COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Gynaecological cancer in Australia

FRIDAY, 23 JUNE 2006

CANBERRA

BY AUTHORITY OF THE SENATE

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Friday, 23 June 2006

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

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

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

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 9.08 am

LLEWELLYN, Dr Huw Richard, Private capacity

CHAIR (Senator Moore)—The Senate Community Affairs References Committee today commences its inquiry into gynaecological cancer in Australia. I welcome Dr Huw Llewellyn, a pathologist from ACT Pathology. Do you have any comment to make on the capacity in which you appear?

Dr Llewellyn—Thank you. I am a histopathologist at ACT Pathology and I am appearing in a personal capacity.

CHAIR—Dr Llewellyn, you have received information on parliamentary privilege, protection of witnesses and the rules of appearing before a committee?

Dr Llewellyn—Yes.

CHAIR—You know that we prefer to have evidence in public but if for any reason you would like to go into an in camera situation, please let us know. We have your submission. You said that you wrote it very quickly and that you wanted to share more information with us. Would you like to make an opening statement? We will then go on to questions.

Dr Llewellyn—Yes, certainly. I became aware of the committee’s existence and the call for submissions only at relatively short notice and therefore my summary is perhaps briefer than I would have liked and, as I state in it, unreferenced. I am more than happy to expand on this in a written form and give you full references but I realise, given that you are all lay people, it may be best to stay as we are, otherwise I might give you a large amount of jargon which would not clarify the issue. But I am more than willing to give you any more information in terms of references and other documentation after this meeting.

CHAIR—I suggest that we talk today and then if you would care to provide that documentation afterwards we could look at it with the secretariat’s help. But I think it is good for us to have a talk today so that you can get your points across.

Dr Llewellyn—So would you like me to speak?

CHAIR—Yes, please.

Dr Llewellyn—Thank you, Chair. There is one thing that I have become aware of since making my submission. It is a document called *Priorities for action in cancer control 2001-2003*. It was written by the Cancer Strategies Group in 2001. It is a Department of Health and Ageing document. I would like to read from that. The group covered all forms of cancer that were important. They looked at cervical cancer and priorities for action. In 2001 they stated:

> Developments in human papilloma virus (HPV) testing are likely to have a major influence on cervical screening in the future. This virus is believed to play an important role in causing more than 95 per cent of cancers of the cervix ...

There is a reference attached. They said:

> It has been suggested that combining a test for HPV infection of the cervix with the Pap test when screening for cervical cancer could identify a very low risk group of women (those negative on both tests) who would require screening once every five years or even less frequently. Such a development could make a change in screening interval more acceptable to women and to health practitioners, but might also make the present proposal obsolete.

They were talking about increasing the screening interval. They said:

> However, further research is required before changes to screening policy could be made based on HPV testing.

Then they summarise the position. Part of the summary which I wish to draw your attention to is this:

> Introduction of human papilloma virus testing in tandem with Pap tests as a component of cervical screening could also have a major effect on the efficiency of cervical screening in the future, and these developments should be monitored.

Five years on, this has still not really been given sufficient attention. There has been very little research here in Australia on this. I think part of the reason is that Australia has one of the lowest incidence and mortality rates for cervical cancer, so there may be an element that people perhaps feel there is not any need to do anything more. There is also the fact that everybody can see that a vaccine to prevent cervical cancer is very much on the horizon and that maybe there is nothing more to do as the vaccine will come along and all our problems will be solved. I made the point in my submission that this vaccine will only prevent 70 per cent of cancers and it has to be given to young women before they become sexually active so as to prevent infection by the virus. Therefore we have a cohort of women who will be substantially but not completely protected against this virus but effectively everybody else in the population will be unprotected and will therefore need to be screened, and the effects of that will take 10 to 20 years to make themselves felt. The result is that we will have to continue screening not only for the women who do not benefit from the vaccine but also for those who are getting the vaccine and benefit from it.

Another thing is the recent advance, whereby we have one test but also a number of others coming along which are very good at identifying the viruses that are closely associated with cervical cancer. We now have an opportunity to add to the pap test and improve the efficiency of the cervical screening program. I have to go back a little bit and point out that the cervical screening program is extremely effective. Although people have argued in the past as to how effective, there is very good data that has now arrived from the UK, which goes back many years, to show that cervical screening is far more effective than we ever realised. The same applies here in Australia. It is also unique in that, with breast cancer or colorectal carcinoma screening, we are looking for small cancers that either have not spread or have a good prognosis, whereas cervical screening is not looking for cancer; it is looking for precursor lesions—the things that go on to cancer. By identifying those precursor lesions—they are often called dysplasia—and removing them, we have prevented the cancer from occurring. It really is a very good program in that it prevents cancer rather than identifying and then treating it.

Going back to HPV testing, currently we have HPV testing as a Medicare schedule fee item being rolled out for what is known as ‘test of cure’. Test of cure is where a woman has a precursor legion identified and treated in a colposcopy clinic. We can then test the woman for HPV and if she is HPV negative, we can say this woman has been cured of her dysplasia or precursor. Therefore, she can go back to a normal screening interval and does not need such close follow-up. That is accepted as a given. The other use for HPV testing is for triage purposes. Of all the abnormal smears, the commonest type of smear is what is known as an equivocal smear in that the abnormalities present in the smear are relatively subtle. It is difficult to know what to do for the best for these women because, although most of these smears turn out to be nothing much, some of them actually have significant precursor lesions in them and some even have cancer.

There has been a landmark trial in the US—and you will probably hear it bandied about by other people who make submissions—called the ALTS trial. This was conducted by the National Institutes of Health, one of the major US health research organisations in North America. They looked at this problem for the simple reason that the various doctors—the pathologists, the oncologists et cetera—could not agree on a strategy to deal with these women with equivocal smears. So they decided to conduct a very large trial, which is extremely well designed to test which option was the best. There were three options: take the woman to colposcopy immediately, a program of repeat pap smears or HPV testing. They found that HPV testing was by far the superior option. It identified as many women with significant precursor lesions as a colposcopy, but it saved 50 per cent of the number of colposcopies. So it is an excellent method of triaging these women with equivocal smears.

Certainly, if you look at the American Society for Colposcopy and Cervical Pathology website, you will see they are now revising all their cervical guidelines to reflect all this new information. If you look there, you will find that the proposal that will probably be accepted as the first method of treatment of women with equivocal smears—they are called ASCUS smears in the US—is by HPV testing.

CHAIR—Dr Llewellyn, can we have the name of that website again?

Dr Llewellyn—I will have to get it to you.

CHAIR—That would be wonderful.

Dr Llewellyn—I will send it to you and you can have a look at that. There are discussion boards with quite a lot of vigorous debate from various people saying what is required. The United Kingdom has also been looking at this issue and has had three pilot programs in three cities across the UK to see whether this is a worthwhile option. Subsequent to that, cost-effectiveness analyses have been done in the UK and in the US by the ALTS investigators that state that HPV testing for triage is a cost-effective option. So, naturally, people like me are quite excited and quite enthusiastic.

The Medical Services Advisory Committee sat in 2002, when all of this information was still in the process of being disseminated and the ALTS investigators had not actually completed their work in the follow-up and analysis of the data. So, unfortunately, the timing of that determination was a little early, but who could have told that that was the case at the time. What we would like—I think a lot of my colleagues feel this way also—is for AMSAT to return to this determination as a matter of urgency and to look again at the data that has subsequently been published, in conjunction with what data we have in Australia, with a view to try to get HPV testing for triage for Australian women.

You are obviously aware of the controversy that has attended the NHMRC guidelines review. The sad part, I have to point out, is that had we been able to use HPV testing for triage for these women for equivocal smears, a lot of the heat would have been taken out of these arguments currently attending the NHMRC guidelines. Unfortunately, what happened was that the NHMRC committees decided to use that Medical Services Advisory Committee determination as their best evidence, despite the fact that there was a steady stream of papers coming from other investigators which were freely available to everybody else and to all of us involved in this debate. Therefore, one could not get HPV testing for triage on to the table as an option. Consequently, we are now behind the play, so to speak, for HPV testing for triage, and that is certainly something that needs to be dealt with promptly.

Thirdly, we come to the most exciting part of HPV testing, which is to use it as a screening test, as has been foreshadowed by the Cancer Strategies Group report *Priorities for action in cancer control 2001-2003*. This is quite a major development, but it also needs to be carefully considered because it will change in a very major way the way in which we perform cervical screening. If one is going to change from something that has been embedded in our consciousness and in the way we practise medicine for many years to something new, we have to be careful. We have to proceed cautiously and on the best evidence. We do not want to change from something that has been seen to be working very well currently to something that is perhaps somewhat unknown.

The Dutch, the British and some of the Americans have been doing a number of studies to see whether this is a worthwhile option. I mentioned in my submission the ARTISTIC trial in the UK which is due to publish its first results in the next few months and also in 2007. As I have said, they have spent $3 million on the trial. That is a lot of money for a trial but that is what they cost, because they are very big and very complex to run. One does not spend $3 million of taxpayers' money lightly, as I know you would say. The reason they have done so is that they need the information as to whether primary screening using the HPV testing is going to be a viable option. All the indications from the United Kingdom are that, provided this ARTISTIC trial produces sufficient high-quality data that supports primary HPV testing, this is the way they will move.

I think it is probably a bit late, given that it takes four or five years to run one of these trials, for Australia to do its own trial. Therefore, we will be reliant on using their data to inform our decisions here. I think if one wishes to go ahead with this, first of all, we need the department of health and the politicians to make a commitment that this is something that we should pursue based on best scientific evidence. We do not want carte blanche to have a go and see if it works. It needs to be done on an evidence based approach. To do that, I believe, we need to take the best people that we have here in Australia, experts in the field, and bring them together. They should then be given the task of deciding what data needs to be pulled together, what evidence needs to be pulled together and what studies need to be done to inform the decision whether or not to proceed with primary screening using HPV tests.

I am sure that we have the expertise. It is a question of drawing it together and finding a good leader who can get everybody pulling in the right direction. I am not asking this committee to give us a large sum of money to do this. I am not asking for primary HPV testing to be introduced tomorrow. My aims are much more conservative and much more limited than that.

What I want to see is a commitment. I think if the department of health and the politicians give us the lead then the medical profession will fall in behind and give it their best shot.

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

Senator ADAMS—That was really good. Practically, how would this work if we were to do it? I am sorry, Gary, but we are going into a bit of detail here!

Dr Llewellyn—How would it work? Shall I talk a little about triage first?

CHAIR—Yes.

Dr Llewellyn—Triage would be basically grafted onto the existing screening program: women would have pap smears. Then if they had an equivocal pap smear result, they would have to have the HPV test. The most efficient method of doing that is to take a pap smear in such a way that you have cells available for DNA analysis. It is a question of getting the right sample. ThinPrep is advertised quite a lot in women's magazines and in GP surgeries. It is quite common. ThinPrep is basically what is known as liquid based cytology. Instead of the cells being smeared onto a glass slide at the GP's surgery, the spatula that is used for scraping off the cells is washed in a medium that preserves the cells. This then is taken to the laboratory and a machine is used to get the cells onto the slide as a nice, flat disc of cells. There would be a little disc of cells all nicely spaced out so that you could see them all, whereas in a normal smear all the cells are piled up high in all sorts of chunks and bits and pieces.

You get a very nice sample to look at down the microscope, plus you have some sample left over which you can use for DNA testing. That is what is known as reflex testing—in other words, the woman has the pap smear and, if it is negative, fine; if she has a high-grade lesion or a significant precursor, she can be referred to the colposcopist; or, if she an equivocal smear, then the lab does the DNA test on the basis of that equivocal smear. The results then come back to the woman with a cytology result saying she has an equivocal smear plus you have DNA result, positive or negative. If the DNA result is positive, the woman goes forward to colposcopy. If it is negative, she can go back to screening. So there is no need for a second sample and the woman is able to be presented with a strategy that is very clear-cut and quite efficient. She does not have to come back in six, 12 or 24 months for extra smears and worry about what the answers are going to be. She knows exactly what the next move is: colposcopy or back to screening.

That is another thing that excites me because, as I say, these equivocal smears are quite common. Basically, they make me tear my hair out every day. I just do not know what the best thing to do for these women is. I see them and I think: 'These abnormalities here on the pap smear don't look very much,' but, in the back of my head, there is a small alarm bell going off. There is a very small risk that there might be an underlying cancer and there is also a risk, somewhat larger, of a significant precursor lesion being present, even though the abnormalities are quite small.

With this strategy, it is quite clear. We know what to do. If the HPV test is positive, off to colposcopy; if it is negative, back to screening. It is a very efficient way of working. As I say, it provides a woman with a strategy of what is best to do—an efficient way. It stops me worrying at night whether I have made the right decision whether a woman should go to colp or whether she has repeat pap smears.

The other way you can do it without using a liquid based cytology is that you do a pap smear in the normal way and then the spatula is dipped into a culture medium for the cells, so you have a conventional pap smear and a separate pot for the DNA test. You do not have a ThinPrep sample, you have an ordinary pap smear, but you still have that sample there to do a reflex test. That is why I get excited about this strategy. It is so efficient and so easy.

The second part, obviously, is a much bigger change. What we are going to do if we go to primary screening is that, instead of doing pap smears on all women every two years, we decide that, instead of using a pap smear, we are going to use the DNA test. The DNA test is better in this situation because it detects more of the precursor lesions. The pap smear is not very good at detecting precursor lesions and that is why it has to be done every two years. If you have a test that is better at detecting the precursor lesions then you can do the test less frequently. So you save money in that women do not have to go to their GP or to a practice nurse every two years, they can go every five years. In doing that test, you take the same samples effectively and those women that test negative have another test in five years or even longer. If the DNA test is positive then we use the cytology sample to triage them. So we actually turned the thing on its head. Best practice today is to use the pap smear plus DNA triage. What we are going to do is to flip that over and use DNA testing as a primary screen and then pap smear triage. What you are doing is using the ability to pick up precursor lesions from the HPV test plus the pap test, the microscopy looking for abnormal cells, to rule out the benign look-alikes. You are combining the best elements of the DNA test with the best elements of the pap test.

Now clearly this is a big change and, as I say, everybody gets excited, including me, and says, ‘What a wonderful opportunity we have’ but it has to be proven in the field. We have to know that this is going to work in practice. The theoretical data is there, but if you read the literature—I can give you the very nice commentary on this from the best investigators from the US—basically it says, ‘Proceed with caution’. But we need to start thinking about this, putting it on the radar screen now and getting our best experts coordinated to make this a likelihood.

Senator ADAMS—So the DNA sample is taken from the same smear?

Dr Llewellyn—Yes, we just put it into a liquid.

Senator ADAMS—What I was getting at was that there is no difference for the woman. She is still turning up for her pap smear.

Dr Llewellyn—For the woman there is no difference, she just has to turn up less frequently.

Senator ADAMS—Once she has had the original test.

Dr Llewellyn—The vast majority of women who will be testing negative for the DNA do not need to have their cells looked at. The sample will be there in the lab but it will not be looked at.

Senator ADAMS—If this program were to be taken up it would obviously mean lab staff would have to do more examinations. How are you going to get on in that respect?

Dr Llewellyn—It will not, actually. First of all, this DNA test is done by machine; it is not done by people. And the opportunity is there for the machine to do the donkey work for us. In other words, it is doing the hard yards. Normally, when women have pap smears and the smears come to the lab, most of those smears are negative. So our scientists who do this screening are looking for a needle in a haystack. We are using a machine to get rid of not all but most of the hay, so that you have the same number of needles, or possibly even more needles, but less hay. Now your task is much easier because you have removed the negatives but you have a sample where there is an enriched number of abnormals.

Senator FERRIS—Can you give us some idea of the cost involved?

Dr Llewellyn—That has to be worked out. You have quite rightly pointed out that we need to look at cost-benefit analyses and that will depend on getting home-grown data. We need our own data. You cannot use a cost-benefit analysis from overseas, although it would guide you; you need to look at your own data. And that is another reason why we have to obtain local data to inform decisions. Sure, there will be costs for the DNA tests, but you will be doing them less frequently and the number of pap smears that you have to look at will be reduced. So you will be paying more for DNA tests but paying less for pap tests.

Senator FERRIS—Is the DNA test available now on Medicare?

Dr Llewellyn—Only for test of cure. I think I might have been talking about this before you came in.

Senator FERRIS—Yes, I apologise.

Dr Llewellyn—It is all right. It has been approved for testing women who have had a significant precursor lesion treated by colposcopy. Once that woman has been treated normally, we watch her more closely for the possibility that her precursor lesion might return. But, by doing a DNA test, if that test is negative you can say that the chances of this woman having a return of her precursor lesion is very low so then she can go back to normal screening. That is a very useful thing for the woman and for us, because we do not have to keep looking at a pap smear at yearly intervals for the rest of her life.

Senator FERRIS—So there is a Medicare rebate on it under those circumstances.

Dr Llewellyn—For only that circumstance. So what we would like is a Medicare rebate for triage purposes and, as I say in my submission, the evidence for triage is at least as good as that for test of cure. What I have not made quite so clear in my written submission is that, if we had had HPV testing for triage, all the heat that has been generated in the NHMRC guidelines would not have occurred. We would all have been happy, instead of everybody going off in different directions—me being upset and annoyed and writing letters. I would not have needed to do that—I would have been a very happy person—if I had had my HPV testing for triage.

Senator FERRIS—I imagine a lot of women would have been, too.

Dr Llewellyn—I think they would have been happy, too, and they would have been given a good set of guidelines that they could see were comprehensible.

Senator FERRIS—What if a woman decides to pay for it herself? What is the cost?

Dr Llewellyn—I think it is $80. Okay, if you are in Struggle Street and $80 is the difference between food on the table and food not on the table then that is a lot of money. But I say to women who are not in that situation: ‘How much is it going to cost to have an electrician or a plumber turn up to your door and say hello?’ That puts it in perspective.

Senator FERRIS—It cost more to fix my washing machine before he looked at it.

Dr Llewellyn—Indeed. Let’s be honest about the cervical screening program in Australia. One of the reasons for its success is that the government funds pap smears through the Medicare rebate. So a woman can go and have a pap smear, and—let’s be honest—she can go any time she wants; she can have one every year if she wants, or every six months if she wants; the government will stump up the money to pay for that pap smear to be read. So there are no barriers to women having pap smears, and that is the beauty of the cervical screening program. There is no excuse really for not having a pap smear.

But there is a barrier to women getting HPV testing for triage purposes. It is 80 bucks. It is a barrier. Let us be quite frank about it, and do not think I am being discriminatory: if you look at cervical cancer and the precursors, we know from the UK data that the people who have precursors more frequently are the people from poorer backgrounds. It is not the sleek ladies from Toorak who get it. I am not wishing to be unkind, but it is the people from West Footscray, the immigrant populations and the Indigenous people who have precursor lesions.

Senator FERRIS—Has any data been collected on this? Have any pilots at all been run?

Dr Llewellyn—For triage purposes we have the ALTS trial. It is brilliant. It is a landmark trial. It is the best trial I have ever seen in cytology. It is head and shoulders above everything else that I have seen. If we go back historically quite a bit, pap smears have been done for 50 years. Because it is 50-year-old technology, nobody said, ‘Look, before we start, we have to do a trial to see if it works.’ It did not work like that. George Papanicolaou, the chap that this is named after, started by doing pap smears on his wife. That is how he started out. He said, ‘Let’s look for cancer,’ and then people said, ‘That’s a good idea.’ So it has gradually grown up.

Even as recently as 1988, up until 1988, in the UK, cervical screening was done very haphazardly. As a consequence, their cervical cancer rate was amongst the highest in the developed world. It is only since 1988 that the UK government have decided, ‘Look, you’ve got to get serious about this,’ and they have put everything in place to give them a program that is organised.

Australia has actually been quite organised. It has had a very long and strong history of cervical screening going back many decades and has been very successful at it. But our very success has actually lulled us into a false sense of security with respect to HPV testing. We are a little bit behind the play. That is another reason why I want to get this onto the radar screen with your committee.

Senator ALLISON—This question is unrelated to your submission, but I am interested, since you are involved in pathology. I forget the exact name of it, but I think the new form of pap smear screening is called ThinPrep.

Dr Llewellyn—Yes.

Senator ALLISON—Can you comment on the worth of that over the currently funded system.

Dr Llewellyn—I will express a bias here, and I will tell you where my bias stems from. I was brought up on conventional pap smears. That is how I learnt how to look at pap smears.

Senator ALLISON—Sorry?

Dr Llewellyn—I was brought up to look at ordinary pap smears, conventional pap smears, and my skills are best developed for conventional pap smears. Now they have come along with ThinPrep. I look at these and I say, ‘All the nice little subtle things that I am used to dealing with aren’t there.’ They have been cleaned out, because it gives you a nice sample, without all the ‘gubbin’, so to speak—all the inflammatory cells, all the other things in the background—that one is used to. I tend to have a liking for a conventional pap smear, so I tend to have a little bit of a bias against ThinPrep.

The usefulness of the ThinPrep sample is that you have one sample in a pot of liquid which you can use to get the cells out of to look at down the microscope, and the pot of liquid can be used then for the DNA test. So you have one sample which you can use for looking at the cells down the microscope and for looking at DNA. That is the beauty of it. So, in what we are doing now, which is using the pap smear or the ThinPrep for the primary screening, for women with equivocal pap smears you can use that sample for the pap smear, for the cells, plus the DNA for triage purposes for equivocal pap smears. Then, if you turn it around the other way, which we hope will occur in the next five or 10 years, if you want to use DNA testing as your primary screening modality, then you can use that sample and, if the sample is positive for DNA, you can say, ‘Right, we’re going to look at the cells,’ and you will have the sample there waiting for you.

That is the significant advantage of liquid based cytology, ThinPrep. The other advantage is that the samples are easier to look at. We have screeners, scientists who have to screen out the abnormal pap smears. I should explain that when the samples for pap smears arrive in the laboratory, we have scientists who screen every smear. They basically winnow out the chaff. They screen the samples and find the abnormal smears. Generally speaking, the normal smears are reported as normal and filed away. The abnormal pap smears are then looked at more carefully. They are given to people like me to look at to decide what we are going to say is the abnormality present.

With liquid based cytology, it is an easier sample for the screeners to look at, because there are fewer cells. A certain percentage of smears cannot be read, for a variety of reasons, and have to be repeated. In the UK it is very high, and the British have found that by using liquid based cytology the percentage of smears that have to be repeated can be minimised using liquid based cytology. The next advantage—and this is where people start to disagree—is that the proponents of ThinPrep, or liquid based cytology, say that you can pick more precursor lesions.

Unfortunately, the data on that can be argued one way or the other, depending on your bias. Also, I think it is fair to say that the increased detection of precursor lesions is not so great. If it were so great there would be no argument; everybody would be saying, ‘Yes, there is a better detection of precursor lesions.’ So, to me, the fact that people argue over it suggests that maybe the improvement in detection of these precursor lesions using liquid based cytology is not all that great. I think it is probably fair to say that there is an improved detection rate. But, as I say, I do not think it is that impressive.

The final possibility with these liquid based cytologies is that they have developed a scanner that automatically scans the samples and finds cells that need to be looked at more closely. This can then be fed into a computer as a set of coordinates on a microscope slide and given to a screener, and the computer and the microscope say, ‘Look at this cell down this microscope; what do you think of it?’ It still has to be read by a screener, but the scanner is saying, ‘We’ll find the questionable cells for you and then you can look at them and decide what you want to do with them.’ That is unproven technology as yet. It holds promise for the future, and there is a very large trial that has been undertaken in the UK with these scanners to see whether this is a worthwhile option. I personally feel that one should not worry too much about scanners and about whether one is going to go down the track of liquid based cytology. The reason for that is that if you look at the test characteristics of HPV testing and at how good they are as a test—and this gets into some rather difficult science to explain to lay people—you will see that they are very impressive. This brings us back to the excitement that has been generated. If we look at the theoretical test characteristics of HPV testing, we see that they are very impressive. But the problem is that, even though they are very impressive, they are unproven in the field. That is why we have to do these expensive clinical trials and get together people across a broad range of specialties to advise on how best to bring primary screening with HPV to fruition.

Senator ALLISON—Thanks very much.

Senator ADAMS—I am looking at what you said about the advisory committees. They are obviously limited with the members having to be expert in so many areas.

Dr Llewellyn—Yes.

Senator ADAMS—You have a recommendation here that the National Breast Cancer Centre be set up to plan and conduct relevant research. Could you expand on that?

Dr Llewellyn—Yes. Until about a year or two ago the various screening programs, breast and cervix, had their own national advisory committees—NACs. For a reason that I do not understand, they were changed. The irony is that the British have set up their own NACs with the same set-up as Australia has rejected. They have only relatively recently formed their own advisory committees which are very similar to what we used to have as the old NACs. So the Brits have copied Australian practice and we have rejected it for these other committees. Unfortunately—and I do not wish to be critical—these committees are now one size fits all. You have a committee that basically has to provide advice on new technologies for cervix, breast, colorectal and all the others.

It is not fair for specialists in breast screening to be told, ‘Look, we want you to advise on cervical screening.’ It does not work like that. My personal preference would be to go back to the old NACs. But if that is not possible, we should then say, ‘Okay, we have a problem here in that we want to decide how best to deal with using HPV for primary screening in the cervix. We will have to bring together a committee that can focus all its expertise and all its time on this one problem.’ I am not worried too much about going back to the NACs in a way, as long as we have a committee or group of people that has been charged with the task of investigating this one major problem. Rather than trying to go back to the old NACs, it is probably best to accept that we have got this committee structure that we have now and say to the department of health, ‘Look, we have a problem here that is quite a circumscribed problem. It is going to need long-term input over some years. We need to bring these people all together in one place.’

Also I think you are going to have to say, ‘We are going to need resources to do the research.’ That is another point that perhaps I was not making in my written submission. If you look at screening programs, you just do not find the pap smears and colposcopies and the GPs et cetera. Also do not forget the registries, because they are an important part of this. You do not just fund those; you actually have to have a research budget to provide information as to how you are going to keep up to date with developments. So if you are going to have a committee you have got to fund the committee plus you have got to give it a research budget. You also have to make that committee then accountable for that research budget and say, ‘You can’t go off following your own personal ideas about what you should do.’ You have got to say, ‘Your research budget is here to solve a problem; that is, how best to go about introducing this new technology and how best to provide us data to introduce this new technology.’

There is a responsibility on both sides. There is a committee that needs to be convened and there needs to be funding for the committee and for research, but there is also a responsibility on the people that are appointed to the committee that they then follow the terms of reference of that committee and do the relevant research—not research that they might want, but research that is relevant to the problem at hand. The committee then should also be responsible. I am not sure whether it should come back to the parliament or it should go back directly to the minister. It should be making reports on a regular basis to the minister saying, ‘This is what we have done and this is the progress we have made,’ so it does not just become another talking shop.

Senator ADAMS—Have you approached the minister?

Dr Llewellyn—We have not done that. I will tell you what we have done. A medical services advisory committee had an internal review of its procedures. We wrote to the medical services advisory committee pointing out that the decision on HPV testing for triage was superseded and had actually been criticised in the international literature, and that they needed some way of reviewing their decisions promptly in view of rapidly evolving scientific literature. We have written to the minister about the guidelines. We have also written to the NHMRC, to Professor John Shine and Professor Alan Pettigrew in person. There is a letter from our college supporting what we have written to those individuals about the NHMRC guidelines and our concerns with them. I can make those letters available to you if you wish.

CHAIR—Are they recent letters?

Dr Llewellyn—They were written in the last year or so.

CHAIR—Have you had responses to them?

Dr Llewellyn—We have not had one from either John Shine or Alan Pettigrew. We also sent a letter to the minister and we did not get a response to that.

CHAIR—What about from the department?

Dr Llewellyn—No.

CHAIR—Not yet? Okay.

Senator HUMPHRIES—To clarify what you said earlier about the reason for the need for Australian research, you were saying that the British research is not adequate because we do not get the chance to see how cost efficiently the same services or same protocols could be rolled out in Australia. Is that the reason?

Dr Llewellyn—The broad principles of cervical screening are the same. It does not matter where you are. The problem is that the disease burden is different in different countries. As I have said, the cervical cancer incidence rate in Australia is very low. The reasons for that are twofold. We have a good screening program, but the disease burden might have been lower before we started. But it is very difficult to get that data. Cervical screening has been progressing over 50 years and the way we screen has improved over 50 years.

Senator HUMPHRIES—Why might the disease burden be lower or different?

Dr Llewellyn—If you look at historical data, you will find that the incidence of cervical cancer in unscreened populations—populations who do not have the benefit of cervical screening—varies by a factor of 16. So if you go to Colombia and look at their data, you will see it is very high. If you go to Israel, it is very low. The reason for this is basically quite simple. We now know that the virus, HPV, is not the only cause but is the necessary cause. If there is no virus, there is no cancer. But there are other factors involved. So we know that the more virus there is, the more cancer there is. The more virus there is depends on the sexual mores of the population at hand. We know from historical studies that cervical cancer is related to the number of sexual partners and age at first intercourse. Those factors are operating through HPV infection.

The disease burden in Australia probably ultimately reflects the screening activities of the screening program and also the prevalence of the HPV virus and the various types of virus that are in the population, which again are mediated by sexual mores in the population. Another factor is that incidences of cervical cancer in developing countries have been declining, even before screening came about. That is probably related to general improvements in health. It has also been postulated that women are having smaller families, fewer children, and that might be affecting it. This is a fascinating topic in itself, but I think I am heading off in a different direction.

If we wish to work out cost-effectiveness studies, we need to look at the disease burden. If there is no disease, there is no point doing it. But if there is lots of disease and you do the test then your gain is that much greater. It will affect your cost-effectiveness analyses. Let me give you an example. The problem with all of this is that the countries that do the best with cervical screening are those that have the most money to do it, such as Australia, Europe and North

America—the developed countries. In fact, these countries have relatively low incidences of cervical cancer. The people who could really benefit from all of this are those in sub-Saharan Africa and Asia because they have large numbers of women who are not screened and have the biggest burden of disease from cervical cancer. That is where HPV vaccines are going to have the biggest impact. If you can vaccinate the women, and do it once only, then you are going to have a big impact on the cervical cancer instances in countries with the biggest burden of the disease. In order to do the cost-effectiveness studies, you have got to rely, by and large, on home-grown data.

Senator ADAMS—You are saying that we are obviously not going to know the results for the first lot of vaccine for 20 years.

Dr Llewellyn—Yes.

Senator ADAMS—Those young women will have their vaccine and then would they have a pap smear in two years time? What are you going to do?

Dr Llewellyn—That is the problem. Because the vaccine prevents 70 per cent of the cancer, it will probably prevent 70 per cent of the precursor lesions. So there will be a group of women who are going to come through the system, so to speak, with a very low likelihood of having precursor lesions. Do you see that?

Senator ADAMS—Yes, I do. That was why I was asking.

Dr Llewellyn—You are spending all this money on pap smear screening and you cannot find the things. The things that I would see once or twice a week will become once or twice every two or three months. It becomes very inefficient. Also, as I have alluded to in my written submission, for any test, no matter what it is, when the prevalence or amount of disease in the population declines, the test becomes less efficient because, whilst the disease declines, the benign look-alikes stay the same. Of the women who have pap smears, some of them will have a colposcopy, but the colposcopist will be saying, ‘We have these women with abnormal pap smears but I cannot find anything.’ It will become dominated by the benign look-alikes. Because all the disease has been prevented, all you are left with are the benign look-alikes. Women will get a colposcopy for not very much gain. It becomes unsustainable. It is a very difficult concept to come to grips with and even my colleagues in screening scratch their heads on this one, so I do not expect you as lay people to understand what I am driving at. If you prevent a lot of disease, the screening becomes inefficient and that is where the HPV testing is going to have to come in. It will become a decision that will have to be faced. You cannot use a pap smear on its own for screened women; I believe it will not work.

Senator ADAMS—That is why you were saying before that it is really more important to do the pap smear and go to the DNA.

Dr Llewellyn—No. For screened women, use the DNA first and then bring in the pap smears.

Senator ADAMS—I just wanted to ask that question.

Dr Llewellyn—That is probably what is going to happen. It is not something that has been well described in the literature, but it is there. The theoretical basis is there to say that the screening program will become very inefficient for vaccinated women; an HPV test will have to be used for vaccinated women. Ultimately, whether we like it or not, we are going to have to change.

Senator ADAMS—I was trying to work out whether I was not getting it right.

Dr Llewellyn—To be quite honest with you, I think it is something you should actually bring as a question. You should ask people who have made submissions: will the pap smear based screening work for vaccinated women?

CHAIR—We will put that on notice to all the departmental people who are here. We will get that.

Dr Llewellyn—People might not agree with me, but that is all right. Let us see what opinions people come up with.

CHAIR—Thank you, Dr Llewellyn, and thank you for your patience this morning. Please give us that supplementary information. The committee is due to report on 19 October, so there is time. I am very pleased that you got the information so you could join us today.

Dr Llewellyn—Thank you very much for the opportunity to present my ideas to you this morning.

[10.06 am]

HARDY, Mrs Vickie Anne, Member, OvCa Australia (ACT and region)

HARRISS, Mrs Erica May, Member, OvCa Australia (ACT and region)

HARRISS, Ms Jane Elizabeth, Director, OvCa Australia (ACT and region)

CHAIR—Welcome, and thank you for joining us. You have received information on parliamentary privilege and the protection of witnesses and the evidence that you give. You know that we like to have evidence given in public, but if there is anything you would like to share with us in private, please ask and we can arrange that. We have your submission. Senator Ferris has explained that she has been called away and she deeply apologises for that. She will be back if possible. I know that she works closely with you. Do you have any comments to make on the capacity in which you appear?

Mrs Harriss—I am currently undergoing treatment for ovarian cancer.

Mrs Hardy—Like Erica, I am undergoing treatment for ovarian cancer.

CHAIR—Thank you. Would you like to make an opening statement, after which we will go to questions?

Ms Harriss—Yes. Essentially, most of the information that we wanted to provide is in our submission, but we would like to read a short opening statement.

CHAIR—Please do.

Ms Harriss—First of all, we would like to thank the committee for initiating this very important inquiry and for inviting us to provide you with a personal perspective from those who are actually fighting ovarian cancer. We are part of a national ovarian cancer awareness network. Erica and Vickie are also members of our small, voluntary, awareness raising group. As they said, both Erica and Vickie are currently fighting recurrences of ovarian cancer and are more than happy to answer questions you have about their experiences of this particular gynaecological cancer and their respective journeys through the health system.

During the time of the inquiry, you will obviously hear a raft of statistics from research institutes and government departments about the incidence of the disease, survival rates et cetera. We are here to provide a human face to those statistics; statistics which actually represent mothers, daughters, partners, sisters, businesswomen, friends, carers, colleagues—in other words, women who contribute an enormous amount to our society and our economy and whose loss cannot be captured in a simple statistic.

From our perspective, the development of an early detection test or mass screening program for ovarian cancer is the single most important factor in saving the lives of more than 800 Australian women each year. A well-funded and nationally coordinated research effort to this end is critical. In the absence of such, a medical community that is well informed about the symptoms of ovarian cancer and the best treatment path for patients diagnosed with this disease is currently our only real defence. Sadly, the personal experiences of women in our support group suggest that such knowledge and education is currently inadequate. Most women were misdiagnosed, potentially robbing them of valuable time.

Community education is also important. However, it is very difficult to sell the ovarian cancer message as there is no single call to action for women to help prevent the development of the disease. There is no cervical cancer Pap smear message or breast cancer mammogram message that we can turn to for women. We welcome parliament's interest in this issue and we would like to thank you for your personal support in establishing this inquiry.

CHAIR—Mrs Harriss or Mrs Hardy, would you like to open with some comments or wait for questions?

Mrs Harriss—I would support what Jane has just said: it is incredibly important that an early detection test be developed, and the sooner the better. From the other point of view, because there is no such screening test at the moment, our only form—as Jane has said—of defence really is awareness. That has to be awareness from the point of view of the medical profession, who tend to not even think that there may be a possibility of ovarian cancer. So it is important that both the medical profession and the general community of women are aware of this very insidious disease.

Mrs Hardy—I totally agree with everything that Erica said. We are going through the same thing and we have come up against the same problems, so we would like something to be implemented and supported from the ground up. Our doctors are our first port of call, so they really have to look closely at women when they go in and inquire about anything to do with abdominal pain. We want them to actually take notice and do something straight off and not further down the track, because quite often that can be too late. Once again, mass screening and some early detection would hopefully be our main priority and our main focus for where our money could go.

Senator ALLISON—You say in your submission that it is important that there are gynaecological oncologists and that Canberra does not have such persons. Would you explain a bit more as to why that is important?

Ms Harriss—Statistics show that women who are actually treated by a gynaecological oncologist have better survival rates than those who are treated by general gynaecologists or general surgeons. I guess that because of the size of Canberra and the incidence of gynaecological cancers in our region we do not have an on-staff gynaecological oncologist. We are lucky to have access to a group of wonderful gynaecological oncologists in Sydney—Professor Neville Hacker, whom I think you will talk to in Sydney, and his team. They travel fortnightly to Canberra but, when women are undergoing surgery, they have to go to Sydney for that surgery because their gynaecological oncologists want to be involved in their ongoing care. While the surgical support in Sydney is very good, it means that women are taken out of their communities. They are away from their families or their families have to then make arrangements to stay in Sydney to be close to their mothers or wives or daughters. That can provide a financial impost on families. It is quite difficult. Generally, women are in hospital for around 10 days before they then come back to Canberra to begin their treatment, whatever treatment it might be. Chemotherapy is generally the thing at that stage. Having to go to Sydney does provide additional stress on families and the women themselves, from both an emotional perspective and a financial perspective.

Senator ALLISON—You also complain about the fact that communications between gynaecological oncologists and medical oncologists is often poor. I would ask you to expand on that.

Ms Harriss—They often take a different approach to treatment, whether it be a surgical or a chemical approach. When you have two people managing the same disease they often are in communication but they often have a different approach to the treatment paths they suggest. There is no right or wrong answer. As Erica’s oncologist said to her at one stage when she was being presented with different options, ‘There are no right or wrong answers in terms of the treatment of this particular disease.’ But when you are then asking women to make a decision as to what treatment path they should take, it is a difficult thing for them to do. Perhaps Erica or Vickie could give you an indication of their personal experiences in this area.

Senator ALLISON—And this is because the two professions do not speak with another? They speak individually to the patient, as it were, and the patient then has to toss up between the two points of view, whereas if they talked together there would be a better chance of the best option being put to the patient.

Mrs Harriss—I am very lucky because my gynaecological oncologist and my oncologist in Canberra do communicate, so I have been very fortunate in that respect. In fact when it was suggested to me last year that ovarian cancer had reoccurred I had these options: I could do nothing; I could have chemotherapy; or I could have tamoxifen. I had to make that decision. Fortunately the oncologist had been in touch with my gynaecological oncologist, who rang me and said, ‘Go for broke and have the chemotherapy.’ But if I had been left to make that choice myself, which does happen to some people, I really would not have known where to go and I would not have had anybody to really guide me. I was fortunate in having my gynaecological oncologist ring me and say, ‘Go for broke.’

Senator ALLISON—So perhaps a recommendation out of this might be that women should be encouraged to tell their treating oncologists and gynaecologists to talk to one another? What would you suggest that we recommend?

Ms Harriss—Women need a project team with a project manager.

Senator ALLISON—A project manager?

Ms Harriss—Yes, a project manager. We refer to my mother’s gynaecological oncologist as the ‘project manager’.

Senator ADAMS—You really need a multidisciplinary team to cover the whole thing.

Ms Harriss—We need a multidisciplinary team. That is another area where there is difficulty, because women are not provided with access to dieticians and counsellors, and certainly from our perspective not provided with access to psychosocial support. It depends on how they come into the system, whether it is through the private system or through the public system. Ironically, in the public system some of our women have had access to counsellors, but not in the private system because it is an additional cost. They are not offered that cost option. So, yes, we need a project team that can help women to make the decisions. When women are presented with choices about decisions they have to make when they are in a pretty tough situation both physically and emotionally, it is very difficult for them. If they have not got an advocate of their own or strong support, it is a very difficult thing for them to do.

Mrs Harriss—As we have said, before I was first diagnosed with ovarian cancer I was certainly misdiagnosed for some months; it is very often misdiagnosed. When I was eventually diagnosed and was sent to the gynaecological oncologist, my question to him was: ‘Why hasn’t this been detected before?’ His response to me was: ‘Erica, 80 per cent of the women who come to me in your situation ask me that very question.’ So, from that, I think we are very desperately in need of an ovarian cancer awareness campaign. We are doing that in Canberra to the best of our ability, but it needs to be a nationally coordinated ovarian cancer awareness campaign to make sure that GPs are very aware and consider the possibility of ovarian cancer. I was told my symptoms were vague, and that is what they say about ovarian cancer. But nobody considered it, and I knew nothing about ovarian cancer. So it is terribly important as far as I am concerned to have a mass screening or early detection test. But, in the interim, it is incredibly important that we have a national awareness campaign.

CHAIR—Mrs Hardy, would you like to add to that? I saw that you were nodding.

Mrs Hardy—Because we are going through very similar things, it is always the same experience. With my first one, I suppose in one respect I was very lucky. I was in Melbourne so I was rushed through emergency. I was told it was gall bladder and blah, blah. It ended up being cancer. I had fantastic support because I had family down there as well. But then I had to come back to Canberra. Everything happened within a matter of days. You come back here, you are told by the gynae-oncologist down there that you will have so many treatments and that varies once you get here. There is a difference between what the gynae-oncologist says and what the oncologist here says. There is no magic number for anything but things change all the time for you. It is very confusing. There is no information out there for you to be able to find support or anything like that. There is absolutely nothing. If it were not for the small group that we have, we would all still be floundering around trying to work out what to do or who to speak to.

My gynae-oncologist in Melbourne at the time—I have one in Sydney now—said to me: ‘We’re the best people to do the operation compared to the other surgeons. I can guarantee you’ll be back within two years if not. That’s just a fact. I don’t care what anyone tells you.’ Unfortunately for me I was still back in 2½ years. That is the luck of the draw, I suppose. But for most women, your best treatment is to go for the gynae-oncologist. As Jane said, to have that support here would be just fantastic instead of all of us trying to get to Sydney. When I was told the second time, on Friday I had a feeling, Monday I had the scan and Thursday I was operated on. It is a big upheaval. There is no time to think. Your husband has to stop work, you have to rush up, get it all over and done with and then start your treatment. You have to come back here. I could write a book on all the different hospitals I have been in. The difference between the private and the public system is huge. Women out there, even the ones in the chemo ward, have said the same thing—that there are so many women that go through but there is no support for them. They would be more than happy to help get things up and running so that we can support each other and follow through on it instead of us all floundering around and worrying about the money side of things.

Senator ALLISON—Before we lose that train of thought, could you expand on the differences between private and public sector hospitals?

Mrs Hardy—With the public sector I know when my sister-in-law went through breast cancer everything was just laid on thick and fast for her.

Senator ALLISON—In the public system?

Mrs Hardy—Yes. Admittedly that is probably because she was in Sydney at one of the bigger hospitals or whatever but she had anything she wanted—the counsellors, the dieticians, you go off to meditation, you go here, you go there. I said, ‘Oh really?’ I have had nothing. I cannot even find out where I go to find these things or how to start it. I do not know who to talk to. But for her in that hospital system everything is there. It is just unbelievable. I said, ‘Oh my God, how lucky are you?’

Senator ALLISON—Were you treated in a private hospital?

Mrs Hardy—I did have a choice the first time I came back here because the oncologist does both areas. I went and had a look at both. When you are not feeling well the last thing you want is all these people, everything just looked like a mish-mash to me at the time. I am not saying that it was; that is how I felt. I thought. ‘I want peace and quiet,’ so I went for the private. You are out of pocket just a little bit but that really was not my concern at the time. I did not know that there would be a difference, so it was just how I felt at the time. When I think back I think, ‘Gosh, would I have been better off going into the public and then all these other options may have been open to me, I don’t know.’ I still cannot find out where to go and what to do if I wanted any support. It is lacking badly.

Ms Harriss—As part of our small group, we are lucky enough to have a retired general practitioner. He gives us the occasional reality check in terms of the medical profession. When we talked to him about doctors considering ovarian cancer in the first instance, as opposed to going down all the other tracks and then finally getting to looking at ovarian cancer, he said that that almost militates against what they are trained to do. They are trained to look at the most likely cause of the disease before looking at the least common cause of the symptoms, which is generally ovarian cancer. That works against what women need. Women need GPs to consider ovarian cancer first and to rule that out to the best of their ability. We know that it is a really difficult disease to detect and that it has vague symptoms, but every one of our women has had very similar symptoms—the symptoms are actually there and they tell a story. We need to ensure that the medical profession considers that story and that possibility first, rather than way down the track—six, seven, eights months later. We have even had stories of women who have had their gall bladder removed because they thought it was a gall bladder problem, and only then—not even then—did they find that it was ovarian cancer. Without an early detection test, we are saying that you need to consider these symptoms first, rather than going down the track of what is least likely to be the cause of the problem.

Mrs Hardy—I recently spoke to my doctor about what he would have done. I spoke to him just before I had gone to Melbourne and said, ‘I’m feeling ill.’ He said, ‘When you come back, we’ll run tests.’ I spoke to him recently and said, ‘What would you have done? Hindsight is wonderful; we know it is ovarian.’ He was in shock and was surprised that that is what I had. I said, ‘What would you have done?’ He said, ‘I wouldn’t have tested for that.’ As Jane said, he would have gone down the path of doing all the other tests. Depending on how bad you were, it may not have even come onto the radar. I asked him what he does now. Fortunately, with me getting what I did, he said, ‘With any woman who complains of abdominal symptoms, I do the pelvic’—something good has come out of it because he is on the ball. He is one doctor who looks at that first instead of looking at it further down the track. Quite often looking at it further down the track is just too late, because it is so aggressive.

Senator ADAMS—I would like to come back to the reason I mentioned the multidisciplinary team. I have had breast cancer and went through the public system, and I cannot say anything better than that. I am from rural WA. I tell any of my friends who are diagnosed to go public, because you have the breast assessment team, which is absolutely brilliant. A lot of private patients have been like you: unfortunately, they have fallen through the cracks and ended up depressed and with real problems and that does not help them with their recovery. But, first up, we have that model—it is there—and if it can be pushed and brought into ovarian cancer, that would be absolutely brilliant. As far as physio goes, lymphoedema is a problem. I was going to ask you whether any of the people within your group have lymphoedema from having ovarian cancer.

Ms Harriss—No.

Senator ADAMS—It is great that you have not. Speaking about travel, as I said I am a rural person and I would like to ask you about the Patient Assisted Travel Scheme. If any of your people have to go to Sydney, can they access that scheme? How have they got on with that? Do they know about it?

Mrs Hardy—No—that is our point: we know nothing. I do not know anything, and I do not know where to start.

Ms Harriss—We were told about the Patient Assisted Travel Scheme by a gynaecological oncologist. On accommodation, when Erica went through her first surgery, I could stay on site at St George Hospital in Sydney. The second round of surgery was at the Royal Women’s Hospital in Randwick and I could not get access to any accommodation there. You are then looking at private costs for hostel accommodation as close as possible to the hospital. But, yes, we were made aware of the Patient Assisted Travel Scheme.

Senator ADAMS—None of you took it up?

Mrs Hardy—I do not know whether I slipped through the cracks because the first was in Melbourne and then when I came back I saw a fellow from Sydney and then had all my treatments; perhaps it is to do with the communication between them all. For the second one, I went up to Sydney to have it done and I suppose we were lucky that my husband’s sister lived not all that far from Kogarah so that made accommodation a bit easier for us. As for anything else, no-one told me anything at all about what I could or could not claim. That is why I was talking about having someone like a project manager who could let you know what things are available to you and where to go for them.

Senator ADAMS—I wonder if we could follow the model of the breast-care nurse. That person is your prime contact when you first go, takes you through the whole system and is there when you come back. You have that contact to go right through it with you and I think that is very helpful.

Mrs Hardy—I went to the first national OvCa meeting in Melbourne in February. That was the main point from all women, whether they were from the country or even Melbourne itself. It is such a huge city and, like Sydney, they were all over the place so they could not get together to form a group like we had; there are hardly any in Melbourne. The main complaints were the lack of support, and having to come into Melbourne and find accommodation and all that. For most of the women who were down there it was their second or third time, so things had not improved. There is a lack of communication between all the agencies, from your gynaecologist down. Your GP is your first port of call and he has to be informed but quite often the GP was not informed on anything; he did not get information. So there are a lot of areas that need to improve, to help the patient.

Senator ADAMS—Could you take this question on notice from me? I am looking at the Patient Assisted Travel Scheme right across Australia at the moment and I would like to know from your members or colleagues whether they have had any problems, whether they know about the scheme and how they have been able to access it if they have.

Ms Harriss—Certainly.

Mrs Hardy—I was not able to access anything because I did not know about it; now I do.

Senator HUMPHRIES—I want to ask about the availability of services in Canberra. Did you go to Sydney because the best services were there or because the only services were there?

Mrs Hardy—That is the gynae-oncologist there. He is the man that you need to operate on you. Your choice, as Jane was saying, is to have him or a local surgeon. I was once told, ‘You’re best to go with your gynae-oncologist; otherwise you will be back again.’ You go for the best; you cannot muck around.

Ms Harriss—There are no gynaecological oncologists in Canberra. There is a coordinated program of bringing the Sydney based gynaecological oncologists to Canberra and we understand they visit other areas of regional New South Wales as well. They are a terrific team and probably among the best of the best, so we are lucky that we have access to them. But you also have the other side of the issue—the problems that it causes when you have to travel and families have to uproot and travel. That program is coordinated out of the Canberra Hospital. There is a nurse coordinator as part of that group who coordinates those visits and she is very supportive.

Mrs Harriss—When I was first diagnosed I was told that I would have to go to a gynaecologist. I went to the gynaecologist within a few days. He told me what the problem was and what was going to happen and then said, ‘But I won’t be doing the operation.’ He immediately got in touch with the gynaecological oncology people in Sydney to arrange for them to see me and take over my case because he realised that that was the best thing. So I think that the gynaecologists in Canberra are very aware of that and very prepared to go to the gynaecological oncologists.

Ms Harriss—Now they are, although we are also working through a health bureaucracy, obviously, and there are the politics within the health bureaucracies, and there are some egos—need we say—so not all people are referred to gynaecological oncologists. Most are now, as Erica says. I think they have got the message. The Ovarian Cancer Network as part of the NBCC put out the patient guidelines, which we printed, laminated and sent to every single GP in Canberra, so hopefully they now know the correct treatment path for women who are diagnosed in Canberra. But it can be hit and miss.

I understand that it is a lot worse in regional and rural areas. We are lucky in that we have the level of support that we do, but other areas do not necessarily have that. In other areas, they do not necessarily know the correct treatment path. We are reasonably lucky. I guess Canberra is still considered a large regional area. We can only imagine what women in smaller communities go through. We certainly feel for them.

Senator ADAMS—Have you sent the guidelines that you have circulated to the department?

Ms Harriss—I guess we assumed that the department would have access to them through the NBCC, because they were developed by the NBCC. Again, I was just doing a bit of a web surf, looking for information. I was not aware of them specifically myself, but I found them on the NBCC site. I thought that this was something we had been thinking about doing for a long time, and they were there, so I just printed them off and sent them out.

I guess that is another issue, in that the NBCC have done some good work. They did a terrific little booklet on understanding epithelial ovarian cancer, a consumer guide which is very useful. But I think their distribution networks leave a lot to be desired, and Canberra was pretty much left off the distribution list. I got copies sent down, and we again did a mail-out to all of the GPs and the medical oncology areas.

We have put together a very unsophisticated little resource kit, which we have provided to the oncology units in Canberra to provide to any women who have been newly diagnosed, and we have had a lot of support from the oncology nurses. They were crying out for that information themselves. We talked with them about it, and they said that they were ready and waiting for us to provide them with that level of support. So that needs to be nationally coordinated. As you said, if we can use a model that exists and is working well that has been developed for women with breast cancer, we can go down that track.

Senator ADAMS—I would just like to suggest to you that you might contact the CEO of Breast Cancer Network Australia, Lyn Swinburne, and have a talk to her. I have been very involved with that for the last nine years. That group of women are all survivors of breast cancer, so that is the thing—they are people like you. The National Breast Cancer Centre is for the research arm of it, and then you have the Breast Cancer Network coming underneath as the advocacy one. They have done all that work, so do not reinvent the wheel. You can just adapt it. It is much the same symptoms. So please follow that up. And there is the My Journey Kit, which was put together once again by people who had gone through the journey. You can do exactly the same by just changing it around, because not much will be different in that respect.

Ms Harriss—We are part of a national network. The main office is located in Melbourne, and we understand that they have been doing a lot of work with the breast cancer people in terms of picking their brains, if you like. When Vickie was at the consumer forum, they had prepared a DVD.

Mrs Hardy—A DVD which is fantastic and should be given to every woman that goes through this. That is something that we would like to see that we can put into our kits. It is very basic. It was done by Professor Quinn, Karen Livingstone and all the other workers down there. It is brilliant. But we only have one copy here that I brought back. I keep thinking that it is something we need to get as well.

Senator ADAMS—There is just one other thing. I guess your group will be speaking to Cancer Australia now that the board has been set up. Former senator Jocelyn Newman is on that, and she has actually had both, so you have a very good person there to perhaps talk to.

Ms Harriss—Certainly, our national team will be following that up and making representations to them. Thank you.

Senator CAROL BROWN—You have mentioned your resource kit. In your submission you also mentioned some of the community activities that you have undertaken. Can you provide some more information on the sorts of activities and what form they take?

Ms Harriss—To give you an indication of who we are, we have a group of up to about 16 people who come along but are a core group of about half a dozen volunteers. Over the last four years we have run two major information sessions at the Canberra Hospital, the first involving Professor Hacker and the second involving Dr Greg Robertson, who are part of the team of gynaecological oncologists who come to Canberra. They were both really well attended by the public. Unfortunately, there was not a lot of attendance by the medical profession. We have also worked with GP Education Australia and have helped them run three local area network sessions for GPs in Canberra. They were quite well attended by GPs.

We have done some basic advertising on milk cartons on the symptoms. We have done three lots of direct mail to GPs in Canberra. I think they got a little sick of us after a while! We have done a community service announcement. We have had a lot of in-kind support from Canberra businesses. We ran public information stalls at the major shopping centres during Ovarian Cancer Awareness Week. We have done some basic public relations. Erica and Vickie told their stories to the *Canberra Times* and the *Chronicle*. I have done radio with both Alex Sloan and Louise Maher. They were very supportive of us as well.

Erica is a resource for her oncologist in terms of teaching his students about diagnosing the disease. In terms of fundraising, we are about to sell Christmas cards, coming up to Christmas. We do those sorts of things. We have done a fair bit during a short time with limited resources. There was a community service announcement that ran not only in Canberra but also through regional New South Wales. WIN TV picked it up for us and were very supportive in that effort. We are doing a range of small bite-sized chunks of work to keep awareness on the agenda.

Senator CAROL BROWN—And you have done all that with donated and/or fundraised money?

Ms Harriss—We run charity stalls at the Fyshwick Markets. We have received a community service grant from the Southern Cross Club and have done other fundraising—sausage sizzles and things like that.

Senator CAROL BROWN—So it is a very small amount.

Ms Harriss—It is a very small amount. We have been running on the smell of an oily rag for some time—for four years.

Senator FERRIS—What sort of reaction do you get when you run these stalls and information days and so on? Do you find that women are largely oblivious to this particular form of cancer? Have you ever thought about why that might be the case?

Mrs Harriss—I had an older woman at the last information stall we had at the Woden Plaza who, when I went up to her with a brochure and spoke to her, said, ‘Oh, I won’t get that. I’m too old.’ I said, ‘You’re not.’ We also have a lot of people who come up and say they have never heard of ovarian cancer. I was in that same situation, so I cannot be very critical. But that is quite true. We also find that when we are giving out our brochures it is the men who discourage the women from taking the brochures.

Senator FERRIS—Do you think there might be some confusion in the general umbrella of gynaecological cancer between pap smears and the protection that they might offer?

Mrs Harriss—Yes, I have actually had it said to me, ‘You don’t need to worry about that. You have had a pap smear.’ And you have to say to that, ‘A pap smear does not detect ovarian cancer.’

Mrs Hardy—Their attitude is that they are not going to get it. They do not know anything about it, so it will not happen. They just ignore it.

Senator FERRIS—Why do you think that might be the case? Have you ever considered why this particular form of cancer and the links are so poorly understood?

Ms Harriss—I think it is because, as I mentioned earlier, it is a very difficult message to sell. You cannot say to women, ‘Go and have a pap smear. Go and have a mammogram. Look for changes.’ It is a very difficult message to get across. You need to say, ‘Look for all of these symptoms. If you have those symptoms for more than a couple of weeks, see your doctor.’

Senator FERRIS—It is not just checking for lumps, is it?

Ms Harriss—No, it is not. Check your ovaries! That is a bit difficult.

Mrs Hardy—It is intangible. You cannot feel it.

Senator FERRIS—There is no simple bumper sticker like we have been able to develop with breast cancer and some other forms of cancer such as, ‘Have a pap smear.’

Ms Harriss—That is right. When you do say to women, ‘Go and see your doctor if you have these symptoms,’ a lot of doctors still say, ‘Why do you think you could possibly have this? This is very rare.’ We have had criticism for unnecessarily scaring women. I think I said in our submission that we think it is much more frightening to be suddenly diagnosed with a disease like ovarian cancer. When Erica was diagnosed, our immediate reaction was, ‘Great. Whip the ovaries out. Everything will be fine.’ And then you find out a little more about this disease. That is why we say that the single most critical need is an early detection test and mass screening program, so we actually have something where we can tell women, ‘This is what you need to do.’ And we need to educate GPs, so that if a woman does present with these vague symptoms because she has had her awareness raised about this disease, she is not then made to feel that she is a hypochondriac or told, ‘Why are you worrying about it? Don’t worry about it.’

One other woman came up to me after she heard me on the radio. She actually knows me personally. She is an older woman and she said, ‘I’ve got these symptoms.’ Whenever she went to her doctor, he said, ‘You don’t need to worry about gynaecological issues any more. You are in your late 70s. You don’t have to worry about them’ She had large ovarian cysts. Fortunately, they were benign. But she had been suffering for years with those, because she had been told, ‘You’re old. You are not going to get these forms of cancer.’

Mrs Hardy—You are told that you are either too old or too young.

Ms Harriss—Exactly.

Mrs Hardy—You are told that you do not slot into the perfect profile or, ‘You get it between this and this. You don’t do anything about it until you get to that age.’ You have that mentality that you come up against.

Mrs Harriss—A couple of months ago when I had to go for one of my blood tests at the pathology section of the Canberra Hospital, the lass who took the blood from me said, ‘Why in this day and age is ovarian cancer not detected at an earlier stage? Of all the people who have come in, I have only had one person say that her GP had picked it up. The others have all been fobbed off.’ That is the general story. When I was diagnosed, my sister in Adelaide went to her GP and his reaction was, ‘I don’t know much about ovarian cancer.’ There really is a case for a mass screening and early detection test or a national awareness program.

Mrs Hardy—It should be brought up to the level of the national breast cancer awareness program.

Mrs Harriss—Yes, that is right, and of other cancers.

CHAIR—Is there anything you would like to add? We will be talking to your national group because this committee will be going to Sydney and to Melbourne. There has been extensive interest in the issue, which you will be pleased to know. If there is anything you would like to add, we are not reporting until October. If you think of information or stories or if you just want to know what we are doing, please be in contact with the committee.

Mrs Hardy—We will.

CHAIR—I had that feeling. Thank you so much and thank you for your patience. As always, we are running behind time. Good luck.

Senator FERRIS—You can read the *Hansard* on the website. If there was anything you wanted to raise out of anything you read there, please just contact the secretariat and we would be very happy to clarify it if you need it.

Ms Harriss—Thank you. Once again, we would like to thank you for your support in establishing this inquiry.

Mrs Harriss—And we are also appreciative of the fact that we can put a human face to this disease.

Senator FERRIS—And positive ones.

Mrs Harriss—Yes, very positive ones.

CHAIR—Thank you.

Proceedings suspended from 10.50 am to 11.00 am

HARDING, Mr John, Head, Health Registers and Cancer Monitoring Unit, Australian Institute of Health and Welfare

TALLIS, Mr Kenneth, Acting Deputy Director, Australian Institute of Health and Welfare

NORTHCOTT, Ms Suzanne, Executive Director, Centre for Research Management and Policy, National Health and Medical Research Council

CHAIR—Welcome. I know you are all experienced at coming to these things. You have got information on parliamentary privilege and the giving of evidence. You know about the in-camera process, if you choose to request it. As government officers, you are not required to answer questions on the advice you may have given in the formulation of policy or to express a personal opinion on matters of policy. Senators are reminded not to ask questions leading to that form of answer. I now invite all of you or any of you to make an opening presentation and then we will go to questions.

Mr Harding—Thank you for inviting the institute to make a submission. We found that the previous Senate inquiry into cancer services wanted an overview of the statistics in that area, so we thought that this time, in making our submission to this inquiry, we should get in first and provide you with an overview of the statistics—on incidence, mortality, survival, onset, expenditure and so on—that we have in our databases.

Briefly, the data on incidence and mortality shows that the National Cervical Cancer Screening Program has been extraordinarily successful in reducing the incidence and mortality of cervical cancer. In contrast, if you look at the other gynaecological cancers, the numbers of new cases and deaths have been increasing. However, I want to emphasise that we need to interpret those numbers carefully. The increase in new cases has been nearly wholly due to population increase of women in the age groups susceptible to developing those cancers or being diagnosed with those cancers.

The actual age standardised number of new cases per 100,000 females has changed very little since 1991. For cancer of the uterus it was 14.3 per 100,000 women in 1991 and it is estimated to be 15.1 now. For ovarian cancer it was 13 in 1991 and it is has fallen slightly to 12.7 now. For cancer of the vulva, vagina and placenta, it has been around three cases per 100,000 over that full period.

When you look at the death rates, for cancer of the uterus the age standardised death rate has fallen slightly from three cases per 100,000 females in 1991 to 2.8 in 2004. For ovarian cancer there has been a more significant fall, from 8.6 deaths per 100,000 females in 1991 to 7.5 in 2004. The institute does not have any clinical expertise in this area but suspects that the fall in the death rate for ovarian cancer has been due to some improvements in diagnosis and treatment. I will not go through all the other statistics that we have presented in our submission, but we are more than happy to provide any more detailed analyses if required and the statistics I have here to the secretariat.

CHAIR—Thank you, Mr Harding. Mr Tallis, do you want to make an opening statement?

Mr Tallis—No, thank you, Chair.

CHAIR—Ms Northcott, would you like to make an opening statement?

Ms Northcott—Yes, I would like to make a brief one.

CHAIR—Please proceed.

Ms Northcott—Thank you for the opportunity to appear and also for the opportunity to provide a submission to this inquiry. As you know, the National Health and Medical Research Council is the primary government agency for the funding of all health and medical research. In this financial year its total expenditure from the medical research endowment account will be in the order of $460 million, of which about 22 per cent—or almost $100 million—will be allocated to research in the area of cancer, so it is the burden of disease against which most expenditure is allocated.

I am sorry the figures do not match up exactly, but, in 2006, $8.1 million of that expenditure will be allocated to gynaecological cancers. I think our submission provides a breakdown of those project grants and people awards et cetera. There is also a large proportion of research that is funded in the area of cancer that cannot be allocated to a specific type of cancer, largely in the area of basic research, which may have relevance for a range of different sorts of cancers and other conditions. There is also research in population health, clinical research and health services research which is relevant to more than one cancer and would not be picked up in that $8.1 million.

In addition, as our submission pointed out, the NHMRC is responsible for the development of a range of guidelines. Our submission talked about screening to prevent cervical cancer and guidelines for the management of asymptomatic women with screen-detected abnormalities. They were endorsed by the NHMRC after being developed by another organisation, the New South Wales Cervical Screening Program. The objective of those guidelines is to assist women and health professionals achieve the best outcomes for the management of abnormal pap smear results. They involved very wide consultation in their development with consumers and with a wide range of experts and clinicians, and the distillation of the very best international evidence about how to deal with asymptomatic cervical cancer. They have been disseminated very widely and are regarded as the gold standard in terms of management of that type of cancer.

Senator HUMPHRIES—I will ask about the way in which the NHMRC funds research in this country with an eye to what occurs in similar funding bodies overseas—or funding of any sort, I suppose, going on overseas. To what extent does the NHMRC say, ‘There is good work going on in the United States or Britain or France or something in a particular area. We could therefore make a choice not to fund that because we think this research is what we could rely upon. We will therefore do something that they are not doing’? Is there any kind of international scoping in that sense?

Ms Northcott—That does not happen explicitly but it is an implicit part of the process. All of our research is peer reviewed. That involves the very best people. So if they are looking at gynaecological cancers, it would have the very best people who are working in that area assessing applications and who would be aware if the same work is going on overseas or, indeed, if it is going on in Australia. The key criteria in terms of funding are around excellence, significance and relevance, and we would not duplicate research that is already going on. But, quite often, there will be research that is not exactly the same, and you would not want to rule out something on the basis that it is similar to it. It would need to be exactly the same. People are really interested in looking at the big issues, at finding the cure for a disease that creates a lot of burden of disease. Therefore, there will perhaps be a number of teams looking at different proteins or different sorts of mechanisms that are involved in the same disease. There is a race for publication and finding the cure, so, unless it was exactly the same, it would not be knocked out.

Senator HUMPHRIES—Do you have any direct connection with the medical services advisory council?

Ms Northcott—No.

Senator HUMPHRIES—Should there be a role for the NHMRC in a process like that?

Ms Northcott—Possibly. We have been talking to the department over the last couple of years. It has not been on a frequent basis but there has been an identification that that would be an issue that we could talk about. The NHMRC is increasingly working in what we call ‘policy and practice focused research’ or strategic research. Whereas five to 10 years ago, two per cent of the MREA would have been allocated to strategic research, it is now in the order of about 20 per cent of the MREA that is allocated to strategic research.

The purpose of such research is to address issues like the government’s national research priorities, where there are areas of great need in which there is not the commensurate research effort being made. Indigenous health is obviously an area like that. We are working with a range of people. We now have 15 partnerships with non-government organisations, helping them to manage research processes. On behalf of the Department of Health and Ageing we are working with them to fund four priority research programs into palliative care, primary care, dementia and there is another one which I cannot remember. If you take palliative care, there we are working to identify the areas within palliative care that are not receiving significant enough attention and the research questions that you would want to ask there. We are working to fund scholarships and build capacity in researchers working in that area. We are also working to fund research that will answer some of the questions that we need to know, the answers to which are not coming up through our normal schemes.

Senator ADAMS—Mr Harding and Mr Tallis, you have a very detailed chart here of the lifetime cost of cancers which I am quite interested in. I notice that ovarian cancer is a lot higher compared with lung and breast cancer. I am quite surprised that it is higher than lung cancer. Why is the treatment cost for ovarian cancer so much higher?

Mr Harding—We can provide breakdowns of these costs into hospital costs, medical costs, other treatment costs and so on to give you a better feel. I suspect that the costs of ovarian cancer are related to the higher mortality rate and perhaps higher interventions. But, again, I think you would need to be talking to one of the medical experts on what is driving those costs.

Senator ADAMS—The reason I am asking is that the previous witnesses were talking about the difference between the public and private health sectors and the way they have gone through—most of them having gone through the private side of it. Are these estimates for the public hospitals?

Mr Harding—No, this is total health system costs.

Senator ADAMS—As you can see, even with private health insurance, it is a pretty big cost. Then you add on costs for those who need to stay in the city and have their treatment and all the other costs. It really is a very high cost personally as well as to the public purse. That is something I wanted to ask you about. You have said here that the survival rates are declining for cervical cancer and cancer of the uterus and ovarian cancer. What do you attribute this to?

Mr Harding—The differences in relative survival?

Senator ADAMS—Yes, the fact that the survival rates are declining. Can you give us an outline why this is happening with treatments and any other issues that might be there?

Mr Harding—As I mentioned in the introduction, survival is a function of incidence and mortality. The incidence rates have been pretty static. The death rates have been declining slightly. As I mentioned earlier, we do not know what the clinical background to that is—whether it is a function of better diagnosis and better treatment. I know from the roundtable discussion earlier in the year that there were a lot of submissions saying that diagnosis was poor and so on. But the evidence on survival appears to be showing that there has been a small improvement occurring. To what extent that is due to efforts like the effort that has been put in by the ACT ovarian cancer people, who made a submission to you earlier, who are out writing to every single GP and publicising diagnosis, is unknown. If that kind of effort was happening around Australia, you would expect there would be a greater awareness among GPs and improved diagnosis before you get to the stage where mortality is more likely to occur. But I am speculating there; I am not a clinician.

Senator CAROL BROWN—Further to that, you also indicate that there is an increase in the rate of new cases of ovarian and uterine cancer. Do you have any view on why that is occurring?

Mr Harding—That is being driven by the ageing of the population. The statistics we gave on the average age of a first diagnosis for ovarian cancer is 62 years. The ageing of the population is leading to an increase in the number of cases of women in that age group. The population of people in their 60s and 70s is growing at a much faster rate than the population as a whole, and that is driving the increase in the number of cases.

Senator CAROL BROWN—It may also be because of the awareness campaigns that are run in the community.

Mr Harding—I cannot comment on that.

Senator ALLISON—Mr Harding, I was fascinated by some of those statistics and by the international comparisons. Australia is doing well in terms of both the incidence of and mortality from gynaecological cancers in comparison with other OECD countries. What puzzled me were the big differences between us and world-wide figures for both incidence and mortality. Can you explain that? There are some cases, such as cancer of the uterus, where we are on a par with world-wide figures but there are others where we are a lot higher, such as ovarian and cervical cancers in both incidence and mortality. Are there big variations in countries not listed here, such as the Asian countries or perhaps countries less well developed, if I can put it that way? What are we to make of those figures?

Mr Harding—There is enormous variation among countries in cancer rates depending on diet, lifestyle, socioeconomic status and so on. We think it is much more relevant to compare Australia with countries such as Canada, New Zealand, the United States and the UK, which have populations with similar eating and exercise habits and socioeconomic status et cetera, so that we are comparing like with like. You would have to break down the disease patterns in some of the other countries—for example, in African countries the life expectancy is much lower and people are more likely to die of something else before they get to an age where they develop cancer—if you wanted to compare Australia with them. Australia, Canada, New Zealand, the UK and the USA and so on are among the countries with the highest life expectancies. Countries with the highest life expectancies have the highest number of people living to an age where they are more likely to develop cancer because they have not died of an infectious disease or some other condition.

Senator ALLISON—I understand how good it is to have that comparability. One of the submissions I was looking at earlier—and the reason why I am drinking green tea—said that green tea is beneficial in preventing gynaecological cancers, but it seems to me that, if we are not looking at the countries that drink green tea, for instance, we are not learning enough about prevention.

Mr Harding—Looking at ovarian cancer then, the South-East Asian countries have an incidence rate of 7.2 per 100,000, for Australia it is 8.9 per 100,000—not greatly different. The mortality rate in South-East Asian countries is 4.1; in Australia it is 4.9. How comparable that is in terms of diet and so on, I think you would need an NHMRC research project.

Senator ALLISON—I understand. The institute also collects data about the factors everyone has identified—smoking, diet, exercise—as the usual predictors of disease, or at least opportunities for prevention of disease. Were you able to match that in any way with overseas comparisons? Do Australian women eat more fruit and vegetables? Is that a factor in all of the figures you have looked at?

Mr Tallis—We can provide you with figures on that. There are known differences in risk factors. We have very low rates of smoking in Australia. Generally speaking, we have a fairly good diet. We do not do too well on obesity at the moment, as we know, and some physical activity. If you would like to have those risk factors split into the same sorts of dimensions as these, we would be happy to provide them. Just a day or two ago, we published the latest *Australia's health*, which does this rather comprehensively. We would be very happy to walk you through those things.

Senator ALLISON—But there has been a criticism, and I forget the details, I am sorry, about a nutrition survey, which was once done routinely in this country and is not now. As I understand it, it has not been done for some years. Can you confirm that?

Mr Tallis—It has not been done for some years. Discussions are in progress about mounting such a survey, and our departmental colleagues can tell you about how that is going. There is a prospect of such a thing.

Senator ALLISON—A prospect? Excellent.

CHAIR—Mr Tallis, you said you have just released the latest Australian health data.

Mr Tallis—Yes, *Australia’s health 2006*, which is our biennial bible of the health report of the nation.

CHAIR—And when was the bible released?

Mr Tallis—It was released the day before yesterday—Wednesday.

CHAIR—It just snuck through.

Mr Tallis—We would be happy to provide you with a copy.

CHAIR—I think you said that another report is about to be put out, when you gave your figures in your submission. Does anyone have any questions for the NHMRC?

Senator ADAMS—Yes. Thank you very much for the data you have provided on the research grants. I would like to know what criteria the NHMRC use to award grants, and does more funding go to research and to causes, screening or treatment, and why?

Ms Northcott—No, it does not. The grants we have provided on the first 4½ pages—program grants, project grants, a range of people support awards, fellowships, scholarships, et cetera—are awarded on the basis of excellence. They are not awarded on any criteria other than excellence, which is feasibility, the track record of the investigator, the significance of the piece of research. Every year there will be a variation in research funded by disease or funded by population, health, clinical, basic et cetera. It is only when we come to our strategic research, of which there are not very many in the area of gynaecological cancers, which is not surprising, because we have not run a strategic process in that area, that the same criteria apply, but obviously it is a call into a very narrow area of research.

Senator ADAMS—When someone gets a grant and they do research, how is it evaluated?

Ms Northcott—We have introduced much more stringent reporting processes over the last four years. We replaced our old conditions of award, which basically required people to say that they had spent the money in accordance with what it had been allocated for, but there was very little checking on the scientific progress of the grant. We have now put a lot more effort into evaluating grants overall. We also audit a smaller number of grants very thoroughly in terms of the outcomes of the research to make sure that the quality of the research is maintained. We have introduced an evaluation outcomes working committee of the research committee, so there is a much more robust framework for evaluating all of the research that is funded by the NHMRC.

The other important thing to consider when thinking about whether we are confident that the research we fund is of high-quality is that there is a very intensive process at the front in reviewing grant applications. Only about 20 per cent of grants get funded, so a lot of excellent research misses out. Ten people will sit around the table—this year, anyway—consider about 60 grant applications over the course of a week and make recommendations. Between 20 and 25 per cent of the best grants from across 48 panels will be recommended for funding. It is a very risk-averse process, selecting the grants in the first instance. At the end of the process most researchers will have more than one grant and they will come back through the process to apply for more funding. As certain grants run out they will apply again. Part of their application will be demonstrating what they have achieved with the money they have received in the past. The peer review process is a very strong component.

At estimates you asked about applications in terms of gynaecological cancers. We have gone through those. Overall, the success rate for applications in terms of gynaecological cancers is significantly higher than it is for applications in general. In 2006—grants commencing this year—the success rate of all applications dealing with gynaecological cancers will be 44 per cent. That is well over 100 per cent of the average rate for applications in general.

Senator ADAMS—That is very pleasing. I have another query on the evaluation. If someone defaults, if they spend all the money but it is substandard result, what do you do? Is there any penalty?

Ms Northcott—It depends on the definition of a substandard result. The nature of research is risky, so sometimes they will not prove the hypothesis. They might find out something else that is very interesting, though. That would be the basis of a new application in another area. If they used the money for something for which it was not appropriated, then the money would be recovered and they would be in breach of the deed of agreement. Depending on how they had used the money, the institution would start looking at processes around research fraud or scientific misconduct. If they have misused funds—if they have not done anything fraudulent with them but have spent them on a purpose for which they were not appropriated—then the Commonwealth Crimes Act might come into play. It is the nature of research that some things will not be proven.

Senator ALLISON—I wanted to put to you some of what has been said to us in submissions about the level of funding for gynaecological cancer. At the roundtable you gave us some figures—

Ms Northcott—I am not sure that we did give you figures. Are they not Department of Health and Ageing figures?

Senator ALLISON—Possibly.

Ms Northcott—I think the cause of confusion at estimates was that it was not our submission. We have only provided a submission to today's hearing. There was a departmental submission.

Senator ADAMS—Senator Ferris might be able to answer that question when she comes back.

Ms Northcott—When I went back we were not able to find any submission that had been provided to the roundtable, but if I can answer the question, I will.

Senator ALLISON—I am sorry, I have not checked this, but were there major differences between what the department said was the level and the breakdown of spending on gynaecological cancers?

Ms Northcott—I have the funding here in terms of what we are spending.

Senator ALLISON—I want to run through the criticisms that were made. It was said that gynaecological cancers other than cervical were not listed in major initiatives or documents relating to female cancers, the emphasis being on breast and cervical cancer.

Ms Northcott—You would need to talk to the department about that. That was not in the NHMRC data that was provided in that submission.

Senator ALLISON—So you do not agree?

Ms Northcott—The figures that I have and the figures that we have provided to the committee do not include breast cancers. I did look at the department's submission and I thought that some of the criticism was a bit unfair because there was a strong focus, it seemed to me, in the department's submission around the National Breast Cancer Centre. They have a very strong mandate in relation to ovarian as well as breast cancers. I thought that might have been some of the confusion but it is not our submission, so I will leave that to the department to follow up.

CHAIR—Senator Allison, we might ask the department directly because the officers who were at the roundtable are with us again today. Ms Northcott, could you stay while the department gives evidence? I think some of the questions were about NHMRC research so it is probably one of those occasions where if we have the two groups together it would be better.

Senator ALLISON—I want to ask a broader question. How does NHMRC determine what the priorities and emphases are within gynaecological cancer research?

Ms Northcott—It does not. That comes up through the application process. We fund on the basis of excellence. There tends to be a strong correlation between areas which have a large burden of disease and the research that is funded by NHMRC because researchers are clearly interested in finding answers to conditions that are important in terms of the burden of disease suffered by the community. There is a strong correlation between the national health priority areas and burden of disease but there is not a direct correlation.

Senator ALLISON—We have heard time and time again in submissions that ovarian cancer in particular, because it is difficult to detect and so on, is missing out and the disease burden argument is precisely why people say insufficient money goes into research in this field.

Ms Northcott—I am not convinced that is the case. I just provided the success rates for applications dealing with gynaecological cancers. As I said, they are significantly higher than the success rate applying to all research in general—twice as high. It may be that we are not receiving sufficient applications dealing with gynaecological cancer but that if we received more, given the success rate, more would be funded.

CHAIR—Have you told us how many you get? Have we asked that question before because it is not in your submission? Did we ask you at Senate estimates about how many research applications you received on the issue of gynaecological cancers?

Ms Northcott—Just in 2006?

Mr ABBOTT—Perhaps over the last budget period would be useful.

CHAIR—What could you give us, Ms Northcott?

Ms Northcott—I have figures going back to 2000.

CHAIR—They are exactly what we want.

Ms Northcott—I am happy to table those rather than going through them. In 2006, for example, so that is for grants that commenced in January of this year, 43 applications were received and 19 were funded, giving a success rate in the order of 44 per cent.

Senator ALLISON—I am sure you have regular processes in place to determine which grants should be successful and which should not. I wonder whether it is the general lack of awareness of gynaecological cancers in comparison with breast cancer, which has a very high profile and is well served with both services and research. We are hearing that ovarian cancer is not much talked about, it is a difficult area and so forth. Does the NHMRC send signals to researchers who might make grant applications that this is an area that in terms of the disease burden the NHMRC might look more favourably upon? Does that ever happen?

Ms Northcott—We do have strategic priorities and we are in the process of reformulating or drafting the strategic plan for the new triennium that commences on 1 July. That needs to be adopted by the council and sent to the minister by the end of this calendar year and a range of strategic priorities will be identified through that process.

Senator ALLISON—Who do you consult with in developing the strategic priorities claims?

Ms Northcott—The minister and the Department of Health and Ageing. We are very happy to receive submissions from people who are interested in identifying priorities.

Senator ALLISON—Who would know that you were going through this process? How do you disseminate that information?

Ms Northcott—It does not actually sit in my area, so I am not sure of how that process is run. My understanding is that there is very wide consultation around the strategic plan. Obviously it is a strategic plan, and it is not of any value if everything across the health sector is identified as a priority.

Senator ALLISON—Can we ask you, then, about gynaecological cancers, particularly ovarian cancers and uterine cancers?

Ms Northcott—I can certainly put that into the process. I cannot make any guarantees, given the number of people in areas that will have—

Senator ALLISON—No, I am asking what you have had so far that informs you in that field.

Ms Northcott—I am not aware of anything.

Senator ALLISON—How close are you to putting that to the minister?

Ms Northcott—Quite a way. We have six months after the start of the triennium to provide it to the minister. I believe that that is the case. As I said, it is done by another branch in the NHMRC. The research committee, which is coming into place on 1 July, will also have priorities. The government, broadly, has priorities for research—the national research priorities—which will form an important part of the strategic plan, as well, because government expects us to continue to fund research in those areas and report on it.

Can I go back to the issue of whether enough money is going from the NHMRC towards gynaecological cancer. While I have said that we do not have a process that would say that more money should be spent through regular grant processes on ovarian or gynaecological cancers, I am not sure—and we would have to do an analysis—that the claim that not enough attention is given through the NHMRC research processes to gynaecological cancers can be upheld. It is not a simple process of going through and saying that all the disease that is experienced by the Australian community adds up to one. There are co-morbidities; there are a whole range of issues as to why you cannot say, ‘Twenty per cent of individuals suffer from mental illness; therefore, 20 per cent of funding for the NHMRC’s MREA should be directed towards mental illness,’ given issues around co-morbidities and so on. I can say that about $8 million this year will be directed out of the total MREA towards gynaecological cancers, of which almost $6 million is for ovarian cancers. You would need to do an analysis of how that lines up with the burden of disease in the national health priority areas. You also need to remember that close to another $36 million is spent on basic research, much of which may have relevance to cervical gynaecological cancers as well as breast, lung and so on. So almost $6 million is directly for ovarian cancer, but a lot of other research is going on as well.

Senator ALLISON—You say that a substantial proportion of research funding is going towards gynaecological cancers and related malignant neoplasms. You have given us some actual figures, but what is it in percentage terms?

Ms Northcott—I will be very quick; maths is not my strong point. As I said, we spend about $100 million a year on cancers overall, which is about 25 per cent of total expenditure. Of that, $8 million is specifically in relation to gynaecological cancers.

Senator ALLISON—That is eight per cent?

Ms Northcott—Yes.

Senator ALLISON—It is very easy to work out.

Ms Northcott—It is eight per cent of the expenditure on cancer, so it is two per cent of the overall expenditure. But that is research that specifically mentions ‘ovarian’ in its title. It aims to increase knowledge in relation to ovarian or other gynaecological cancer, so it excludes the basic research, which may be relevant to those. It might be working on malignancies, but it is not specific. It does not have ‘ovarian’ in the title, so it has not been picked up through a search on gynaecological or ovarian, uterine, cervical et cetera.

Senator ALLISON—Of course, there are other funders of research into cancer, and a whole range of other fields. Is there any attempt to collaborate on a big picture of where the funding is going to make sure that certain groups of cancer funding are not overlooked? This is essentially what is being put to us in the submissions.

Ms Northcott—It is probably best to talk to the department about the establishment of Cancer Australia. I understand that one of its mandates will be to produce a research agenda for cancer in Australia. The NHMRC has increasingly worked with the various state cancer councils. Over the last five years we have helped a number of them develop their own research priorities, where they have their own research budget. They understand that the NHMRC funds a lot of basic research and, given their budgets are small, they would like to make sure that they are spending on areas that may be less well targeted through the NHMRC processes.

Senator ALLISON—Aside from cancer councils, what other organisations make decisions in the gynaecological cancer area?

Ms Northcott—I am not aware of any others, but we are also increasingly assisting cancer councils with their peer review processes.

Senator ALLISON—Thanks for that.

CHAIR—Mr Harding, your submission says that a detailed statistical report on ovarian cancer is to be produced imminently.

Mr Harding—That has not been finalised yet, but it certainly will be before your October deadline.

CHAIR—Would you make sure that we get that when you do it?

Mr Harding—Yes.

CHAIR—Is that being done through your area?

Mr Harding—Yes.

CHAIR—There was a particular question about the treatment cost for ovarian cancer.

Mr Harding—Yes. We will provide some supplementary information giving a much more detailed breakdown of the costs for each of the gynaecological cancers, and also for breast cancers, so that you can see the relativity.

CHAIR—That would be great. For NHMRC, I read through all of the data you gave us. It was very interesting; we had not seen that before. A number of research projects in this area have just started in recent allocations, but a number have been completed. Are they published?

Ms Northcott—Certainly, people have six months after the end of a research project to provide us with a report on the outcomes of the research, but obviously, both during the time the research is funded and as it is completed, they will seek to publish in a range of academic and scientific journals.

CHAIR—Some are so medical and so scientific that you would not even open the front cover. Others seem to have a more sociological approach. For example, there is ‘The attitudes and understandings of women with gynaecological cancer’ and ‘A study of the attitudes and experiences of Australian-born and immigrant Middle Eastern women’ from the University of Melbourne. There are a few there that you could read and understand.

Ms Northcott—We increasingly require our researchers to write their final reports in lay language so that they are accessible to the average consumer.

CHAIR—After the hearing we might see whether some of them will be accessible in relation to the research we are doing and get in contact with you, because a number of them look specifically at the issues we are looking into.

Ms Northcott—The best way of doing it would be for us to do it for you, but the secretariat may also do it. The research is owned by the universities; it is not owned by the NHMRC. We own the final reports, but we do not own—

CHAIR—Are the reports public when they come to you?

Ms Northcott—It depends on whether researchers are seeking to publish findings. We do not like to provide things that might jeopardise their ability to publish, so we usually would contact the institution and ask them to release the information.

CHAIR—I know that the stuff that you have given to us is broken up into different kinds. I refer to the study that has just commenced for which funding has just been given to the University of Sydney, to Professor Harnett for a qualitative study of the experience of advanced ovarian cancer. Is there a document that actually indicates what the expected process for that is? Is there some kind of contract?

Ms Northcott—Yes, there would be his application.

CHAIR—Is that a public document?

Ms Northcott—It is not a public document but the University of Sydney may agree to provide it to the committee. It would be a decision for them.

CHAIR—I have only one more question. It is to do with evidence that you may or may not have heard this morning from Dr Huw Llewellyn. Did you hear that?

Ms Northcott—No.

CHAIR—He raised the issue of the NHMRC guidelines and certain concerns about them. In your submission you said there was widespread consultation about the guidelines and their development. Was there disquiet? Obviously, with anything like that there are different opinions in terms of what is the final result. I am trying to get some indication as to whether these guidelines did create a degree of debate and whether there were groups that felt the guidelines were not the best outcome from the process.

Ms Northcott—As I said, they were externally developed guidelines, so they were not developed by the NHMRC but under our legislation we can endorse the guidelines. I am not aware of any disquiet, but, once again, the development of guidelines is an area that sits outside my branch, which is responsible for research. I can take that on notice.

CHAIR—Please take that on notice. There has been a particular issue raised about assessment as to the area of pathology in the guidelines. There has also been a statement that a letter was sent from the college as to their concerns about those guidelines to which, as I believe from the evidence, there has been no answer. So please take that on notice.

Ms Northcott—Yes, I will.

Senator ADAMS—Will you be working closely with Cancer Australia? Will you have any connection with Cancer Australia?

Ms Northcott—We do not at the moment but we certainly work very closely with the area of the department which has responsibility for Cancer Australia. I have not heard any news about Cancer Australia for probably a couple of weeks. I am not even sure if the CEO has been announced.

CHAIR—We were hoping to hear some news very soon.

Ms Northcott—So it really doesn’t exist in terms of being an organisation with whom we could liaise, but I imagine that there will be a relationship once they are up and running.

Senator ADAMS—But as far as the membership of Cancer Australia—and, unfortunately, I have not got the list with me—is concerned, I guess there would be a research person on it. The department might help me out with this later.

Ms Northcott—I do not know. Also, our council has just been announced and the minister has not yet announced the principal committees of the NHMRC.

CHAIR—When is that expected, Ms Northcott?

Ms Northcott—The new committees and council take effect on 1 July.

CHAIR—So between now and 1 July there will be public announcements?

Ms Northcott—Yes.

Senator ALLISON—I have been looking at the schedule of the program grants and at the big money—the $14 million of NHMRC funding. One of the criticisms that we have received about descriptors for research funding is that gynaecological cancer really gets mixed up with breast cancer and a whole range of other cancers. It seems to me, given the very brief project title descriptions, that that is what has happened with the biggest chunk of funding. Take ‘Control of reproductive processes’ for instance. There is $4.3 million for that. For ‘Towards an understanding of genetic basis of breast and ovarian cancer’ there is another $4 million—and there is also ‘Towards cancer control: population and molecular strategies’. All of those three big project grants could not be said to be specific to gynaecological cancers. Would that be fair to say?

Ms Northcott—That would be fair. This is a list of all the grants where any of the gynaecological cancers and the word ‘cancer’ have come up; I did ask that before I came to appear before the committee. For example, of the Lumley grant, ‘Perinatal outcomes following treatment for cervical dysplasia’, I asked, ‘Can I be absolutely confident that it does have “cancer” within the grant application and that it is not just talking about cervical dysplasia?’ I was guaranteed that these deal with gynaecological cancers. It is quite likely—very likely, in fact—that some of those program grants are not specifically only about ovarian cancers, but it is often very hard to tease that out.

Senator ALLISON—I am sure it is hard to separate them out but if we are looking at the disease burden then I think it is reasonable for us to say, ‘How do we assess that? How do we assess whether enough funding is going into this area to deal with that disease being an issue?’

Ms Northcott—I have another table, which I only had done up yesterday, which breaks down expenditure by types of cancer. For example, $5.74 million this financial year in terms of ovarian cancer; I would say that that figure is for grants that are specifically aimed at dealing with ovarian cancer.

Senator ALLISON—Have you provided the committee with that table?

Ms Northcott—No, I have not, but I would be very happy to do so.

Senator ALLISON—Is it possible, Chair, that we could have that tabled? If we could get that tabled, Ms Northcott, that would be good.

CHAIR—I think that is the end of our questions. Thank you very much. Thank you for your patience and we will await the supplementary information you have agreed to give us.

[11.51 am]

ADDISON, Ms Linda, Acting First Assistant Secretary, Acute Care Division, Department of Health and Ageing

BLACK, Dr Andrew Peter, Medical Adviser, Office for Aboriginal and Torres Strait Islander Health, Department of Health and Ageing

KEMP, Mr Ian, Director, Cancer Section, Chronic Disease and Palliative Care Branch, Department of Health and Ageing

KNIGHT, Prof. Rosemary, Adviser on Cancer Control, Department of Health and Ageing

LEARMONTH, Mr David, Deputy Secretary, Department of Health and Ageing

LYONS, Ms Margaret, First Assistant Secretary, Health Services Improvement Division, Department of Health and Ageing

POWELL, Ms Linda, Assistant Secretary, Chronic Disease and Palliative Care Branch, Department of Health and Ageing

PRIMROSE, Dr John Gregory, Senior Medical Adviser, Medical and Pharmaceutical Services Division, Department of Health and Ageing

ROBERTSON, Ms Samantha, Acting Assistant Secretary, Medicare Benefits Branch, Department of Health and Ageing

SMITH, Ms Carolyn Margaret, Assistant Secretary, Targeted Prevention Programs Branch, Department of Health and Ageing

CHAIR—I welcome officers from the Department of Health and Ageing. I extend my apologies to all of you. I know you are all very experienced in this process but we have gone well beyond time and I apologise for that. It is an occupational hazard but we should not take you for granted.

You are all experienced at coming to these hearings, but I will run through the process so that we have it on record. You know about parliamentary privilege; you know about evidence; you know about the right to have evidence heard in camera if you choose. You also know that you will not be required to answer questions on the advice you may have given in the formulation of policy or to express a personal opinion on matters of policy, and we as senators know that as well. I invite any or all of you to make an opening statement and then we will move on to questions.

Mr Learmonth—I think we could go straight to questions, Senator.

Senator ADAMS—I will start with a question about Cancer Australia. As I said, I do not have a list of the members, unfortunately. Could you tell me whether there is someone with research expertise on Cancer Australia?

Ms Powell—Yes, there are quite a number of members of the Cancer Australia advisory council who have expertise in research—for example, Professor Sanchia Aranda; Christobel Saunders is a well-known researcher in this area; Professor David Currow conducts extensive research related to palliative care; and Professor Ian Olver, who is now CEO of Cancer Council Australia—obviously they are a very significant research funder—would be well tapped into the research community and issues associated with cancer research. So there are many with various research expertise on that council.

Senator ADAMS—I have had a number of letters from consumers about the make-up of Cancer Australia and the fact that there is no bona fide person on that body—and I know it is not a representative body; I have tried to explain that. Later on, if the members do change, I wonder whether the department could take that issue on board. I know that former senator Jocelyn Newman fully understands the issues of gynaecological cancer. However, this issue has been raised again, especially since the membership of the advisory council was released. Could we have it noted that the consumers of Australia would like to have a bona fide person on that council. Perhaps the department could think about that.

Senator FERRIS—I think some of you were here for the evidence that we heard earlier this morning from Erica Harriss and her group about the difficulty of making members of the community, particularly women, aware of various gynaecological cancers, in particular ovarian cancer, and the difficulty of selling the message of awareness, because it is not possible to talk about a pap smear or examining your breasts or other well-understood preventative measures that are now available in the community. Given the level of mortality for ovarian cancer and the relative successful treatment now of gynaecological cancers such as uterine cancer and breast cancer, has the department ever considered an awareness campaign for ovarian cancer? Have any of the officers discussed it with any of the national bodies? Have you worked together on any particular solution or do you see that as being something that the National Breast Cancer Centre has had responsibility for? If so, are you satisfied with the way they have dealt with it? I know there are a lot of questions in there, but I am just interested in the general response to those issues.

Ms Powell—I guess one of the points that has been made several times this morning is that it is not a common cancer and the symptoms are really quite vague and hard to pinpoint. That is one of the reasons that a lot of the awareness raising efforts are targeted at GPs. I think another thing that was touched on this morning was the National Breast Cancer Centre guidelines for GPs, which were recently released and very widely disseminated, on identifying, managing and treating ovarian cancer. In the development of those guidelines, I know they worked very closely with the national OvCa body, and that is where a lot of their efforts have been placed. There is information for consumers on the Australian government’s HealthInsite website, and there is general information also provided by OvCa and the government has provided funding to OvCa for their awareness raising programs as well as their support for women with ovarian cancer.

In terms of your comment about the National Breast Cancer Centre, they have been working closely with the consumer groups in that area and have recently finished a major national consultation with consumers of ovarian cancer. That is fed into some of their guideline development as well.

Senator FERRIS—There are some amazing and quite frightening stories about women who discover that they have ovarian cancer after they have been misdiagnosed, sometimes for months and months—even years in some cases, tragically—by GPs who simply do not pick it up. This is not a criticism of general practitioners at all, because I know how difficult it is to pinpoint these things. Much of the information that is available is information that is available when somebody has got the diagnosis, whereas with breast cancer or gynaecological cancers people now know that you can take preventive steps—you can have a pap smear, you can examine your breasts, you can go for a mammogram. But, with ovarian cancer, there is no preventive structure around it, where women have it built into their thinking that they need to be aware of this particular form of cancer. I know that the answer is to find an early test for it—and we will be looking forward to hearing about that from people later in this hearing. Have you ever thought about whether it is possible to work with some of these peak bodies to develop, if you like, a slogan like the slogans that have been developed for breast cancer and cancers related to pap smears, which have been so successful?

Prof. Knight—The National Breast Cancer Centre has done an excellent job in working with consumers, as Linda Powell has said, but, as well, they have been working to raise awareness. As you said, unfortunately there are no easy messages and no prevention strategies at the moment. Nonetheless the most important one is appropriate detection referral by general practitioners. The National Breast Cancer Centre has just recently published their guidelines for early detection and referral as well as a consumer guide. There is excellent information on their website, and they have been working constructively with the community. I think we have made enormous strides, although clearly much more could be done.

Senator FERRIS—I agree.

Senator ADAMS—I will follow on from that. Would the Divisions of General Practice, the ADGP, be able to pick up on this as a promotional thing?

Prof. Knight—I am aware that the National Breast Cancer Centre has been working very closely with ADGP and in fact has been one of the vehicles by which they have disseminated their guidelines to general practitioners, so there is a close working relationship there with the government's ovarian cancer program.

Ms Powell—The guide for GPs has only quite recently been released and has been disseminated very widely. It covers the symptoms, how to assess them and how to test for possible ovarian cancer. It also gives some guidelines for working with patients through that. I have a copy here.

Senator FERRIS—Can you table that for us?

Ms Powell—I would be very pleased to, yes.

Senator ADAMS—Getting onto multidisciplinary care, which I was talking about before—the teams—I note that in November 2006 there will be a Medicare item for that. What promotion is being done to get that moving?

CHAIR—Mr Learmonth, we are aware that the government's response to the cancer inquiry was tabled during the week. That was one of the specific recommendations of that inquiry. I have not read it yet, so I apologise if information you are about to give has already been published. We just have not had a chance to read that report. So, before we start, we apologise if we are asking you to give us information we should already have.

Ms Robertson—The multidisciplinary cancer care item that we are proposing to include in the Medicare Benefits Schedule is part of the Australian Better Health Initiative which was announced as part of COAG. The item itself is still in development. We are holding a meeting with the relevant medical professional groups next Thursday, I believe, to bed down some of the detail around the item. What we would expect is that it would operate very similarly to the multidisciplinary items we currently have in the Medicare Benefits Schedule, where you get a range of medical providers sitting around the table talking about the best and most appropriate treatment for a particular person and the type of cancer they have. As part of the Better Health Initiative, we were hoping that there would be some support through the states and territories for cancer care coordinators.

Senator ADAMS—Is there a promotional part to that? You are really trying to get people to take it up?

Ms Robertson—Once the item is developed and it goes to the Medicare Benefits Schedule, we work closely with the AMA and the relevant professional groups to disseminate that within their membership—for example, if we had a representative from the College of Surgeons, we would expect them to go back and communicate that with the College Of Surgeons. I think Linda may be able to comment further on the promotional activity under the Better Health Initiative. I do not have the other—

CHAIR—Which professional groups have been involved in the consultation on this item?

Ms Robertson—Which ones so far?

CHAIR—Which professional groups are considered the relevant groups?

Ms Robertson—I do not have the list with me at the moment.

CHAIR—Can you give that to us on notice?

Ms Robertson—Yes, I can take that on notice. What we do is contact the AMA and ask them whether they will convene a meeting on a specific issue. We do give them some suggestions about the sorts of groups that we would want. They then consult within their membership and come forward with representatives. I have not yet seen the list of attendees for next week's meeting, but I can certainly table that as soon as I have it and let you know which groups are going to be there.

Senator ALLISON—The NHMRC talked earlier about the process of establishing the priorities for research funding. Apparently it is the department that advises the NHMRC and it then comes back and gives advice to the minister—which seems a bit circular. What sort of consultation does the department do outside its own department on these priorities, vis-a-vis the area that we are looking at today?

Prof. Knight—Late last year a workshop was held to discuss issues in relation to Cancer Australia and one of the main issues was about the research agenda and asking people from the cancer community to identify what they thought were the main priorities in research. It is one of a number of initiatives around consultation with the cancer community in relation to research.

Senator ALLISON—Who attended the workshop?

Prof. Knight—There was broad representation; it was from right across the cancer community—oncologists, consumers, allied health workers, members from the department, researchers and state and territory representatives.

Senator ALLISON—Is it possible to give the committee a list of those present or at least of the organisations represented?

Prof. Knight—There is a report from that workshop, which is in the public domain.

Senator ALLISON—And you can provide that?

Prof. Knight—Yes.

Senator ALLISON—Thanks. This is a broader question. There was a time when Australia had a national policy on women’s health. As I understand it, we do not have one now. Can someone comment on why this might be the case?

Ms Powell—Related to it is that the federal and state and territory governments have agreed on a set of national health priorities. That has been one of the drivers in responding to some of the burden of disease issues, and cancer has been identified as one of the national health priorities by all jurisdictions.

Senator ALLISON—When did the national women’s health policy disappear as a policy document? It is possibly prior to 1996—I do not know.

Ms Powell—We will have to take that on notice.

Senator ALLISON—It was brought to my attention some time ago that Australia does not have a policy on women’s health. It might be one of the reasons why some gynaecological cancers have received less attention than they might have otherwise.

It seems to me from reading the submission that there is a lot of focus on cervical cancer. Can you indicate why this is the case? Most of the submission seems to be about cervical cancer. What about ovarian cancer, vulval cancer and those other cancers which still have very high incidence? I know that the incidence of cervical cancer is up there, but it is not that much higher than some of those other cancers, particularly when you group them together.

Prof. Knight—Where the evidence exists the government has in place effective and appropriate programs. In fact, there is excellent evidence about how to prevent and control cervical cancer. That is one of the reasons for the strong attention and it is also because of the enormous achievements that have been made in cervical cancer. The ovarian cancer program is managed by the National Breast Cancer Centre. You will notice that there is also a submission from the National Breast Cancer Centre where they cover those issues. Indeed we have covered off the main figures and the work that has been done by the government in ovarian, as much as anything else, from a national policy and programs perspective, is a question of the relative incidence of the disease.

Senator ALLISON—Why was ovarian cancer lumped with breast cancer when cervical cancer is in a separate category insofar as the attention of the department is concerned?

Ms Powell—The National Breast Cancer Centre was set up about 10 years ago and it was a very innovative model at the time in response to the high incidence of and mortality rate from breast cancer. It is a model that has worked really well. They have identified a lot of the key issues. Because it works so well ovarian cancer, because a lot of the issues are quite similar, was given to the National Breast Cancer Centre to continue the work along with that model.

Senator ALLISON—Did you say ovarian cancer is quite similar to breast cancer?

Ms Powell—No, a lot of the issues are similar such as multidisciplinary care, the concerns that consumers have, the importance of communication and the referral pathways. Those systemic type issues are similar for breast cancer and ovarian cancer. The National Breast Cancer Centre has a very strong track record in that area and, in fact, has done an excellent job with the ovarian cancer program.

Senator FERRIS—But there is no public identification with it.

Senator ALLISON—That is right. That is the issue.

Senator FERRIS—We are talking tops and bottoms here in terms of the body. If what we are trying to do is to raise the awareness of it in the community then sheltering it within a very good structure does not work. I do not deny it is a good structure and I think they have done fantastic work. But when the words ‘ovarian cancer’ are not even part of the name, it does nothing to raise even community questions about it.

Prof. Knight—With the National Breast Cancer Centre program it also identifies that it is the ovarian cancer program. When the government instituted the ovarian cancer program, it was really because the data showed that over half of all women with ovarian cancer do not get to see a gynaecological oncologist which is the best pathway of care. The National Breast Cancer Centre had been successful in improving pathways of care and referrals particularly from GPs which the Commonwealth government also has responsibility for. So this was the area where it was felt that indeed, as Senator Adams said this morning, the lessons that had been learned in breast cancer could be well extrapolated to ovarian cancer. In particular, without the evidence of an effective and appropriate detection test, there was the need to improve the referral pathway for women and also there was a similar set of issues that could be dealt with.

Senator FERRIS—Could it be something as simple as saying National Breast and Ovarian Cancer Centre. At least you have the word out there, because it is not out there now. People just talk about NBCC. It is not even part of their acronym.

Senator ALLISON—Why would you separate cervical cancer from ovarian cancer and both of them from other forms of cancer—uterine cancer, for instance, which has very high rates even though there is success in avoiding mortality.

Prof. Knight—There is a screening program for cervical cancer, so in that sense it is very similar to the breast cancer program and both breast and cervical cancer screening are organised in much the same way by the Commonwealth, states and territories. The screening element is what is common to both for breast and cervix.

Senator ALLISON—So there is no intention on the part of the department at this stage to look at a broad program of awareness about gynaecological cancer other than breast cancer?

Ms Powell—That would be a matter that Cancer Australia would consider.

Senator ALLISON—Would consider.

Prof. Knight—One of the principle elements for Cancer Australia is a strong arm in relation to consumer information and awareness. It is one of the three arms of Cancer Australia that the government has identified that it will pay attention to. That is certainly a matter that they will be considering in the very early days.

Senator ALLISON—Does Cancer Australia take advice from your department in this respect?

Ms Powell—Cancer Australia will take advice from its advisory council. We will work closely with them and exchange and share information, but they are a separate statutory agency.

Senator ALLISON—You heard the witnesses this morning say that women who are survivors of ovarian cancer, in particular, say that they knew nothing about it prior to finally being diagnosed—and, for some, having been misdiagnosed on many occasions. Doesn’t that suggest that there is urgency? How long do we have to wait for Cancer Australia to get around to this?

Prof. Knight—There has been a lot of work done by the National Breast Cancer Centre in relation to raising awareness of ovarian cancer. Principally, it has been targeted at general practitioners because that is the group that is most likely to detect early ovarian cancer.

Senator POLLEY—But shouldn’t we also be making the female population aware of it? Surely the government has a responsibility to lead the charge there. It has taken so long for young women to realise the benefits of Pap smears and self-examination. Surely we cannot afford to wait any longer and we should be taking the lead.

Prof. Knight—One of the areas in relation to ovarian cancer is ensuring that when awareness is raised, we have processes and detection mechanisms in place to be able to address that awareness.

Senator CROSSIN—Do we have them?

Prof. Knight—We are still awaiting the randomised control trials for early detection, for a safe, accurate and effective diagnostic test.

Senator ALLISON—So we are not going to do anything about this until we have the screening mechanism?

Prof. Knight—I believe there are good awareness mechanisms in place at the moment through the National Breast Cancer Centre and also working very closely with OvCa, as has been said this morning.

Senator POLLEY—Can you outline those for us, because it is failing to get out to the public?

Prof. Knight—The National Breast Cancer Centre have done a number of forums around the country raising awareness with community groups, particularly regional groups. They have also worked with the general practitioners and the gynaecological oncologists to assess best pathways of care. They have had a number of working groups and steering committees, which have put together the guidelines for the management of epithelial ovarian cancer, and have taken part in radio and media awareness and general awareness sessions in relation to Ovarian Cancer Week. It is covered quite well in the National Breast Cancer Centre’s submission.

Senator FERRIS—I notice on your card that in 50 per cent of cases where women report a vague sense of tiredness as one of their symptoms, they are diagnosed with ovarian cancer. Even if you were just able to develop a poster that had four questions on it, asking: ‘Have you this? Have you that? Have you this? Have you that?’ and saying, ‘Ask your GP about ovarian cancer,’—you can see in the statistics that of 50 per cent of women who report a vague sense of tiredness, 77 per cent who have abdominal symptoms go on to be diagnosed with ovarian cancer, so it couldn’t be too difficult to work out four critical questions with something at the bottom that says, ‘Ask your GP about ovarian cancer,’—then the person is taking the lead. All your consumer information, wonderful as it is, is, if you like, reactive—that is, post diagnosis, often post surgery and sometimes post chemotherapy. It is a more proactive way to suggest a woman can deal with this issue. There are some clues on here as to how that could be done.

Prof. Knight—The problem with ovarian cancer is the diffused symptoms.

Dr Primrose—Those are the symptoms reported by people who have been shown to have ovarian cancer, but easy fatigability and tiredness is probably the commonest symptom that people present to general practitioners with. The causes range from psychological disorders through to anaemia through to heart failure or just work related stress and so on. There are a huge number of causes of that particular symptom. We will get the most value out of educating doctors to look at the combination of symptoms of abdominal discomfort—particularly lower abdominal discomfort and abdominal bloating associated with malaise, feeling unwell and lack of energy—and to take those symptoms seriously and investigate them.

The way these can be resolved is just by the tried-and-true measures of medicine that go back to Hippocrates: taking a careful history, performing a full physical examination, and that includes a pelvic examination, looking at appropriate basic investigations and then more advanced investigations such as an ultrasound and so on. Our medical students are trained to do these things. I have been a medical tutor in the universities of Sydney, New South Wales and Queensland, and a student who does not take cognisance of that group of symptoms, take a careful history, do an examination, is not going to do very well in the viva part of their final examination. This is all standard, simple medical practice that we try to drill into our students.

Senator POLLEY—Following on from that, it is admirable to make sure that GPs are aware of this, but I think it is more important to make sure that women are aware that the symptoms they are experiencing are going to be listened to and that they know what to look out for. In my state—and I am sure it is the same throughout regional Australia—it is difficult to get in to see a GP. The cost of health is extending families' budgets, so the last people who will go to the doctor in a family home will be the mother. We have to make sure that women are aware that these are serious issues that need to be addressed, and they have to be made aware of it. I see that we have not had a campaign on this issue. We have with other cancers, but we have not with this. Also, we have figures here that are numbers relating to the cases. I was wondering whether or not the department could provide a breakdown of the numbers of those women who have been diagnosed from non-English-speaking and the Indigenous communities.

CHAIR—That could be a question for the previous witnesses.

Ms Powell—That is a question we would have to ask of AIHW, the provider of the data.

Senator POLLEY—Would you mind taking it on notice then—is that okay?

Prof. Knight—It is approximately four times.

CHAIR—I want to follow up on something in this whole area. You said earlier in your evidence that there has just been a round of consultations with the consumer groups in this area. I am interested in whether the issues raised by some of the senators here about the issue around the breast cancer and the ovarian cancer key body, because we have had that a number of times, came up in that round of consultations. You can take that on notice.

Prof. Knight—I am afraid I cannot answer that question. You would have to put it to the National Breast Cancer Centre.

CHAIR—So the amount of consultation was not auspiced by the department?

Prof. Knight—The National Breast Cancer Centre is funded by the Commonwealth department, but they are an independent group.

CHAIR—Right, but the round of consultations with the—

Ms Powell—The consultations that I referred to—

Prof. Knight—No, it was part of their program.

Ms Powell—with ovarian cancer consumers was run by the National Breast Cancer Centre.

CHAIR—So it had nothing to do with the department.

Ms Powell—That is right.

CHAIR—That is what I wanted to clarify. I will ask them that question, because it seems to me that this issue has come up regularly. I cannot see why it would be a surprise.

Senator ALLISON—I want to go back to the emphasis on cervical cancer that you have explained. Looking at the figures provided by the Institute of Health and Welfare in their cancer series No. 30, they show that the number of cervical cancers is expected to decrease by 34 per cent, which is excellent, but it also shows that ovarian, uterine and vulvovaginal cancers are expected to increase by 25 per cent. Are you aware of those figures, and will that feed into this process of establishing priorities that is about to commence?

Ms Powell—Yes, we have a copy—

Mr Learmonth—Sorry, Senator, if I recall correctly, I think there was some discussion with AIHW about those figures, and I think it was a discussion which suggested that the rule of figures were misleading, and the incidence controlled for population change, ageing population, showed that the figures were actually very stable for those cancers.

Senator ALLISON—I do not have the paper in front of me. We should have asked this question of the institute, I suppose.

CHAIR—The institute did make that comment when they gave their evidence.

Senator ALLISON—Did they? I beg your pardon. Your submission talks about the initiatives on Indigenous cervical cancer. The rates of cervical cancer are five or six times higher in Aboriginal communities than elsewhere, and we can all imagine some of the reasons for that. It seems that the Commonwealth is not doing very much about it. All I could find by way of initiatives was preparation of standards and guidelines for cervical screening. Why is this? Why are there not more measures and programs in place to deal with this very serious problem?

Mr Learmonth—Before our OATSIH person turns up, I would say that, to put it in context, there has been significant investment in OATSIH generally. There has been a 260 per cent increase in the last 10 years or so. That is a real increase of 160 per cent.

Senator ALLISON—How much of that was in gynaecological cancer?

Mr Learmonth—This is broadly in the context of health services, treatment services and so on. There have been significant improvements in the workforce. That population has also benefited from population-wide measures such as cervical screening programs and so on. I think the evidence as to the improvement is in one set of figures I have, which is that mortality from cervical cancer has dropped by 50 per cent over the recent three-year period. It is certainly having an effect.

Senator ALLISON—There are 12 cases per 100,000 women in Indigenous communities compared with 2.5 cases per 100,000 non-Indigenous women. What is the target? What does the department expect to achieve out of the current programs that are in place?

Dr Black—I am not sure that there is a specific target.

Senator ALLISON—Why not?

Dr Black—For example, those figures are drawn from the Northern Territory and they are only mortality figures, so they are working in very small numbers. As David just mentioned, whether or not there is a true decrease is not clear yet. It will take quite a period of time with the small mortality numbers. We are probably more interested in improving the ability to identify Indigenous people across other markers such as, perhaps, participation in cervical screening, which would be more relevant in a small population or, as the people mentioned in that particular research paper, being able to look at statistics more widely across other states in Australia would certainly be useful.

Senator ALLISON—What is the participation rates in screening Indigenous people compared to non-Indigenous people?

Dr Black—It varies.

Senator ALLISON—What is the average?

Dr Black—I cannot give you an average for the whole of Australia. I was looking at some figures for specific regions in the Northern Territory. For example, in Central Australia it is around 61 per cent, which is equivalent to participation for the Australian population as a whole. In other areas, it is certainly lower—between 30 and 40 per cent in the central creek region and Arnhem Land.

Senator ALLISON—Is there a plan for improving those figures in Arnhem Land and the rest of the Northern Territory?

Dr Black—The approach of OATSIH has certainly been to develop primary health care services which are able to provide a range of services, of which cancer screening is one. We have data that is available through the service activity reports for all services from OATSIH funds and that shows a growth in the number of services over the last five years. Around 80 per cent of them provide cervical screening services.

Senator ALLISON—I am sure we can measure services, but when can we start measuring outcomes? When can we start seeing that mortality rate drop and when can we start seeing increases in the screening reflected in the figures?

Prof. Knight—Addressing screening within Aboriginal populations is a complex matter but the department has an advisory committee solely made up of Aboriginal and Torres Strait Islander women to advise on the most appropriate methods, approaches and culturally relevant ways to introduce screenings so that there is a strong focus on the process in ensuring that the communities are involved in the uptake of screening.

Senator ALLISON—That is good. What is the status of that work?

Prof. Knight—It is very difficult to estimate the uptake of the screening rates partly around—

Senator ALLISON—I mean the status of your advisory group. Where are they at? Are they just beginning to talk? Have they gone through the process and developed some plan?

Ms Smith—It has been in place for a while. One of the things that group has taken the lead on is actually developing the *Principles of practice, standards and guidelines for providers of cervical screening services for Indigenous women.* That has been disseminated to relevant health professionals.

Senator ALLISON—When did that happen?

Ms Smith—That was a couple of years ago. I would have to take on notice the exact date.

Senator ALLISON—So that group is still meeting and advising you. What is the next project?

Ms Smith—One of the other things that we have been talking to that group about is doing a video that would educate Aboriginal and Torres Strait Islander women about issues around colposcopy in a culturally relevant way. That has been identified by the group as a priority area.

Senator ALLISON—This is not for cancer? Is this for colon cancer?

Ms Smith—It is colposcopy.

Senator ALLISON—I am sorry but I am not familiar with that.

Ms Smith—Colposcopy is the follow-up procedure you have after you have a Pap smear. I will ask Dr Primrose to describe it.

Dr Primrose—It is like looking at the cervix with a telescope. It magnifies the cervix and you can see lesions on it. You can stain it to look for abnormal areas and take punch biopsies of suspicious areas.

Senator POLLEY—I want to take this one step further. We have had evidence in other hearings that I have been involved in that there is an increase in STDs within the Aboriginal community, particularly among young children. Is there anything—and we are talking about sexual abuse—that the department is looking at to ensure that these programs are handled sensitively and that the uptake is going to be reinforced in coming years? If we know that there is an increase in STDs and sexual abuse, are we already starting to plan for the next decade to ensure that the services are taken up?

Dr Black—What services are you saying this in relation to?

Senator POLLEY—They are in terms of making sure that gynaecological issues are addressed so that the young women who now have these diseases are going to get appropriate treatment on an ongoing basis. Otherwise, there could be an explosion of cancer within that community.

Dr Black—As I was saying before, there is certainly the intention to strengthen primary health care and to make it as comprehensive as possible. The introduction of the child health check and the adult health check is about providing very comprehensive assessments and addressing issues related to STIs, as well as cancer screening as it becomes available. Obviously, the greater the coverage that services are able to provide to communities the larger the percentage of the population that will be able to access those services.

Senator ALLISON—The Cancer Trials Australia program does not list any trials for gynaecological cancer. Is there some reason for that that we know?

Prof. Knight—Sorry, but which cancer trials are you referring to? The Australia-New Zealand clinical oncology gynaecological trials are quite well established and have just received funding from the department.

Senator ALLISON—I am referring to a submission that we have got that says that no gynaecological cancer is listed in the Cancer Trials Australia program group. I am sorry but I do not have any further information on that.

Mr Kemp—Is that infrastructure support for clinical trials?

Senator ALLISON—I am just telling you what is in the submission. There is nothing beyond that, I am afraid.

Mr Kemp—There is infrastructure support for the clinical trials component of the Strengthening Cancer Care Initiative. Within that the government is allocating $5 million per annum over the next four years for infrastructure support for clinical trials. In 2005-06 the government provided infrastructure support to the 10 national clinical trials groups, and one of those was the gynaecological clinical trials group. From memory, it received $440,000 to help support the work of that clinical trials group to undertake clinical trials in that area.

Senator ALLISON—I am going all over the place and I apologise for that. At the roundtable we conducted, the figures that were being spent on research for gynaecological cancer were disputed, to say the least. I think the department undertook to come back to the committee with more accurate figures of research funding as it relates specifically to gynaecological and not breast or a range of other cancers. Your submission does not do that; it repeats the $44 million through the NHMRC. As we discussed earlier, bits of the work of the NHMRC are gynaecologically related, but that funding is certainly not central to the big programs that are worth $14 million. Were you not able to distil, out of the total budget, the gynaecological research funding?

Ms Powell—We did provide research figures from the NHMRC after the roundtable. This morning Ms Northcott, the NHMRC representative, added to that, and I know that the NHMRC provided further details in its submission.

Senator ALLISON—We still have a list that adds up to $44 million. It seems difficult to get a grasp on how we compare the money spent with the disease burden and the rate of mortality—which seems to be very high for some cancers within the gynaecological sphere as well as for gynaecological cancers generally.

Mr Kemp—From memory, at the roundtable we were asked to provide some information on NHMRC grants relating to ovarian cancer. We took that on notice and passed it to the NHMRC to provide that detail to us. We then forwarded it to the committee.

Senator FERRIS—I think we have that now, Senator Allison.

Mr Kemp—In relation to the cancer research component of Strengthening Cancer Care, the government indicated that there would be four initial priorities, one of which was for the detection of ovarian and breast cancers.

Prof. Knight—If my maths are right, on a rough calculation of the figures provided by NHMRC this morning regarding the burden of diseases, approximately four per cent of all cancers are gynaecological cancers, which attract eight per cent of cancer funding. So the research funding is essentially double the proportional burden of diseases.

Senator ALLISON—What is the eight per cent drawn from?

Prof. Knight—I could not tell you. Ms Northcott provided that evidence this morning.

Ms Northcott—The total expenditure on research by the NHMRC this calendar year will be approximately $450 million. Of that $450 million, almost $100 million will be spent on cancer—

Senator ALLISON—That is what we discussed earlier.

Ms Northcott—Yes, we did—and, of that $100 million, just over $8 million is being allocated to cervical, ovarian and uterine cancers.

Senator ALLISON—Expenditure cited in the same submission relates to men and women and cancer broadly—I realise that two thirds of this relates to hospital care—and shows enormous differences, according to the Institute of Health and Welfare, in the per capita spending on cancers for men and women, particularly for the over 65-year-olds. In fact, it is twice as high for the 75-plus-year-olds and almost twice as high for the 65- to 74-year-olds. Is there an explanation for that? Are men getting more cancers than women are? What is going on?

Prof. Knight—Yes. Regarding the rate of new cancers, one in three Australian men and one in four Australian women will get cancer before the age of 75.

Senator ALLISON—Three and four do not suggest a doubling of expenditure.

Prof. Knight—No. You would have to look at the breakdown of the expenditure. I cannot give you an explanation for it now. It is probably related to life expectancy.

Senator ALLISON—But that would suggest that more would be spent on women, wouldn't it?

Mr Learmonth—I think that question is probably best directed to the AIHW.

Senator ALLISON—These figures are from the AIHW. I am directing this question to you in a policy sense, asking you whether you have looked at this and wondered why, as we are doing.

Mr Learmonth—The short answer is: not that I am aware of.

Senator FERRIS—I am puzzled about who would direct a campaign. If the department decided, in a policy sense, that it would be a good idea to have a campaign—as it has had in the past on pap smears and breast self-examination—would it direct a body like the NBCC to come up with a plan and a budget, or would it make a policy decision that it was going to happen and ask such a body to develop a campaign and come back to it? There is a bit of a push-me pull-you here. I am confused about who would have responsibility for deciding whether it was a good idea to run a similar sort of national campaign on, for example, uterine, ovarian or some other form of cancer. Does the department rely on such a body's innovation and thinking, or does the department come up with the policy and tell such a body to develop a plan?

Prof. Knight—If it were within the remit of the National Breast Cancer Centre, which has responsibility for breast and ovarian cancer, the government would take advice from the National Breast Cancer Centre about the appropriate messages and, indeed, the evidence base on which one might raise awareness.

Senator FERRIS—So it would be up to them to come to you and say, 'After looking at all the figures regarding incidence and mortality, we have decided it is a good idea to run this sort of campaign.' You then would say, 'You develop it as a proposition and put it up to us.' Is that the way it would work? I want to know so that, when Dr Zorbas comes before us, she does not say, 'Oh, that is a job for the health department.' I want to know where the responsibility lies so that I can chase it down with another witness; that is all. I would be grateful if you could clarify that for me.

Mr Learmonth—I am not sure that there is a neat answer to this. Certainly one of the key remits of Cancer Australia is to make recommendations to the government about cancer policy and priorities, and this is one of the priorities that we will be looking at. If they, in their expert view, put a view to government that there should be a community awareness campaign, the government would consider that. How it might roll out in terms of who would be responsible for its conduct and how it might be executed would depend on the nature of the campaign.

Ms Powell—But you could be certain that there would be a lot of close work between Cancer Australia, the National Breast Cancer Centre and the department.

Senator FERRIS—I am trying to chase down who might be the initiator—that is all—so that, when we get future witnesses, they do not flick it back to you.

Mr Learmonth—Almost any of those bodies could initiate a campaign—the department, Cancer Australia and NBCC.

Senator FERRIS—But it is unlikely to be the department.

Mr Learmonth—The question is: who would make the decision about funding and executing it? It would be the government, on advice from the department and those bodies.

Senator FERRIS—But you would not necessarily initiate it?

Prof. Knight—A skin cancer awareness campaign at the moment is being run by the department. It depends entirely on who has responsibility for it and the government takes advice from a number of different areas.

Senator POLLEY—Is the department going to initiate a campaign?

Prof. Knight—On ovarian cancer?

Senator POLLEY—Yes.

Prof. Knight—Not that I am aware of.

Mr Learmonth—One is not planned at the moment.

Senator FERRIS—Let me chase down the skin cancer campaign, because it is a perfect opportunity to clarify the point I am trying to get to. Whose idea was it and by what process was it developed?

Ms Smith—That was an election commitment of the government.

Senator FERRIS—Fine, but that does not answer my question. Did it come out of your department, or did it come from some agency or body in the community who decided it would be a good idea and sold it to you and you took it forward to the government?

Mr Learmonth—There is no formula about these things.

Senator FERRIS—That is what I am trying to find out.

Mr Learmonth—I am sorry, there is not an easy formula to give you. The government will take a view on advice that the department puts to it. The department is constantly looking at areas of concern and formulating advice and recommendations to government. The government will consider those and make its decision. In this kind of circumstance, it would also take into account the views of bodies like Cancer Australia and the NBCC. So there is no neat formula as in, ‘It must be initiated here.’ It might well be initiated in more than one place or in any of those three places—NBCC, Cancer Australia and the department. But the question is whether that advice will be provided and whether the government will then take a decision to fund and execute such a campaign. Any of those bodies could make such a recommendation to the government.

Senator FERRIS—So if we were to ask those bodies whether they have considered such a campaign, it would be quite within their realms to answer?

Mr Learmonth—Yes, or whether they are recommending one to the government. That is part of their ambit.

Senator FERRIS—That is exactly what I wanted to find out.

Ms Powell—And in fact the NBCC could run such a campaign if it could fund it within its current funding arrangements for ovarian cancer.

Senator FERRIS—Thanks for clarifying that.

Senator ADAMS—I would like to come back to pap smears and vaccinations and where we are moving forward—which is quite rapid—in that area. The questions that I am going to ask are really pathology type questions. We have talked about pap smears. DNA is now becoming very important as far as pap smears go and there is technology and randomised trials overseas that are looking at the introduction of the primary HPV testing and then with a pap smear triage of abnormal results. Is the department looking at this or has it just been pushed aside?

I know that the 2002 decision of the Medical Services Advisory Committee only allows for tests of use. But we have had a pathologist giving evidence—and it is quite startling evidence—that Australia is really being left behind in this respect. I am just wondering if once again we get back to the National Breast Cancer Centre as perhaps conducting irrelevant research, and it possibly could be funded by the NHMRC into the introduction of primary HPV testing with pap smear triage of abnormal results. To go on the evidence we had today, when the new vaccination comes on board, those people are still going to have to have pap smears for the next 20 years. To cut down on costs, if DNA were able to be tested when they came for their first pap smear and that DNA were negative, there would be no need for these people to come back and have pap smears every two years. It is probably a health prevention thing as well. We have had some pretty good evidence on it, and I would like to explore the fact that these randomised trials have been very positive overseas.

I correct what I said earlier: the decision made in 2002 by the Medical Services Advisory Committee was for tests of cure, not tests of use. They were for tests of cure but not for anything else. So, with the way the vaccination is going to go, that will change the pathology of the pap smear, therefore the DNA seems to be the key to it. It will probably be more expensive at the start, but if they do not have to come back for pap smears for five years or so it is going to help.

Dr Primrose—I cannot give a full answer to this, because I have not worked with the Medical Services Advisory Committee, MSAC, for quite a while, and I think we will need to get some information from them. The basic principle of immunising against the oncogenic—in other words, cancer causing strains—of human papilloma virus is to basically give the vaccine to girls who are virgins, prior to the age where they are at all likely to have intercourse. As to the testing strategy that you specify, at the time where they potentially first become eligible for screening—perhaps 18 or after the time of first intercourse—

Senator ADAMS—Where are you living!

Dr Primrose—I do not want to prejudge anything. The strategy would be to do this molecular test for HPV and, if it is negative, you avoid doing subsequent pap smears. I am not sure to what extent MSAC has looked at that. We could get some information from that area and submit it later on. I think that is the way to go.

Ms Smith—MSAC did look at these issues previously, but the vaccines on the way for HPV are a very new development. I am not aware that MSAC has considered the issues around HPV testing in terms of the impact of a vaccine.

Senator ADAMS—We have had a request that they revisit it, because a lot of trials are going on in the rest of the world and we are not doing anything. The next request was whether it would be something that the National Breast Cancer Centre would be able to do with NHMRC funding, just to look at it. I am looking forward. As I said, it is probably more a health prevention thing, but it is something that we should be looking at now. If the DNA is done and there is no abnormality—it is negative—it will save you having to spend extra money on people coming back to have pap smears. This might be something worth exploring with respect to the Indigenous community, too. Once the DNA is done, what do we do?

Ms Smith—The other thing is that the Australian Technical Advisory Group on Immunisation is currently assessing both the HPV vaccines that are likely to be available on the Australian market. One of the key issues they are looking at is not just the vaccination issues but how the availability of a vaccine will impact on the cervical screening program. They have appropriate expertise that has been added to the group to allow them to look at those issues. This is an issue that is receiving quite a lot of attention at the moment.

Senator ADAMS—It seems to be galloping ahead fairly quickly, so I would not like to see the department left behind on it; that was why I wanted to ask the question. Another comment was that the new structure of the new technologies committee is a little difficult because of the number of areas of expertise there are now. That committee has to cover cervix, breast, colon, ovarian and prostate cancers. It is a difficult issue because, now that we have experts in every field, each cancer is becoming a very expert area. The comment has been made that this committee is not able to do its job properly. That is probably putting it in the easiest way. I would like a comment on that. I am not being rude about the membership of it; it is just about—

Ms Smith—Which committee are you talking about?

Senator ADAMS—We are talking about the new technologies committee.

Ms Smith—We have an Australian Screening Advisory Committee, which has a policy and new technologies working group—is that it?

Senator ADAMS—That is probably the group he is discussing.

Ms Smith—Those committees are in a state of flux at the moment. AHMAC has recently taken a look at the whole committee structure that reports to it—

Senator ADAMS—Why?

Ms Smith—and is in the process of amending the whole committee structure. The sorts of advisory mechanisms we have on screening are being considered as part of that process, so some change is happening in that area.

Senator ADAMS—It is just that comment. I refer to these areas of expertise, as technology moves on. We used to have an orthopaedic surgeon and that person could deal with any part of the body; now, of course, we have experts on all the different areas of the body. It is becoming much the same with the cancers. I just wanted to hand that comment on. I think that is probably enough from me.

Senator ALLISON—I notice that in your submission, under the heading ‘Prevention’, there is a long section on reducing the risk of gynaecological cancer, which is all about smoking. I wonder why it is not broader and why the department is not also looking at exercise, diet and all the other factors that other submissions have drawn to our attention.

Ms Powell—There is a range of programs within the department dealing with diet, exercise and nutrition. There are the initiatives under the Australian Better Health Initiatives, there are many programs funded through the diabetes program and through our health promotion area, and there are programs in place for childhood obesity and for school children et cetera.

Senator ALLISON—Why was smoking singled out in the submission?

Prof. Knight—Because it remains a fact, unfortunately, that tobacco exposure is the single greatest preventable risk in all cancers.

Senator ALLISON—Do we have the data that suggests it is a greater risk than all of those other factors that I mentioned.

Prof. Knight—Yes, we do. The International Agency for Research on Cancer in Lyons has documented that fairly substantially.

Senator ALLISON—Can you update the committee on the remarks that were made by the institute earlier about the nutrition study. It is some time since Australia has done a nutrition study and there was one imminent, but there was not a lot of detail about it.

Ms Smith—It is not my direct area of responsibility though it is being done within the Population Health Division. I think there has been some discussion through the estimates process about the fact that the department is pursuing the conduct of another study and is engaged in active discussions with the states and territories about repeating the National Nutrition Survey.

Senator ALLISON—Some discussions.

Ms Smith—The department has committed some funding towards that project and there is a process of negotiation with the states and territories about their contributions and some very active work happening to make that a priority.

Senator ALLISON—I have a question about removal of the lymph nodes in many treatments of people with cancer. I know that often multiple lymph nodes are removed. Can you indicate to the committee the status of PET scanning, which I understand is able to see whether a cancer has reached a lymph node or not? This PET scanning is not available in all circumstances. Is it the case that some lymph nodes are being removed unnecessarily because we do not have that PET scan analysis?

Dr Primrose—Lymph nodes can be removed for three reasons when you are managing cancer. The first is for diagnosis—is a cancer there or not? The second is for staging the disease—has it spread to the regional nodes? The third is that it can be therapeutic, so you are trying to extirpate not only the primary tumour but the draining lymph nodes. Positron emission tomography has not been studied in all types of cancer. It has been particularly heavily studied in lung cancer and there are a range of malignancies for which PET is currently subsidised through Medicare. I do not have a current list of those, but I think that the staging algorithm will vary from cancer to cancer. The other thing is that if you have to remove the nodes as part of the definitive surgical attack on the tumour, you are going to do that anyway. I think for cancers like cancer of the cervix, if you are doing a radical hysterectomy, excision of the pelvic nodes that drain the cervix is an integral part of the surgery and then at the time of the operation these can be examined under frozen section. If they are involved, the next echelon of draining nodes can be removed. I think it really depends on what particular malignancies you are talking about.

Senator ALLISON—Let me put the question in another way. If a treating gynaecological oncologist was uncertain about removing the lymph node, is there any barrier through the Medicare funding of a PET scan to do that in that circumstance to clarify the question as to whether the node should be removed or not?

Dr Primrose—I think we would need to get you a list of the currently approved PET items so that you know what—

Senator ALLISON—I am not sure it would make any sense to me, Dr Primrose.

Dr Primrose—With most gynaecological cancers, you are talking about the patient having an operation. At the time of the operation, the surgeon will palpate or feel the back of the abdomen to try to detect lymph nodes there. So they will look at the whole lymphatic drainage, say of the cervix.

Senator ALLISON—Yes, I understand that and there will be some who will say, ‘Take it out anyway whether or not the cancer is there.’ I understand that. I am asking you: is there Medicare funding to do a PET scan should the treating doctor consider that it is possible that a lymph node may not have to be removed, if the cancer has not progressed there? I can imagine that there are all sorts of other circumstances but it is a simple question. Is Medicare funding of PET available in those circumstances?

Dr Primrose—I guess it would be, but it really depends on what your overall treatment strategy is. I think we would need to get those PET items and look at the ones that particularly relate to gynaecological cancer and see how they impact on the treatment strategy. Is that helpful?

Senator ALLISON—That is what this inquiry is about: gynaecological cancer.

Dr Primrose—But not breast cancer as well.

Senator ALLISON—Let us put breast cancer in as well.

CHAIR—Yes, everybody else does.

Senator ALLISON—I am sorry that I am not up to speed on the latest on this but I do remember that there were restrictions placed on what PET scans could be used for. I had the privilege of seeing a PET scanning machine in a hospital and I was told how fabulous it was at detecting things like when cancer reaches lymph nodes. But I do not know what the current status is with regard to funding for those scans.

Mr Learmonth—We will take this on notice and give you a considered answer.

Senator ALLISON—Thank you. Also under ‘Prevention’ in your submission, you mention chlamydia, which is of course an important issue—and part of our inquiry is looking at sexually transmitted infections. The measures that you propose in your submission seem to me to be reliant on other programs. Leaving that aside, you say there should be health education about chlamydia. What precisely has the department got by way of programs? Does that health education extend into schools? Are we reaching young people—in particular girls—over the risks of sexually transmitted infections such as chlamydia?

Ms Smith—You would be aware that the government announced funding of $12.5 million over four years for chlamydia prevention. We are about 12 months into that project. We are just about to announce funding for the Chlamydia Targeted Grants Program. We advertised for projects towards the end of last year. In fact, we were delighted to receive many applications to fund a variety of projects in the area.

Senator ALLISON—What is the worth of the total applications?

Ms Smith—From memory, we got about 10 times more applications than we were able to fund. But we are going to be looking at a range of projects that will include education as part of those projects. Young people between 16 and 25—young women in particular—will be a key priority group in that.

Senator ALLISON—Will there be a universal spread or are the programs that are successful in this application process going to be for a community here, another one there and another one up there? Will they reach all of the target audience: every young person in the country?

Ms Smith—The first phase was targeted grants. They will be for particular projects or particular communities. One of the criteria was that those projects had to have national applicability, so we are looking for things that have been proven to work in that particular project or that particular locality and could be rolled out nationally at a later stage.

Senator ALLISON—Presumably, $3 million will not do that.

Ms Smith—Yes. The second phase of the project is actually looking at pilot sites. We are actually going to be looking at doing chlamydia screening in four pilot sites that will primarily be GP settings. We will also be looking at an Aboriginal medical service as one of our pilot sites. The aim of the chlamydia project at the moment is to actually trial a variety of approaches. It is acknowledged to be an area that needs attention but we still do not have enough information and enough evidence on what will work in a community wide setting. So this phase of what we are doing is about looking at what works in preparation for a broader roll-out later on.

Senator ALLISON—So phase 2 will commence when?

Ms Smith—We are looking at commencing phase 2 towards the end of this year.

Senator ALLISON—Is that still part of the $3 million?

Ms Smith—No, that is part of the $12 million.

Senator ALLISON—So how much is budgeted for phase 2?

Ms Smith—I would have to get the exact breakdown.

Senator ALLISON—Is there another phase after that, or is phase 2 the balance of the $12.5 million?

Ms Smith—From memory, phase 2 is the balance of the $12 million, but there is obviously an evaluation component of both the targeted grants and the pilot sites, which will essentially be phase 3.

Senator ALLISON—I am sorry; over what period of time does that—

Ms Smith—That was $12.5 million over four years, and that was announced in June last year.

Senator ALLISON—So it will be four years before we can see the effectiveness of some of those pilots and then some time later, when programs have rolled out, more universally?

Ms Smith—Yes.

Senator ALLISON—And there is no budget at the present time for that later stage, being beyond this—

Ms Smith—The budget at this point is for the four-year period.

Senator ALLISON—It takes four years to do all this? The pilots in GP settings, for instance—how long are they taking?

Ms Smith—I think they were planned to run over about 18 months, but I will have to check the exact time period.

Senator ALLISON—If you are able to tell us, it would be good for the committee to have a bit more detail about the grants that have been made so far out of that funding.

Ms Smith—There will be a public announcement about the grants quite soon.

Senator ALLISON—Will any of this go into schools, or is it all going to be GPs?

Ms Smith—There will be a variety of settings. I will have to check whether schools are one of those, but certainly young people are being targeted.

Senator ALLISON—But you do not know if it is schools? Does anyone else have—

Ms Smith—There were a number of projects. I would have to go back and check that detail.

Senator ALLISON—I understand. It would seem to me to be important that it is schools. Does the department not have that as one of its priorities for these grants?

Ms Smith—We have not specified the settings in which this will take place. We have tried to specify the priority groups. So you will see that we have tried to target those groups that are of highest risk. Young people are clearly a very big priority. So are men who have sex with men, and so are Indigenous people.

Senator ALLISON—So, apart from GPs, how else do you get to young people if they are a priority?

Ms Smith—I think some of the projects have proposed quite innovative ways of getting to young people. I know one of projects that I have heard about in the UK is using SMS as a way of getting to young people for education. We received a wide number of applications. There has been no public announcement of which ones have been successful, so I do not think I can give you the precise detail at this point. But certainly we are expecting an announcement very shortly, and we are happy to forward that to the committee as soon as it is available.

Senator ALLISON—Did you do any preparatory research on the level of ignorance, if I can put it that way, about chlamydia and how one gets it?

Ms Smith—We have been lucky. We have a chlamydia implementation committee that has been established to advise the department, and that includes a number of people who are working very actively in this area and a number of people who are doing research in this area. One of them whom you might be familiar with is Professor Frank Bowden, who is based here in Canberra at the ANU and at Canberra Hospital. He has done a lot of research in this area and has been able to share that with the department.

Senator ADAMS—Senator Allison has just reminded me about something, so I may as well continue on in that vein. Lymphoedema seems to be quite a problem with people who have gynaecological cancer and with those who have breast cancer as well—being a sufferer of it. With the chronic disease schedule and enhanced primary-care items, I have had a number of physios come to me and say, ‘Look, this is impossible.’ They are trying to treat lymphoedema, whether it be of the arm, the lower limb or the body. It really does take a lot of sessions of physiotherapy to deal with it, with the massage—and then of course with the garments and the expense of the garments. It is certainly a chronic disease. It is never going to go away. You can improve it, but you will not remove it.

Looking at it from a rural patient’s perspective, it is very hard to get, firstly, an appointment with a physio—it takes me three weeks to get one appointment—let alone a session or a series of appointments with them. From what I know about the items and lymphoedema at the moment, there have to be three other allied health professionals involved, so you end up getting only three or four treatments. I am wondering whether the department could take that on board when those item numbers are being looked at, because the situation is impossible.

If you can cure or just help someone, it will cost the health system so much less. Once again, this is probably getting into the area of health prevention, but it is something that is coming up more and more. I do not know about the PET scan as far as looking at the lymph nodes but, as more and more surgery is done—especially of ovarian cancers that unfortunately are not being diagnosed early enough—these people end up with lymphoedema.

Mr Learmonth—We can certainly take that on board. Those items have been reviewed and changed already.

Senator ADAMS—I know they have. Because of this issue, you need probably two weeks of continual massage to even make a difference with it. Also, it is very expensive and so a lot of people do not bother. For rural patients, as I said, it is just so hard because you cannot get access to one appointment, let alone five one week and five the next.

Mr Learmonth—That can certainly be taken into account when we review the items.

Senator ALLISON—One of the submissions points to the fact that there are only 35 gynaecological oncologists in Australia and that the RANZCOG projection is that Australia needs one of these per 400,000 of population. That leaves us short by 14 gynaecological oncologists—that is, a 50 per cent increase is required. What steps are being taken by the department to ensure that there is that increase? And when are we going to get one in Canberra?

Ms Lyons—Within my division is a branch that has responsibility for workforce. As I know you are very well aware from our discussions at estimates, at the moment health workforce issues are at the top of the list, not just of this government but of all governments. The Council of Australian Governments is meeting in July and will be considering a number of recommendations in relation to health workforce, and specialists and gynaecological oncologists particularly fall within that category.

Senator ALLISON—It is on the list?

Ms Lyons—I cannot honestly say to you that it per se is on the list. I know that a number of specialties are on the list and that radiation oncology is one of them, but I would have to take gynaecological oncology on notice.

Senator ALLISON—It has also been pointed out that about 40 per cent or, I suppose, about 12 of those oncologists are close to retiring age. Please take that on board as well. Another whole area that we have not really touched on much with the department is that of the psychosocial supports for people who are undergoing surgery in particular. What is the department’s thinking in this area? Have we made enough progress, and what sorts of plans are afoot?

Prof. Knight—Australia leads the world in having the inaugural psychosocial guidelines for people with adult cancers. Those guidelines were developed initially by the National Breast Cancer Centre for breast cancer and were expanded subsequently to cover all cancers. There has been a considerable amount of work done by a number of different bodies but it has primarily been spearheaded by the National Breast Cancer Centre to engage with the medical profession to have a number of communication, professional development and upskilling workshops, to disseminate the psychosocial guidelines at all of the different cancer centres and to make consumers aware of them. There has been a roll-out program in relation to the psychosocial guidelines. Certainly, it is strongly acknowledged and recognised that psychosocial care is an important ingredient for people with or who are affected by cancer. There has been substantial work in that area. The WHO approached Australia to ask if they could use our guidelines.

Senator ALLISON—The guidelines are one thing, but what about the services themselves? Are they adequate? Are all services meeting those guidelines? If not, when will they be likely to? What are the agreements with the states on this issue, given that the states are the ones that largely provide them through the hospital system?

Prof. Knight—As you say, Senator, it is a matter for the states and territories around the provision of health services.

Senator ALLISON—And you have had no talks with the states about this?

Prof. Knight—No.

Senator ALLISON—When the guidelines were produced, did you hand them over to the states? What did they say when you gave them to them?

Prof. Knight—The states and territories were previously represented on a consultation advisory body for cancer to provide advice to the government. Certainly, I am aware that in New South Wales, for example, there has been some roll-out of the guidelines. Each state and territory has a cancer plan. There has been quite a deal of interchange with the states among the cancer community. I am aware that they are paying attention to many of those issues. New South Wales probably leads the way in this arena.

CHAIR—Isn’t this an issue for Cancer Australia? In the cancer inquiry we were told that this kind of process was supposed to have been on the agenda for what was then going to be Cancer Australia. Now Cancer Australia is almost here. That particular issue came up during that inquiry about those guidelines and exactly the same issue about what was to happen to it. We were quite clearly told then that it was for Cancer Australia.

Senator ALLISON—All right. We will pursue that with them. We also heard earlier today that there are big differences in terms of the psychosexual/social support between private hospitals and the public sector. Were you aware of that? Were you aware that people who are covered by private health insurance might imagine they are getting a superior service when in fact they are not? Is this just a Canberra phenomenon or is this widespread?

Prof. Knight—There are a number of patterns of care studies in relation to cancer and the patient journey. It is not possible to give an overall response because it does vary widely, not only across treatment sites but even within states and territories and across different provisions. There is a wide variability in relation to those patterns of care and services and how they happen.

Senator ALLISON—Is that wide variability acceptable? Is it widely variable in both the public and the private sectors?

Prof. Knight—I could not tell you what the difference is between the two different sectors. I am not aware of any data that looks at that specifically.

Ms Addison—I can probably answer to some extent in relation to coverage by private health insurance funds. To some degree, the current arrangements in terms of how private health insurance can provide benefits for in-hospital treatment versus out-of-hospital treatment are reflected in the treatment experiences that people have. They receive greater benefits with in-hospital treatment but the health funds are not legally able to cover the care in the same way in an out-of-hospital setting. Therefore, people have reported to us—and we are aware of it—that they have had different kinds of treatment experiences because of the way their private health insurance is currently structured. It is one of the reasons behind making the reforms related to the board of health care, to enable services that substitute for or are part of hospitalisation to be covered in the same way as if they were provided in hospital.

Senator ALLISON—What is the evidence of how much of this psychosocial support in the public system is provided within hospitals?

Prof. Knight—I am not aware of any data that would directly answer that question.

Senator ALLISON—What we have heard—and I will ask this question more broadly—is that those services are in the hospital, so there is a physiotherapist, there is a psychosexual social worker and there is a psychologist there in the hospital. That is what we heard this morning.

Prof. Knight—It varies enormously from public hospital to public hospital and from private hospital to private hospital. I do not think it is possible to generalise across all of Australia in relation to that. I understand the comment that was made this morning, but you cannot generalise it immediately to all of Australia.

Senator ALLISON—So the guidelines are as true for the private sector as they are for the public sector?

Prof. Knight—Correct, for all patients.

Senator ALLISON—What do they say about psychosocial supports?

Prof. Knight—They say that it is very important that, from the first point in fact of suspicious lesions or uncertain diagnosis, all people with cancer be well supported through the cancer journey and provided with referral mechanisms to people who can help them deal with those psychosocial issues all the way through.

Ms Powell—I have a copy of the guidelines here, which I will table. But just to give you an indication of the sorts of things that they cover, they talk about the importance of understanding the challenges of cancer and how people react to issues ranging from emotional, social, financial, physical and psychological issues to issues of survival and dealing with the end of life. They talk about the importance of care coordination and care provided by treatment teams to all patients with cancer. They talk about how physicians and health professionals could discuss issues ranging from prognosis to diagnosis and treatment with patients, as well as giving practical and financial support, emotional and social support and ensuring continuity of care, including through to the end of life. Then they talk about issues requiring special consideration such as culture, age, ethnicity, sexual orientation and geography. I would be happy to provide a copy of those guidelines.

Senator ALLISON—It does not say, for instance: ‘Hospitals should provide this service and it should be for these kinds of people.’ It is a more general statement about the need?

Ms Powell—It talks about the needs of patients and the sorts of services that might be provided to them. It is not that prescriptive.

Prof. Knight—Increasingly, much of cancer care is taking place in the community, so I think it is not the setting that is the critical variable but indeed the psychosocial support across all the different settings.

Senator ALLISON—But, in the case of someone presenting to a public hospital, who funds those extra services? Is it the state government, as an extension of the hospital?

Prof. Knight—Correct.

Senator ALLISON—And we have got this difference with the private sector, which cannot do that. Can people who might, for acute care, be dealt with in the private sector then access psychosocial supports in the public sphere?

Ms Addison—We would have to take that on notice, but the funding of those arrangements through the public sphere is largely the responsibility of the states and territories.

Senator ALLISON—I understand that. I have no further questions.

CHAIR—In following on from that, the effective use of complementary therapies was an issue that came up extensively in the committee’s inquiry into the cancer journey. In this inquiry we have had some evidence that people going through treatment get great relief from some forms of complementary therapy, which of course is not covered by any of the processes. The message that we got in the extensive cancer inquiry last year seems to be coming through again at the initial stage of this inquiry. I think we have taken way too much of your time—well over an hour and 20 minutes longer than you thought you would be here. I hope your enterprise bargain is very strong to cover these things!

This inquiry is due to hand down its report in October. We have three public hearings scheduled for Sydney, Melbourne and Perth. We would welcome the department's attendance at or involvement in those hearings. A very valuable aspect of other hearings we have had is that people from the department have been available to attend. Thank you so much for your evidence and your submissions. We encourage your ongoing involvement in this process.

Committee adjourned at 1.23 pm