COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Response to petition on gynaecological health issues

FRIDAY, 3 MARCH 2006

CANBERRA

BY AUTHORITY OF THE SENATE

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Friday, 3 March 2006

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

Participating members: Senators Abetz, Allison, Barnett, Bartlett, Mark Bishop, Bob Brown, Carol 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 and Wong

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

Terms of reference for the inquiry:

To inquire into and report on:

Response of committee to petition on the management and prevention of gynaecological cancers and sexually transmitted infections.

WITNESSES

Committee met at 10.02 am

GOWER, Mr John David, Chief Executive, Gynaecological Cancer Society Inc.

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

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

HEFFERNAN, Ms Margaret Ellen, Private capacity

KEMP, Mr Ian, Director, Cancer Section, Department of Health and Ageing

LEE, Mr Simon John, Chair and Director, National Ovarian Cancer Network (OvCa Australia)

MAZZELLA, Mrs Kathleen Faye, Founder, Gynaecological Awareness Information Network (GAIN Inc.)

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

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

CHAIR (Senator Moore)—Welcome and thank you for choosing to be a part of something that I think is going to be a little bit different for us. Hopefully we will be able to achieve a lot out of this Senate Community Affairs References Committee roundtable discussion. We are very grateful that you have all been able to attend this morning and that you have come to discuss the health issues raised in the petition circulated to the Senate in December last year. I know you have all seen that petition and have knowledge of it. I am sure that most of you know each other through different meetings and conferences that have been held. The issues that were raised in that petition are important to all of us.

In running today’s proceedings—I do not know if I like the term ‘running today’s proceedings’—I am hoping that we will be able to have an orderly, free-flowing discussion. I am not going to put a stopwatch on, but I ask that everybody be aware that the process is to be a shared one and we have limited time. My intent is that we will be able to work through the issues on the petition. With Christine from the secretariat, we will go point by point down the petition and keep it to about 30 minutes on each point. That will ebb and flow but that is the aim. I remind you all that, as a formal committee activity, the proceedings are covered by parliamentary privilege, and I am sure that you have received information on that. The committee members intend to limit their own contributions because we are here to listen to you. That is a discussion I have not had with the committee yet, so it is now on record. But it is more of a discussion than anything else. We have had a discussion paper circulated and we will work through that. If you have any questions, please raise them straightaway; it is easier that way. Before we begin, do you have any comments to make on the capacity in which you appear?

Mrs Mazzella—I had a radical gynaecological cancer and I have a personal interest with women in the community and raising the voice of their stories.

Mr Gower—The main thrust of the Gynaecological Cancer Society is patient care and family and carers of a non-clinical nature.

Mr Lee—The National Ovarian Cancer Network is an independent charity that was formed to increase awareness of ovarian cancer specifically and to provide support and information for women and their families.

Prof. Hacker—I am a gynaecological oncologist and Director of the Gynaecological Cancer Centre at the Royal Hospital for Women in Sydney.

Ms Heffernan—I am a gynaecological cancer survivor of 14 years now. I am a gynaecological cancer activist. I initiated and project managed this petition.

Ms Robertson—I am senior psychologist in the Gynaecological Cancer Centre at the Royal Hospital for Women in Randwick.

CHAIR—Thank you, and thank you, Ms Heffernan, for your work in getting the petition organised, because it has stimulated this discussion. My copy is in very small print, but the first issue that has been raised is the issue of the increase in research funding for the development of a screening test for ovarian cancer. I propose that that be the first dot point that we consider. Who will be brave enough to start the discussion?

Prof. Hacker—I can say something about that. Ovarian cancer, of course, is the gynaecological cancer that carries the highest mortality, so it is the cancer that we are most in need of a screening test for. It has a five-year survival rate of about 40 per cent, which is about half the five-year survival rate of breast cancer and endometrial cancer. The rate for cervical cancer is a little lower than that, but cervical cancer has a screening test, the pap smear. There is a common misconception in the community that a pap smear diagnoses all sorts of gynaecological cancers—ovarian cancer and endometrial cancer—and if you have a pap smear you are clear. But of course that is not the case. The idea of being able to screen women for gynaecological cancer per se is not realistic. We have to look at each one individually.

At present there is no effective screening test for ovarian cancer. There is a test called CA125, which is a useful test for monitoring patients with established cancer. For example, during chemotherapy you can tell whether it is responding to the treatment or not; you can tell if it relapses if the test rises. But this test is very non-specific. It is commonly elevated in conditions other than cancer and it is commonly not elevated in patients with early disease. So what you want to do if you are going to improve the mortality of this disease, of course, is to diagnose it while it is confined to the ovaries. We do not have an effective test to do that at this point.

Until now, trying to find a test has been something like finding a needle in a haystack because we have been looking at chromosomes and seeing if they look a bit abnormal, and that is never going to achieve an effective test. But we now have, since the human genome project, means, technologies, for looking at the individual genes. We know that there are something like 40,000 genes in the human genome. We have looked at 50 epithelial ovarian cancers in our research program with the Garvan Institute of Medical Research. We have found there are something like 350 abnormal genes in patients with ovarian cancer. So if we are going to find a screening test, it is going to be related to these 350 genes. We have eliminated 39,650 but there are 350 that we still need to look at if we are going to get the answer.

These genes produce proteins and the proteins circulate in the bloodstream. It should be possible, with a concentrated effort, to find a test for this disease. It may not be a single test, because there are several different types of epithelial ovarian cancer, but the commonest is the so-called serous type of cancer, and we are concentrating our efforts on looking at those serous cancers. So, unlike the situation five years ago, where this was like looking for a needle in a haystack, we now have the wherewithal to come up with a test, but obviously it takes a lot of time, effort and money.

Ms Heffernan—The research thus far has been mainly funded out of private enterprise or community donations. The government gave half a million dollars over two years, but in Australia we are very privileged that at the moment we have got three major research centres looking at ovarian cancer and looking at different aspects of the screening. As Professor Hacker has said, they have now had this major breakthrough in identifying what genes are relevant to that disease. But if we are to have a significant breakthrough in a preventative screening measure, it is no longer feasible to rely on community donations, which simply are not filling the need. Having regard to the half a million dollars over two years between these three centres, we were having a conversation earlier and discussing the fact that the cost of running these on a shoestring is a minimum of half a million to three-quarters of a million dollars per year, per research team.

Because of the very small pool of funding available at the moment, we are not getting the breadth of researchers into that. With an increased and substantial government contribution to ovarian cancer research, it means that more scientific researchers can be employed to gather more data, more samples and therefore fast-track this preventative screening measure. Is it true, Professor Hacker, that we would still be a minimum of five to seven years away from a test that you would feel you would present?

Prof. Hacker—Something of that order, yes.

Ms Heffernan—If we look at the mortality or the number on the data that was presented with the petition, between 1983 and 2001 there were nearly 21,000 women diagnosed with ovarian cancer, with 55 per cent of them dying, so we are looking, in the past five years alone, at 7½ thousand having died. If we are going to wait another five to seven years for a screening test, that will involve another 8,000 to 11,000 women—and then there is the multiplier effect of the dysfunctionality of their families et cetera.

Mr Lee—A key thing to understand about ovarian cancer compared with other forms of cancer is that there are really no specific symptoms associated with it. Women can think that they have got some problem with their ovary. We do have a fair amount of evidence that women do experience symptoms, but they are vague and nonspecific. They could be things like backache and fatigue rather than something specifically gynaecological. As a result of that, women are not seeking treatment early enough. So the majority of ovarian cancers are being diagnosed at an advanced stage where it has progressed beyond the ovary and, very often, beyond the pelvis into the abdomen and beyond that.

The result of that is that the majority of women with ovarian cancer are going to have to undergo extensive surgery and probably multiple occurrences of chemotherapy treatment. Very often the disease progressively becomes more resistant to chemotherapy. The result is that they go through more and more treatment and become further debilitated as a result—which is why we see a very high mortality rate for this disease. There is a firm belief with any form of cancer that the earlier we can catch it, when it has not spread from its primary site, the better the chances are of being able to cure it. The evidence for ovarian cancer is that stage 1 cancers—those that were confined to the ovary in the first place—have exceedingly good prognoses, in the region of 90 per cent cure rates.

So we have to somehow intercept this cancer before it is spread. There is not sufficient information for a woman to know that she has got that disease, and that is why it is so important that we develop some form of effective testing mechanism and screening program that can intercept the disease before it becomes a lethal condition.

When we look at the statistics in terms of mortality, ovarian cancer sits up at about No. 5 in terms of the most common causes of cancer death in women. So it is not far behind breast, colorectal and lung cancer; then you are suddenly getting down to pancreas and then ovary. It is a very serious condition for women, but it has largely been not recognised as a major medical and social problem. It is very important that we see significant investment in research to find a way of detecting and intercepting this disease earlier, before it has a chance to make women’s lives a misery and destroy the lives of their families and their friends.

Mr Kemp—I would like to outline the Australian government’s contribution to research in this area. Through the Strengthening Cancer Care initiative, $17.6 million has been made available over four years for a dedicated cancer research budget. One of the priorities for this funding will include the early detection of breast and ovarian cancers. In addition to that, the National Health and Medical Research Council provides funding for research into cancer, including gynaecological cancers. Since 2000, $14 million has been provided for research into ovarian cancer.

Senator FERRIS—Is it possible to get a breakdown of how that $14 million has been distributed?

Mr Kemp—I will endeavour to get that information through the NHMRC.

Senator FERRIS—So it is actually provided and then the distribution structure is through the NHMRC.

Mr Kemp—Basically, through the NHMRC, people submit applications for funding on various topics, and then the NHMRC assesses the proposals and funds proposals on the basis of merit.

Senator FERRIS—I think it would be useful if we were able to get a breakdown of how that has been distributed.

Senator ALLISON—It has already been handed out for research, has it?

Mr Kemp—Yes, that is the money that has been allocated since 2000.

Ms Heffernan—May I ask Mr Kemp a question? Even though $14 million has been allocated, how much of that was actually distributed by NHMRC for ovarian cancer? Because my understanding is that these major research centres have not been allocated anywhere near that realm. So, even though $14 million has been allocated, how much was actually applied?

CHAIR—Can you provide that data, Mr Kemp? The allocation has been made but then we actually need to see how it has been used as well; it is like two different databases. Can we get that?

Mr Kemp—We can certainly provide you with details on how the money was allocated.

CHAIR—That would be fine.

Prof. Hacker—Can I just make one more point about symptoms. This is about a study that we did in our unit and published last year. We took 100 women with early-stage cancer and 100 women with advanced cancer. They were of similar age; we matched them for age. Both groups of women presented with things like abdominal pain and abdominal swelling. In 70 per cent of the early stage and 70 per cent of the advanced stage women, the symptoms were investigated and a diagnosis made within three months. So, in spite of the fact that women were presenting fairly early and were being appropriately investigated, most women, 70 per cent, will have advanced disease at the time of diagnosis. So you cannot rely on symptoms to diagnose this disease in its early stages.

Senator HUMPHRIES—Can I get some reassurance that spending money on research in an area like this is a better investment for us as a community than investing in, say, general cancer prevention measures like programs to increase exercise levels, improve diet and reduce smoking? I assume those are factors which have an impact on ovarian cancer, as they do on other forms of cancer. There are so many competing priorities in health that it is always hard to know whether an injection of money into a particular area is a better spend than on other areas. What can you say about that in respect of ovarian cancer?

CHAIR—Actually, a few people want to comment on that.

Prof. Hacker—I think a screening test for any cancer has got to be money well spent. If you look at the pap smear for cervical cancer, we have a very low incidence of cervical cancer in this country. It is still higher than it needs to be, but that is because women do not present for the pap smear; only 60 per cent of the population have regular smears. But if you had regular screening and it is offered regularly there would be a very low incidence of cervical cancer in this country. If you look at developing countries that do not have screening, they have a very high incidence. If you look at Indigenous Australians, there is a very high incidence. So I think any screening test is money well spent. If you can prevent or diagnose early, when it is potentially curable, then of course mortality is going to be markedly reduced.

CHAIR—Mr Lee? I thought you might have a comment!

Mr Lee—From the evidence we currently have with regard to ovarian cancer, the causes are not understood. There are a number of known risk factors which seem to influence the incidence of the disease, and there is some implication that those will involve lifestyle factors, but the evidence currently in terms of things like smoking and diet is not particularly strong—that is the truth, I think. The one behaviour that can reduce a woman’s risk of ovarian cancer is taking the oral contraceptive pill. It appears to be that ovarian cancer, if you like, is the result of prolonged, multiple ovulations over a period of time. Therefore, the evidence is not really there to suggest that the sorts of behavioural interventions that women can take—in other words, lifestyle things—will reduce the incidence of the disease other than taking the oral contraceptive pill, having several full-term pregnancies and breastfeeding your offspring.

CHAIR—Almost mutually exclusive. Ms Heffernan, did you want to make a comment on that?

Ms Heffernan—I think any education awareness programs for the overall wellbeing and health of the community, particularly preventative ones, are absolutely critical, but we know that not every member of the community is going to follow the protocol or the advice.

It is also compounded by people in rural and regional Australia that may not have access to those programs, or do not participate in them. I have just spent three days up in Western Victoria talking to rural women about gynaecological health. Many of them do not buy the daily newspaper because they simply cannot afford it; they do not have access to support groups and things like that, and even though they might be physically fit, the incidence of smoking and other things like that are still fairly high in those regions. We have to continue looking at lifestyle behaviours and their impact on cancer, because it is known that obesity, smoking et cetera contributes to a range of cancers.

We have had pap smear screening in place for several decades, but it is well known that because of cultural factors in Indigenous communities and in some sections of our migrant communities, they simply do not have access to it or will not uptake that because of the invasive nature of the test. There is also the fact that many women are also very ignorant about their bodies, and particularly their gynaecological and reproductive systems. Despite having monthly periods and babies, I would defy the majority of women in the community to be able to specifically name each anatomical part, and so we have heightened ignorance. I know there is big government funding going into obesity at the moment, which is prevalent and which is also a contributing factor, but we cannot say with certainty that every woman at risk of ovarian cancer is going to follow that protocol and then minimise it.

We also have the compounding issue that if we do follow the protocol—my family, genetically, are very prone to a range of cancers, including gynaecological. Do I then feel guilty because I am not smoking, that I am doing this, this and whatever? That needs to be an additional program that continues to be funded parallel to fast tracking these preventative measures for ovarian cancer. With both funded equitably and on an ongoing basis, we can then significantly reduce this.

Mr Gower—The specific treatment of ovarian cancer is very expensive, and we know that the mortality rate is very high so that is a diminishing return. There are two issues. Education is certainly one of them. Educating women and educating doctors—specifically GPs, who do not see gynaecological cancers very often and who often misdiagnose them for that reason. Education is one issue, and it really needs to be funded properly at two levels: patient level and doctor level.

We need, if we can, an ovarian cancer-screening test because it kills a lot of people. It is very expensive, and we can do it. There is the talent in this country to develop that test. It is going to cost some money and it is going to take some time, but it just simply needs to be done. The emotional cost to patients and their families is incredibly high, and the outcomes are awful. It is something we need to do.

CHAIR—Mrs Mazzella, do you have any comment on this particular point?

Mrs Mazzella—Only that I agree with everything that has been said here. It is about awareness, it is about education, and it is about the building of confidence. It is totally lacking and it needs to be done, so what is being said is really good.

CHAIR—Mr Harding, do you have any comment on this particular point about funding?

Mr Harding—The institute put out a publication about six months ago on health expenditure costs for various cancers. In fact, of the gynaecological cancers, ovarian cancer is, quite truly, more expensive. The average lifetime cost calculated—this was for 2000-01—was almost $20,000 compared with $17,200 for cervical cancer, just under $12,000 for breast cancer and just under $12,000 for uterine cancer. The figures are correct; it is one of the more expensive ones. Also, given the mortality rate, this is based on a shorter lifespan, so the actual cost per life year would be considerably higher.

I have some figures from a database called Globocan, which is put out by the International Association of Cancer Registries, where you can compare cancer rates from around the world. Our incidence rate is somewhat lower than for most other countries. The age standardised incidence rate for Australia was 8.9 per 100,000 population compared to 11.6 for Canada, 12 for New Zealand, 13 for the UK and 11 for the USA. Our mortality to incidence ratio was pretty much on a par with the others. So we are not doing any better or worse, although the UK appears to be doing somewhat worse than we are in terms of mortality to incidence. That is how we are going in terms of an international scale of treatment and so on.

I would be interested to hear from Professor Hacker and others their comments about what research into a screening test is going on in other countries.

Prof. Hacker—The genomic and proteomic work that we are doing is being duplicated in other countries. It is a race, I suppose, to see who comes up with the test first. Clearly, if a screening test were developed, not only would it be of tremendous benefit but it would be a source of tremendous income, too, for whomever was first to develop it.

I suppose research teams tend to guard their work a bit. I am not a basic researcher, but that is how research teams tend to function. We are not alone in doing this, but I think there are not many centres, even if you count those in the rest of the world, that have the resources to do it. Genetic research is a high-technology and a high-cost type of research—for example, to analyse the 50 ovarian cancers cost $1 million, and then all of that data has to be analysed. It is very expensive and time consuming and it needs a lot of expertise.

Senator FERRIS—Just on the topic of educating general practitioners, I think it might be useful to mention my own experience. Some of the people at the table know that I have recently undergone surgery for ovarian cancer. I presented with only a symptom of a strange sense of tiredness, which I could not throw off despite having a couple of early nights. I went to my GP and was told that I had glandular fever. Despite a blood test being available for glandular fever, I was not offered one until I asked for one and found that I did not have glandular fever. I subsequently presented at casualty at Canberra Hospital, because I continued to feel worse and worse. I had to insist on having a CT scan, because I was advised by a doctor there that they were expensive. It was only when I said ‘And I am valuable’ that I was able to convince them that I should have a CT scan. Within a few hours of that CT scan, a whole range of things came into play.

What I am giving you a practical example of is the need, firstly, to give GPs some education on this and, secondly, to have a procedure in place so that, when people present with strange symptoms and they ask for something like this, they are not made to feel guilty because of its cost.

Ms Heffernan—I would just like to go back to Senator Humphries’ point and then comment on Mr Harding’s statement. Clearly, you want some guarantee on any government contribution into scientific research that there is going to be some outcome. Mr Harding has already indicated that the incidence of ovarian cancer in Australia is around the global average. We know that research is also being done in America and England, and I am led to believe that there is collaboration at an international level at the scientific meetings where these researchers present their findings. So each is building on the other.

In Australia we are very lucky that we have such a committed and dedicated specialist research community who are really focused on trying to minimise the incidence and trauma of this particular cancer. Let’s forget the other range of gynaecological cancers at the moment that are also as worthy, it is just that ovarian cancer has the most impact and the highest incidence of death. The fact that these three research collaborations at the moment in Australia have managed to make the progress and achievements they have on private enterprise and community funding is extraordinary. Now how is the Australian government going to look its constituency in the face and say, ‘We listened to the case of women in Australia but we have chosen not to fund a screening test’?

We want to contribute to work that has already been done. Professor Hacker has identified that they now know what genes cause this and that with a significant contribution of government funding combined with the community and private enterprise commitment and support that will be ongoing it would be the most worthwhile investment that this government could make in terms of women’s health. Even though Mr Kemp has identified $14 million, my understanding from the research I have done and what I have seen in the figures is that not all of that $14 million has been allocated to ovarian cancer research. I am really looking forward to perhaps getting some of that data when it becomes available. The NHMRC have very strict guidelines on what they fund but my understanding is that these three centres are not getting a significant share of that pie although they have proven that they are making advances in these screening tests.

Ms Powell—We should be able to provide you with a list of where that $14 million has been spent. My understanding is that $14 million is what has been paid out in grants for research into ovarian cancer but it may well have been spread over a very large number of organisations, I do not know, but we will be able to provide you with that information.

Senator ADAMS—It is over six years

CHAIR—When could we get that? Is that something that would be easy to obtain?

Ms Powell—I would have to go to the NHMRC. I am not sure how quick that would be, but I would not imagine it would be very long.

Senator ADAMS—Yesterday I was at the AMA breakfast and because we had this forum coming up I spoke to several GPs—ones that specialise in gynae work—about whether there were any guidelines for a start for GPs in how to actually diagnose the symptoms or look at the symptoms and find out. We got on to the case of practice nurses doing pap smears. One GP was very strong on the case that every woman going to have a pap smear should have a pelvic examination as well and it should be done by a GP not by a practice nurse. I am a great supporter of the divisions and their practice nurses so I got into a little bit of an argument with that. Firstly, are there any guidelines for GPs, what are they given in their training and also what do you feel about a practice nurse doing pap smears versus a GP doing a Pap smear and a pelvic examination?

CHAIR—Senator Adams, that is really a question for the fourth dot point. I will ask people to hold that information until we get to that level or else we will lose focus. I do apologise. Mr Gower, you were wanting to comment?

Mr Gower—Senator Ferris, I am sorry for what happened to you. It happens to a lot of women every day and that is the sad thing. You did something about it, you did not accept that there was nothing wrong, and you went and did something about it. A lot of other women do not, for whatever reason, and then it is too late. So, for some years, we tried running continuing medical education courses for GPs. They do not come. It may well be that one of the things that we have to think about in the future is some way of compelling GPs to come and be re-educated and retrained.

Ms Robertson—I just want to make a final statement. The psychological morbidity associated with ovarian cancer is huge. I have worked with women who have been having chemo for almost nine years straight. You can imagine the impact that is having on not just them but their families. Their lives completely change.

Senator ALLISON—Professor Hacker, what you described did not sound like screening to me. I may be misunderstanding the nature of your work but, in identifying the genomes which are likely to bring about cancer, you are going to identify a population of people most likely to have ovarian cancer. Where does that then take you? That is not so much a screening test for the cancer as for the propensity for the cancer. Is that right?

Prof. Hacker—Not necessarily, no. It would be nice if you had a precancerous phase that you could identify, like you do with cervical cancer, so that you could treat the precancer and nobody gets cancer. We do not have that luxury with most cancers. When you do a mammogram, you are diagnosing cancer not precancer. With ovarian cancer, in the absence of a precancerous phase that we are aware of, what we would be trying to do is to diagnose stage 1 cancer of the ovary. As Simon said, the cure rate for that is something in the order of 90 per cent. So that would be much better than the 40 per cent survival that we currently have. It takes less treatment—four cycles of chemotherapy—and most of them are cured. We would have a significantly different situation if we could diagnose ovarian cancer while it is confined to the ovary. The idea would be that it would be some sort of annual screening test or something like that or a blood test.

Senator ALLISON—The human papilloma virus vaccine development is so exciting for women in terms of cervical cancer. Is there any evidence to suggest that ovarian cancer is caused by a virus and may also be able to be dealt with through a vaccine?

Prof. Hacker—No. There is no evidence for that.

Senator ALLISON—Is that because we do not know or the evidence is that there is none?

Prof. Hacker—There is no evidence to date, anyway, and it is extremely unlikely that it is caused by a virus. About 10 per cent of women have this hereditary type of ovarian cancer. In that group of women we recommend that they have their children at a relatively early age and then have their ovaries taken out, so they have a prophylactic oophorectomy. That stops them getting ovarian cancer. Maybe if you could identify other women at risk through the genetic process you could do the same thing. You could recommend that they have their ovaries taken out, at least in their 40s, or before they get the disease.

Senator ALLISON—That is quite a drastic prophylactic measure, isn’t it?

Prof. Hacker—Yes, it is a drastic step. But ovarian cancer in the current situation is a drastic disease. Women who have these genes sometimes elect to have prophylactic mastectomies too to try and avoid breast cancer.

CHAIR—We will move on to dot point 2, which is the one looking at the issue of Indigenous women and women from other cultural backgrounds. A number of your submissions addressed that issue. Would anyone like to start? Perhaps you, Ms Heffernan, as you have just talked about doing workshops with women and the particular issue of Indigenous women and women from other backgrounds.

Ms Heffernan—I am currently studying for a PhD about the community attitudes to and awareness of the human papilloma virus vaccine and I am examining Anglo, Chinese and Indigenous—both remote and urban—communities within Australia. Given the aetiology of HPV and its sexual transmission, there is some concern that, among those cultures with entrenched values and morals about sexual activity pre marriage, there will be resistance to uptake of this vaccine.

The inoculation rate of Indigenous children is half that of the general population. The incidence of cervical cancer among our Indigenous women is twice what it is among the rest of the Australian population and so is the mortality rate. There are sectors of our multicultural communities, particularly those from patriarchal cultures or those of Islamic faith, which are very resistant to pap smear screening, especially by a male doctor, because of the invasive nature of it.

We also need to be aware of—and what I am looking at is—the transubstantive error factor of the message that is given out to the Australian population with the assumption that one message is going to reach all quarters. It gets back to my comments to Senator Humphries previously that, whilst we have these education programs, they are only hitting a specific sector of our community.

We know that in our Indigenous communities mainstream print based messages et cetera often do not reach those that need them most. There have to be a lot of customised and visual programs. I must say there has been a lot of effort with Indigenous health workers and government funding to Indigenous health at this stage. However, what is of concern—and the reason why I identified this and that nearly 3,000 people, male and female, who signed the petition supported it—is that the one way we can reduce the incidence of cervical cancer in the Indigenous population particularly is through this HPV vaccine, because we now know that HPV16 and HPV18 are necessary causes of cervical cancer. There are some other strains of HPV that also contribute to it, but they are the two strains that are necessary for you to catch cervical cancer and vulval cancer, and this vaccine, as I said, will stop that.

My understanding is that this vaccine has already gone to the FDA for fast-tracking and that it is going to be available to the Australian public around 2008 at the latest. At the moment, they are still doing the economic modelling on this and identifying at what age it should be given to children. They are thinking pre sexually active so it would probably be targeted at early secondary schoolchildren.

The ballpark figure on the costing at the moment is around $70 per vaccination, and you need three jabs. We know this is reflecting and paralleling the hepatitis B vaccination, which took 10 to 15 years before there was widespread Australian uptake of it. The factors for reduced uptake of the vaccine for hepatitis B, which is also sexually transmitted but is also blood-borne, through dirty needles or whatever, were the cost, the sexually transmitted nature of the disease and the very low levels of awareness. In order to reduce the incidence of cervical cancer in the Indigenous population, we are going to have to make that vaccine affordable to that population. It may be in the first instance that the government put heavy subsidies on the vaccine for, especially, remote Indigenous people.

I have not had a breakdown of the incidence of the range of other gynaecological cancers, but you will note from the submission you received that the incidence of cervical cancer in Queensland is eight times the national average. This is because of the factors that I have just identified. So I would really encourage the government in its largesse to maintain the current funding and support for the pap smear screening but also to look very specifically at the economic modelling of HPV vaccine for Indigenous communities.

Mr Gower—We have actually funded some research into gynaecological cancers in the Indigenous community, looking at Thursday Island and those sorts of places. There are cultural problems. Husbands will not let their wives be tested for a pap smear. It is not allowed. If they have been tested, when the results come back, people are not there anymore; they have moved on. If they are there and appointments are made for treatment, they do not turn up. When they do turn up, it is too late. So there are some real problems with the treatment of gynaecological cancers in the Indigenous community. That is why I have to say that Margaret is 100 per cent right: we really do have to vaccinate, because all of us have been spending a lot of money over a lot of years, and frankly we are getting nowhere, because of the cultural problems.

Ms Heffernan—The other factor around cultural acceptability of preventative measures is that my research also shows that the term ‘cancer’ or anything associated with cancer in the Indigenous population, particularly among females, is stigmatised. They are reluctant to use the word because it is almost like pointing the bone—to use a metaphor—at themselves. In my discussions with the Aboriginal health workers in Central Australia, they say that, even though they can bring the women in for an initial test or screening, follow-ups or ongoing care are almost impossible because of their nomadic lifestyle and also this resistance to accepting the diagnosis. They virtually go away to die. And then of course that has all the ramifications within their communities of the psychosocial aspects that plague us all. But it is a particularly big problem in the remote areas.

Mrs Mazzella—I was invited to speak at Aboriginal Women’s Health in Campbelltown. After I went home, I got an email: ‘Thank you for speaking,’ the writer said, ‘because you allowed me to be more open with the next group of women.’ She said: ‘We saved a woman’s life. But it is more the open dialect within the Aboriginal community that we have to try and encourage so that they can all start with their secret women’s business, but they actually start talking about gynaecological health issues.’ So I thought that that was quite interesting.

Ms Powell—I have some general information about some of the activities the department is doing in this area. We have established the Aboriginal and Torres Strait Islander Women’s Forum, which advises the Australian Screening Advisory Committee on strategies to improve the participation of Indigenous women in breast and cervical cancer screening. This forum has an all-Indigenous female membership comprising state and territory government representatives and representatives from the National Aboriginal Community Controlled Health Organisation. It provides an opportunity for members to consult with their own communities, to support and encourage the development of proactive and health promoting plans for increasing the take-up, so I guess it is a recognition of the sorts of issues that you have just raised.

There is also a program called the Healthy for Life program, which is getting $102 million over four years from this financial year to support immediate improvement in the health of Aboriginal and Torres Strait Islander mothers, babies and children, encouraging increased screening and treatment for chronic diseases. That includes also looking at issues related to increasing the take-up of screening for cervical cancer.

The National Service Improvement Framework for cancer, which was endorsed by health ministers at the end of last year as part of the National Chronic Disease Strategy, will also be looking at issues related to cervical cancer screening. The government is moving at the moment to create a new organisation called Cancer Australia. Should that be passed by parliament and established, it will also be looking at this as one of its priority areas.

Ms Heffernan—Chair, may I ask Linda Powell: what percentage uptake has there been thus far as a result of the Aboriginal and Torres Strait Islander Women’s Forum that is being designed to increase uptake in screening?

Mr Kemp—I cannot answer that.

Ms Heffernan—Would you be able to get the data for us?

Mr Kemp—We can have a look at the activities of that particular forum and the work that they are doing in that area.

CHAIR—It is one of the key priorities of that group, isn’t it?

Mr Kemp—Yes, absolutely.

Ms Powell—We will find out some specific information and get back to you on that.

Ms Heffernan—Is the model then going to be applied to, say, far-north Western Australia, the Northern Territory and other areas that also have low uptakes, mainly around the Torres Strait Islands and North Queensland area? I am doing my PhD with the University of Melbourne and within that group there is currently a WHINURS project that is looking at sampling 2,000 women—Indigenous and non-Indigenous—to look at the incidence of HPV in those communities. My understanding from Central Australia is that there is still extremely low uptake. Professor Hacker has identified it at 19 per cent in parts of Queensland. If your initiative has significantly increased participation, we would really like to have a look at that model and strategy so as to be able to apply it to other activities that we are involved in.

Ms Powell—Certainly the national forum looks at issues right across the country. Perhaps I could provide the committee with some further information. If you wanted to follow up more directly, I would also be happy to facilitate that.

Ms Heffernan—Thank you, I would appreciate that.

Senator POLLEY—I would just like to make a comment on this issue. In light of the recent trip that this committee took out to some of the remote areas and the evidence we have had before us through the petrol sniffing inquiry, my concern about our Indigenous community is that there has been evidence given that there has been an increase in sexually transmitted disease. There is also an increase in the abuse of young women, so I see this as being a critical factor in terms of being able to educate that community that they need to have availability of this testing. I see that the potential for this problem could be increasing dramatically on a daily basis.

Mr Gower—There are poor figures that come out of the Indigenous community, particularly in North Queensland. The figures are rubbery. The last time I was up at a meeting of the Indigenous communities in Cairns was about 12 months ago, and the reality is that their pap screen rate is probably eight or nine per cent. That is appalling but it is the reality. Linda, if you are looking seriously at ways to overcome the problem, that has been happening for a long time and unless you can overcome the cultural problems you cannot overcome the problem. That is why I really urge that we look at the vaccine, because that overcomes the problem—it circumvents it.

Senator WEBBER—I would like to make a comment with particular regard to the north-west of Western Australia. I am sure it is something that Senator Adams knows about as well. I am sure it is the same in Central Australia, although Western Australia, in terms of its Indigenous community, has a larger number of small communities than, say, the Northern Territory does, so you are looking at even greater isolation than they have in the Territory or Queensland.

Therefore, the vaccine is something that interests me personally. One of the issues is that people therefore have to come in to town to access testing, screening or whatever. With a community of, say, 150 people you are not likely to get the medical professionals out there. From my understanding, having dealt with some of these communities, one of the reasons women don’t come in to town to do that is because they have to leave a very vulnerable family behind, and there are a lot of social problems that go with leaving young children. There are a lot of unspoken cultural problems there that we have to address as a community before we will get people to have confidence. It is not necessarily the cultural problem of saying, ‘I don’t want such an invasive process.’ It is the cultural problem of leaving your children behind, having regard to some of the other social problems that those communities have.

Mrs Mazzella—What are the plans for educating the community about the HPV vaccination? I spoke at the Western Australian cancer conference and asked Alan Coates what was being done about education. I was told, ‘Once the vaccination is ready, then we’ll educate.’ But it is on television, it is on the front page, and Professor Ian Fraser has got this award, yet we have to wait until the vaccination is ready and then we will start educating. It seems to me that there is a bit of a gap there and I want to know what is happening about that.

Ms Heffernan—I can answer that. The two pharmaceutical companies that are developing the vaccine, GSK and Merck, have advisory groups which contain representatives of clinical and consumer groups. I know PapScreen Victoria and other pap screen providers or agencies around Australia are also contributing to that. I know there has been extensive work done on identifying what is going to be the appropriate consumer message to encourage uptake of the vaccine so that it does not create stigmatisation of people who have a human papilloma virus—and anyone who is sexually active will have had it at some stage. It will also be looked at as a preventative measure against cervical cancer. So the media and communications strategies are in development. It is of concern that there be a unified voice. Unfortunately, a comment was made in parliament recently that it was going to create promiscuity. We know that the hepatitis B vaccine did not cause promiscuity and that it was great that that issue was raised because it then stimulated debate. The education message is going to require sensitivity and a uniform message to be put out. But it is under way and happening.

Mr Kemp—I wanted to comment on the process for the HPV vaccine. As Ms Heffernan has just indicated, there are two vaccines that are being developed. Both are in the investigational phase. They are not yet registered for use in Australia by the Therapeutic Goods Administration. CSL and Merck have developed the Gardasil vaccine, which has just completed phase 3 trials. GlaxoSmithKline, GSK, has a vaccine that is in an earlier development phase. It is fair to say that it targets HPV16 and 18, which accounts for about 70 per cent of cervical cancers. Before any new drugs can be released in Australia, obviously they must undergo a licensing process with the TGA. CSL and Merck have submitted an application for the licensing of Gardasil. My understanding is that GSK has not as yet submitted an HPV vaccine licence application to the TGA.

Vaccines can be provided with government support in Australia through two mechanisms. The first is via the National Immunisation Program. The NIP is a joint initiative of the Australian and state and territory governments, and vaccines approved for inclusion in the NIP are provided to specific age groups at no cost. The second government support mechanism is the Pharmaceutical Benefits Scheme, which subsidises the cost of particular drugs and vaccines.

As of 1 January 2006, both funding mechanisms require pharmaceutical companies to submit applications to the Pharmaceutical Benefits Advisory Committee, the PBAC. The PBAC is responsible for making recommendations to the government based on research findings and economic evaluations. Obviously, the likelihood of either vaccine receiving funding or government support is dependent upon this process.

CHAIR—The indications are that it is very early. It is an issue that, when something is discovered and publicised, people have an expectation. It comes into the third and fourth discussion points exactly. Does anyone else have anything they wish to add on the dot point about the Indigenous population and people of other cultural backgrounds? I note that there was not much specifically put on the record about other cultures. Senator Humphries, I hope that is going to be your point.

Senator HUMPHRIES—Yes, it is. It is slightly off this topic, but it is a gynaecological issue and it is about other cultures—that is, the issue of female circumcision. A few years ago, the ACT and other states, I know, legislated against people being involved in female circumcision. I just wondered if that is still an issue—whether that round of legislation has fixed the problem or whether it still occurs.

Mr Gower—Up until about a year ago, we were getting probably 10 to 15 complaints a year. In the last year, we have not had any. I was talking to one of the reconstructive surgeons a couple of weeks ago and he had had no call on that particular side of his talents—again, for a year. So I am not sure why but it seems to have stopped, or at least the reporting of it.

CHAIR—Anyone else on that point?

Ms Heffernan—In terms of people from those cultures who are not presenting for cervical screening or other preventative measures—I must admit I have not done much research into genital mutilation at this stage—there was a large research project done by Natalie Wray in Melbourne where she looked at Middle Eastern communities and their attitudes towards gynaecological cancer. Her findings showed that the word ‘cancer’ in these cultures, similar to the Indigenous communities, has this real connotation of either stigma or death, and therefore it is simply not discussed.

Now, I know that our cancer councils, and therefore government funding, have done a fantastic job on making information and literature available in a multitude of languages. What I think would be useful would be to do an audit on the readability and sensitivity of that information relative to a particular culture, their dialogue and the way they speak about those conditions. Again, this links back to communication we are going to need to do about the human papilloma virus vaccine.

Natalie’s findings also showed that in those cultures where there are high levels of patriarchy the women either have to present at an examination with a male doing all the talking or do not go because of the invasive procedures. Or, if they found that they had a particular virus or condition, they would resist discussing it with their partner. So there were levels of heightened ignorance.

But I think there is an opportunity here. Obviously, there are wonderful initiatives happening that are currently being funded by the government, but I would suggest there is also scope to go and do an audit on the content of the knowledge and education programs we are getting out there. Is it written for our dialogue? How much are we getting reference groups in to advise us?

Prof. Hacker—On that point, I saw a paper yesterday when flipping through a journal that came across my desk which addressed this very point for Mexican-Hispanic women in the United States.

Ms Robertson—I have it here. It is very interesting. It is entitled ‘Cervical cancer educational pamphlets: do they miss the mark for Mexican immigrant women’s needs?’ It says that traditional educational pamphlets we devise just have no meaning for many of these women. They do not understand what some of the anatomy is. If we have a moment, I might read a couple of the comments from the participants. The interviewer says:

> Can you tell me why they do a Pap?

The participant says:

> Well, I want them to check me because I’m scared of having cancer.

The interviewer asks:

> What type of cancer are they looking for?

The participant replies:

> Well, I think, cancer anywhere—wherever it’s ‘born’. It could be in the uterus, or like one of my husband’s relatives that died of pancreatic cancer.

That is the sort of thing I mean. There are cultural sensitivities and there is a lack of understanding about anatomy, and I think probably a lower socioeconomic group brings in a lower literacy level.

Prof. Hacker—This paper also looked at the level of education needed to read these pamphlets which, I think, usually require grade 8 or 9 level of education. This is probably much higher than, for example, most Indigenous women would be capable of reading or understanding.

CHAIR—If we can get the reference of that paper, we will then circulate it to all the committee. I think it covers this item and the one about raising general awareness, which is one that is very important. One of the submissions we received talked specifically about the use of interpreters, though I am not sure which one. Was it yours, Ms Heffernan?

Ms Heffernan—May I comment on the interpreters. When I was researching for this, I noticed actually that there is a national interpretive service available that is administered from New South Wales and is only marketed within New South Wales. It is the cost of a local call and it has the main mixed-culture languages available. But if it is only marketed in one state, it means that the rest of Australia is totally ignorant of this seven day a week translation and interpreter service. Perhaps there is an opportunity here to do an audit on the current government funded resources like that, particularly for remote and regional centres. We are simply not disseminating the information out to those communities.

CHAIR—Ms Powell, do you have any information on that?

Ms Powell—I can add a little to that. I know that Centrelink provide a national telephone interpreter service close to 24 hours a day, though I am not sure of the exact details. It is available nationally and it is marketed nationally. I am confident that most Centrelink offices in Australia would be aware of that. That is obviously specifically related to issues concerning Centrelink payments. There is also a national telephone interpreter service that is run by the government, and I think some parts of it are on a user-pays basis and that it is able to be used moderately broadly. They are at least two services that are very comprehensive and very widely available.

CHAIR—We will take the point on board. I do apologise because I have read it in someone’s submission for this inquiry. They mentioned the need for interpreters to be available, probably for all health services but particularly for women and their families on these issues.

Senator WEBBER—When we talk about interpreter services, we are talking across the board about people who come from other cultural backgrounds. We do not actually talk about interpreter services for our Indigenous population.

CHAIR—And we should as well.

Senator WEBBER—That is something that none of us have been able to address yet, but I think it would help in terms of getting that education out to those remote communities.

Senator ADAMS—As an example, I come from Kojonup right down in the great southern region of Western Australia and our next door town, Katanning, has a very large Christmas Island community. Because the abattoirs are situated there, a lot of the women and men work there.

We had a woman’s health forum. We had 20 Christmas Island women, most of them aged between 50 and 70 and who did not speak English. They have a very young Christmas Island health worker there, and she is excellent. Those women came by bus. They were brought with two men. They had to have permission. They were not allowed to stay for lunch even though they had a special lunch for them. They were supposed to be back in their homes by lunchtime. It was really amazing. What we got from the interpreter was that it was the first time they had ever been able to sit around a table and discuss sex and those sorts of health issues. They had never been allowed to do it because it was a forbidden thing. We were all given different tables to go to. It was very interesting. They were so delighted. They all came and hugged and kissed us because they had actually been allowed to talk about it.

It is hard in this day and age to think that this generation of people are like this. They are having a lot of trouble with their younger people. They are marrying into different cultures and the things that the older ones were taught to do the young people are just going away from and they cannot control them. So they have huge issues. They were pleased.

A lot of them would have been going through menopause. I know they have a very different sort of menopause from what we do. It was a big awakening to me and to a lot of others that here right within our community, with the internet and all the other things going on, we still have this. We really do have to be aware of it. The health worker they have is excellent. She is about 20 and she has such a huge issue to deal with. The female circumcision issue was raised but that was very much a taboo subject so nothing more was said. I know they have been doing some investigations in that area. It was very interesting.

Ms Heffernan—I note that in the points we are discussing today we are not really targeting the tyranny of distance and geographical isolation as a separate issue. There is a report from the AIHW, which the breast cancer group put a lot of effort into, looking at various issues around cancers. Even though there were not many examples of gynaecological cancers, they did say that a survey of women with breast cancer found that 32 per cent had to travel more than 100 kilometres for surgery. Those same conditions would also be experienced by women with gynaecological cancers.

It is not just the surgery, it is the follow-up treatment and the access to support services, focus groups, psychosocial support and things like that. What the breast cancer group have done very well, particularly in Victoria through Lyn Swinburne, is develop the *My Journey Kit*. During treatment a woman is given a kit with direct contact numbers, relevant websites and whatever. The book that I wrote has some of that information in it but that assumes everybody is going to want to read a book.

In the funding of the needs of women with gynaecological cancers it is not just our Indigenous women and women from other cultures, it is all women. We are very lucky that in Australia we have about 28 gynaecological oncologists that are of world standard. We are very lucky with that high quality of treatment. They also have multidisciplinary care teams but, as I know from experience, once you have finished your treatment you are virtually there and they are on to the next woman. My psychosocial, psychosexual reactions did not kick in until nine months after treatment and management by my specialist. It was only that I had spiralled right down to the bottomless pit that I finally rang my specialist and said, ‘I think I’m going crazy; I need some help.’ I then found out that I had post traumatic stress syndrome, and 60 per cent of women with gynaecological cancer experience that. Once I knew it was normal I was able to rebuild my life and I have dedicated my life since to making sure no-one else has to experience that.

In terms of government funding for customised educational messages, my point is that I have been trying to get private enterprise to fund—I have got permission from Lyn Swinburne to do this—the development of a dedicated gynaecological resource pack that I want to make free to every woman diagnosed with a gynaecological cancer in Australia—and there are how many thousand a year? At treatment they would be given that pack. It would have all this information about interpreter and translation services, useful websites and points of contact for consumer groups like GAIN. The pack would be customised to whatever the cultural sensitivities and needs were. It would reduce a lot of this trauma. I did some costings and for $130,000 for the initial start-up and then for another $30,000 a year every woman and their family could be supported in that way.

CHAIR—Ms Robertson, I know you will be wanting to comment on those things but I would ask you to hold off until we get to that level.

Ms Robertson—That is right. There are a lot of things there.

CHAIR—We are getting there. To pull this bit together, is there anyone who wishes to add anything particularly on the issue of different cultures? No, there is not. We will follow up information from the department about interpreters and so on. We have moved to what will continue to happen in research funding for increased awareness and prevention of gynaecological cancers to the same level as cervical cancer, and we have talked about awareness and prevention. Professor Hacker, would you like to kick off on that one in terms of that particular point about increasing specific funding to those areas?

Prof. Hacker—Yes, Chair. This little booklet, *Clinical Practice Guidelines for the Management of Women with Epithelial Ovarian Cancer*, was produced by the National Breast Cancer Centre during the ovarian cancer program which the federal government set up three or four years ago. These are the first guidelines that have come out of that. The booklet has been widely distributed to general practitioners, gynaecologists and the like. We tackled ovarian cancer because that was what the program was set up to do. There is no reason why the other cancers—endometrial cancer, vulval cancer and cervical cancer—could not be tackled in a similar way. I think there could be a companion thing for the layperson, which is what Margaret was talking about. There are various websites set up. Ros could talk about this because we have done something with this in New South Wales that is for both the layperson and the professional person, to educate them about the disease, in this case ovarian cancer—or is it for general gynaecological cancer, Ros?

Ms Robertson—Yes, it is.

Prof. Hacker—So there are website based things that are starting to be developed. I think that, with the internet freely available and most people being reasonably computer literate these days, that is probably a reasonable way to go.

CHAIR—I am going to make a decision to put (3) and (4) together, so we are talking about primary health workers and GPs as well when we are talking about awareness and so on. I think Ms Robertson was going to supplement Professor Hacker’s comments on those particular issues. Then we will go to the department.

Ms Robertson—I wanted to mention what we have developed. I have been working on a project in New South Wales. First of all, we developed a website—which is on the little bookmark here. That website was ostensibly for women. They could get into the website and look at psychosocial issues, so they could read about the sorts of reactions they may have and whether those would be normal. They could read about sexuality concerns and everything covering psychosexual and psychosocial aspects. As for what we did then, we thought we could develop this further and have a resource for health professionals—meaning social workers, nurses and psychologists—so we have extended it to that. Since then we have developed another section of this website which targets GPs, so we have developed an e-learning course for GPs. We have had that accredited with the Australian Society of General Practitioners. A GP is able to go onto that website and do a course. He can look at all the aspects of guidelines for gynaecological cancers plus all the psychosocial aspects.

Ms Heffernan—Do they get points for doing that course?

Ms Robertson—Yes. It has been accredited and they can gain points from that. That is just one way that we have tried to target that problem.

CHAIR—Before we go to the department, and I know Mr Lee wants to comment, the particular focus of the point was on funding in terms of increased funding for the process—

Ms Robertson—Sorry.

CHAIR—No, in terms of the information you provided—and it seems very valuable and completely focused on the issue. Can you give us any indication of the cost of that and how that was borne? We are talking about whether there is a need for further funding generally. If your particular group has been able to do this work, I am interested to see what the funding implications of that were.

Ms Robertson—I am sorry, I cannot give you the actual funding information, but it grew out of GMCT, which is the Greater Metropolitan Clinical Taskforce in New South Wales.

CHAIR—Which is linked to New South Wales Health?

Ms Robertson—Yes.

CHAIR—Could we hear from the department and then we will go around the table.

Mr Kemp—I wanted to make a few comments about the National Breast Cancer Centre, in addition to Professor Hacker’s. Obviously, the National Breast Cancer Centre is Australia’s peak body for breast and ovarian cancer control. Basically the centre fosters an evidence based approach on diagnosis, treatment and support for women at risk of or with both breast and ovarian cancers. The objectives of the centre are: to provide accurate information about risk factors and appropriate services for high-risk women, to ensure that all women with breast and ovarian cancer are diagnosed as early as possible, to ensure that all women with breast and ovarian cancer received optimal care, and to ensure that women diagnosed with breast and ovarian cancers, and their families, receive adequate psychosocial, physical and practical support.

As part of the activities of the Breast Cancer Centre, they have produced a range of resources for women with ovarian and breast cancer and also for health professionals. One of those documents is the *Clinical practice guidelines for the psychosocial care of adults with cancer*—

which is a world first—and there are also the other documents that Professor Hacker has mentioned.

Ms Powell—Apart from funding the National Breast Cancer Centre, under the Strengthening Cancer Care project there is another $2.5 million for this financial year to improve professional development for cancer professionals, counsellors and GPs. There are also a large number of other cancer education programs that are funded. It is quite a long list, but just to give you some examples: in June last year, Minister Abbott announced that the government was going to provide $12.5 million for increased awareness, improved surveillance and a pilot testing program for chlamydia. There is a targeted grants program for chlamydia which will provide more than $3 million for projects specifically addressing high-risk groups, including Indigenous and young people. And the Australian government has committed $812 million over five years for states and territories through the Public Health Outcome Funding Agreements, which include covering cervical cancer screening, sexual and reproductive health, and a range of women's health issues. That is an increase of $21 million over the past five years.

Mr Kemp—I will make one other final point. The federal government has funded the Breast Cancer Network Australia to help produce and distribute the My Journey Kit. A key resource that is contained in the kit is a guide for women with breast cancer that has been produced by the National Breast Cancer Centre.

CHAIR—That is the one to which you referred, Ms Heffernan?

Ms Heffernan—Yes, and it is the one which we would like to replicate for gynaecological—

Ms Powell—It is good to hear that you think it is useful and successful.

Ms Heffernan—Exceptionally so. I cannot endorse it highly enough. It is just brilliant.

Mr Kemp—It might be useful to contact the National Breast Cancer Centre if you are looking at expanding—

Ms Heffernan—As I said, Lyn Swinburne, who is the chair of that, has already given me permission to adapt that, but it is a matter of trying to get funding for it.

Mr Lee—The Ovarian Cancer Program initiative of the National Breast Cancer Centre has been invaluable; it has been an incredible move forward. Mr Kemp referenced it in some other documents. One of the key things that have come out of there, besides the clinical management guidelines, has been a consumer version of the clinical management guidelines. That helps women who have been diagnosed with the disease and their families understand things. A couple of items have also come out on education and awareness. One has been a guideline for general practitioners in how to manage women presenting with non-specific and persistent abdominal or pelvic symptoms. That guideline takes them through excluding other causes but then leads them, where necessary, to an examination of the ovaries as a potential source of problems. A small guideline also went out to help explain to GPs the value in the appropriate use of the CA125 blood test, which is part of the diagnostic tool kit for ovarian cancer. Unfortunately, that has been the subject of a great deal of discussion on the internet, and many women have become misinformed as a result of it. So there have been some valuable things.

The Ovarian Cancer Program was started up with half-a-million-dollar funding from the Department of Health and Ageing over two years, and I believe that that funding has now rolled into what the National Breast Cancer Centre have, which I think is probably in the region of $5 million a year. There is still a lot of work to do. These sorts of things require resources and effort in order to distribute information. Just getting information out to general practitioners sounds easy, but then you realise that there are 25,000 of them and just to mail them something is going to cost you at least $25,000 to start with. General practitioners also have a fairly limited amount of time. I might say that they have a limited attention span, as well, but they have limited time.

CHAIR—You could say that they have limitations.

Mr Lee—They certainly do. Everybody wants to send them a message in Ausdoc or whatever. Even putting inserts into magazines and using other ways of getting to them is problematic. Some significant effort and investment is needed to make sure that GPs are brought up to speed on what they need to know. In terms of community awareness, something we have seen from our patients is that women who have been diagnosed with ovarian cancer and, I am quite sure, other cancers would have liked to have known more about the disease before they were struck with it. Generally—and I will generalise—women seem to take more care of their personal health than men. They want information. We find ways through our organisation and other retailers or whatever to produce information booklets and leaflets about ovarian cancer. We also have cultural and linguistic issues that need to be addressed, so we need to get information out there that is well composed and credible. Another role that, for example, the Ovarian Cancer Program at the National Breast Cancer Centre provides is quality assurance around the information that is disseminated. But there are a lot of women out there, and they still need information that is communicated through diverse channels. We cannot just simply rely on written information; we obviously need to use any other form of communication that is appropriate. There is immense opportunity and a very great need to invest further in those initiatives.

Mrs Mazzella—To follow on from the last comment, GAIN has established a National Gynaecological Awareness Day, and we are working towards an international gynae day as well. This a fantastic way to bring all these issues together—and the women’s voices—and then we can perhaps deal with them. We can encourage Aboriginal women’s groups to celebrate in the way they want to celebrate, but they also learn on the same day. I thought I would comment on that to perhaps try to see how we can get some funding to back the day so that we can educate the public.

Ms Heffernan—I would like to pick up on some of the comments that have been made around resourcing education and awareness in the broader community. Professor Hacker has commented on using the internet and websites; but—and this is absolutely vital given the number of younger women now being diagnosed with gynaecological cancer—the average age of diagnosis for most gynaecological cancer is 55 to 60 years, and a lot of these older women are not regular users of the internet. Therefore, we cannot assume that just funding internet resources will target all sectors of the population, particularly those in remote areas or with lower levels of education. So I encourage the government to keep funding the sorts of resources you are distributing for ovarian cancer.

In Australia we are lucky not only with the quality of our medical teams but also with the commitment our cancer councils have to cancer in general. But what bothers me is that it is a state-by-state based activity and there is a lot of duplication of resources, which I think needs auditing. The Cancer Council New South Wales recently sent me an excellent package of its latest booklets and pamphlets on gynaecological cancer, sexuality and psychosocial issues around cancer. That information is first-class, but it is only to be promoted within New South Wales. I would like to see better integration of those resources so that, instead of state-by-state duplication, we look at who has developed an ideal resource—it could be Ros’s website or these booklets coming out of the Cancer Council New South Wales—and adopt it as the Australian resource. We are a population of only 22 million—that is not very many—and we have six groups each disseminating their own information.

I would like to thank the NBCC very much for their contribution to ovarian cancer. They were approached because they had processes of modelling in place. The audit they have done on psychosocial reactions—which we will get to on the next point—has been fantastic, but what concerns me is that gynaecological cancers are now under the umbrella of breast cancer. Breast cancer has enormous funding and enormous awareness, but I think that merging gynaecological cancer into that consortium is no longer appropriate. I would like the government to consider the establishment of a national gynaecological cancer centre along the lines of the NBCC to assist awareness, prevention and education. That way, with appropriate resourcing, we can do an audit of what sort of information is out there, what is the difference in messages and how we can customise it to our diverse communities. Ovarian cancer is at the forefront at the moment because of the late stage of diagnosis and huge mortality, but there is just as much devastation with vulval, endometrial and uterine cancer. My cancer was from pregnancy. We have issues of fertility, sexuality and so on. If that were incorporated into a dedicated national gynaecological cancer centre, all the issues we are talking about today could be dealt with in a very efficient and cost-effective manner using the National Breast Cancer Centre as a model.

CHAIR—You have raised a number of key points that I would like to come back to, including the constitutional issues of the state and federal activities and the separation of the gynaecological aspects away from the umbrella of breast cancer, which has been raised on a number of occasions. I also want to come back to Senator Adams’s point about the use of other health professionals. We will now have a short break.

Proceedings suspended from 11.40 am to 11.53 am

CHAIR—Before the break we were combining issues 3 and 4, which were generally to do with funding for education awareness processes for the community and practitioners. Ms Heffernan had just completed a comment that covered a great deal of ground, in particular with the issues of probable fragmentation across the country, with different groups doing different work, and some concerns about that. We also had the issue of the umbrella organisation, which we know as the Breast Cancer Network, with the ovarian cancer groups linked to that, and whether that has positives and negatives—and I think it does. We also had on record Senator Adams’s question, which she will repeat, about education of GPs and the use of other health professionals. I know that Senator Ferris has further comments on the issue of the medical process. That is where we are and, before we ended, Mr Kemp wanted to make a comment on the national process. Is that right?

Mr Kemp—Yes, I wanted to make a couple of comments about Cancer Australia. It is a key component of the Strengthening Cancer Care initiative. Basically, one of this new agency’s key functions will be to provide national leadership in cancer control and also to better coordinate and liaise between the wide range of groups and providers with an interest in cancer. At a national workshop regarding its scoping there were a number of issues raised about where it could focus its attention. The issue of the provision of nationally consistent authoritative information was certainly indicated. It is highly likely that Cancer Australia will perform a function such as that in relation to better coordinating national activities that are out there that I think Ms Heffernan indicated a little earlier and also in relation to ensuring that we have nationally consistent evidence based information.

CHAIR—Mr Kemp, would it be fair to say that those issues cover all forms of cancer, not specifically gynaecological issues?

Mr Kemp—Very much so.

CHAIR—Would the issues that Ms Heffernan raised about diversion and fragmentation be picked up in that general process?

Mr Kemp—Correct.

Mr Gower—In reading the questions, we are basically talking about increasing the level of awareness of other gynaecological cancers, up to the level of cervical cancer. That is fine, but one would hope that we could do better. Cervical cancer screening is on the decline, so we actually want to do better than that. We are also talking about GPs and other heath care professionals. It is all about education. I come back to what I was saying before: we need to directly educate and inform women. The quickest and best way to do that is through glossy magazines, the media, the radio and so forth. It is simple. They are there and they are read and listened to. We know the message. It is not brain surgery—sorry, Professor Hacker.

CHAIR—Mr Gower, could you give us the message? It would be nice to have it on record.

Mr Gower—Essentially, we need to say to every woman in Australia, ‘If you have any bleeding that is not associated with your cycle, you’ve got cancer until you prove otherwise.’

CHAIR—We might have some discussion about that.

Mr Gower—It is tough love. The point is that Simon and his organisation do a wonderful job of informing Australian women about the symptoms, numerous ones, of ovarian cancer. Every time he runs an ad somewhere in this country, our emotional support help line rings off the hook. So it works. We really need to do more of that. We need well-written articles in the glossy magazines that women read. We need it discussed in radio programs that women listen to. It is really pretty simple. On the other side, we need to train and retrain our GPs. They see gynaecological cancer so rarely that they can be excused for missing it, and they do. The ones who need the retraining are the ones who do not come to CME courses. The ones who do come probably do not need it. So, again, that is fairly simple: make it mandatory.

Mrs Mazzella—I do not see why we need magazines to educate us. Why isn’t the health department or the education department teaching us about these issues? I do not know whether I am allowed to say this, but there is a women’s health play that goes internationally that teaches women that they have a vagina when actually they have a vulva. I know that I have said once that calling a vulva a vagina is like calling a penis a scrotum. They are two completely different things, but because of society’s sensitivity we are not dealing with the truth. Sometimes the magazines have very fluffy education. That was one thing.

The other thing concerns the GAIN’s National Gynaecological Awareness Day last year. To coincide with our day, 150 GPs met at the University of WA. They raised a lot of gynaecological health issues, including STIs and cancers. I think, at a national level, if we could encourage the doctors to come and do that then it would help simplify things. I thought I would mention that.

Mr Lee—With respect to education and awareness amongst general practitioners and also other clinicians, I think one of the key things is we have doctors like Professor Hacker here who are specialists in the treatment of gynaecological cancers, and we have already mentioned that there are quite a few specialists in this country. We have a good supply of them. In the case of ovarian cancer, only 50 per cent of women diagnosed with ovarian cancer are being diagnosed and treated by such a specialist. This has a significant impact on the outcome of their treatment in many cases. In particular, those women with an advanced disease require very extensive and very skilled surgery which only gynaecological oncologists have been trained in and have developed that expertise. That whole referral pathway and education starts certainly at the general practitioner level and possibly with other specialists to whom that patient may have been referred. General surgeons, for example, who may decide to take on a case of ovarian cancer, when they should not do, all need to be educated to ensure that they direct the patient to the appropriate facilities and specialists for the treatment. As I say, we are only getting a 50 per cent hit rate there, which I think is very disappointing and is not good for the women of Australia.

CHAIR—Ms Heffernan**,** I will come back to you on that point, but I think there are a couple we want to follow up. I thought at this stage Senator Adams’s point about the whole medical process may be relevant at this time. Senator Adams, can you ask your question again so we can refresh our minds.

Senator ADAMS—As I said, it is about the multidisciplinary team and perhaps using it as the divisions of general practice with their practice nurses versus the GP. At the moment, the practice nurses are doing the pap smears and answering all the questions. I would consider that, truly, they are quite capable of doing that. But it was about the palpation and also about a pelvic examination in conjunction with having the pap smear. Could you comment on that.

Prof. Hacker—I certainly think that nurses are just as capable as doctors of taking a good pap smear. In terms of the pelvic examination, I guess it comes down to how many you have done, how many abnormal pelvic examinations you have done and how many pelvic masses you have felt. Most women have a completely normal pelvis. Most women going along for a pap smear will have a completely normal pelvic examination because the reality is that ovarian cancer is uncommon. Therefore, nurses may not pick up as effectively as doctors the odd abnormal one. Also, you cannot detect all ovarian cancers, even though when you see on the scan that there is a mass there, you cannot always feel it. It is a very unreliable method of diagnosing ovarian cancer.

Senator ADAMS—I have one more issue. I have been very involved with BreastScreen WA and getting on to your messages. My face is often seen on the back of a toilet door! We had photos of 12 women and, on all the pamphlets that went out, these questions appeared: ‘Is it time to have your mammogram?’ ‘Have you had your mammogram?’—all those sorts of issues. We had a great discussion about the most likely place—because TV was little bit too expensive; we did a little bit—for any woman, whether or not she was in a culturally diverse community, to be able to see something, and someone came up with this idea of a photo on the back of a toilet door, as everyone has to go to the toilet. It was amazing.

They started off in several suburbs and big, busy bus stations and that sort of thing, just to trial it, and it was absolutely incredible. Even now people say, ‘Yeah, I was sitting on the toilet and there you were looking at me.’ But it is a very powerful message. You can go to Aboriginal communities, anywhere. You can put up these notices asking, as you were saying, ‘Have you had a pap smear,’ or something like that, and they really do work. Our screening in WA has gone through the roof since a number of high-profile women have been diagnosed with breast cancer. As Jeannie was just saying to me about when Dr Gallop resigned with depression, it is incredible how those hotlines go mad.

I was also a consumer rep for Breast Cancer Network Australia. I was part of the rural committee that did a lot of work on the My Journey Kit and also on the national breast cancer book. I was trying to see if you had the early breast cancer book there, because I have quite a few comments and photos in that book. When you have had something happen to you, you think, ‘What can I do to help other people?’ It is so important that you can get statements from normal people saying: ‘Look, this happened to me. This is the way I coped with it.’ Especially on the psychological side of it, it is really difficult if you do not know.

I had eight months in Perth going through chemo and radiotherapy. I had to keep myself really busy. Women who go to the city may not be able to drive, but one of the things I say to them is: ‘For goodness sake, there must be a course that you would have loved to have done, so go and enrol in the local TAFE or wherever in the city’—often the breast cancer assessment team will have contacts for them to do it—‘and do a course to keep your mind off yourself. Do something that you really want to do. You just trot along for your treatment. It takes an hour for your radiotherapy; the rest of the day you can do your study and whatever and be involved with a group of people.’ That is very important.

Senator FERRIS—I should have added these two remarks, and then I wanted to make a remark about something else, which is part of this area. One of the other things I would like Professor Hacker to comment on—on the record, because we informally discussed it in the corridor—is that I had 10 blood tests, and none of them were the CA125. I was asking Professor Hacker whether CA125 could be hopefully included as a blood test on a particular age or genetic profile sooner or later.

The other thing I wanted to say was in relation to educating GPs. My GP did not give me any kind of examination when I presented with those odd symptoms. I accept that my symptoms were presented oddly. I had no other symptom. Nevertheless, in retrospect I think the pelvic examination would have been helpful because my ovarian cancer was picked up when I had a palpation of my abdomen.

There is one other thing I wanted perhaps Ros to raise in some comments. When women have completed their treatment—whether it is radiotherapy, whether it is chemotherapy—it is a very interesting sensation when the clinic that you have been attending tells you that you are free, you are finished, your treatment is over, it has been successful and you can now go out of there and feel free. Most women I have spoken to feel terrified; they feel anything but free. They feel that their safety net, the life raft, is being removed from them. I would be interested in Ros's comments about whether she feels there is a need for some loose arrangement for those women, who then go on to monthly or three-monthly visits to their oncologist. I do not know whether or not there might be something that Simon might want to add. Whether it is breast cancer, ovarian cancer, uterine cancer or whatever, I feel that many of them feel very frightened about life without their safety net. Any comments on that would be useful as well.

Prof. Hacker—We do not encourage people to use CA125 as a screening test because it has too many false positives. There are lots of other conditions that are common such as endometriosis, fibroids, pelvic inflammatory disease that also cause an elevation of the CA125. You can spend a lot of money unnecessarily investigating it when you use it as a screening test. The other thing is that only 50 per cent of patients with stage 1 ovarian cancer will have an elevation of the CA125, so half the time you are going to miss what you are looking for. We need a more effective screening test. We have already talked about that. But if you had a screening test then we should put it on television, in glossy magazines, wherever you can put it, behind toilet doors even. That is the message that should be conveyed, if we had a good message. The message has to be simple and easy to understand. If you had a screening test, this test should be done every year and there should be no argument about that, just like pap smears and mammograms should be done every two years. They are screening tests that work, if you have them done. The only thing we can do at present is in that group of women who have the hereditary risk: if you have a family history of breast or ovarian cancer, go and get a transvaginal ultrasound, get your ovaries imaged. Do not have a pelvic examination, that will miss it most of the time too—get a transvaginal ultrasound, that will absolutely diagnose any abnormality on the ovaries. Those are the messages that have to be got out there.

Senator ALLISON—Professor Hacker, this may be a stupid question but why do we not use ovarian ultrasound to screen women?

Prof. Hacker—Because it would not be cost effective and it would not be a very acceptable test for women to have a transvaginal ultrasound on a regular basis.

Senator ALLISON—What do you mean by transvaginal?

Prof. Hacker—It is a probe that is placed in the vagina.

Senator ALLISON—So it cannot be done externally?

Prof. Hacker—You can but it is not quite as effective as the transvaginal test. With women who have a family history of breast or ovarian cancer, we screen or keep those women under surveillance until such time that they have had their family when they will normally undergo prophylactic removal of the ovaries. We recommend that they have six-monthly transvaginal ultrasonic examinations because that will diagnose ovarian cancer as early as it is possible to diagnose it.

CHAIR—Because of their high-risk nature?

Prof. Hacker—Because of their high-risk nature but it is not something that you could recommend for the whole community.

Senator FERRIS—Not even on an age profile?

Prof. Hacker—I do not think so.

Ms Robertson—I think what Senator Ferris has brought up is a very important point. Apart from the emotional rollercoaster that women are on when they are going through treatments soon after diagnosis, that is the period of time I often find that women will come back to see me or seek out somebody in the department to talk to because they feel really isolated and alone. We are actually doing a small study in our department at the moment to try and determine the unmet needs of women who have just completed treatment or chemotherapy specifically. We think there might be things that perhaps we are not addressing. That is a really important issue and there is also the fear of recurrence because the moment you have finished treatment, for those of you who have been in treatment I think that is the most frightening time, you are just waiting for the next recurrence, waiting for those signs.

Mrs Mazzella—The trouble is that when women do have gynaecological cancers and they start to learn about all of this, and they go to the cancer centres, there are not a lot of women brave enough to go to a support network. Therefore you suffer on your own. It is the stigma that is attached to it that we have to try to break down. I notice that the uterine cancer statistics are double those of the cervix, and yet what does the average woman in the community know about uterine cancer? It is time we learnt about these things.

Ms Heffernan—I would like to comment on the issues around GP awareness and the management of gynaecological cancers. For Hansard’s recording purposes, the source is the AIHW General Practice Classification and Statistics Unit. When we look at the top 10 referrals made by GPs in the management of cancer between 1998 and 2004, prior to 2000 there was not one referral listed to a gynaecologist. Out of the total number of referrals made by GPs between 2002 and 2004, gynaecologists were 3.7 per cent and, in the period prior to that, 2000 and 2002, 2.8. That is alarming when you look at the percentage of women with a gynaecological cancer or precancerous condition.

I think part of the reason for the low level of referrals to a gynaecologist, let alone a specialist gynaecological oncologist, is the low level of awareness. But I do note that with the recent material developed out of the National Breast Cancer Centre on ovarian cancer, they have done a very simplified poster checklist for GPs. It is about seven steps—‘If a woman presents with this, do this, then do that, then do that, then do that.’ You could almost put it on the back of the toilet door. It is a fantastic resource. I would like to know how many GPs have read that, taken note of it and apply it. That is just for ovarian cancer. I think there is scope for development of a similar resource for the whole range of gynaecological cancers on a very easy, step by step checklist.

As we know, and as Simon referred to, of the full number of women diagnosed with a gynaecological cancer, not 100 per cent of them are treated in a gynaecological oncology unit or by a gynaecological oncologist. There is still a reasonable number—because of the tyrannies of distance, money, a whole lot of factors—being treated by GPs or gynaecologists. With respect to the forum that Simon referred to that was held in Melbourne last Sunday—I didn’t attend that but I have spoken to a couple of ovarian cancer survivors who did—I said: ‘Give me something I can take to this forum.’ They said that their overriding concern was that at their initial presentation to their general practitioner with symptoms which they intuitively knew were abnormal for their normal bodily function, those symptoms were overlooked or ignored.

It is exhausting to have to go and demand. Because of my history I am lucky that I have an internal ultrasound every year. They think: ‘Here comes Margaret. Just give it to her to shut her up.’ But I am privileged because I know that is not available to every woman who may want it. We get tired—because of the constraints on Medicare, the cost of service provision and whatever—of having to ask for these tests. If you have a misdiagnosis initially, I am not saying that doctors are bad doctors. It is just that, as Professor Hacker is saying, they don’t see that many of these cases per year. So given the very small number of referrals by GPs in the management of gynaecological malignancies, I think we need to look at the level of education and awareness.

Senator FERRIS—Has Mr Lee any comments on my post-treatment issue?

Mr Lee—Absolutely, Senator. Yes, I would like to respond to that. It is a very common situation across all sorts of cancers. People have been in a very supportive environment—getting a lot of attention, seeing a lot of doctors and a lot of nurses—and that whole experience is quite traumatic as well. To come out of the end of it is probably to feel, ‘Great, I have finished it,’ but also most people do actually feel quite abandoned by the system; they feel pushed out.

Yes, my patients tell us, especially if they live in rural areas, that there is no support—full stop. There are no support groups for them to engage with. And although at that point you have completed your surgery, for example, and your chemotherapy and your tests look good, you are generally kept under some form of surveillance. So as much as you have been freed from the system, every now and again you have to come back for further blood tests. That, of course, raises the spectre that this disease may come back at some point. So women then go through periods of having the dread, the foreboding, of the next blood test and its result. For many women with ovarian cancer, at some point that blood test and then the subsequent consultations are going to result in their being told that the disease has returned. I think the evidence that we now have in terms of the psychosocial and psychological impact of being told that your disease has come back is that it is actually more traumatic than the original diagnosis. So it is absolutely crucial that these support mechanisms continue. We have a beautiful model of multidisciplinary care and it very much revolves around the hospital and the centre, but we need to continue to provide that support to those women and their families for a considerable length of time after they complete primary treatment.

Senator ALLISON—So why don’t we, Mr Lee?

Mr Lee—I think part of it is funding. We do not have the funds to supply the staff to do that. In terms of basic follow-up, it is very much up to patient to come back to the specialist unit. In some breast cancer models there is a coordinating nurse who helps provide more continuity of care over a longer period of time. In ovarian cancer, for example, and in other gynaecological cancers, we do not see that. I do not believe that the facilities have the funds at the moment to sponsor that sort of care.

CHAIR—I know Mrs Mazzella and Ms Robertson have comments on this area and a lot of documentation.

Mrs Mazzella—I would like to check whether the precancerous conditions fit in this environment or not. Women are having hysterectomies, sometimes due to precancerous conditions, and sometimes they suffer. You might think that if you do a hysterectomy they live happily ever after but sometimes they do not. I wonder how many hysterectomies are being done because of precancerous conditions. I would like to know how those women are coping. I would like to see that sort of evidence.

Also, I was told—and we are getting onto vulval cancer here—that GPs have one hour of education on vulval awareness—one hour of vulval education. I wonder whether we could perhaps increase that, because a lot of women who end up with vulval cancer have been doctor-shopping for a long time before they are finally diagnosed with a cancer. There are only 314 in Australia a year, but those 314 sometimes suffer quite greatly. We need to hear their voices alongside all the others.

CHAIR—It gets down to those degrees of specialisation, doesn't it?

Mrs Mazzella—Yes.

CHAIR—Professor Hacker, do you have any comment on that particular issue, of the education of specialists, when you get down to quite specialised cancers that are not that well-known by anyone really?

Prof. Hacker—We see about 20 vulval cancers a year in our centre. A very common story, unfortunately, is that the woman has gone along with an itch or something like that and either has not been examined at all or, if she has been examined, she has been told that it is probably a fungus infection.

Really, the simple message is that you must examine the patient and if anything looks abnormal take a biopsy of it. They are the only two messages that are worth getting out to GPs. They are simple messages but they are ignored most of the time. When GPs come to courses they are given those messages but they do not always follow them. And it is—

Mrs Mazzella—I am sorry to interrupt but I had something to add and I did not want to miss out. Sometimes, because of litigation, doctors may be reluctant to even check the vulval area. That is where I think we women need to have a better understanding so we can ask doctors to do that.

Prof. Hacker—I think you should insist, obviously. Women should insist, but they are reluctant to do that. They like the reassurance: 'It's just a fungus infection. Take this Canesten and it'll go away.' So, if a doctor says it is nothing to worry about, naturally they are delighted with the news. But really you need to be examined and, if there is anything at all abnormal, you need to have a biopsy. It is a two-minute procedure in the office under local anaesthesia.

Mrs Mazzella—It is all about breaking down the stigmas, isn't it?

Prof. Hacker—Yes, but there is a very large stigma associated with vulval cancer, and many women are reluctant to have an examination. They would much rather take a cream.

CHAIR—Does some of that go back to the concern about overtesting? GPs have had some information over previous years that perhaps they should not be using too many tests. I do not know, but—

Prof. Hacker—I think it is a time constraint. You have to get the woman up on the couch. She has to get partially undressed. It just takes time; whereas if you can write a prescription for some Canesten and the next patient comes in it is quick and easy.

Mrs Mazzella—But I know one lady who had creams for 20 years and ended up having her clitoris, vulva and lymph glands removed. But she was too reluctant to—it was only when a chemist said, ‘You want to be careful with this cream,’ that she followed it through a bit more. The doctor would write the script, and she would just say, ‘Thank you very much,’ and she would just get on with it. But, the whole time, things were developing. Perhaps there are only a few that this happens to, but I think we as women have to jump on board a bit more with the information and awareness.

Prof. Hacker—Like cervical cancer, vulval cancer usually does have a premalignant phase. It usually looks white, so it sort of looks like a fungal infection, and it is very easy to pass it off as that diagnosis. A biopsy is very simple to do, but we need that education, I guess, that awareness among GPs that that is what is expected. Although it is a very uncommon disease, it is a common cause of litigation because of delayed diagnosis.

CHAIR—It is one that has been raised.

Prof. Hacker—Yes, misdiagnosis.

Mrs Mazzella—But the fact that we can talk about this in this environment here today is just huge—that we are bringing these issues out—so I am very happy that this is coming forward.

Prof. Hacker—I think that this brings up the need for this ovarian cancer program to be extended to a gynaecological cancer program.

Senator ALLISON—Hear, hear!

CHAIR—Make it wider?

Prof. Hacker—This has been good to the extent that we have had at least an awareness of ovarian cancer, but in fact all of the gynaecological cancers are very distressing for women. The psychosexual consequences, the fertility consequences, the menopausal consequences—all of these things are much more distressing than getting bowel cancer or pancreatic cancer, so I think that we really do need a gynaecological cancer centre to address all of these issues, in the same way that this has been able to quite effectively address ovarian cancer.

Mrs Mazzella—I think that we can learn a lot from the breast cancer women—we do not need to reinvent the wheel—but I know that there was a thing about sexuality and breast cancer.

It used to bother me. I would think, ‘What about sexuality and gynaecological cancers?’ which is sometimes a different issue.

CHAIR—It was good of you to say that, Mrs Mazzella, because that leads straight on to Ms Robertson, who has produced a lot of documentation, and leads on to the point about the psychosocial and psychosexual care.

Ms Robertson—I will just make a couple of comments, firstly about vulval cancer. It occurs in women usually above 75 years of age.

CHAIR—They are the most common statistical—

Ms Robertson—Age group.

CHAIR—Over 75?

Ms Robertson—Is it not, Neville?

Prof. Hacker—Well, the incidence is high then, yes, but it also occurs in younger women as well.

Ms Robertson—But those older women are the ones that I see most often with vulval cancer. It is just so devastating for them, because they cannot even talk about their genitals. They do not often know what is going to be taken away. They do not know what the clitoris is. They do not know what the labia are. It is really difficult for those women. A lot of them have said to me: ‘I just feel so isolated. I feel like I’m probably dirty.’ It is a very big thing for an older woman to have to talk about those issues with a doctor.

Mrs Mazzella—Can I just interrupt again. GAIN is having a Vulval Awareness Day on 1 April to coincide with the one held by the women in America and England who have had vulval cancer or the same vulval issues. By doing this I think we can help the next lot of women who come through, so that the stigma is not there as much. If any other groups around Australia can celebrate that day as well, that would be good—although there is the issue of how you celebrate ‘vulval day’ and attract women to come and learn about it! We are doing it at a Catholic hospital, which is fantastic. If we can get in there then we can start to filtrate it right around Australia.

CHAIR—I am sorry to do this to you, but I cannot let that go past. How are you promoting Vulva Wednesday? Just how do you, in the Australian community as we know it—

Senator WEBBER—Claire will organise it for you in Brisbane, I am sure!

CHAIR—How do we draw attention using a word that most people will not recognise anyway but that they vaguely think is something they do not want to know about? Apart from the people who already know about it, how on earth do you get that kind of issue to the wider community—to the women that we have been talking about, the ones that are not aware yet, and their families? What are you doing?

Mrs Mazzella—I have just won the Zonta award for Western Australia, and they know—I advertised through Zonta. The National Council of Women are advertising it in their newsletter and the WA Women's Policy Office are advertising it as well.

CHAIR—So you are using the existing women's networks as much as you can.

Mrs Mazzella—Yes.

CHAIR—How about the reaction of the media?

Mrs Mazzella—They are reluctant. They are sort of, 'Oh, it's naughty—girls' stuff.' But, if we do it this year and we do it again next year and the year after, it will just roll off the tongue in the end and people will think, 'Well, so what?' That is the way; you have to just do it.

CHAIR—Thank you, Mrs Mazzella. I am sure we will follow up on that and we will take that on board. That is 1 April. Any problems with that date?

Ms Robertson—April Fools' Day!

CHAIR—Yes, that is my point! There is no concern about using 1 April?

Mrs Mazzella—No, but there have been some funny comments about the date.

CHAIR—The second last dot point in the petition looks at the need for psychosocial and psychosexual care. Ms Robertson, we were very pleased to get the degree of information you sent through to the committee, but I would encourage you to put some stuff on the record, for the *Hansard*: how you see those issues being handled in Australia, the work that you have done and perhaps what we as a community can do.

Ms Robertson—As we have all been talking here today, we have been getting the picture that not only is gynaecological cancer life threatening but also it has some very specific problems for women in that it really does affect their sexual functioning and their body image—the whole emotional aspect of femininity. That is unusual for cancers. Obviously, men have prostate cancer and have erectile difficulties, but women with gynaecological cancers are really affected in this way. I do a lot of sexual counselling with both the patients and their partners, and it has an enormous impact on their relationship. For example, women with ovarian cancer usually have their ovaries removed; therefore, they become menopausal and their libido drops. Also, they are having chemotherapy, so they feel sick; they feel tired. So their whole sexual functioning is affected in those ways. Emotionally—we have looked at the studies—approximately 33 per cent of women are affected psychologically in terms of developing an anxiety or depressive disorder after treatment for gynaecological cancer, depending of course on the site of the cancer and how long the treatments will take. Extended chemotherapy probably really takes its toll on a woman.

Sexual functioning figures: the range is huge, again depending on the site, but the figures that are coming out are around the 80 per cent mark for sexual dysfunction after treatments. With vulval cancer, for example, the clitoris is often removed and the labia are removed, so sensation in the vulva is affected, which means difficulty in being aroused. As Neville said, when we have young women it is it is particularly hard for them. I have to say, though, that I have not seen a lot of breakdowns in relationships as such. Most partners are very supportive from what I can gather.

Psycho-oncology has grown as a profession in the psychology arena in the last 10 years. The Cancer Institute of New South Wales has just appointed eight psychologists in big centres around New South Wales. However, taking up Simon's earlier point about support, there is nobody in rural areas and it is very hard for women to get help once they have gone home. This is the sort of thing I am concerned about: how do we reach women in the outback? A lot of them ring me up, but that is not often that helpful. We need to have people on the ground in areas outside the big centres.

Ms Heffernan—To follow on from what Ros is saying, the NHMRC has stated that most gynaecological cancer centres have a full-time psychologist as part of their multidisciplinary team. I asked another gynaecological oncologist, Michael Quinn, who is unable to be here today, whether that is the case in Victoria, and he said no. So I encourage the government to look at the provision of psychosocial and psychosexual counsellors and specialists in major treatment centres.

But, as we have heard today, not every woman is going to be treated in a major cancer centre. So what happens to them? In my experience, my psychological trauma kicked in around nine months post treatment and then took several years to reconcile. In terms of sexual dysfunction, my particular cancer was caused by a hydatidiform mole pregnancy. This is totally curable in Australia. There has not been a death from nonmetastatic gestational trophoblast disease for more than a decade now. But, to give you an indication of the impact, I knew that if I got pregnant again within 12 months there was a very strong chance of the cancer recurring.

In the book that I wrote, one of the women who had my cancer waited 12 months and then got pregnant. At the birth of her child there was an abnormal placenta. They noticed that the cancer had recurred and had developed into choriocarcinoma. The cancer transferred across the placenta to the baby. That child was three days old and in the Royal Women's Hospital having chemotherapy. She was in the Royal Women's Hospital and was exceptionally sick for 12 months. Luckily, her husband had enough long service leave and income protection insurance that he was able to take 12 months off to care for his wife, her newborn baby and their three-year-old child at home.

It was always my fear that I would get a recurrence. My husband and I used to talk about 'dressing for sex': when I was on the contraceptive pill and using condoms and barrier cream, I might as well have put a paper bag over my head and we would have been all right. When I turned 52, people could not understand why I was so damned excited. It was not about getting older; it was about the fact that the incidence of getting pregnant was significantly reduced. My husband was walking around with a huge smile on his face!

In terms of education about the impact on sexual functioning, John Gower's group in Queensland has developed the most fantastic resource and checklist—it is in the book I have given to Jeannie—about the impact on vaginal moisture, dryness, libido or whatever. It is a single page and I think it is a wonderful resource which should be duplicated if John gives permission. All GPs should have it so they can refer to it when women present, post treatment, and start talking about psychological or sexual difficulties. I noticed also that, for every ache or pain, I would go to my GP. I was a frequent visitor to him for a short time. He was fairly switched on and managed me well. But I think we should get this sort of information out—that there may be sexual dysfunction and psychological dysfunction. As well as informing women about preventive issues and how to check for lumps and bumps, they should also be informed that there are other issues post treatment. In terms of psychosocial and psychosexual issues, we do not have the resources on the ground at the moment. There are not enough trained people to cater for all the needs, but I think we can do a lot to educate GPs on how to manage women presenting with these symptoms.

CHAIR—Mr Kemp, I am wondering if there is currently any information of that kind.

Mr Kemp—As I mentioned before, the National Cancer Control Initiative and the National Breast Cancer Centre have together produced clinical practice guidelines for the psychosocial care of adults with cancer. The guidelines have proven particularly useful clinically. They provide information about the emotional impact of cancer and strategies to treat and reduce the impact of problems when they occur. The guidelines are a world first. The National Cancer Control Initiative, in conjunction with the National Breast Cancer Centre, has developed a dissemination and implementation strategy for the guidelines, and the first two modules of a four-module program have already been implemented. Those revolve around health professional summary cards. They give the abridged version of things.

CHAIR—They might read those—that is what you are hoping.

Mr Kemp—Indeed. Consideration is being given to modules 3 and 4. They are around a consumer summary card as well as a rural and remote strategy.

CHAIR—Mr Kemp, the department is funding and distributing those—is that correct?

Mr Kemp—That is correct. Moving on to COAG and issues around a specific MBS item for multidisciplinary care, on Friday, 10 February the Council of Australian Governments agreed to a health action plan of more than $1.1 billion. The plan includes a major package of measures that are focused on the prevention and early detection of chronic disease. The package includes a number of elements, including measures that are targeted at improving communication and coordination between care services especially as to cancer. As from November 2006 there will be an MBS item for case conferencing which will increase support for cancer specialists to bring together all of the experts working with an individual patient. That is currently being developed. It will bring together the range of experts necessary for a multidisciplinary case conference. In addition to that—picking up something that Simon raised a little earlier—as part of the COAG process, the state and territory health services will also improve the coordination of treatment of and support for cancer patients, including the use of care coordinators. It is important to note that as well.

Mrs Mazzella—I want to check that health consumers are included in that case conference. Were they invited to that?

Mr Kemp—The actual item itself is currently under development, and there will be appropriate consultation with bodies. I am sure there will be consumer representation as part of that process.

Mrs Mazzella—Thank you.

Mr Kemp—In addition to that, under the Strengthening Cancer Care Initiative there is an initiative that provides support for the development of cancer support groups. There are small grants of up to $90,000 as seed funding to support groups in the areas of bowel, lung and ovarian cancer as well as other cancers. So far there has been one completed funding round and another round is currently under way. OvCa Australia has been a recipient of one of those grants.

CHAIR—It is clear that some of the recommendations of the Senate inquiry into the cancer journey did have some impact, Mr Kemp. I am pleased about that. Mr Gower, I know that you want to comment particularly on the issue that you can produce all this stuff for GPs but then what happens to it.

Mr Gower—If I can take a different tack for a moment, I hope those guidelines for the next round of funding are changed a little so they are not so heavily dependent upon self-help groups. The fact is that 50 per cent of women who are treated for gynaecological cancer are treated in private hospitals so, whilst it is true to say that most of the large public treatment centres have social workers and access to clinical psychologists and psychiatrists, that is not so in the private sector. You are looking at fully 50 per cent of the women who are treated for gynaecological cancer not having direct access to social workers or psychs. We really need to address that. Would you agree?

Ms Robertson—Absolutely.

Mr Gower—I put it to you that one of the ways we need to address that is to set up a fund whereby women can go and see private social workers and private psychs and it is billed back to government. That is one of the ways I really think you can spend not a lot of dollars and get a hell of an increase in effectiveness.

Senator ADAMS—To comment on that, coming back to the breast cancer side of it, I deliberately went—because I had the knowledge about the breast assessment centre and our two main hospitals in Perth—as a public patient. What a difference in comparison to friends of mine I had to support and help later: every three I was back there and then every six months as I got further out. It is wonderful: now I go once a year, which is a milestone that you really look forward to.

But it is amazing how, going to have that mammogram every year, in the week before you think, ‘If this comes back, how am I going to deal with all these issues?’, like Jeannie had to before. You think, ‘Oh, going through all that again!’ But knowing full well that I had that multidisciplinary team, that back-up—not just my oncologist or anyone else—looking at and considering my case just gave me a terrific lift. With the fact I can go back every year, having gone back every six months, my poor oncologist probably thinks that he is my GP, but often I do not have time to go to a GP. I have a range of questions and we have a great discussion, and I come out of there feeling on top of the world and that I can now go forward. I can see what you are saying: the private sector does not have that support—

Mr Gower—It is 50 per cent.

Senator ADAMS—I think this is where the problems are with a number of people who go there: they are absolutely left floating, and probably you, Ms Robertson, get them at the end, when it is too late.

Ms Robertson—I do not work in a private hospital, obviously, but I hear that quite a lot: there is no infrastructure, there is no—

Senator ADAMS—You have hit the nail on the head, so I just thought I would mention it.

Mr Gower—To continue a little longer, we also run a national emotional support help line, which is a 24/7 support line. That is used in all states. If you have some spare dollars, please throw them at me and we will advertise that throughout the country so we can have that support help line used more often. The cancer councils in each state actually refer to that line, so we are not duplicating, and we think that is very important.

The last thing we did a couple of years ago was to develop a pilot program because we, unlike Ros, noticed that there was an increased risk of partnership breakdown in gynae cancer partnerships. In fact, our national research pointed to something like a 20 per cent increased risk. What we did was invent a pilot program aimed at educating the male partners because, at the end of the day, that is the weak link in this particular area. Most of us males are not terribly good at this, but we can be if we are given the right information and the right training. So we developed a pack which we have now trialled in Queensland, and it has been very successful. We would look at rolling out that program—teaching the male partners to be more supportive and better carers—throughout the country if there is any money to do that as well.

Senator HUMPHRIES—Could you give an example of what you mean? What sorts of things do men need to do better?

Mr Gower—Sure. Essentially, our information showed that it was the old fight or flight reflex. Male partners first of all try to fix the problem and find out they cannot. They then become overwhelmed by the emotional side of things and, unfortunately, an additional 20 per cent of them run away, literally, not because they specifically want to but because they feel helpless and useless and most men do not like that. What we are still analysing is what percentage of those extra breakdowns are caused by something that we can do something about, and that is teach the men how to cope better—giving them better coping skills and showing them how they can be more supportive. We do that with CDs and with booklets that we put in a pack.

CHAIR—Mr Gower, can we have one of those packs? That would be very useful. Then we could stimulate some more questions. We will get Senator Humphries to test that for us!

Mr Gower—You will love it, Senator!

CHAIR—Well, it just seems appropriate!

Senator HUMPHRIES—When would be a suitable time to comment?

Senator FERRIS—I just wanted to add a couple of things. After diagnosis, I think it is very important for people to have access to some form of counselling. For many women, this comes as a huge shock. They do not know how to manage it, how to think it through. I was fortunate that I did have somebody I could talk to about it, and that made a huge difference. But I know that, particularly in the private sector and even in the public sector, some women do not know that they can ask for a staff psychologist in the hospital to come and visit them quickly after diagnosis. I think that is very important.

I think that, when we are talking about the post-operative support services that are available, we should not overlook the hospital's dieticians. One of the characteristics of chemotherapy is a loss of appetite—or even just as a post-operative symptom, I suppose. I found the hospital dietician team who came to visit me enormously helpful and they were ultimately very successful in assisting me. I do not think we should overlook that when we are talking about psychological support services, because the whole dimension of food and cancer is a very important one as well.

Mrs Mazzella—I just wanted to give Senator Humphries's an example about men which he asked for earlier. In my own case, my husband had five heart bypasses after he had to take care of me, because he did not know how to converse about it. He had to be strong, but internally he was just suppressing whatever was happening. So I think we do need to work on the men's side of things—which comes back to mental health, the topic of discussion at the moment. But a lot of gynaecological issues are very much mental issues because of the way society deals with these things. If we can deal with gynae health a bit better then perhaps we can eliminate some of the mental health problems as well. I wanted to mention that.

One more thing: like the breast cancer women, when I connected with another woman who had the same cancer as me, it was so powerful. And you can see the breast cancer women and how they connect with each other; it is very bonding. I think if we can do that with gynaecological cancers that would be a good achievement.

Ms Heffernan—I would just like to make the comment that I think our approaches to our personal management of cancer depend on our personality type, and that is also dependent on age range. I know that when my mother was diagnosed with breast cancer—she was by then in her early 60s—her attitude and her approach to the way she managed it was: 'The doctor knows everything. He's told me what to do and I'm going to do it.' I was totally the opposite. I refused to start chemotherapy until my specialist had given me the postgraduate books on it and blah, blah, blah, and then I became the patient from hell. And then, in between, you have got a third type. So I think when we are looking at interventions, resources and whatever it is not just a matter of looking at cultural appropriateness, levels of education et cetera; it is also about looking at personality types.

For instance, I am assuming that Senator Ferris is a very assertive woman and also that, because of status and whatever, she was able to go and very quickly get those resources, as I was. But I know that the majority of women lack either awareness of the availability of those resources or access to them because of the tyranny of distance, financial struggles or other personal issues. I think that in any resource development around this, and there is a lot to be done on the psychosocial and psychosexual side—we have made huge leaps in the last five years, I might add—we have got to take into consideration that not everyone is going to be proactive about getting this sort of help or going to even know it is there. Until this morning, I did not know that John Gower's group had that emotional support help line.

As I was saying earlier, it is not practical at the moment to place a specialist counsellor in every centre or hospital, regional or rural, because there is simply not the trained number of people and a lot of them do not like to work out in the bush. However, we can set up information help lines like this as the first port of call, and then the person taking the call can either refer them on or manage it there. But again this requires funding for the dissemination of the information and for the knowledge that that service exists as the first point.

CHAIR—In the interests of time, I have decided that we will be going to 1.15 pm. You would have expected that.

Senator FERRIS—We could go all day.

CHAIR—We could, and that is possibly something that could come out of this morning. The last dot point on the petition—before we go to some kind of statement from everybody so that you have a chance to put something on the record before we conclude, and that includes the senators—is a general one. It recommends:

- Increased funding for research and prevention of Sexually Transmitted Infections and their links with gynaecological cancers and infertility, especially Human Papilloma virus vaccine funding—

we spoke about the HP virus earlier today—

and chlamydia prevention.

There was information from the department about that and it was also raised by other people. This is very much a general point, but I wanted people who had comments on this to have the opportunity to speak. Would anyone like to speak on this last point of the petition? Ms Heffernan, what were you after particularly when you developed this point?

Ms Heffernan—At the time of developing the petition and taking up the issue of HPV, there was not the knowledge and awareness of the progress of that. I think that has been well discussed today, and the economic modelling, as I said, around the HPV vaccine is being considered at the moment. I would like to reinforce my earlier comment that, in any government funding or subsidy around that—whether or not it is going to become part of the National Immunisation Program—huge consideration and priority funding be given to those pockets of the community where there is still a very high prevalence of cervical cancer, and then the rest can be rolled out.

My other concern is that chlamydia is an infection which is one of the greatest causes of infertility. I am sure Professor Hacker can comment on the incidence of this, but it is absolutely prevalent. Now, I know there are education interventions being done with adolescents and through school programs about barrier protection, with condoms and things like that, but I really do not think the message is adequately getting through to our youth when they start to be sexually active, and they are really not aware of the consequences of chlamydia especially. Once we get the vaccination for HPV rolled out, we are going to significantly reduce the incidence of HPV 16 and 18 and therefore dysplasia and genital warts. Chlamydia, I think, is now the next STI that we need to put a lot of government attention on and give funding to. Could I ask you, Professor Hacker, to comment on the incidence of chlamydia that you see in your environment?

Prof. Hacker—I do not treat chlamydia—

Ms Heffernan—You do not; I just realised!

Prof. Hacker—so I cannot really comment, but it is an endemic problem in the community and it is a major cause of infertility. But I think if you are going to get at problems like chlamydia you have to go to the high schools, haven't you? It is too late once the girls have left high school; most of them are sexually active by that stage. I think you really have to get the message across in the high schools.

Mr Gower—Unfortunately, I think that is also too late. Our thrust for some time now has been that we really need to talk to prepubescent boys and girls. If we are going to do the job properly that is what needs to be done; anything else is literally starting off behind the eight ball. In my state of Queensland that is a hell of an ask. If you want to talk to young children about sex, that is not good. So we are up against that, and I suspect it might be a national trend.

The reality, as the professor would be able to tell you better than I, is that it has to be before there is any sort of sexual activity. Believe it or not, we are now down to single digit figures. So if there is a message I would ask you to take away it is this: to do the education properly we need to start with the very young. We need to be very careful about how we do it but we do need to start with the very young, otherwise there is not a hell of a lot of point.

Mrs Mazzella—I need to say that one of my biggest betrayals was not being informed that I had the human papilloma virus so that I could protect myself and have an understanding. That was 11 years ago, and things have changed somewhat. But I am still concerned when I speak to a lot of young girls that they do not understand about HPV; obviously it will happen with the vaccination and everything that is ready. I also would like to say that doctors do not have time to sit and explain. Let us say a woman has been diagnosed with a sexually transmitted infection and she gets upset or whatever. It is a half-hour consultation, and the doctors do not have a half an hour to deal with these issues, so that is a major problem. That is the same for chlamydia as well.

Mr Gower—Most practice managers are telling GPs that they have 6.5 minutes to diagnose and treat the average patient. After that they are starting to lose money.

CHAIR—What is that information based on, Mr Gower?

Mr Gower—That is based on a costing by the business managers of the larger practices—that is, how much they earn divided by what it costs. That is all the time they have. So we might be being hard on GPs, but they do not have a lot of time. That is why I have to urge you to consider that if we can do something, such as vaccinating, that is another strain taken off the system.

Prof. Hacker—When I was a young gynaecologist training in Brisbane in the early- to mid-1970s, a schoolteacher friend of mine asked whether I would give a lecture on sexually transmitted diseases to his group of 13- and 14-year-old girls and boys. He had to get permission from their parents for them to attend the lecture. I think only two parents said that they did not want their children to be talked to about these things. I must say that the students were extremely interested, and I think they were very receptive. I would think that is the sort of thing that could easily be introduced into the schools. It does not have to be given by a doctor. It could just be part of sex education.

Mr Gower—We are running a pilot program in Queensland next year, doing exactly that. It has to be done. The information available at the moment quite frankly is not good enough, and it is being delivered too late.

Ms Heffernan—I would like to see condoms being more accessible to youth. We had a politician in Victoria who suggested that condom vending machines be put in schools, and she was almost laughed out of the community. In fact the basic premise of what Mary Delahunty was trying to say was quite sound. You can readily buy condoms in supermarkets now, but I think avenues of that should be paralleled with better education, not only of the children but also of their parents.

Because I am researching HPV at the moment, I am frequently having conversations with my 16-year-old daughter. I say that, when she becomes sexually active, she must use condoms and have this vaccine. Her reaction is, ‘Oh, Mum, do we have to have this conversation now,’ sort of thing, and she rolls her eyes. But it is just about reinforcing that message. There is a need to look at our current education processes and programs that we are delivering and also to do an audit amongst secondary schools around Australia to find out how many of the students themselves are using barrier protection. We need to know how effective the education staff think their programs are and whether we need to be changing the message. I know that *Cleo* and *Dolly* and a lot of the mainstream magazines get the message out in a fairly sensational way, but it is a start.

Prof. Hacker—I think the only consequence that young people feel they have when they start sexual activity is pregnancy. But, of course, the consequences of HPV infection, chlamydia and herpes are very real and lifelong. These are things you will have for life. So that education lesson needs to be got across.

Ms Heffernan—There is a vaccine under way at the moment for the herpes simplex virus that is going to be absolutely revolutionary, once that is admitted, in reducing that. So it might also be worthwhile for your committee to look at what is happening in chlamydia research and with prophylactic vaccines or whatever given the increasing rates of infertility and the psychosocial distress when all of a sudden you get to a point where you want a baby and you find out that you are infertile. There are all of the community ramifications around that as well.

CHAIR—I do regret that we have run out of time for general discussion. I think the point that was raised, which was that we could go on for much longer, is a good one. I would actually like everyone here who has given up their time to have the opportunity to make a final comment. It may well be a final request to the committee. It is entirely in your hands. We can start with the department. You do not have to comment, but I would be surprised if you do not. We would like some final comment after this morning’s activity that we can take forward.

Ms Powell—I guess I would just sum up by saying that the government does have a really big commitment to reducing the burden of cancer. It has the Strengthening Cancer Care Initiative, which was close to $200 million over five years to 2008-09. We have talked a lot about the range of programs covered under that so I will not revisit any of that this morning. Probably the other big area is the National Breast Cancer Centre. We work very closely with them to do a whole range of programs including education and prevention work. One of the things I am really looking forward to is the establishment of Cancer Australia, which I think will go a long way to addressing some of the specific issues that were raised here such as coordination, speaking with a single voice and making best use of the resources that are available to try to address some of the important issues that have been raised today. I would also like to extend an invitation to any of you, if you want to get further information about any of those initiatives that we talked about this morning, to please feel free to contact me or Ian. We are happy to engage with you on a one-to-one basis.

CHAIR—Mr Harding, I know that you were not able to contribute in the debate but I know that your organisation has a wealth of knowledge in terms of the information in our country.

Mr Harding—I just wanted to note that the National Breast Cancer Centre has in fact commissioned the institute to produce two compendiums of the latest statistics for both breast cancer and ovarian cancer. We are due to publish that by the end of June this year. We will be trying to include the latest incidence, mortality and survival statistics as well as hospitalisations and international comparisons and so on in those reports. I know also that the National Breast Cancer Centre has been working with consultants to try to come up with a packaging of simple information messages for consumers to distil both the statistics and other consumer information for breast and ovarian cancer patients. That has been under way for some weeks.

Mrs Mazzella—I would just like to say thank you for the opportunity today—I think has been just wonderful—and for the petition that Margaret Heffernan has put forward. I would like to ask you to support us for our National Gynaecological Awareness Day to bring forward the community voice. I want to say also that GAIN is not just about cancer; it is about all of the gynaecological issues. Thank you for today.

Mr Gower—Thank you for putting today together and thank you, Margaret, for your petition in the first place. The message I would like you to hear is that we believe that research into an ovarian cancer test is necessary. It is a good investment. If you look at downstream costs, it is a cheap investment. We would urge you to look at that very seriously. The second thrust is education. It always comes back to that. We need to educate women to be more knowledgeable about gynaecological cancer, to be more assertive if their doctors are not and at the same time we need to, if necessary, forcibly educate GPs to be more knowledgeable about gynaecological cancer. It is a two-pronged thrust. We need to offer emotional support and, seriously, we are not talking about a lot of money to do these things. Most of the research in those areas has been done and, as I keep saying, the message is known; we just need to get it out there.

Mr Lee—I think John just said it all. I would like to thank all of you for the opportunity to meet with you today and I agree with everything that John has said with regard to research, support and so on within our community. I would like to say that cancer patients are special people and gynaecological cancer patients are even more special people in many respects. We have been able to see today that they have some very specific needs, some of which we are addressing within our community, but I think we can go a lot further to provide that level of support to make that cancer journey less traumatic for them and for their families. I am hoping that we can see a way forward from here that will result in a definite and measurable improvement in the lives of those women.

Prof. Hacker—I would like to thank everybody too for the opportunity to come and talk about these issues. I think that the single most useful thing that we could do is to develop a screening test for ovarian cancer. As John said, it would be money very well spent. It is a feasible thing to do. We have three excellent teams that are already working on this. We know that cancer is a genetic disease; we did not know that 10 years ago, but we know it is caused by abnormal genes. We even know now what the abnormal genes are in ovarian cancer. I think it is a feasible thing; it just needs some money thrown at it. We are presently spending probably $1.5 million a year or thereabouts between the three centres. If we trebled that, the teams would be three times as large and the research would happen three times more quickly.

Ms Heffernan—Ten years ago I had a dream, at the risk of sounding like Martin Luther King. In what I wanted to contribute to the gynaecological cancer sector, getting something of national significance achieved was the only way forward. I cannot thank you senators enough today. I know Senator Allison tabled the petition on behalf of half-a-dozen of you and I had other emails of support. Thank you for your vision and initiative in moving this dialogue and debate forward. I would also like to thank Mr Kemp and Ms Powell for attending today. It is very important for us to hear first-hand of the government department’s commitment to cancer. I think the new Cancer Australia initiative is going to have a profound impact not just on gynaecological cancer but on all cancers. I see the next five years as significantly reducing the burdens we are now facing. Having said that, I would really like to encourage your department to put the spotlight, after today’s discussion, on gynaecological cancers and look at what ratio of that $200 million is actually being allocated to gynaecological cancer. Is there scope to provide more at the moment for ovarian cancer screening research and also for the increase of psychosocial and psychosexual resources whether they be print, people on the ground, help lines or whatever?

With respect to education and awareness, we have put the spotlight on GPs. I would love to see some legislation brought in where, as part of their annual professional development, some of their points have to be in a reproductive cancer, whether it is gynaecological or prostate, because we are developing the resources but the message we are hearing from all over is that they are not sufficiently aware of it. I also think that another way forward in terms of education, awareness and management of psychosocial and psychosexual issues is to look at the National Breast Cancer Centre as an ideal and preferred model but, in the immediate term, to start looking at the establishment of a national gynaecological cancer centre that can work and integrate with the National Breast Cancer Centre, so it is not to diminish or take away from the work that they are doing. I think they have managed ovarian cancer well, but it is not the only cancer. There is a lot more to be done. I would also like the government to give consideration to establishing that resource as well. Thank you. I am delighted to be here and to witness such energy and passion from senators.

Ms Robertson—Without going over the same thing again, thank you for inviting me and our colleagues to present to you the case for ovarian cancer and all the other gynaecological cancers. My main point would be support for women. I would like to think of women having a lot of support after they have left major centres where there is support. I do not know how we can get to all those people.

CHAIR—Would any of the senators like to make some comment?

Senator ALLISON—At the risk of too much sharing of compliments, I think it has been fantastic that both Margaret and Kath have pushed us to do this. You have done that very effectively, so thank you for it. The committee now has to consider what else it will do with this information. We have used a rather unusual procedure in referring the petition to a committee and our only requirement is to respond to the Senate in whatever way we determine, so you might want to have another word about what we should do next. I would also say that what is on the books for consideration in the next sitting week is an inquiry into sex education which I am really hopeful will get up. That will be, not for this committee but for the education committee, a major way of highlighting some of the issues that you have raised today. If anyone has any ideas about whether these 3½ hours were enough or whether we should open this question up more broadly and where to go from here, we would like to hear them.

Senator ADAMS—Firstly, I would like to congratulate Senator Allison. She is the one who has pushed it from our area but it has been great. We have had seven senators involved and I can reassure all of you that we certainly are not going to let this go. The fact that there are three of us here, two of us having breast cancer and Senator Ferris with ovarian cancer, with the experience of these diseases means we can understand so much more about it. With the department and everything, the whole thing has gone very well. We have got so much out of it and hopefully you have got something from us as well.

Senator FERRIS—My comments echo everybody else’s. It is the first time I have been part of a Senate committee where I have had a personal interest to declare that is outside the mainstream. I think it has been useful for me to be able to add a dimension of constructive criticism but also to recognise the fantastic support services that are available in the public hospitals. I cannot speak more highly of them, and I have done so on a number of occasions publicly already. I just wish we could find a money tree. We are all searching. I do appreciate, knowing how busy all of you are, that you have come here today. I especially feel very privileged to have been part of the discussion. Thanks.

Senator HUMPHRIES—I also found today’s session very illuminating and the arguments put very persuasive. Thank you.

Senator WEBBER—Same here. It has given me the opportunity to focus on these issues a bit more and learn something. Thank you all for giving up your valuable time. I know the department have taken a few things on board that they are going to provide additional information on. I would like to suggest that perhaps then, as people that have been part of this roundtable, we can have a look at that and try and work out whether we do think it is something that we need to pursue a bit more and where to go from there. Like Lyn said, if you have any ideas after we have had a look at that additional information, we would be happy to receive them.

CHAIR—Thank you very much. We will call this part of our journey to a close. We encourage people to continue circulating information. I would like to thank Hansard this morning. I am sure they will need a lot of follow-up with some of the terminology that has been used, but I am sure they have learnt a lot as well. I think that this roundtable format where people can discuss issues has been valuable. It is something that we can learn from as well. Please continue the discussion. It is much more than a dialogue. There are so many voices to be heard. I also want to put on record my appreciation to the secretariat. They have pulled this together very quickly, and I thank them.

Ms Heffernan—Chair, could you inform the representatives here today what the next steps of the process are? Your committee clearly is going to convene and discuss the issues raised today. What are the options that will come out of that discussion and where do we go after that?

CHAIR—It is very much a learning experience for us as well because, as Senator Allison said, this is an unusual methodology. Basically as a committee we will review the *Hansard* record and the submissions to see whether there are any clear recommendations that come out of them. The next point of the process after this mechanism is for us to give a report back to the Senate stating that we have had this process and the issues that came out of it. There is no clear path after that. There are a number of things that could happen. We could be convening meetings and looking at having a further inquiry. There are no rules. We are open to suggestions on where to go next.

Ms Heffernan—Would there be likely to be any recommendations around increased funding made prior to the next budget?

CHAIR—We will not know that until after we get together.

Senator WEBBER—I guess that is what I was hinting at. When we get the information back from the department, I would recommend that those of us that have been part of the inquiry have a look at that and work out whether we want to go along that line, whether we think it is easy to make recommendations at that time, or whether we need to pursue the issue a bit more.

Senator FERRIS—Once we get that NHMRC information I would very much like to circulate it to you and get some feedback on what you know about that funding and research and what evaluation you might place on it. I am disappointed we have not been able to have that here today.

Ms Heffernan—That would be good.

Committee adjourned at 1.23 pm