, of those numbers, 50 per cent may well be referred to other types of surgeons as opposed to gynaecological oncologists. We heard evidence this afternoon that the advice to demand to see a gynaecological oncologist was felt to have saved a woman’s life; that at that point in her treatment she had, on someone else’s advice, said, ‘I must see a gynaecological oncologist,’ and was thus referred. The issue was that referrals are not being done effectively, they are going to other types of surgeons or the newest surgeon or whatever. What is your experience in Western Australia? It seems that this hospital is known as the place to go if you happen to have gynaecological cancer. What percentage of women are referred here as opposed to the other types of surgeons that we have heard about? Sometimes that can result in damage. From your understanding in Western Australia, GPs outside Perth and also inside Perth, what is the percentage of people referred to here as opposed to other places?

Dr Leung—We are very fortunate in Western Australia in that our gynaecologic cancer service has been very well established and very well known throughout all the members of the medical fraternity, not only general practitioners but other specialists. In general, the general practitioners will recognise a cancer and will send the patient appropriately to one of the three of us or to the cancer service that is provided here. It does not happen infrequently, but if a person is in the country and they need to be seen because of some unusual presentation and they are assessed by the general surgeon, generally the general surgeons in those country towns would pick up the phone and call us and say: 'Look, I've got this, and this is what we've found. Would you mind taking over the care?'

We are very fortunate in that we do have a high profile here and we have a good working relationship with our colleagues in other disciplines, not only in general practice or gynaecologists but also general surgeons, urologists and anybody else who may happen to come across a patient who has a gynaecologic cancer.

In terms of proportion, I would say over 90 per cent of gynaecologic cancer cases are managed by our service as a whole. Yes, there will be times where somebody has an operation and they suddenly find, 'Oh, dear, this is not quite what I expected.' Nevertheless, I do not think they are too compromised, in the sense that that person will either pick up the phone at that time or get somebody to call us from theatre at that time and seek advice, which does happen. Or they will do what they can and refer that patient to the gynae oncology service for further management.

Prof. Millward—I have worked in cancer centres in Sydney and Melbourne as well as here in Perth. I cannot give you figures, but I think it is undoubtedly true that there are fewer inappropriate referrals and less inappropriate care by non-gynaecologic oncologists in Western Australia than there are in New South Wales and Victoria. I fully support what Dr Leung has said. Part of that is because the unit here provides very prompt advice and is well known and very collegiate in how it interacts with other surgeons and referring doctors.

CHAIR—My last question is to do with data registries. I know that some of you have seen the cancer inquiry report from 12 months ago, where there was significant evidence from Western Australia about the quality of data management in this area and the need to have a national standard, and the quality that needed to be there. Your submission talks about the need for appropriate data management. I would like something, if you choose, on the record this afternoon about the importance of appropriate data management and the need for registries. We had evidence at one place about the databases that are used; that Australia has been using COSA and there is a move in Sydney to another one that is more international, through the New South Wales hospital centres. They are going to be going to something beginning with 'Ph', I think. They showed me the book. I cannot remember the title. It was all to do with the fact that we do not have effective data management and often in the trials that we have the data management is not done as well as it ought to be, so we lose the value. I would appreciate some comments on that basis.

Prof. Millward—I will start on that. To some extent you are asking about a number of different things.

CHAIR—I am. But I am trying to get a lot on the record.

Prof. Millward—Cancer registries, which every state has, are an important requirement for recording the number of cancers there are in the community and tracking the number of cancers and deaths from cancers. Western Australia is no different from other states in requiring cancers to be notified to the Western Australian Cancer Registry. However, the amount of data that is collected about an individual cancer by the state cancer registry is limited. Usually, just what type of cancer it is and certain, if you like, basic facts about that case are recorded, such as how old the patient was et cetera.

It certainly does not capture the stage of the cancer and it does not capture other important factors about that cancer that we now know may be important in comparing treatment outcomes. So what you are referring to, I think, in New South Wales is a move to augment the data that is captured by the state cancer registry with a uniform data set that is collected on all cancer patients, which is more detailed on the general aspects of cancer but also has specific modules for different types of cancer, so that different cancer data is collected from breast cancer, bowel cancer and ovarian cancer. That is very important indeed. We do need a national benchmark for this, because we really cannot have every state coordinating things within the state and at the end of that have every state doing it differently.

CHAIR—Is it true that the registries all operate separately now and they do not talk to each other?

Prof. Millward—The cancer registries currently operate, yes, separately. They do not combine their data; they are all individual. What I think is important is that the same data be collected. It does not necessarily have to be collected by the same group—just as long as the same data is collected throughout the country.

CHAIR—Senator Adams has just given me the Australian government response to our recommendation in our cancer report, which was that it is a state responsibility.

Prof. Millward—It may be a state responsibility, but there are certainly ways that the Commonwealth could encourage this. One of them may be to tie specific funding towards the provision of data using a common agreed cancer database. But, again, I do not think it is critical which one it is or whether the one that is being done in New South Wales is better than the one in Victoria, as long as there is agreement to use one.

CHAIR—Some of the evidence we have had from different areas has been that budgets do not extend to maintaining data managers in their units, and that one of the first things that is knocked off is a full-time data manager; that they tend to, if they have them, be a part-time position or one that is not fully funded. Is that the experience in WA?

Prof. Millward—I would agree with that in general. I think people like to collect data, because everybody likes to see how they are doing and how their patients are doing. But doing it at the scale of an individual unit or an individual hospital is of very limited usefulness. If that is seen as, if you like, some sort of optional extra to clinical care rather than a basic element of clinical care, then, yes, in times of budget squeezes that position will be one of the first to go. It has to be seen as an important part of clinical care.

The surgeons have been pretty good in promoting the need to collect data on operative mortality and major complications from surgery. There is no doubt that everyone recognises its importance. There are ways, as I have said, to encourage and indeed mandate that this data be collected and be resourced properly.

Senator WEBBER—Thank you very much for your submission. It makes a number of useful recommendations. One of the recommendations I notice in there is about the establishment of a national gynaecological cancer centre. We have received evidence from both sides of that argument. I have learnt only by being part of this inquiry that the National Breast Cancer Centre does ovarian cancer. I thought breast cancer centres did breast cancer, but apparently they do both. That was an interesting exercise. Some people say that what we should do is build on the good work that they have done and make them into this big thing that will deal with women's cancer; that we should therefore look at changing the name or leave their name as it is, but somehow or other we will all learn that that is where you go. But then we get recommendations about establishing a stand-alone separate gynaecological cancer centre. Which would be best? The committee will recommend one or the other.

CHAIR—Perhaps.

Senator WEBBER—What do you mean 'perhaps'? It will. Which would be the ultimate?

Dr Leung—Obviously, from a gynaecological oncology point of view, we would prefer a freestanding or a separate entity that is then not consumed by the Breast Cancer Centre.

Senator WEBBER—Thank you. That is what I wanted to know.

CHAIR—Professor Millward, are you wanting to express an opinion on that?

Prof. Millward—I would support what Dr Leung says, but if that is not the case and we end up with a national women's cancer centre, I very much hope we will have a national men's cancer centre at the same time.

Senator ADAMS—I wish to add that I have read the response regarding the data. It states that the Australian government will refer this matter to Cancer Australia for consideration in the context of its leadership role in cancer control. And then it goes on to say that it is a matter for the state or territory to which the data belongs. Also, I have just quickly had a look at the recommendation on travel and accommodation from the Radiation Oncology Jurisdictional Implementation Group, which I was a member of in terms of patient access. They state that they would like to have it standardised across Australia, and the government response was that it falls outside the jurisdiction of the Australian government. I have spoken to the minister and I do think that with the evidence that we have gathered we will be able to look at it from a whole-of-Australia profile and see where we can go, because practically every state is tearing its hair out over this. The Commonwealth gave it to the states in 1987. I think that we must look at it from a national perspective. We hope to use the evidence gathered here to be able to push that forward.

CHAIR—Does anyone have anything they would like to add on the record this afternoon? You have waited very patiently all day. Thank you for that. We are not due to report until October, So if there is anything that does happen in the next couple of weeks that you think we should know about, please let us know. For the sake of this afternoon, is there anything people would like to add on record today?

Dr Leung—On behalf of the members of my panel, we wish to thank you for your time as senators, busy people as you are, for listening to our submission, because I think this is a very important area that is overlooked. If there can be any good that comes out of your recommendations that can be implemented, that would be fantastic.

CHAIR—Thank you very much. We appreciate your time and also the use of your wonderful hospital.

Committee adjourned at 5.16 pm