COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Gynaecological cancer in Australia

WEDNESDAY, 2 AUGUST 2006

SYDNEY

BY AUTHORITY OF THE SENATE

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COMMUNITY AFFAIRS REFERENCES COMMITTEE

Wednesday, 2 August 2006

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

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

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

Terms of reference for the inquiry:

To inquire into and report on:

Gynaecological cancer in Australia, and in particular the:

a. level of Commonwealth and other funding for research addressing gynaecological cancers;
b. extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer;
c. capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions;
d. extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers;
e. extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers; and
f. extent to which experience and expertise in gynaecological cancer is appropriately represented on national health agencies, especially the recently established Cancer Australia.

WITNESSES

Committee met at 9.30 am

OLVER, Professor Ian Norman, Chief Executive Officer, The Cancer Council Australia

SUNDQUIST, Dr Kendra Jane, Manager, The Cancer Council Australia

COUZOS, Dr Sophie, Public Health Officer, National Aboriginal Community Controlled Health Organisation

CHAIR (Senator Moore)—Welcome. Today the Community Affairs References Committee continues its inquiry into gynaecological cancer in Australia. This is the second day of hearings in Sydney and we look forward to our discussion today. We appreciate the efforts people have made to come and share with us in this very important inquiry. The committee has asked some individuals and organisations to appear together. This is only so we can get more evidence before the committee. There is no priority given; it is just a matter of getting as many witnesses before us as possible. I acknowledge the traditional owners of the land in this area. I welcome representatives from the Cancer Council of Australia, the Cancer Council of New South Wales and the National Aboriginal Community Controlled Health Organisation. Is there anyone here from the Clinical Oncological Society of Australia?

Prof. Olver—Dr Sundquist and I can represent that organisation. I sit on the executive of that group and Dr Sundquist is a member.

CHAIR—You are both wearing double hats.

Prof. Olver—Yes.

CHAIR—You have information on parliamentary privilege and how we operate. If you have any questions, please let us know. We have before us the submissions that your various organisations have supplied. Would any of you like to make an opening statement before we go to questions from the committee?

Prof. Olver—Thank you. I will lead off by highlighting three points from our submission. We have been thinking about the most effective way to increase support for women with gynaecological cancer. We have looked to the success of organisations such as the National Breast Cancer Centre. What we see as the major challenge is how to translate that success into all cancers. It is difficult to see it being done one cancer at a time; there could be 30 to 100 different national organisations. With gynaecological cancers we are perhaps in a fortunate situation in that the National Breast Cancer Centre has already expanded its activities to include ovarian cancer. Just looking at it, we have come to the conclusion that probably the most efficient and effective way is to add the other gynaecological cancers and cover women’s cancers with an organisation that is already up and running, and has been operating over the last 10 years.

The second point in our submission that I would like to highlight is about screening. It is a difficult area sometimes but, if you do not have an effective screening test for a disease—as is the case in all but cancer of the cervix in this cluster of cancers—it is not the case that any test is better than none. An inaccurate screening test is actually harmful. It can tell women that they do not have cancer when they do or that they do have cancer when they do not. At the very least, it can lead to invasive procedures that are unpleasant and ultimately unnecessary. Our thoughts about what you do in this situation if you do not have an accurate screening test are that you need targeted research and funding to find such a test. We think that is a strong point, particularly now in ovarian cancer.

The third point we would like to make is that in Australia we have a very successful program of screening for cancer of the cervix. But the trouble is that the success does not extend to every part of the community and particularly not to the Aboriginal community. Therefore, we believe—and we have said this in our submission—there may be special measures required to improve outcomes in this group, such as exploring the feasibility of fast-tracking immunisation or the HPV vaccine particularly in that group—as an initial group, as the most disadvantaged group. Perhaps at this stage I will ask Sophie to take up some of the issues that we have identified for Aboriginal women.

Dr Couzos—Thank you. I think Professor Ian Olver has articulated very well the discrepancies and the inadequacies of the current health system's approach to cancer, particularly cervical cancer, in Aboriginal and Torres Strait Islander women. I just want to make the point that that is the leading cause of cancer death in Aboriginal women. It is the No. 1 cause of cancer death in Aboriginal women, whereas it ranks 14th in the non-Indigenous female population in Australia. So there is a huge discrepancy in the burden of disease. The other major point is the inequity, particularly at the federal level, of the national cervical screening program in reaching the Aboriginal population. We have very limited data at the federal level on the accessibility of the programs that have been developed to reach underscreened women and how effectively those programs target Aboriginal women. It seems inexplicable that the Commonwealth Department of Health and Ageing is unable to report in its formal evaluations of these programs how accessible these programs are to the Aboriginal population.

CHAIR—Thank you. Dr Sundquist, do you want to make an opening statement?

Dr Sundquist—Yes. I perhaps should clarify that I am not a medical doctor; I am a doctor of education.

CHAIR—Thank you for that, because it gets quite confusing.

Dr Sundquist—I suppose my interest in women with gynaecological cancer and in prevention is more on the supportive care side and the psychosocial aspects of experiencing gynaecological cancer. We know that it has a huge impact on women and their families. It goes to the core of women's sexual and reproductive health in that it has impacts on fertility, body image, sexual response and sexual and intimate relationships. I think it is very important for women and their families and friends to have access to quality information when they need it, at the right time. We know that, when someone is diagnosed with any cancer, it is family and friends who often get on the internet and do the searching. Access to information is important. Also important is access to good quality, patient centred care and to multidisciplinary teams and gynaecological cancer experts, I suppose, wherever possible.

CHAIR—Thank you very much. Now we will go to questions.

Senator ALLISON—Professor Olver, I take you to the first point you made about where to place gynaecological cancer in an institutional or a structural sense. We have had submissions already to the inquiry suggesting that there should be a gynaecological cancer centre. It is not clear about the role of Cancer Australia in all of this. I think you say in your submission that you support Cancer Australia as a leader in coordinating gynaecological cancer care in Australia. Can you outline what you know of Cancer Australia's response so far to this issue? We understand there is no representation as such on that council for gynaecological cancer. Can I ask you to expand on your point there?

Prof. Olver—I should declare that I am on the advisory council to Cancer Australia. The advisory council has not yet met. It is due to meet on 1 September, so Cancer Australia I suppose as an entity is not up and running. Some parts are in place. I think Ian Kemp has been seconded from the Department of Health and Ageing to run the Cancer Australia Section. There still has not been an announcement of the CEO of Cancer Australia, but the selection committee has made a recommendation to government on an individual. So we have not seen any output from Cancer Australia as yet, but everything is moving towards that, and, as I say, the first meeting of the advisory council.

I have made one point about the advisory council, and that is that all of us who were approached to sit on that council were not approached with any designation at all. I wear a number of hats, I guess, in the cancer community and I have no idea which of them, if any of them, I was specifically appointed to that council for. I think the idea was to develop a body of expertise that covered quite a wide spectrum. If you look at very specific areas, for example, there is no radiation oncologist on the advisory council—

CHAIR—That has been mentioned, Professor.

Prof. Olver—I understand that. So it is highly unlikely that there can be a representative of particular tumour types—lung cancer, breast cancer and so on, although breast cancer is represented, as it happens. We at Cancer Council Australia are very strong advocates of the formation of Cancer Australia as a body that could bring things together, because one of the difficulties in Australia is there are little bits of organisations and people doing things all over the place, and not only in organisational things—supportive things and research. Something that could focus that in would be a good idea. We see Cancer Australia as a portal of entry into government—into the minister's office, if you like—and the exit portal of government communicating with the community.

But how is Cancer Australia going to function? Our strong belief is that Cancer Australia will function by leveraging from organisations that are already doing things. They are not going to start everything from scratch. They do not have the funding to do that and it would be a duplication. It would be quite different from the reason that Cancer Australia was set up if they wanted to create everything. So when we are looking at our relationship with Cancer Australia, it is highly likely that in areas where the Cancer Council has been very active in producing guidelines and public and GP information that Cancer Australia may well ask us to be part of the implementation arm of the things they want to do, just like they may well ask the National Breast Cancer Centre in their area of breast and ovarian cancer to be the implementation arm. That would mean two things. It would avoid duplication and it would also mean that things could get up and running very quickly, because you would be using organisations where the mechanisms for producing things are already well in place.

In answer to your question, I suppose I see Cancer Australia finding out where everything is in the community around Australia and then making sure that it is all coordinated instead of diverse. There are things like gynaecological oncology trials groups and there are organisations that have been responsible for patient information, GP education and so on. We need to know where they all are and how they can be most effectively used to give out similar messages.

Senator ALLISON—Is this the audit that you refer to—the audit of research that is being done?

Prof. Olver—That is one part of the process of finding out where everything is.

Senator ALLISON—So Cancer Australia will audit research that is being done. Will it look at the effectiveness of that research as well? Is that a role for it?

Prof. Olver—I think the key issues in research in Australia is to determine what are the big questions that we need to answer in a range of tumours and what are the big questions that we in Australia have the capability of answering. It is no good competing against, say, a multi-billion dollar group in the United States that are going along a research line. In my opening remarks I made a comment about targeted research. If in ovarian cancer, for example, you thought the biggest question was that we needed to find a good screening test for ovarian cancer, then you would organise the funding so that you were saying: ‘This is targeted funding. Applications from people who are working in this area will be invited to try and solve that question.’ The audit tells you who is doing what, where. But the next stage is the strategy of how you are going to most effectively use the research dollar.

Senator ALLISON—On that subject of competitiveness and research, how do you rate Australia’s effort in terms of the amount of money going into research in this field?

Prof. Olver—I believe that Australia have been very productive for a relatively small amount of money compared to—

Senator ALLISON—That was not what I asked you. I am trying to get at what you think about the quantum—of course we are better than anybody else at spending the money. I will put the question in a different way. What sort of funding level should Australia be looking at in this field?

Prof. Olver—There is a spectrum of research; one end is clinical trials, and then there is psychosocial research and so on. So it is difficult to talk about ‘a’ level of funding. You have to consider what you are going to spend the money on. For example, the initiative that is currently in place, the Strengthening Cancer Care initiative, which has already provided funding to clinical trials groups for infrastructure funding so they did not have to use the specific project funding to fund their secretariats, has been very useful. But it is only for a very short time, so that would have to be continued. And it is a fairly small amount. Double or triple that amount could easily be used effectively in just that setting. Then there are whole areas like psychosocial research that are almost not funded at all, so you need to start from scratch there and build up a capability of researchers and, again, identify the questions that it will be of most benefit to the patients to have answered. So it is not a figure; it is a set of areas that you think are going to be most productive for the patients.

Senator ADAMS—I notice you have quite a section here on regional services, especially radiotherapy. In WA we have a bit of a problem because our radiation oncology is all in Perth. I note the communities that you have named here of course have populations that are so much greater. Probably our biggest problem is access, with the Patient Assisted Travel Scheme. Do you have any experience with your patients not being able to come in because of the actual cost and the accommodation issues?

Prof. Olver—Yes. Up until recently I was practising in South Australia, in Adelaide, and we took on the challenge of how to best service the Northern Territory and rural South Australia. South Australia is a little bit different from other states in that the biggest population centre outside Adelaide is only 23,000, so there are not going to be linear accelerators put outside metropolitan Adelaide. The usual figure quoted is for a linac to drain a population of 250,000. It is still the case, apart from the trial in Victoria of single machine units, that most people advocate for double units to cover breakdown, so you are talking about a drainage population of about half a million. We would like to make the exception of the Northern Territory, which is a special case, and I think a linac or two linear accelerators there would be very helpful. But these days you can run them from remote areas.

From our own experience, there are some things people do have to travel for and some things they do not. One of the things we were very keen to do was to make sure that patients in remote and rural areas had access to the best of multidisciplinary opinions about how to treat their cancer. That can be exported from big centres to remote centres without anyone travelling, with new technologies such as telemedicine. One of my specific interests was linking Adelaide and Darwin and Alice Springs with telemedicine to enable a patient to get the full range of opinions, despite the fact there were no radiation oncologists outside Adelaide and right to the northern tip of Australia.

When you have got the multidisciplinary opinion, two things may happen: (a) if radiotherapy is not appropriate, you may save the patient from travelling at all, because chemotherapy is more portable, and (b) if they do have to travel, given that you have almost done an initial consultation by telemedicine, when they do travel they hit the ground running and can almost have their planning appointment the same day as their initial appointment, so you can limit the time that they have to travel to major centres.

If they do have to travel, what sort of support do they need? I think they need to travel for as little time as possible, which we have addressed. They need to have somewhere to stay that is fairly cost-effective, and various of the state cancer councils have actually taken that up by buying hotels and making rooms available on a cost recovery basis, which has been something that the patients have fed back is almost the most valuable service they could have received. So the accommodation when they have to come from the rural and remote areas to a major city is important.

The third issue is with the Patient Assisted Travel Scheme. The biggest problem that we have had fed back to us about that is that it is different in every state. That is a victim, I guess, of the state-federal health funding divide, and there will always be the problem that, if you set the limit of 100 kilometres, somebody lives at 99 kilometres and does not get it. It does not matter where you set it, that will happen, but some consistency between states would be helpful in that scheme, hopefully at the highest common denominator, not the lowest.

Senator ADAMS—Thank you very much. That is exactly the answer that I needed. I am becoming like a broken record! I have been very involved with Breast Cancer Network Australia, the advocacy group, and with the National Breast Cancer Centre. In the Cancer Council, you have two different areas, one with research and one with advocacy. Will they be included under Cancer Australia in that grouping—as in using them, utilising their skills and their expertise?

Prof. Olver—I think that Cancer Australia will have to address research as a major question and patient support as a major question. Advocacy is a bit difficult, because an NGO would be a stronger advocate to government than a body that was part of government. They would perhaps be a better portal of entry into government for advocacy. Essentially the potential is to go straight through Cancer Australia to the minister’s office, and that will be an important thing to be able to do. To have an organisation like that will assist us in our advocacy. A body that is able to bring things together and focus things will probably be able to direct government better, because it will act as some sort of filter and be able to extract the concerns of the patients, their carers and the clinicians looking after them—allied health—and what the major issues are that need to be addressed at any one time, and they change.

Senator ADAMS—I have been lobbied very hard, especially when the Cancer Australia council members were appointed. They feel that they just do not have a consumer, but I am fully aware that past senator Jocelyn Newman is a consumer and an expert in other areas as well. But that is another thing. It is really the advocacy, the consumer voice being accessible to the advisory committee. That is probably where I am coming from.

Prof. Olver—There is at least one other person on that committee that I know of that has had cancer and could be a consumer. My initial reaction to the announcement of the committee is that it was quite a clever thing to have someone like Jocelyn Newman, who was a consumer and who knew the political system. That seems to be the ideal. I have had discussions with consumer groups, because it is part of the Cancer Council. We fund Cancer Voices Australia to help them get up and going. My advice has been, ‘You have got to engage Jocelyn Newman, because that’s your portal of entry to that particular committee.’

Senator ADAMS—That is good; it was just to get that idea. On Aboriginal health workers, the Medicare number and pap smears, could you enlighten me as to the best possible way of making sure that we can get the right information for the remote Aboriginal communities?

Dr Couzos—Are you referring to the current Medicare rebate for pap smears by practice nurses?

Senator ADAMS—That is right.

Dr Couzos—It is currently restricted only to practice nurses. Aboriginal health workers who take pap smears will not be able to claim under that rebate, which is an unfortunate arrangement because it sets up a system where Aboriginal health workers are considered less capable and where general practitioners are more likely to employ practice nurses rather than Aboriginal health workers, if there is currently an incentive for the employment of a practice nurse or an Aboriginal health worker. If the Aboriginal health worker cannot generate Medicare claims, obviously a GP will go towards the employment of a practice nurse.

But the vast bulk of employers of Aboriginal health workers are Aboriginal community controlled health services across Australia, and there is already significant evidence of an underspend in relation to primary health care to Aboriginal people. This is yet another example of where a Medicare rebate has been established that, again, marginalises the workforce that is employed by Aboriginal community controlled health services. It is not difficult to remedy this. It is very straightforward to recognise that Aboriginal health workers can also take pap smears. There are not many of them across Australia who can. It is not as though it will break the Medicare budget by extending the rebate towards their recognition. The Medicare Benefits Schedule recognises Aboriginal health workers as having completed training under registered training providers. On the one hand, it recognises them, and a GP can claim a rebate under the Practice Incentive Program to employ a practice nurse or an Aboriginal health worker; but, on the other hand, when it has developed rebates for practice nurses and Aboriginal health workers, it has tended to restrict the accessibility to that rebate to Aboriginal health workers in the Northern Territory only. An example of that is the MBS items for wound care and immunisation, which Aboriginal health workers can claim for but only in the Northern Territory.

So there are really two elements to this discussion. One is that the pap smear rebate does not recognise any Aboriginal health workers at all, and the second is that if it was to recognise them then it must recognise Aboriginal health workers nationally, not just those in the Northern Territory.

Senator ADAMS—There is another debate just being added to this with antenatal care. I know it is nothing to do with this, but I think we are just about in the same area so maybe I can get away with that. I have been lobbied very strongly by midwives because they consider that the Aboriginal health workers and enrolled nurses do not have that expertise. A lot of GPs now are not doing obstetrics, so they are overseeing the obstetrics side of it. So we have got that bone of contention and it seems like the door has been opened, and where does it all go? How are they going to control it?

Dr Couzos—I think this whole debate—and there was a whole issue of the *Medical Journal of Australia* that was dedicated to what type of health workforce we are looking to in the future—arises from the Productivity Commission report. We are looking at a workforce that includes nurse practitioners and physician assistants, and of course at expanding the role of Aboriginal health workers. We need to have a workforce that is able to provide services in those under-served areas in rural and remote Australia. If it means training Aboriginal health workers to do pap smears more, and if other alternatives such as that in relation to antenatal care need to be made and other solutions found, then we need to investigate those sorts of issues. We need to get a workforce in these regions.

Senator ADAMS—I could not agree more, having worked there. Thank you very much.

Senator CAROL BROWN—We heard evidence at the Canberra hearing from ovarian cancer patients that they had quite a lot of problems accessing and finding information about ovarian cancer. They put information together themselves; they went out into the community and talked to people. They even had stalls at markets, I understand. Yesterday we heard from the National Breast Cancer Centre that they have produced quite a lot of literature with a lot of information, so there seems to be some problem with that information getting out to patients. I wondered whether you had a view on how the educational literature is actually getting out to where it needs to go.

Dr Sundquist—It is a very tricky area, and I think what often happens is that the well-educated population is more able to access the information and find out through their networks where the information is. But it is not readily available. If you are trying to target GPs with information, you will find they are bombarded with a lot of information and it is not readily accessible by them. I do not think it is a matter of there being a lack of information, but the materials and ways of dissemination are probably not appropriate. It is always going to be a challenge. We do have a duplication of resources; I think it would be good if it was better coordinated and if we looked at all different access points for distribution.

Senator CAROL BROWN—It was interesting that these women were highly motivated, obviously, and they were looking far and wide for information. I do not know whether they went to the National Breast Cancer Centre; they probably did not. But they could not find it, and they were highly motivated. So they produced their own.

Dr Sundquist—The Cancer Council’s state and territory bodies do have very good information on gynaecological cancers in easily readable booklets. They are accessible; they are free and distributed widely. It is just a matter of people getting to know about it. Of course, our cancer helpline across Australia is an access point. It would be good if people knew they could just ring a helpline and they would be sent information, but unfortunately they do not seem to know that.

Senator CAROL BROWN—That brings me to my next point: ‘if people knew’. There has been a lot of support for a national awareness campaign for ovarian cancer. What is your view on that?

Dr Sundquist—I think anything that raises awareness is a positive thing. One of the issues with ovarian cancer is of course that the symptoms are fairly general. There is a balance between raising awareness, from a more medical perspective, and creating worried well, or people who are just worried about the slightest symptom. From a medical point of view, raising awareness is good, but I think the symptoms are fairly general in a lot of cases.

Prof. Olver—If I may just continue with that point: it is a fine line, but you could have an awareness campaign. One of the things that I used to often discuss with patients and with others in public lectures and so on is that, when you have something with very general symptoms, you do not want everyone that has abdominal upset or a bit of bloating thinking they have ovarian cancer. But, on the other hand, you do not want people to ignore symptoms that could be ovarian cancer. The one thing that ovarian cancer shares with other cancers is that the symptoms are persistent. If you have a bowel upset or something, it usually disappears in a week or two and so on, but any persistent symptom needs to be investigated. Messages like that could well be got out into the community and reinforced without creating a dreadful sort of public panic about a disease that is less likely than a lot of the other diagnoses that would be fitted to those symptoms. But even if you had a diagnosis of something simpler—irritable bowel, premenstrual symptoms and so on—a reasonable public message would be that any persisting symptom needs further investigation.

Senator HUMPHRIES—Let me be the devil's advocate for a minute. Suppose you are fronting the health minister to seek support for some of the initiatives on gynaecological cancer which are in your submission and he says to you, 'We've got money to spend on cancer, but cancer's killing more Australian men than women at the moment and there are much higher rates of death among Aboriginal Australians than among general Australians, so why should we focus dollars on initiatives dealing with gynaecological cancer as opposed to other areas of priority?'

Prof. Olver—I think that is a very important issue. I tried to pick it up in a way in the initial point, to say that there are things now that will be highly beneficial to patients with gynaecological cancers that will actually apply to all cancers, so the trick is to take initiatives that have been successful, like the National Breast Cancer Centre—albeit the question of Senator Brown. We need to do research to find out how to get messages across more effectively. That is an area that can be researched like any others, and there is precious little research in the literature about that. So I think we do have to concentrate on two things. One is the more general picture of how we can do things that will benefit the whole of the Australian cancer community but will therefore also benefit the gynaecological cancer subset, and information and awareness about all cancers, about persistent symptoms, would be a way to do that. Also, a general increase in research funding where gynaecological cancers would be part of that increased funding would be very helpful for the whole Australian community. That is the way that I would deal with that particular issue.

The third thing is that within gynaecological cancers and again all cancers there are disadvantaged groups, and I think it is helpful to think about extra resources in those groups to bring them up to the standard of the rest of the Australian community. So our focus on the Aboriginal groups particularly in gynaecological cancers, particularly cancer of the cervix, and why we might advocate for different things for those than for the rest of the community is because the survival figures, the detection figures and so on are so different from those for the rest of the community. So we would be looking at addressing those inequities, which I think the Australian population would support.

Dr Couzos—I am so glad that Professor Olver finished by making that point because when you asked your question you did make a point about what argument would be required to convince a minister to fund programs for the general population given that there is a higher rate in the Aboriginal population. Unfortunately, there are not any specific programs on a national level that are specifically developed for the Aboriginal population. So we are lacking that. That is a major issue.

Senator HUMPHRIES—Can I ask you to explain that recommendation that says:

> Investigate feasibility of extending recommended cervical screening intervals for asymptomatic women from two to three years

What is the reason for that?

Prof. Olver—There are a number of discussions around cervical cancer screening. One of them is the accuracy and what test you use. The other is the response you use to positive tests, particularly at the mild end of the spectrum, if you like. Then there is the issue that you have raised about the screening interval. There is data from overseas countries—and certainly there is no uniformity about this—that there is very little impact of changing from two- to three-year screening. Looking at all of the parameters including cost effectiveness and looking at the outcomes, it does not seem that there is anything magical about two years. It is very difficult to change from two years to three years, because the expectation is that everyone got it right the first time. But I think these things are dynamic. As we get more data and we can use data from population studies overseas, if there was very little difference and if it was cost effective, that would generate funding that could be used more effectively in other areas of gynaecological cancer.

Senator ALLISON—Professor Olver, are you aware that there is a requirement, as I understand it, whereby a doctor cannot prescribe only the ThinPrep screening for cervical HPV?

Prof. Olver—I am aware that the government, through its advisory bodies, has determined that there is no cost-effective advantage in changing over to ThinPrep screening. I think it is partly due to the great success of the conventional screening procedures. I am not an expert in the area of screening, but you will notice in our submission that because of the particular difficulties in rescreening of the Aboriginal population we have suggested that maybe ThinPrep screening could be most cost effectively and usefully used in that group because the extra sensitivity, particularly if you have trouble following up, would be of particular benefit in that group. We are not advocating for it and we do not have any argument with the research that shows that the difference is trivial, but we do make the point that there are some populations—the Aboriginal population in particular—where that extra sensitivity is going to make a lot more difference than it does in the general population.

Senator ALLISON—Can I just pull you back to the question of why it should be that a doctor must prescribe both if he or she believes that the greater sensitivity, perhaps in terms of Indigenous people, is necessary? Why should both tests be done?

Dr Sundquist—I do not think both tests are done.

Dr Couzos—It is one or the other. Currently only Queensland funds the ThinPrep tests. That is my understanding.

Senator ALLISON—And there is no federal rebate for that—I understand that. This actually came up in a conversation last night. I just wanted to get it on the record to see if you agreed with it. It was said to be the case that a doctor was in fact not able to prescribe ThinPrep without doing the standard current arrangement.

Dr Sundquist—I do not think that is right. I think women are often given a choice and that it is explained to them that this is the pap test and it is a very good test, but there is this other test available if they want it—because there is a cost, other than in Queensland—

Senator ALLISON—Why shouldn’t the situation be such that the doctor makes the decision about which test, in collaboration with the patient, and the rebate—whether it is $28 or some other figure—applies to both?

Prof. Olver—I think the issue comes back to whether in fact a choice can be made between the two—whether there is evidence in terms of one being clearly better than the other in most of the population. You can make that choice in a particular group where you have a particular problem regarding repeat testing, and therefore the extra sensitivity is important. But for the rest of the population and an individual patient, the evidence would not enable you to make an evidence based choice of one or the other. I guess the government is saying, ‘We are not going to fund ThinPrep tests because there is not enough evidence that the difference is clinically important in the wide population.’ They would not allow that choice because they do not have the evidence to make that choice.

Senator ALLISON—Even though the evidence in the United Kingdom is in this direction? And we are not doing any studies here to determine the question one way or the other.

Prof. Olver—If you asked the question, ‘Is a ThinPrep smear slightly more sensitive than the other,’ the answer is yes. Does that matter in the general population in Australia, with its high levels of screening and its low rate of cervical cancer because of that screening program, the answer is no. In the subset population the answer is yes. Nobody is arguing about the slight difference in sensitivity. What they are arguing about is whether that is going to affect the outcomes when spread over a whole population. The data would suggest it will only affect the outcomes in a subset population, not in the general one, and therefore it would not be the best use of the dollar to fund that as opposed to another program. I think that is where the difference lies, as I understand it.

Senator WEBBER—I might move away from screening and back to information. Dr Couzos, given the discussion we have had—and there seems to be a range of knowledge and views about the availability of information on gynaecological cancer—and given the higher incidence and lower rate of screening for women in the Indigenous communities, how accessible, appropriate and relevant is the information that people say is out there to the women and the health workers in Indigenous communities?

Dr Couzos—The information about the burden of disease?

Senator WEBBER—Yes, all of that: the burden of disease, how to look after yourself and so on.

Dr Couzos—Every state and territory has its own health promotion programs from time to time to provide messages on the need for a pap smear and so on. Certainly over the period when I was working in Broome in 1996, there was a big resurgence in the health promotion approach. We had Indigenous radio, we developed specific pamphlets for the whole of the Kimberley region, the health department of WA was very supportive of the initiatives and provided funding and so on. I am sure that similar sorts of initiatives are continuing around Australia in each state and territory.

What is currently lacking is anything from the federal approach. At the time, it was very clear that many Aboriginal women did not realise the significance of cervical cancer, particularly elderly Aboriginal women, who thought that the pap smear issue was somehow linked with-child bearing years and was not relevant to them after their child-bearing years. There were a whole range of misconceptions around the need for a pap smear throughout a woman's life. Since then, there have been many studies that have documented the same thing as well as other misconceptions that exist.

The issue around pap smears is access to health services, their appropriateness and their ability to make a woman feel comfortable in having a pap smear—the health provider being female. Aboriginal health workers are particularly ideally placed in this role. They have the respect and trust in the community and they are members of the community. I think the lack of access issue is fundamental for every health problem that Aboriginal people face, and it is the No. 1 problem.

The other issue is that, if a woman is provided with opportunistic screening for a pap smear, we would like to see that that pap smear is the most sensitive that is available, because if that smear is unsatisfactory, which is highly likely because of vaginal infections and so on, there is a need for a repeat smear. There is normally a huge interval for the Aboriginal population, so you want to make sure you are going to minimise the number of false negatives—and that means a more sensitive test—maximise your opportunities while you have the patient there and get the best result. That is the other issue.

Then there is the issue of provider incentives to general practitioners to encourage patients to take a pap smear while there is that exceptional potential in the consulting room while the person is there. That is why the federal government in 2002 introduced the Practice Incentives Program, where there was a financial incentive to a GP if they provided a pap smear to a woman who was underscreened. That was a good initiative. That funding, which was originally around $71 million over four years, was supplemented in 2005 with another $30 million dollars and again in the last federal budget in 2006 with another $97.2 million. The original program was evaluated in 2004.

The evaluation, however, did not examine how effectively that program targeted Aboriginal women. It is absolutely astonishing. The federal Department of Health and Ageing in Senate estimates in November 2005, when Senator Crossin asked questions, was unable to answer the question about how effectively this program targeted Aboriginal women. That is completely unacceptable. It should be unacceptable that such a program, which is specifically developed to target an under served population, was not able to report whether it had done its job and succeeded in doing that.

With this current federal budget allocation we would like to see this program, which has been extended for another four years, rolled out by the Department of Health and Ageing in such a way that the department will be able to measure how effectively that program reaches Aboriginal women and the program will be accessible to the health providers in Australia that deliver pap smears to Aboriginal women. The vast bulk of those services are Aboriginal community controlled health services.

There are a number of issues that need to be addressed. If the department says it is too hard to do that then why don't they quarantine a proportion of an estimate of the underspent funds through the years or have a proportionate of allocation for specific cervical screening programs that can be delivered in another form outside of the Practice Incentives Program?

Senator WEBBER—Returning to the discussion you were having with Senator Brown before about GP education, I am sure GPs are a bit like those of sitting on this side of the table—you go through days where you get inundated with information and you have busy times so it is hard to make your way through it. When we got evidence yesterday from the NBCC, they talked about the range of publications they produce and said that most of their focus is on GP education. Is there a better way of getting GPs up to scratch than sending them out material?

Dr Sundquist—It is a challenge because, unless it is done in a systematic way, it is always going to be an ad hoc situation. You could look through the continuing professional development programs for GPs, but we know there that GPs can just go along to a conference and get enough points and it is very hard to get them motivated enough to go to specific things that they may not think are particularly important for them. So I think you need to have some coordinated thing but I think you need to have different channels because there is a fine line between too much information and too little, where things go on top of it. The doctors are being bombarded with information from pharmaceutical companies. Certainly Cancer Council Australia is looking at targeted messages for GPs and national messages for GPs, and that is happening now, isn't it?

Prof. Olver—What I said about needing to do research into how to get the message across is actually quite important. We discovered through our guideline work and producing guidelines for GPs—they used to be sent a book of guidelines on whatever malignancy—that the most effective thing we did was to distil the guidelines into an A4 sheet, laminate it and give it to the GPs. They used it. They kept it in their desks and used it on the relatively rare occasions when they saw a cancer. That is one of the problems in general practice: some GPs might see a particular type of cancer once or twice a year, as opposed to all the other things like asthma, diabetes and so on. So we learnt almost by default that the better way of giving written information was a very easily accessible laminated A-4 sheet. We got far better feedback from that than the other methods of doing it.

The difficulty these days is that there are so many methods to choose from in terms of web-based things and podcasts and whatever, but nobody knows what the most effective method is. People sort of guess and go along a line, but there needs to be research done. At least, if you get funding to disseminate information some of that funding should be used in the way Sophie said and in the more general situation as well, to evaluate the impact that information.

Senator ALLISON—Perhaps we should ask the pharmaceutical companies how they do it. They seem to be successful.

Prof. Olver—Well, they do—

Senator WEBBER—They take them out to dinner.

Prof. Olver—and in fact they use academic detailing to individual practitioners. They are the experts in how to get a message across about a particular drug. So some of that information is out there but it is not used as much in the public sector.

Dr Sundquist—If we follow the line of Senator Allison about the pharmaceutical companies, we see that one of the things they are now realising is that a very powerful stimulus for information for doctors is through patients. For example, if a patient comes into a doctor’s surgery with a list of questions that they know are really important and puts the doctor on the spot in terms of information, the doctor will suddenly realise they do not actually know about that and will then try and seek out the information. So I think that is another way—by empowering patients—because you often hear doctors say that the internet makes it so difficult; often a patient knows a lot more than they do about the latest research because they cannot keep up with it. So that is another way of getting doctors to seek information: they know that they are unable to meet their patients’ needs in that area.

Senator WEBBER—I am probably like most women in Australia in that it was not until I started sitting on this inquiry that I realised that the NBCC was concerned with anything other than breast cancer. Because there is ‘breast cancer’ in the name of your organisation I assumed that that is what you focus on. And I am sure, therefore, if I had to support someone who has, or developed, a gynaecological cancer I would probably look for a specialist organisation that had those words in its title before I went to a generic organisation because I would be looking for the specialised and most relevant support. Therefore, Professor Olver, if we were to accept your recommendation that we look at expanding the NBCC to include other gynaecological cancers, should they change their name?

Prof. Olver—It is an issue of branding. The general principle is that, if we do it disease by disease, the poor guy with adrenocortical cancer will never get a national organisation to deal with that rare a malignancy. Looking at it generally, I think there was an advantage. It clearly was a difficulty for the NBCC because putting ‘and ovarian cancer’ at the bottom of the logo did not really do much and it is all a branding exercise, and I do not have expertise in that area. I am aware that perhaps the breast cancer lobbies may not wish to lose their particular brand. Our recommendation may not necessarily be popular, but, looking at how you do it across the board, I think these things have to be more generic. I think gynaecological cancer services will be up and running far more quickly with an organisation that knows how to do it and is developing that expertise all the time. It would be the first to recognise that a lot of the messages about breast cancer have not hit home. But it is 10 years down the track—it does not have to start from scratch—and it is learning from that. So, generically, yes I would add gynaecological cancers to the body of expertise, and the issue of how you brand it to make sure everyone knows about it follows from that.

Senator FERRIS—Picking up on that issue, some of the evidence that we received yesterday suggested that, whilst the NBCC have done some excellent work both with breast and with gynaecological cancers—ovarian cancer specifically—there are in fact a number of strings to that bow, if you like, which have not been covered by the NBCC. They include evidence that came from the nurses on training and some comments on general education policy, which came from other witnesses. It makes me wonder whether, in thinking about the Cancer Australia body as an umbrella, if you like, there would be an opportunity within that structure for various of the main cancers. I am thinking perhaps of lung cancer or maybe a respiratory cancer grouping, using the model developed by the NBCC but recognising that there are specialty groups which are perhaps more appropriate in a fuller sense. For example, if there were to be a gynaecological grouping, that would include recommendations for nursing education, the psychosocial work and the general education work, which some of my colleagues have covered this morning. These are currently not covered within the structure of the NBCC and probably cannot be. The NBCC cannot do everything, though they have produced some marvellous material. This grouping could use the modalities of the NBCC but perhaps recognise that some of these major cancers would fit currently under the Cancer Australia logo. Could you comment on that?

Prof. Olver—I think that is precisely what Cancer Australia's remit is. It will learn from and develop what has gone before it so that, if the terms of reference of the NBCC limit it from doing certain activities, then in focusing and reconstructing how things are done you would simply broaden the remit to include those activities. The NBCC has nothing to do with funding research, for example, so that is a separate stream.

Senator FERRIS—That is my next question.

Prof. Olver—In my view, the government have set up Cancer Australia to do just that, and the challenge is to take the model that the NBCC has, leverage from that and decide how you will construct the support and the educational aspects of cancer to cover all the malignancies. In the interim, though, it will need to use the organisations that are already doing it and make sure that that keeps on going, but it may broaden them. I think it is just opportunistic that, since the NBCC has taken over ovarian cancer, that is the way you may solve the gynae problem most effectively and efficiently while you are reconstructing the way the government does its cancer business of looking after the groups that need better education and finding better ways of getting the message out to the patients and the people who look after them. I agree with you—I think that is precisely the challenge for Cancer Australia.

Senator FERRIS—My second question relates to the competition, if you like, in research. I had the opportunity at dinner last night to sit with two of Australia's very eminent researchers in women's cancer. Perhaps without knowing that each of them had done so—although they may have prearranged it; I am not sure about that—they both expressed concern about the current structure for funding using myriad small bodies. You also referred to it in your opening statement. There are various small bodies which are raising money and putting it into smaller agencies, particularly in Melbourne and Sydney, rather than all of the money raised going into a pot. They were not necessarily suggesting the NHMRC, but a pot of some sort where the money could then be dispensed to prioritised research. Applications could be received from individual researchers or teams that might then be able to contribute to that research, rather than small groups duplicating work that has been done overseas. I see that you are nodding, so perhaps you know the answer. Both of them told me that it was incredibly frustrating because it wastes precious resources on work that is often already being done overseas more effectively, and it uses our scarce resource dollars.

Prof. Olver—I think the most important part of the question is establishing what the research priorities are. It does not matter whether you have small organisations or large ones, we need to know which questions Australia can most effectively answer using the strengths of its current research team and the capabilities that we have. We know that Australia has been capable in the past, and continues to be, in leading the world in certain areas in the right type of research. I think the HPV vaccine is a great example of that. We need to identify those priorities. We need to have some research funding that is about the big question, if you like.

Instead of having a three-year grant you could have a 10-year program. We supported the Australian ovarian cancer initiative, where there is a large database from which a lot can be learned by collecting all the data on ovarian cancer and marrying specimens with clinical details. A lot more can be learned about the disease, and information on genetics and things could ultimately lead to our screening tests and so on. So the key part of the question is to identify those research priorities. I think it would be useful if there were not a whole lot of little groups funding them. What is being done now needs to be identified because the worst duplication is where you do not actually know that another group in another state is doing the work.

Senator FERRIS—Does that happen?

Prof. Olver—Yes. I cannot give you specific examples in gynaecological cancer, but I think that if you asked most researchers if they knew most of the important research being done around Australia in their field—for example, what clinical trials other groups are doing—the answer would be not necessarily, except in the areas where national groups have been formed, like the breast cancer group and, to a certain extent, the gynaecological oncology group, ANZGOG, where there is an attempt to bring it together so that members of that group do things in a coordinated fashion. I think that is a very important direction for research.

The other thing is that we have to broaden our idea of what research is. The NHMRC mechanism has been very successful, but you cannot help noticing that psychosocial research under that banner is poorly funded. When it is poorly funded it discourages young investigators to go into that field in the first place and it becomes a vicious circle. So expanding the idea of what the most useful research is that you can do for the patient is part of what you are suggesting. We need to identify those big research questions and then, hopefully, through Cancer Australia try and encourage all the funds to be strategically directed towards those big questions.

Senator FERRIS—Do you think that perhaps it would now be opportune to establish a cancer research fund outside of the NHMRC structure?

Prof. Olver—I suppose generically I have always believed—and the whole thrust of our submission is that we are trying to suggest this—that every time something needs to be done someone sets up a different organisation. I would perhaps like to see the existing structure used more effectively.

Senator FERRIS—So you are suggesting that the NHMRC might have its terms of reference broadened to encourage a broader definition of what is research?

Prof. Olver—It has changed over the two or three decades that I have been involved with it in response to the different needs of the research community and there are large projects—some of the big genetic projects and so on—that have been got off the ground under the NHMRC, so it is not just about project grants as there are big programs now. But if an area of need is identified, such as a gap in the funding of psychosocial research, I would be trying to use the current mechanism to address that issue to try to stimulate it, rather than create new structures every time there is a problem, because in my view that is what Cancer Australia is trying to discourage.

CHAIR—Professor Olver, I have two questions that come out of the inquiry that this committee did a couple of years ago on cancer in Australia. There were a range of recommendations, some of which have been picked up and some of which have not. I want to ask about two particular areas. One is clinical trials and the other one is data collection. They were involved in very strong pieces of evidence in the cancer inquiry and they have come out in the submissions that we have had now. I am interested in your organisation's view, Professor Olver—and also particularly in the view of the Indigenous population as well, Dr Couzos—as to the situation with clinical trials particularly in gynaecological cancer: access to them, funding of them and how they fit. These questions pick up very much on Senator Ferris's questions about research. The second thing is data collection. It was a huge issue in the cancer inquiry as to the various ways in which data was collected and the fact that it was state based and the state systems did not talk to each other and also in terms of how the data is collected and how it fits into the international scene. I would like to get something on the record from your organisations about those two issues.

Prof. Olver—In our organisation we clearly think that clinical trials are very important. Our state organisations put millions of dollars into research each year in clinical trials. We believe in—and we strongly support—the Strengthening Cancer Care initiative that has attempted to get some system into the clinical trials environment by encouraging groups to form national groups and by then providing the infrastructure for those groups so that there can be some system for investigators to do clinical trials under national umbrellas and those groups, as national groups, can then be better able to interact with international groups, which you need to do in trials of adjuvant therapy. Australia on its own does not have the numbers in any malignancy to do them on its own. With widespread disease smaller numbers are needed and you can do them within the country. There needs to be more of that infrastructure funding. Strengthening Cancer Care has been a good start. Going down to the micro level of some of the groups that I am involved with, it has been nice to have but it is just starting to fill some of the gaps and there is no guarantee that it is ongoing, so it is not perhaps as secure as it could be.

So that initiative simply needs to be taken further and the funding needs to be secured over longer periods of time so these groups can be confident that they can develop a program of research rather than doing a bit here and a bit there. And they can be internationally competitive, for example, in being able to attract new drugs and so on into their clinical trials groups, because they have a guaranteed output because they have the structure to do that. So I think the structure now on a national level is very important to stimulate clinical research.

Then you have to engage the clinicians to invite patients to participate in clinical trials and you have to educate patients about what clinical trials are, because the participation rate depends on both. It is always difficult if somebody says, 'So you want me to be a guinea pig,' because that is not what it is about. It is all about offering additional opportunities to standard treatment that may actually help not only future generations but also the patient you have sitting before you. So there needs to be education of the patient and education of the clinician once the structures are in place to deliver the trials.

On the question of data collection or cancer registries—again, a casualty perhaps of the state-federal divide—it is absolutely essential that we record precisely what our cancer and our mortality rates are and that we are able to pick the trends that become apparent when you introduce programs like screening programs and so on. We need to be able to identify those trends and be able to do something about them or at least affirm that a program has hit its target. And there is no substitute for meticulous data collection. There are areas in Australia that have done it very well. But they are subject to the vagaries of state government funding and some states that in the past have led the nation are now not quite so prominent in that because the funding for the registry is not there.

The Australian Institute of Health and Welfare trying to bring it all together is obviously very important, but I gather there are some issues of states with particular legislative structures not being able to make that data available in the same format as others. Of course, issues of privacy, while they are very important—

CHAIR—I was hoping to get that view.

Prof. Olver—in individual terms, in terms of epidemiological research, where it is de-identified, they should not impact. The community, I believe, should see that a cancer registry is its greatest tool in finding out how its health services are performing in cancer, because you can compare state by state and nation by nation. So, given that it is de-identified, rather than focusing on privacy issues in epidemiological research, where you are interested in whole populations, it should be seen as one of the great community resources for checking up on the efficacy of the health system.

CHAIR—Dr Couzos, clinical trials in Indigenous populations: I feel sure you have a comment on that.

Dr Couzos—It is hard to know where to limit the answer to that question, really.

CHAIR—Just don’t!

Dr Couzos—Maybe I should start with the late Dr Puggy Hunter’s quote on this subject. Puggy Hunter was the Human Rights Medal recipient in 2001, and he always used to say that Aboriginal people have been researched to death ever since Captain Cook landed in Australia—although he used to say it in a much funnier way than that. But the message is that, yes, Aboriginal people have been researched extensively, and Aboriginal representative bodies are very sensitive to that issue.

The type of research, however, that has been undertaken involving the Aboriginal populations has been of a much lower level of quality, if you look at the NHMRC level of evidence levels. That is, they have been descriptive studies, surveys, case studies—that type of study—and very few have been randomised control trials or clinical trials or intervention type studies. Very few of those have been conducted in Australia involving the Aboriginal population. As to why that is the case, I guess it just depends on what the research question is. Researchers within the mainstream research institutions often do not have a link with the Aboriginal population. They are very distant from it. There are many reasons why this is the case.

We at NACCHO have been trying to change that situation. In fact, we were the instigators of one of the largest randomised control trials that was conducted in Australia on chronic suppurative otitis media in Aboriginal children. That was an initiative by Puggy Hunter because of his concerns, firstly, about the health problem and, secondly, that RCTs are not done well in Australia. He took the initiative and said, ‘Well, if no-one else is going to do that type of research, let’s do it ourselves.’ So NACCHO is very keen to encourage randomised control trials, particularly if they are done properly. There are representative bodies of Aboriginal peoples across Australia. Researchers would need to engage with those representative bodies.

With respect to the type of research, RCTs are very expensive. RCTs also need to recognise that, when undertaking research involving Aboriginal peoples, it is even more expensive because you need to build into the research protocol a capacity-building element. Part of that involves, rather than having an external research team come into an Aboriginal community or setting and taking all the knowledge that exists at that level away with them and building their own careers, actually using the local Indigenous workforce in those localities to build their capacity and involve them in the research process and so on. So there are many elements to the conduct of an RCT.

If you are going to employ the local Aboriginal workforce, you need to pay them award salary rates. At the NHMRC, research pay scale rates are much lower than what would be required for, say, an Aboriginal health worker. We found in our trial—

CHAIR—We have not had this evidence before, so we will ask them about the pay scales.

Dr Couzos—In our experience, we employed over 13 Aboriginal health workers across our services to undertake the research. We found that, in our grants submission, the NHMRC would not accept the salaries that Aboriginal health workers were paid as part of their pay rate because they are ranked so lowly as research assistants that the pay scale does not match, even though an Aboriginal health worker’s salary is so low anyway. So we had to seek supplementary funding from alternative sources. The NHMRC would not cover that. That almost prevented the trial from going ahead. That was such a significant barrier. This information is not new to the NHMRC. It is a major stumbling block for any type of research. I could go on.

Human research ethics committee approval needs to be appropriately given. University human research ethics committees may not have appropriate Aboriginal representation to be able to make appropriate judgments. If the research is investigator driven and could potentially be seen as a threat by the Aboriginal community then it will not be supported. There are many barriers that prevent good quality randomised controls from taking place. But a lot of those barriers can be overcome by appropriately involving Aboriginal representative bodies from the beginning. That should be encouraged. They exist, and it is a matter of respect to those bodies and also of recognising their expertise in this area. On the issue of data, we certainly agree with the Senate committee’s views on this. My understanding is that only the Northern Territory cancer registry records Aboriginality. The other cancer registries need to get on board.

CHAIR—Dr Couzos, is it possible for you to give us some supplementary information on the trials, particularly from the Indigenous perspective? In the evidence we had in the cancer inquiry there was some information that indicated that patients who had access to involvement in clinical trials were stronger and their chances of working through the processes were greater. There was evidence on that basis, and we had a demand through that inquiry for more access to clinical trial participation. Yesterday, we had evidence from a woman with gynaecological cancer who had been involved in clinical trials and she spoke of the advantages that gave her in her process. I think the information you have given us from the Indigenous perspective is very useful, so if you would not mind, on notice, giving us some more information, that would be good.

Dr Couzos—Yes, sure. Finally I would like to make the comment regarding the Strengthening Cancer Care initiative that we do not have any understanding of whether there is a commitment under that initiative for more Aboriginal health research with regard to cancer in clinical trials.

CHAIR—It is a general program and there is no specific element—in my understanding—for Indigenous populations.

Senator ALLISON—Professor Olver, we heard yesterday that 50 per cent of women with gynaecological cancer receive inadequate treatment, if I can describe it that way—that is, they are not treated by gynaecological oncologists—and that many have to come back again and again for treatment as a result of that lack of expertise. So a multidisciplinary approach is being suggested. As I understand it, COAG recommended a rebate for a multidisciplinary consultation. Can you fill that out a bit more for the committee? Do you know anything about this? Is that something you would support yourself?

Prof. Olver—I have been involved in a couple of teleconferences with the AMA and the government over this.

CHAIR—That would have been fun!

Prof. Olver—We fully support funding for a multidisciplinary process because we believe that is now the optimal way of treating most cancers. The trouble is that the proposal was to fund it through the Medicare system, and the Medicare system does not reimburse doctors or clinics; it reimburses patients. So there are all sorts of strange ideas that half-a-dozen people will all send a bill to the patient. The patient will not have met most of them because they have been referred into the clinic by a particular practitioner, the clinic will get an opinion and then refer it out. There were comments made that only the treating doctors would be reimbursed under the scheme—and the pathologists and radiologists who had spent quite considerable time preparing for the clinics said, ‘What about us?’ I do not think any of these problems are insolvable.

If the money—I think it is $28-odd million—is available through the Medicare system then we will take it and make it work. It may be that a designated person in the clinic bills the patient and the clinic decides as a group how it will spend the money. It may be useful to have accredited multidisciplinary clinics. You have to have a certain structure before you are able to bill. So there are all sorts of ways this can be done. We are fully supportive of it being done, even if we have to do it through the Medicare system and have to solve some of the logistic problems.

Senator ALLISON—Isn’t part of the problem that most of the expert care is within the public system and public hospitals do not receive Medicare rebates for their work?

Prof. Olver—I think the issue has been that the public sector has been the site of most of the multidisciplinary meetings. I would say that people do not have to be paid to go along to a multidisciplinary meeting once it is established. It is simply the most efficient way of dealing with things. You get the support and other opinions of your colleagues. That is why we were so intent on exporting multidisciplinary meetings: because they seemed to be a core of care. There is no reimbursement in the private sector for them. I think this initiative is meant to stimulate that so that you can have some funding to bring private clinicians together outside of the public system and take advantage of what has been generally thought to have worked very well in the public system and to be the most efficient way of dealing with things. It means the patient has almost a one-stop shop. They get the opinion of multiple clinicians in the one meeting. We think anything that encourages those out in the private sector is an excellent initiative.

Senator FERRIS—My question is to Dr Couzos. Some of the evidence we received yesterday on issues related to the evidence you have given this morning suggested that one of the difficulties with Indigenous health is when a woman meets the Indigenous health worker later in the afternoon in the supermarket and the sense of discomfort and embarrassment that she might feel.

The suggestion was made that perhaps the answer might be to put those sorts of tests in the hands of a visiting Aboriginal health worker from another town and move them around so that you do not necessarily meet the health worker that you have again in the community. I just wondered if you could comment on that. It is a small thing, but I understand it is quite significant in the overall treatment program.

Dr Couzos—I think it is very important, most definitely. First of all, Aboriginal women are entitled to choose their pap smear provider. A choice is really important, and often they do not have that choice. So having an Aboriginal health worker who is skilled enough to undertake a pap smear and allowing the woman to make a choice about whether she would like an Aboriginal health worker to offer a pap smear or whether she would like the GP to offer a pap smear is a great advance in the first instance.

On the second point: in the event that women do not feel comfortable with the situation of an Aboriginal health worker from the community—and not every woman feels uncomfortable about that; many women feel very comfortable about that taking place—then your suggestion is a good one. It is not difficult to implement. I give you the example of the Kimberley. In the Kimberley Aboriginal Medical Services Council—that is a central body that acts as the hub of the central support agency for many Aboriginal medical services across the Kimberley—the Aboriginal health workers there are multiskilled and multitrained to rotate in different areas of work, and there are coordinators who travel across the Kimberley to provide services. So you could easily adopt a system whereby Aboriginal health workers could be visiting all the different sites across the Kimberley at regular intervals and thereby offering an alternative practitioner. So it is a good suggestion. There are ways in which it could be implemented, yes.

Senator FERRIS—Thanks.

Dr Couzos—There is just one more point. The reality of the situation is also that there is such a high GP turnover that it is almost as if it is happening by default, in that you are getting a new GP at regular intervals. So if you feel uncomfortable with the GP that you bumped into in the supermarket you are going to get a new one soon!

Senator ADAMS—I have a quick question regarding the divisions of general practice and NACCHO. How is the relationship going? Are you working closer together?

Dr Couzos—It is going well. We have a memorandum of understanding with the Australian Divisions of General Practice. We have a proposal for a work plan. So that side of things is going well. The problem is in relation to individual divisions across Australia, and there are many of them—120 or 130?

Senator ADAMS—One hundred and nineteen now, I think.

Dr Couzos—One hundred and twenty divisions across Australia. You cannot say uniformly that the relationship between that division and the Aboriginal community controlled health service in their locality is a good one. Divisions get a loading in their core salary of $2.55 per head of Aboriginal person in their locality. That comes in their core budget, but there is no expectation in their reporting to demonstrate what the division has done in enhancing Aboriginal health care. So there is no mechanism of follow-up. The divisional performance indicators do not actually specify a requirement for how that element of their funding is addressed. For some divisions that is a substantial amount of money because they have a large Aboriginal population. So it does depend on the goodwill and the personal relationships that exist at the local level, and sometimes that does not work to good effect.

The reason this is important—and I understand why you are raising this issue—is that the federal government provides quite a bit of funding for the rollout of many programs, not just for cervical cancer but for diabetes, asthma and so on. It rolls them out through divisions with the expectation that their role as divisions in engaging with private GPs and with other primary health care providers in the locality will occur through the divisions. But unfortunately it does not flow through effectively, as one would imagine, for many divisions. For a large proportion it does, but for some it does not, and we are trying to work on that.

Senator ADAMS—Specifically, is it working with the Territory and the Kimberley divisions?

Dr Couzos—I am not up with the latest information. My understanding from the Territory is that it is working well. From the Kimberley it was not in the past, but I do not know what the current situation is there.

Senator ADAMS—Thanks very much; that is good information.

CHAIR—Thank you Dr Sundquist, Professor Olver and Dr Couzos. Are there any final comments you would like to put on record before this segment ends? Of course, if you do come up with some things you would like to share with us later, please let us know. We are waiting for your homework, Dr Couzos! Are there any comments you would like to put on record?

Prof. Olver—No, but we appreciate the opportunity, and we think it has been a very comprehensive discussion. Thank you.

CHAIR—Thank you very much.

Proceedings suspended from 11.05 am to 11.21 am

CROSSING, Ms Sally, Member, Steering Committee, Cancer Voices Australia

STUBBS, Mr John William, Executive Officer, Cancer Voices Australia

CHAIR—Welcome. You have brought some beautiful wattle. It is lovely to see you again, Ms Crossing, after the previous inquiry. I am sorry, Mr Stubbs, I do not know whether you gave evidence in the last one; I just remember Ms Crossing's evidence so well. It was very useful in the last inquiry. I know that you have been before these kinds of committees before, so you have information on parliamentary privilege and the protection of witnesses.

Mr Stubbs—Sure.

CHAIR—I know that either or both of you would like to make an opening statement, and then we will go into questions. So, Mr Stubbs, now you can go forward with your statement.

Ms Crossing—Boys first!

Mr Stubbs—Thank you. I will make the opening statement, and then I will hand over to Sally. I am the Executive Officer of Cancer Voices Australia, and I am joined today by Sally Crossing AM, who is the Chair of Cancer Voices New South Wales and a member of the steering committee of Cancer Voices Australia. I am a five-year leukaemia survivor, and Sally is an 11-year breast cancer survivor, so we have a combined 16 years of cancer experience.

CHAIR—Congratulations.

Mr Stubbs—Thank you. For many people, 16 years in the one area is a career, and so it is for us: the need to get it right for cancer patients in Australia and give patients their voice to be heard. We thank you for allowing us to present to you today on this important issue.

Cancer Voices Australia exists to provide a voice for people affected by cancer. Together, Sally and I represent over 4,500 cancer survivors from over 70 state and national consumer support groups. Cancer Voices Australia is the national consumer organisation representing Australians affected by cancer. It aims to ensure that the voices of people affected by cancer are heard at the national level. Our objectives are to promote the fundamental rights of Australians affected by cancer; to effect improvements in cancer treatment, care and support by contributing to national cancer policy and program development; to promote the value and benefits of consumer participation in the development of national cancer policy and programs; and to provide a forum for member organisations to network and contribute to national activities. We provide a national and independent voice for people affected by all types of cancer, linking and collaborating with established state and territory cancer advocacy groups, including Cancer Voices in New South Wales, ACT, Western Australia, Tasmania, Queensland and Victoria. We are a respected and integral part of the national cancer arena.

We are here today in support of the approximately 4,000 Australian women diagnosed each year with gynaecological cancers. We identify gaps in the following areas: a need for a national coordinating centre, a lack of psychosocial support for male partners and carers, a national public awareness and prevention campaign for all women, and national collaboration amongst researchers into gynae cancers. I now ask Sally to continue.

Ms Crossing—As John said, the main purpose of Cancer Voices Australia is to provide the voice and to voice the needs of Australians affected by cancer. While we are a generic cancer group, we are advised by all of the cancer specific consumer groups. We acknowledge that while many of the issues for people with cancer are very similar—for example, the need for reliable access to information, early diagnosis, best practice treatment options, treatment and follow-up plans, cancer site specific specialist advice, geographical access and the importance of support—some cancers create quite individual needs and priorities. The following are the main points we would like the Senate committee to note. Overarching all of this, Cancer Voices Australia would like to see the National Breast Cancer Centre expanded to include all gynaecological cancers. Adding ovarian was a good step, but this is the logical next step. The NBCC, founded in 1995 following a Senate inquiry very like this one, has an excellent track record in addressing the needs and concerns of women.

The following require urgent national attention. This is a list of dot points which I will leave with you, if I may. Most women with gynae cancers are diagnosed late, when symptoms have appeared. Many women who report symptoms are not diagnosed correctly. Many women are not referred to gynae-oncology specialists. Women in the community are generally unaware of what symptoms to watch for. Education is poor about reproductive anatomy, the connection between known risk factors and some gynae cancers. Other than pap tests for cervical cancer, there are no tests or screening tools. There is less than easy access to reliable information for women. Support services for patients, partners and carers are few and far between. Loneliness, embarrassment and stigma may hinder women from taking action. Rural and remote women are at a further disadvantage in accessing best practice treatment. In some states there is only limited public access to gynaecological oncologists. I am not going to keep saying gynaecological oncologists; I am going to say gynae-oncologists to spare myself.

We call for the following: the National Breast Cancer Centre to take on all gynae cancers. Australian women need a complete set of guidelines for the various gynae cancers, both for clinicians and for consumers, and for this to be managed by the National Breast Cancer Centre. The NBCC should provide comprehensive information about gynae cancers for the community, for the well worried and for those who have been diagnosed. GP education is to be more extensive regarding early detection and diagnosis. Referral pathways to gynae-oncology specialists should be the norm. Referral to support groups and psychosocial services should be part of the treatment plan. I am sure you have heard all of this several times already, but these things are really important.

We call for gynae-oncologists to work as leaders of multidisciplinary care teams and for dedicated research funding to focus on earlier detection and diagnosis. We call for a national plan for gynae cancer research, like the one done for breast cancer, to be developed and implemented and for collaboration among researchers into gynae cancer to be facilitated, possibly in a national research centre. Reform of the states' isolated patients travel and accommodation assistance schemes is very dear to our hearts. Ideally we would like to see this assistance return to the Commonwealth if we cannot get equity throughout the states.

We would like to see the establishment and promotion of recognised centres of excellence in treatment in both the public and private sectors and education about risk factors before women become sexually active. We would like gynae cancer consumer groups to be included in decision making and change making at local, regional, state and national levels. That is very important to us as well.

In discussion with some of our members who have had gynaecological cancer and who have advised us of their issues, one person raised the fact that in New South Wales we have a model which might be of interest to other states. We have four specialist gynae cancer networks which have been developed fairly recently, each of which has a couple of multidisciplinary specialist units and is linked to rural clinics. You have probably seen this good little booklet, the *Directory of gynaecological treatment and support services 2004*, which lists these clinics. This directory was inspired by a very detailed one published by women with breast cancer. It is good that it has inspired booklets about other cancers. We are hoping that we will get directories for all cancers, as recommended by the previous Senate inquiry. This one was compiled for women and GPs by a Cancer Voices NSW member, the Life Force Cancer Foundation, with departmental funding.

Cancer consumers know what is needed and can be change agents through their advocacy and support groups. Cancer Voices Australia has heard some incredibly moving stories from individual women about the pain and shame, broken relationships and broken dreams—not to mention early death—which have been caused by gynaecological cancers. The claim that gynae cancers are the most difficult to cope with as an individual, and often medically as well, is very believable.

We call on the Senate committee to recommend that the points I have mentioned be addressed and to suggest that the National Breast Cancer Centre be commissioned to be the change agent that Australian women affected by gynae cancers need.

CHAIR—Thank you, Ms Crossing, as always. Senator Humphries has a particular point about the little book, and then we will have other questions.

Senator HUMPHRIES—No, I think I have made my point about the little book before. I do not need to remake it.

CHAIR—Eden-Monaro is not in the little book, Ms Crossing.

Senator HUMPHRIES—Yes, it was just a small omission from the little book. It did not include the Eden-Monaro Cancer Support Group. I will use this opportunity to make a different point. I want to ask you about complementary approaches to cancer treatment. You said you looked at the previous Senate inquiry into this. You will note that we spent a lot of time looking at complementary medicine and its impact on cancer treatment. Does that present any issues for you as an organisation advocating for people who have experienced cancer?

Ms Crossing—Not at all. Cancer Voices Australia is quite a new organisation, but Cancer Voices NSW, which has been around for six years, attended the inquiry last year. We were also an integral part of the visit by Dr Barrie Cassileth, from the Memorial Sloan-Kettering Cancer Centre in the US. Together with the Cancer Council NSW, we hosted a whole day looking at complementary and alternative medicine and therapies—because some of it you take and some of it is done to you. As a result of that, Cancer Voices NSW developed a position paper, a copy of which I happen to have in my bag, about exactly what we think needs to be done in that area. I would be happy to speak about that more if you would like.

Senator HUMPHRIES—Just generally, do you feel that there is a need for any sort of major public policy shift in dealing with this area that we are dealing with today? Are there any particular issues around complementary medicine with respect to gynaecological cancer?

Ms Crossing—I cannot really answer that question, but I think all cancers face the same issue, which is access to reliable, authoritative information about complementary and alternative therapies and medicines. We are also calling for the credentialling of practitioners. We would like a lot more research money to be spent on doing proper, ridgy-didge studies on the efficacy. There have been quite a few studies done but, again, people do not have access to this information readily. We would also like the TGA, when it is approving therapies and medicines in this area, to be requested to use the same standards as it does for prescription and over-the-counter orthodox type medicine. At the moment, we have no idea what is really in those bottles. We may know the active ingredient, but we do not know how much is in there, and there are a whole lot of issues in that regard. Those things need to be looked at.

Mr Stubbs—I fully support what Sally says. In terms of complementary therapies or programs, there are a lot of art therapy and music therapy programs that exist in hospitals and support centres around Australia. I think the Brownes institute in WA is probably one of the best examples of that. The Cancer Council of New South Wales, in its latest round of clinical trials, has just issued money to a music therapist in one of the hospitals in Sydney to undertake a clinical trial on the benefits of music through the cancer pathway. It will be very interesting to see what that trial presents. The issue of complementary therapies will never go away. If you have cancer and something is perceived to be the silver bullet, people will go for it. People will hear from one person or one group or other that: ‘This is the best treatment for you.’ We certainly do support clinical evidence to support complementary therapies and we would look to have a lot more regulation in this area.

Senator ADAMS—Sally Crossing AM—well done! That is very well deserved and I was thrilled to bits to read about that.

Ms Crossing—Thank you.

Senator ADAMS—Firstly, let us turn to Cancer Australia. I have had a number of consumer groups lobbying me, including Cancer Voices in WA, and asking me all about this. How is the consumer voice going to be heard? In the opinion of your group, how do you think you are going to access the members of the advisory committee?

Ms Crossing—To be perfectly honest, we were quite disappointed that our suggestions were not heard right from the beginning. Cancer Australia has been in the pipeline for three years now. In the initial stages, we were involved in some consultation but that was just a one-off. We have made it quite clear that we would like to have representation on the board type body, the advisory council, but that has not happened. We have been advised that one or two of the members of the advisory council who have had cancer will be our conduit, specifically ex-senator Jocelyn Newman. We are making efforts to get in touch with her. That may work perfectly well, but it is not our preferred way of having our voice heard. Perhaps at the next layer down, at the executive layer, we may have more success, particularly if they follow the government's own principles for the appointment of consumer representatives which were endorsed last year. At the moment, it is in a holding pattern and we are still hopeful.

Mr Stubbs—We do have very good relations with the Cancer Strategies Group, which is part of the department of health. I understand that some of the people in that area will go to Cancer Australia. So we have certainly made linkages with the correct people. Of course, it is government policy that they will do things in a particular way, but we will just be there knocking on the door and hopefully it will be the front door. It is very important to engage consumers at all levels. When you get cancer, you do not lose the skills that you had before you got cancer. You might be a lawyer, an accountant or a publicist or you might run your own business, so you know what dollars and cents mean. You know the value of a good balance sheet. We can bring those skills to a lot of the committees and we are starting to bring those skills to a lot of the government's committees. We thank them for their involvement in that. We think that that is one thing that we can bring to Cancer Australia and to their various committees. So we would certainly seek to be a member of some of the Cancer Australia committees.

Ms Crossing—If I may add to that: sure, we can bring personal skills, but I think the most important thing that we can bring is the broad view of what people with cancer need. We go to quite a lot of trouble in our various state and national organisations to survey them and canvass them, to make sure we know what their needs and problems are. That is how I have ended up with a series of dot points about this particular cancer. So that is the most important thing we can bring to Cancer Australia.

Senator ADAMS—Let us go to one of your dot points about a patient assisted travel scheme and getting patients in and getting them out and about how they can actually have their treatment.

Ms Crossing—In New South Wales we have been very busy on this one. We did have a little win earlier this year. We managed to get it reduced from 200 kilometres each way—a 400-kilometre round-trip—which was the worst in Australia, despite the state being fairly closely settled on the coast. We have got a long way to go. There are other conditions that we find are quite ridiculous. You have to go to the newest treating specialist, not the most appropriate treating specialist. The slight increase in the petrol element was not much and they hardly changed the accommodation assistance. Anyway, that is New South Wales. All Australians need to have the same sort of access to best practice treatment and these schemes need to be reformed to enable that to happen. It sounds pretty simple but I know it is going to be very difficult to make it happen. You might be able to put some strong recommendations in your report that this be looked at. It has been brought up through 54 radiotherapy reports at a national level, and every time they say that these schemes need to be reviewed and reformed. They seem to have worked better in the days when they were Commonwealth schemes. That is why we suggest that their being returned to the Commonwealth should possibly be looked into.

Mr Stubbs—One of the main issues for cancer patients is certainly to do with borders. When New South Wales patients have to go to Queensland and when Victorian patients have to go to New South Wales and vice versa, there are different rules. There should be one rule for all so that it does not matter where you get cancer, as it comes under the same rule. I also do some work for a leukaemia foundation and I know that the patients say to each other, ‘I travelled 50 kilometres and I received a cheque for $50’ and ‘Oh, I only received a cheque for $30,’ so these anomalies are brought to the surface by the patients. Something needs to be done and I think that needs to be tackled at a national level.

Senator ADAMS—How are your patients getting on accommodation wise with being able to access services, especially coming for radiotherapy when they have to be in the city for a longer time?

Ms Crossing—Speaking only for New South Wales, there is a quite good system of accommodation hostels attached to the major treating hospitals in Sydney which have been funded largely by Cancer Council New South Wales, and of course CanAssist does a very good job here in Sydney with its Jean Colvin Hospital. But there are limited beds, so some people are scratching around trying to find cheap motels and hotels, which is not ideal, particularly when you are feeling at your lowest ebb, and of course you may need to have a carer with you.

Senator ADAMS—That is another thing. Some schemes allow carers; others do not.

Mr Stubbs—That is exactly right.

Senator ADAMS—For a person with cancer that is probably the biggest issue: that they must really have someone with them. But if they are not available or there is no reimbursement for a carer, that makes it very difficult. You have enough problems without having that on top of them.

Mr Stubbs—Yes.

Senator CROSSIN—I initially want to return to the issues you have raised about the lack of psychosocial support. We had a bit of a discussion about that when we met with the GMCT yesterday, about the structures that they have put in place. If you would like to, I would like you to expand on what you think needs to be done. Also, I would get you to comment on the evidence we got from the previous witnesses about the need for more research into psychosocial support and for perhaps a review of the way the NHMRC operate in that they do not necessarily see that as a priority or a valid area of research when looking at a cancer.

Ms Crossing—The first thing I would say, being very familiar with the work of the National Breast Cancer Centre, is that very well studied and supported guidelines for psychosocial care and support exist and have been published for beyond the breast cancer area, for all cancers. My personal view—John may have another view—is that we need to roll these out more into practice rather than spend more time on research.

Mr Stubbs—Very good guidelines were put down by the NBCC/NCCI over two years ago and that is very important. The guidelines have been laid down, but there has been no implementation. These things cost money and money is always the issue. It is very important, especially for the partners and carers of people who have cancer. They seem to be a bit like a lost generation, if I may use that phrase. When a patient has cancer, he or she is in the system, so you have an umbilical cord which holds you to the hospital or to your clinician, whereas your partner or carer is left very much on their own. Quite often they have the family to care for and the business to run, and there is no support for that. So, in terms of psychosocial support guidelines for carers, there is a real void. Some amount of research has been done on that, but it has been fractured. Something definitive needs to be put together.

Ms Crossing—I think the New South Wales Cancer Council has a project at the moment looking at the needs of carers. Kendra Sundquist, who was here, could have given you more information about that than we probably could. We could take it on notice and come back to you.

Senator WEBBER—With your knowledge of the existing guidelines, and particularly when looking at gynaecological cancer, do you feel that they adequately address the specific needs regarding Indigenous and other cultural issues? You may want to take that on notice. We got a lot of evidence yesterday, particularly from the GMCT, about some of the cultural issues that they deal with at Westmead with some women and what it is permissible to discuss.

Ms Crossing—And regarding people from the culturally and linguistically diverse sector as well.

Senator WEBBER—Yes—the psychosocial support that their families would need.

Mr Stubbs—We could certainly take that on notice and get back to you.

Senator WEBBER—Just if you are aware. I do not want to create too much homework. You were talking about the NBCC. I have said to others that I have been aware of the NBCC, but it was not until we started this inquiry that I learnt that they deal with cancers other than breast cancer. I was aware of the important role that they play with breast cancer. Therefore, if they expand their role—and they have started to expand into the area of ovarian cancer—to all gynaecological cancers, should they change their name?

Ms Crossing—Yes.

Mr Stubbs—Branding is very important. There are lots of organisations that are changing their names to encapsulate the various types of cancers that fall under a banner—for example, blood cancers. The Leukaemia Foundation is an example, because lymphoma, myeloma and other blood cancers do not fit under the name ‘leukaemia’ but they are blood cancers. Branding and positioning an organisation to help support people is very important.

Ms Crossing—Perhaps it could be called the National Women’s Cancer Centre—it has the same number of words.

Senator WEBBER—We were having a bit of a discussion about something along those lines, if that is the path that people choose to go down.

Senator CAROL BROWN—I would like to go back to psychosocial care. Is it provided to spouses or carers, one-on-one, face-to-face, in New South Wales? Is there a system whereby you can call people? We have had a discussion about the possibility of this information being available through the internet or e-medicine. I just want to know your view on that.

Ms Crossing—These services exist but they are patchy. In different areas they are better and worse. The real problem is: how do you find out that they exist? We would like your GP in the first instance—and for this to be reinforced by your specialist—to say, ‘These are the psychosocial and other support services in your area.’ Maybe there can be a piece of paper that they can hand out at the time of consultation. The Cancer Council has its helpline, which is extremely good. A number of the cancer centres have counsellors and social workers and so on, but making contact with these people is the big challenge.

Senator CAROL BROWN—With your knowledge and experience of people who have accessed these services, how would you view an internet service, as opposed to a telephone service?

Ms Crossing—It would have to be as well as.

Mr Stubbs—I think you have to have it all. You have to have written, you have to have telephone and you have to have access to the internet. As Sally was saying, the important thing is to get that information and to get it in a timely manner. Whether or not it goes to you or to your partner at the time of diagnosis does not matter, but it is important to get that information to somebody.

Senator FERRIS—One of the issues that has concerned me is that women generally seem to be poorly informed about gynaecological cancer until they are touched by it in one way or another, either personally or through a member of their extended family. Do you think that gynaecological cancers are less well understood than other women’s cancers—for example, breast cancer? Do you have any thoughts on what could be done to change that?

Ms Crossing—I absolutely agree: they are much less well understood. I made the point in my opening address that a lot of women are not really very aware of their own bodies. They are certainly not aware of what to watch out for. I am not. I do not know whether any of us women here are. It is an enormous problem.

Senator FERRIS—What is the answer?

Ms Crossing—Having a successful organisation like the NBCC putting out public health messages. They were very successful in their message to women to watch out for changes in breasts, which is really the only thing you can do, apart from having regular mammography, to detect breast cancer. A lot of breast cancer is self-detected. They did that well. The message is out there. I think women are very much more aware of watching for changes. It is not nearly as easy with gynaecological cancers, but that is the sort of program I believe we need to invest in.

Senator FERRIS—I assume that members of your organisation are women who have gynaecological cancers.

Ms Crossing—Yes.

Senator FERRIS—What do they say to you about the current public debate about women’s cancer?

Ms Crossing—They are concerned that nobody wants to look at it. They are delighted that you are looking at it. For too long it has been something that people would rather not know anything about. They are concerned that their GPs often do not treat them very seriously. It is something you cannot really talk about. It has only been in the last 10 or 15 years that we have been able to talk about breast cancer freely. From talking to women, and I did talk to a number before coming to see you—in fact, we had hoped to bring some with us—I found that they have not got to that stage. They are still living in the embarrassment, stigma stage and really do not know where to turn. That is why we need to have a central, visible, single organisation. We have for breast cancer. Let us expand it and have it to cover all women's cancers. If it is called something like the national women's cancer centre you do not feel any awkwardness about approaching it, because the word 'breast' is not there, the word 'gynaecological' is not there and the word 'vulva' or any other words to describe the female anatomy are not there. That would be a good idea.

Senator FERRIS—If that were to be a model, how would you see that working under the Cancer Australia umbrella?

Ms Crossing—None of us know how the Cancer Australia umbrella is going to work. We have all got ideas on how we would like to see it work.

Mr Stubbs—It has got to be about information and getting that information out. I will add something personal: my mother died a number of years ago of breast cancer. I think she knew she had breast cancer but did not accept it, because women—I hope this is not considered to be a sexist remark—are carers. They look after everybody else first and then all of a sudden realise: 'Goodness me! I'm also sick. Are you okay? Now, I've got to go and get fixed up.' I think there needs to be a very high-profile awareness program that says it is not wrong to talk about these things and to get partners involved too. I think it is time for men to step up, be part of the scene, assist in any way they can and be part of the public face of getting women to make sure that they have the appropriate checks and not be afraid to do it.

Senator FERRIS—I am trying to understand how you would see the structure working. Would you see a renamed NBCC as standing aside from the Cancer Australia umbrella or would you see it as being one of maybe a number of related cancer specialty groups—I suppose, if we use that name—working under the umbrella of Cancer Australia? Does your organisation have a view about that?

Ms Crossing—I cannot say whether the organisation has a view. We did consider it in the beginning when we were looking at how Cancer Australia might work. We rather liked the model that it would be a National Breast Cancer Centre type organisation which included all cancers. But it obviously is not going to be that; they are setting up Cancer Australia as a separate body. Because we have had this difficulty in being part of its development, I cannot actually tell you what it thinks it is going to do, which is a shame, considering we are the national level cancer consumer organisation.

Senator FERRIS—That was something I was going to ask you: could you give us a little potted history of why you decided to go from being what appears to have been a New South Wales organisation to being a national organisation and how you went about establishing that? How are you funded, for example?

Ms Crossing—I will talk about that because I think I probably should.

Mr Stubbs—I will give a brief summary. We are currently funded through Cancer Council Australia, who have given us some seed funding to establish a secretariat. There is a steering committee comprising members of Cancer Voices in each state. They provide input to the secretariat, and we operate in that way. We have within our constitution, which we are just developing, the ability to bring in expert support groups or advisory groups who will advise us on specific cancers.

Senator FERRIS—Did you see a niche in the market in each state—an empty niche, I suppose—that led you to believe that this advocacy group that you had in New South Wales could go national? Is that how it happened?

Mr Stubbs—Yes.

Ms Crossing—Let me give a little history: the breast cancer movement got it all going. I was very closely involved with the Breast Cancer Action Group. I chair the one in New South Wales. There is one in Victoria, and we also have a national group, BCNA—Breast Cancer Network Australia. Other states have various things. There came a time when we realised that it was all very well advocating for breast cancer issues but so many of those issues are shared across the board with all the cancers that you would be doing more good to more people if you took a more generic approach. So that was the thinking behind starting off Cancer Voices NSW, which was in October 2000.

We basically pulled in people we knew—breast cancer people, prostate cancer people—who had already become involved and interested in advocacy in this area. Time went on and we began to think: ‘Gosh, this is working well in this state. How about we approach the other states?’ We started to do that about 18 months ago. Then, because it is quite difficult if you do not already have a track record in specific cancers, we (a) offered to help and advise them and (b) encouraged their local, state and territory cancer councils to assist them by making rooms available, helping them pull together public meetings and so on. That was the next step. Then the logical next step seemed to be to have a peak national Cancer Voices Australia group. As John said, it is federated.

Senator FERRIS—Can you give me some idea of the number of members?

Ms Crossing—There are eight.

Mr Stubbs—There are eight Cancer Voices groups that we classify as members.

Senator FERRIS—But what would you say you represent in terms of membership?

Mr Stubbs—Probably 4,500 to 5,000 people. That is through the support group networks in each state.

Senator FERRIS—Would you think that membership would make you the largest advocating agency?

Mr Stubbs—Probably not.

Ms Crossing—No, the BCNA—

Mr Stubbs—Breast cancer and prostate cancer groups have become very active over the last few years.

Ms Crossing—But we have only just got going.

Senator FERRIS—Yes, I understand that. That is why I asked you the question.

Mr Stubbs—But we do have linkages with those groups, and it is very important to have those. The state groups find that there are the same issues in the states, so it is good to bring those to a national level. You do need both organisations operating because of our federation—that is, because of the national and the state systems.

Senator FERRIS—The reason I am asking the questions is that there do seem to be a plethora of various agencies or organisations. I am trying to, I suppose, work my way through the efficiency and effectiveness of these agencies to ensure that the scarce dollars that are available to fund all of these agencies are being spent in the most effective way. I am not suggesting for a moment that yours is not, but I am trying to better understand why various agencies exist, why they go national, what they do and how they all will fit into the peak agency that the government is trying to establish.

Ms Crossing—Most of the consumer groups are not funded at all; they are entirely voluntary. My Cancer Voices NSW people make donations to us. We have asked some of our stakeholders, like the Cancer Institute NSW, to give us money but we do not actually need a lot of money to be very effective. It is different for a national organisation, because there you are trying to relate to people who are very far-flung, so you really need to have a secretariat. John, for instance, is our part-time executive officer at the national level. But there are other organisations which do pull in a lot of money. They are not government funded in the cancer area, because government will not fund advocacy organisations.

Senator FERRIS—I am familiar with that.

Ms Crossing—So they are funded by the community.

Senator FERRIS—It strikes me that Cancer Voices Australia is a very good, broad advocacy name.

Ms Crossing—We like it.

Senator FERRIS—I hope in the future to see you expand to represent a wide range of cancers so that your voice is loud and clear and your messages are strong, rather than to see all of the individual groups grow like Topsy. They have a very important axe to grind, and I am not suggesting for a moment that they do not have that.

Ms Crossing—It is like a number of pyramids, really. In the state of New South Wales, there are two advocacy groups but a number of support groups that also commit a bit of advocacy from time to time. The idea is that they funnel themselves up to Cancer Voices NSW and then

Cancer Voices NSW channels up to Cancer Voices Australia. That way we can take in the views and needs of a very wide group. We do not control them, but they send up their issues to us to take forward at the national level.

Mr Stubbs—Support groups form for any number of reasons. It may be because one person is incredibly upset at the loss of a loved one and so will set about forming and developing a support group. What we ask to be is the conduit for them to raise their voice at the national level. As I said before, there are so many things that go on in particular states but there are common themes, so we want to pull those common themes out and raise them to the highest level.

Senator FERRIS—How do you publicise yourselves?

Mr Stubbs—We have many delegates on committees and we are represented on a number of committees through the Cancer Councils and the Cancer Institute in New South Wales on federal government bodies. We are in the process of developing a website and issuing publications and issue statements on cancer and there will be a newsletter produced. They seem to be the most effective ways.

Senator FERRIS—Do you have a presence or any sort of material in hospitals?

Mr Stubbs—Not as yet. That will be handled by the Cancer Voices at the state level because delivery of services is provided by the states, so we would see them as the logical people to do that.

Ms Crossing—I might just say that the last time I was in this room was when Cancer Voices NSW had an event to launch a charter of cancer consumer values, which has been widely distributed and is a sort of thing that Cancer Voices Australia may well pick up. I might give you that too.

Senator FERRIS—It would be good if you could table that; thank you.

Senator ALLISON—I want to pick up on the first recommendation that you made. Thank you for giving us all the recommendations, by the way; it is useful for the committee. The first recommendation was about addressing the poor level of education in reproductive ‘anatomy’, I think was the word you used. Do you have some further insights? In what way would you like to see a greater level of education?

Ms Crossing—The women with gynaecological cancer I spoke to before coming here suggested that it should be at the school stage, before girls become sexually active. We cannot broadly say that gynaecological cancer is caused by sexual activity, because much of it is not, but that is the level where information and education for young women should begin.

Senator ALLISON—Some would say that sex education, which this usually comes under, has been too much about the plumbing and not enough about education in a whole range of other sexual and relationships issues. Would you agree with that? Has the plumbing approach failed women so far?

Ms Crossing—It is an interesting question. My personal feeling is that obviously you have got to have a balance of both. But it may well be the case. I do not actually know what girls at school are being told at the moment. I have two daughters but they are in their early 30s so, unfortunately, I cannot check.

Mr Stubbs—I have a 17-year-old who is doing his HSC and he said they talk about everything at school with girls—it is a co-ed school.

Senator ALLISON—So he says it is satisfactory?

Mr Stubbs—He thinks it is very good.

CHAIR—He understands the plumbing?

Mr Stubbs—He understands the plumbing issues.

Senator WEBBER—It is very important.

Mr Stubbs—It is. I think the fact that they talk about these things is very important. They will talk, quite openly, about so-and-so having her period; it is not a taboo issue, as it was in our day.

Senator ALLISON—You made a point several times of saying that the male partners of women with gynaecological cancer need to be involved. What has been your experience with those male partners? Is it lack of knowledge? Also, I really liked what Ms Crossing said about the pain, shame and broken relationships. Can we avoid some of that pain, shame and broken relationships by working with men and, if so, what ideas do you have for doing that?

Mr Stubbs—I think we can. I think men probably need to take it up a notch—maybe I am a bit more metrosexual or something like that. I have a very good relationship with my partner. We are very open about all of these things. With men's illnesses there was probably a taboo. It is this mateship thing. I think that in some areas it has to be broken down. It has to be done through education programs. Men need to be told to be supportive and to be involved in the process. I know that for a lot of people with work et cetera they cannot be part of the whole process. My wife attended every time I went to the doctor so she knew exactly where she stood with my disease. Maybe that is something that clinicians or the government could think about, that it is very important to have your partner with you at the time of your consultation. There are lots of things that are said and, depending on your state of anxiety at the time, they can either slip under the table or over your head. It would help if you had somebody there who could take notes or be part of the process. I think this needs to be encouraged. If that is seen as part of the process, that could be a step in getting men to be more involved.

Senator ALLISON—Is lack of encouragement the only barrier or is this seen by some doctors as a weird thing to do?

Mr Stubbs—It may be seen as a weird thing. I never felt like that with my doctor during my treatment. I think it is about establishing a relationship with the doctor and maybe the partner being encouraged to come and see the doctor, perhaps separately. They can say, 'Look, I have these concerns.' I know that is a very narrow scope for a very broad idea, but I do think it is important to involve the partner. If you are part of the process your understanding grows and, therefore, you can be of great support and assistance to your partner and know what to expect. And, if it does not happen, that is a plus; if it does happen, you are there to be that support person.

Senator CAROL BROWN—Ms Crossing, in your opening statement you talked about the need for more extensive GP education, particularly for early detection. Has your organisation discussed this and discussed what they would like to see happen in this area?

Ms Crossing—That comment was based on my discussions with our members who have gynaecological cancers. They said it is a major problem. It is a difficult one because apparently a GP only diagnoses one gynaecological cancer every couple of years. It is a bit of a no-brainer. GPs need to be very much more aware of cancers in general because many cancers do not show very obvious symptoms. It would be preferable for them to be caught before they show symptoms, but that is pretty difficult. I cannot really say it is an organisational thing. I think it is obvious that it is—

Senator CAROL BROWN—You would be supportive of more continuing professional development in this area.

Ms Crossing—Yes.

Senator CAROL BROWN—We have had quite a bit of evidence about the problem of early detection.

Ms Crossing—We would be very supportive. I think perhaps in undergraduate medical education the cancer oncology curriculum needs to be expanded a bit and baby doctors need to be given a little bit more help on how to detect cancers earlier.

Mr Stubbs—I think in general the college of GPs are asking for things like more training too. But, of course, there is pressure on them and so it is just a part of the system.

CHAIR—Is there anything else you would like to add on record today? Of course, you can give us evidence at any time. Ms Crossing, you referred to a physician paper earlier in your evidence.

Ms Crossing—Yes.

CHAIR—Would you be able to provide that paper for us? That would be very useful.

Ms Crossing—Yes, I can.

CHAIR—Thank you very much for your time, as always.

[12.15 pm]

GOWER, Mr John, Chief Executive, Gynaecological Cancer Society

CHAIR—Welcome. Mr Gower, you have been in these things before so you understand the process. You have the information on parliamentary privilege and the protection of witnesses. I know you have an opening statement, so would you like to share that with us and then we will get into questions and answers. And we have your submission, of course.

Mr Gower—Essentially, we looked at the six elements of the question and we thought that four of those elements we could comment on because of the nature of our membership, so we did that. We thought we could comment in detail on two aspects because of the society's very real activity in those areas. Would you prefer that we go through and look at those? Is that the way you would like to do it?

CHAIR—Yes, that would be fine—what you want us to know from the work you have done.

Mr Gower—The first item, a, looked at funding for research. Obviously some of our members are research scientists, and it is our view that we have some wonderful and very, very talented researchers in this country. We do not export all of them; some of them stay. We have a problem with the fact that there is a lot of duplication of gynaecological cancer research, and that duplication is sponsored by the privacy clauses that usually accompany funding. We believe there ought to be more funding for gynaecological cancer, but we would like it to be done on a federal basis, where it is mandatory that there is full disclosure—in English, we want each of the excellent units doing their own thing, not duplicating. We think that can be done if we can do away with nondisclosure and privacy agreements. The only way we can do that is if the federal government funds it and so it becomes an issue that you have to talk to each other.

Not a lot of money—admittedly I am talking about tens of millions of dollars, but in the overall scheme of things it is not a lot of money—could probably produce and would probably produce some outstanding advances, particularly in detection. You have probably heard from scientists that detection, particularly of ovarian cancer, is not all that far away. All we really need to do is throw money at it. I think we should, but I think we need to have specific groups looking at specific things.

With regard to the capability of the existing health scheme, we believe we have some terrific gynae-oncologists and clinicians. They are not spread throughout Australia as nicely and conveniently as we would like. There are too many in Sydney and Melbourne, although patients in Sydney and Melbourne would probably not agree with that.

CHAIR—And you are located where?

Mr Gower—Did I say Brisbane?

CHAIR—No, you did not. I just wanted to get that on record.

Mr Gower—The reality is that we have absolutely top-class clinicians. We are not going to be able to avoid bringing patients to treatment centres. There is no way around that. The right way to treat gynae cancer is the multidisciplinary approach, and the only way you can effectively do that is to have very specific treatment centres. That means bringing the patients in.

The patient transport system is appalling throughout the country, but that is a state based issue. That is service provision and, effectively, we need to fight that state by state, unless you take it back nationally. As it stands at the moment, we have to fight that on a state-by-state basis. We have an appalling situation in our state where, if you have to come to treatment, you usually are not allowed to bring a carer and you are paid the magnificent sum of $30 a day. Thirty dollars a day basically rents you a park bench, and not much more. Effectively what happens is that organisations like ours pay the difference. That is okay; maybe that is what we are here for, but I would rather somebody else paid. We think that the clinical side is superb. You cannot diversify. Let us fix the patient transport system if we can.

We sent a team to Thursday Island some years ago to look at the problem of why, particularly with our Indigenous communities, cervical testing rates were appalling. They are down to nine per cent. The reality is that it is cultural, and you have heard all this before, I am sure. We just want to reinforce that. We need to look seriously at breaking down the taboos in the various cultural areas, if we are going to see particularly cervical screening increase; but that is going to hold true for any of the gynaecological cancers. It is true that women can be beaten if they even discuss their gynaecological problems with anybody else, let alone a doctor. They do not turn up for treatment, because that is the end of the earth. Appointments are made but they do not turn up, so it is not so much that the clinical infrastructure is not there; we just have to make sure that it is more appropriate to the various cultural needs.

Regarding the extent to which the community and doctors need to be educated, we can deal very quickly with GPs. It is true that the problem area is diagnosis at GP level. One of the previous speakers said that the average GP will see one gynaecological cancer patient a year. That is not far wrong; our suggestion might be that it is two. The other significant drawback is that all of the gynaecological cancers could be 50 other things. Couple that with the fact that women historically consider themselves last—are the kids okay? Is my partner okay? Is my mother okay? Is the extended family okay? If all those answers are yes then they think about looking after themselves. We have to change that if we can. The GPs have a hell of a job to do and they are not used to seeing gynaecological cancer, which can be 50 other things. We advocate, as you know from our submission, a national public awareness campaign. That will take the GPs with it. It will make gynaecological cancer front of mind. That is the only problem. They know their stuff; they know the symptoms; it is just not front of mind.

CHAIR—What do you want from the committee, Mr Gower?

Mr Gower—It is probably what everybody else wants; I want heaps of money. Effectively, if you add up our sums, you will find that we are looking for $22 million. We think that we need to spend $18 million on a national public awareness campaign over five years that will take in TV, radio talkback and magazines. We had it costed, because I figured it would be worth while sitting in front of you and telling you how much we thought was really needed. As near as we can find out, that money equates to the breast cancer campaign, which we think has been absolutely brilliant, so we want you to spend $18 million over five years doing a national awareness campaign. We think it needs to be very well done; otherwise, we are going to convince six million Australians women that they all have gynaecological cancer. So it needs to be very carefully done. But we can do it; there are some very bright people out there. That is the first thing.

The second thing is that we want you to expand our own emotional support helpline, which the Cancer Council modelled theirs on—I had to get that in—and that is costed in there, as well, over a five-year period. The last thing we want you to do is to fund the rollout of our information education program, which comprises 33 pieces of literature that we produce in house specifically on gynae cancer—and I sent you all a box full. As part of that emotional support campaign, we want to roll out our supporting partners program—and we sent you information on all that as well.

Senator ADAMS—I think my Patient Assisted Travel Scheme questions are being answered pretty well. I have been very involved with BreastScreen WA and the Breast Cancer Network Australia. You are talking about where to put your notices and about using TV and radio. One of our most effective ones—and this is not funny but everyone laughs at it—was on the back of community toilet doors. We had a very good ad—I was one of the faces. We had 11 women and then a question mark—are you the next one? A number of people have come to me and said, ‘I was out at Woop Woop; I was here; I was there; guess who I saw on the back of the toilet door?’ They said that it was a really smart way to advertise something, so I just give you that hint for whatever you are looking at doing. It is simple, but women are there and they look at the door so you have their captive imagination for probably three or four minutes.

Mr Gower—You are preaching to the converted. When my daughters were going through school they were not taught their times tables so I put them on the back of the toilet door and it worked fine.

Senator ADAMS—So they did well.

Mr Gower—I am not talking just about television—it is such a powerful medium that you cannot leave it out—but there were in fact seven communication streams that we had the consultant look at. I would do anything to get the message across.

Senator ADAMS—That was just a simple little one.

Senator ALLISON—Can you give the committee some examples of the duplication you referred to in the research effort?

Mr Gower—There are some excellent centres, as you well know, in Australia, and almost all those centres are looking at ovarian cancer. That is fine, except that one of those centres will one day come up with a eureka moment, and all the money being spent by the other centres will in fact be lost. If there is any duplication it really should not be tolerated, because there are just not the funds.

Senator ALLISON—But is there—that is my question?

Mr Gower—Is there duplication?

Senator ALLISON—Yes.

Mr Gower—We certainly think so, yes.

Senator ALLISON—Can you expand on that somewhat. I will tell you why I am asking this question. It is commonly said that a lot of people are doing things and therefore there is duplication and we do not need to add more money to the system of research. I am trying to test that, because it would appear to me that, unless we can put some detail to this, that may or may not be the case.

Mr Gower—I am really going by what our own researchers are telling me. I suspect that we need to ask each of the research establishments what they are working on. I believe that you will find that they are all working on the same sort of thing. That is the sort of duplication that I would like to do away with.

Senator ALLISON—They may all be working on the same thing—that is, looking for a screening tool for ovarian cancer—but surely it does not mean they are all doing the same thing in terms of the way in which they are going about that?

Mr Gower—I agree with you. I think what we have said here is that we want open communication.

Senator ALLISON—Don't we have that with ANZGOG? Isn't that the whole point of that organisation?

Mr Gower—I do not believe we do.

Senator ALLISON—Can you tell us why?

Mr Gower—A lot of the medical research is privately funded, as you know. The clauses in that private funding prohibit the researchers talking to one another about what they are doing.

Senator ALLISON—You are referring to pharmacological research?

Mr Gower—Essentially. That is what we are trying to overcome. We can understand why that is being done for perfectly good commercial reasons. But that system promotes potential duplication and we would like to try to overcome that, if we can.

Senator ALLISON—If that research is being privately funded for the purposes of pharmaceutical companies that is one thing, but what about non private sector research? I thought that was what you were referring to initially. Do we really care that the pharmaceutical companies are duplicating their effort? Shouldn't the emphasis of the research that is publicly funded be on screening procedures per se, not just on pharmaceutical products?

Mr Gower—The point that we are making is that any duplication of funding, whether it is private or public, cannot be afforded. There are so many things that we need to look at that we ought to spend the money more wisely than we are. That is our view.

Senator ALLISON—So how do you go to pharmaceutical companies and say: ‘We don’t think you should spend money on competing with another pharmaceutical company for the same pill. Why don’t you spend it on some more effective screening technique?’

Mr Gower—We were not planning on doing that, because we cannot. Our comment was that, if we are going to come up with new tens of millions of dollars in research funding, we need to ensure that there is complete and open disclosure when those funds are distributed. That is the point we are making.

Senator ALLISON—What funds are distributed?

Mr Gower—If the government comes up with tens of millions of dollars of extra research funding then what we are asking you to do is to ensure when those funds are distributed that they are distributed under an open policy whereby there is full disclosure. That is what we are asking for. I am sure you can do that.

Senator ALLISON—Can you give the committee instances where this publicly funded research does not fit with what you are saying should happen—that is, open disclosure?

Mr Gower—No. I was essentially talking about private funding earlier.

Senator ALLISON—I think we are talking at cross-purposes. I am not sure where it is going.

Senator WEBBER—If the committee is to consider—and at the moment I personally think it should—the establishment of an NBCC kind of model, in establishing an organisation like that how important would it therefore be, in your view, for them to have linkages with the research that is going on? I am a bit concerned that it is all compartmentalised rather than an overall—

Mr Gower—Rather than establishing a central bureaucracy, we favour, if you like, a committee that draws together various elements in each state. Existing units in each state do very well. The problem is that there is nothing to draw them together. The ground rules are different with respect to statistical raising in each state, so it is very difficult to compare what is going on. We are not in favour of setting up a new bureaucracy; we are in favour of coordinating existing units into a cohesive force.

Senator WEBBER—Picking up on that and some of the points that Senator Allison was trying to draw out, when the committee heard from the researchers yesterday they highlighted the need for greater collaboration.

Mr Gower—Excellent.

Senator WEBBER—Most of the research they were talking about yesterday was privately funded or funded by America. They access government research as well. We discussed yesterday whether the public awareness campaign you were talking about was needed. I had to admit yesterday that I did not know the current awareness week existed.

CHAIR—You are going to find it this week.

Senator WEBBER—I am sure I will be found from here on in. Perhaps that is enough, or perhaps we should look at embedding that. Can I get your views on the need for the public awareness campaign.

Mr Gower—There is not enough public awareness. Using our own resources, it will take us 15 years to improve that. Tomorrow you hear from OvCaAustralia. It is a wonderful organisation. They advertise in different states and territories around the country. I always know when they are advertising because our emergency helpline rings off the hook. So there is not enough information about gynaecological cancer. There is some information about cervical and there is some about ovarian—there are another four sorts. The real problem is that women do not present early enough. You have been hearing that for days, and you are going to hear that until the cows come home. That is because they say: ‘I’ve got a low backache. It is nothing—I picked up the grandkids.’ ‘My tummy is bloated. I shouldn’t have had that last biscuit.’ There are a hundred thousand reasons why. We need to, in a cohesive way, tell women what to look out for and we need to do it in a proper fashion so that it is repeated until the story is driven home.

Senator WEBBER—Perhaps within that education campaign—to use some of Senator Ferris’s examples—we need to make them not just better informed but a bit more assertive as consumers of the health services they will then feel they need.

Mr Gower—I think so. There is a lot of evidence where women have presented with symptoms and in truth the only reason that a final diagnosis of gynae cancer was made was because the patient sat there and said: ‘That’s not good enough. I don’t have a cold.’ So effectively we need to educate the patient, and at that same time we will, by osmosis, re-educate the GPs. It will become front of mind. That is certainly true. There are a lot of women alive today who would not be if they had not been assertive about their symptoms.

Senator WEBBER—In looking at not just the role of public education but the support structures and access to information and advice women and their families need, would a specialist service like a gynaecological cancer centre or what have you be a better way of going than, say, just having a generalist women’s cancer centre—

Mr Gower—That is our view.

Senator WEBBER—or tacking the other women’s cancers on to what is already a flourishing and well-known organisation—the Breast Cancer Centre?

Mr Gower—One of the points we made early in our submission was that in Australia we have chosen, for reasons that none of us are very sure about, to treat gynaecological cancer and breast cancer as separate issues. That is the reality. It has had distinct advantages for us and it has had some disadvantages for us. The genie is out of the bottle and I do not think it is rational to try to put it back in. You have developed two streams. I suspect that you need to continue with two streams. Our view is that you need a dedicated organisation, but it does not have to be in a single spot; it just needs to be a coordinating body.

Senator FERRIS—Talk about music for my ears! I do not understand why both the department of health in their evidence to us and the NBCC in their evidence to us yesterday said they did not believe we needed a national information campaign on gynaecological cancers. So I am fascinated that you have not only come to the view that there should be one but you have actually done something about costing it. That seems to me to be a very sensible idea. A number of women have phoned me after I have had articles written about my own experience where I was, shall we say, assertive with my doctor. They have done the same and found that they have had a gynaecological cancer, and they believe that saved their lives. So I want to reinforce what you have said and say that you are certainly very well informed about that. I just wonder if you have any idea why these two extremely effective, efficient and well-informed bodies would be opposing that position?

Mr Gower—I truly cannot imagine. It seems to us to be self-evident that this is required, so I cannot imagine why they would not agree that a national campaign is necessary. There could be 50 arguments from Sunday as to how it should be done or how much should be spent on it, but the fact that we need it is self-evident.

Senator FERRIS—As it was with breast cancer.

Mr Gower—I suspect so. Breast cancer was done so well. If we could emulate that we would be very well pleased, thank you very much. There are some differences, but essentially it is breaking down stereotypes. In this particular case, we really have to appeal directly to women. My only fear with a national campaign is that it has to be done sympathetically so that we do not have all of our GPs and our treatment centres totally overwhelmed by six million women who are sure they have one of the six gynaecological cancers, but that can be done.

Senator FERRIS—In material that the NBCC sent out—or was at the Breast Cancer Network?—to GPs it said that 50 per cent of women who are subsequently diagnosed with ovarian cancer reported a chronic fatigue symptom, an unusual form of tiredness. There are a number of other symptoms which are high in terms of percentage in the overall number of diagnoses. So it would probably be possible to get that down to four symptoms which are high on the ultimate diagnostic list.

Mr Gower—Absolutely.

Senator FERRIS—It intrigues me why these agencies would take the view that they did—but anyway. I want to ask you another question that relates to the divergence in opinion again about whether we should expand the operation of what is a very good organisation—the NBCC—into a women’s cancer organisation or whether we should set up a separate gynaecological cancer organisation using the same modalities, if you like, and move across the ovarian work and then expand it into all these other things that you and other witnesses have outlined. Can you tell me philosophically why your organisation came to the view that it has about having a separate organisation? You touched on it before. Can you expand on it a bit?

Mr Gower—I suspect that it is efficiency and perhaps a little single-minded purpose. If you look at the reason the NBCC does good ovarian work, it is essentially because there was nobody else who could control it and coordinate it. They have done a very good job. I suspect that if you can get a single organisation that has one purpose, gynaecological cancer—and remember, in Australia we differentiate; they do not anywhere else, but we do here—a unit that is looking specifically at gynaecological cancer, inherently that ought to be better. It would be smaller and it ought to be able to react faster. As far as we are concerned, that is good.

Senator FERRIS—One of my concerns is that if the breast cancer organisation as it is currently structured was to lose the words ‘breast cancer’ from its title it may well find that people with breast cancer would not know where to go, and they might finish up not going there when that would be a very good place to go, whereas women with a gynaecological cancer would not know to go to the Breast Cancer Centre unless somebody told them.

Mr Gower—True.

Senator FERRIS—And so, fundamentally, you reach the conclusion that a good organisation should continue its good work and another good organisation should be established with the elements of the first one. I just wonder if that is the rationale that you used.

Mr Gower—It is, and I wish I had written that, because essentially that is exactly it. Anything that would diminish the work of the Breast Cancer Council is an absolute no-no.

Senator FERRIS—Correct.

Mr Gower—And I think that is better served by an organisation that is singularly dedicated to that fact.

Senator FERRIS—The last thing that this committee would want to do is to in any way diminish the excellent work of the NBCC—

Mr Gower—Absolutely.

Senator FERRIS—because it has undoubtedly achieved an enormous amount in the 11 or so years that it has been established.

Mr Gower—I believe so.

Senator ADAMS—I have one more question. I was just looking at some of your notes here about the resources. Lymphoedema is a problem for some people after gynaecological cancers. Do you get many queries about it?

Mr Gower—Yes.

Senator ADAMS—You do?

Mr Gower—I am just trying to think of a percentage. It would probably be 10 per cent of the work that we do. We work fairly closely with the Lymphoedema Association in Queensland. It is not a common side-effect of the surgery but it is not a nice one.

Senator ADAMS—That’s right. So you have got support services with the Lymphoedema Association in Queensland to deal with that?

Mr Gower—Absolutely.

Senator ADAMS—Are physios available to deal with the issue, or not?

Mr Gower—Physios are a bit of a problem in that there are a lot of physios in the private sector who will not do lymphoedema massage. And the reason for that is very simple: it takes too long and they cannot charge for it.

Senator ADAMS—Yes.

Mr Gower—There are some very good public hospital based units and they tend to be overworked. For some time now we have been supporting the training of partners in how to do lymphatic massage so that hopefully we can cut down the number of absolutely essential visits to the physio. And that program works well.

Senator FERRIS—Presumably that is the sort of thing that could come out of a gynaecological cancer centre, since it is applicable to a number of cancers.

Mr Gower—Yes, it is. In fact, it is on our to-do list to try to have the amount of money that private physios get increased to encourage them to do the work, because we do know how overworked the public system is.

Senator CAROL BROWN—I was wondering about your view on the national awareness campaign. I heard what you said about GPs in your opening statement but I just wonder whether, in any national awareness campaign, GPs should be involved so that, to use your words, it takes it from the back of their minds to the front of their minds. I wonder what your view is about that.

Mr Gower—I think in one way we a lucky. There is going to be a fairly extensive advertising campaign for GPs and gynaecologists with the advent of the new guidelines on the treatment for cervical cancer—and that has nothing to do with this; that was going to happen anyway. So that is going to bring it further into their mind’s eye. I think that GPs will be taken along with the national campaign. It is very hard to target GPs; they receive so much in the mail every day.

Senator CAROL BROWN—That is why I was looking at something a bit different from just sending something in the mail to them and having them involved.

Mr Gower—One of the things we have asked the NHMRC to do—and they are going to be responsible for rolling out the new cervical cancer guidelines—is to allow the society to be part of their talks to GPs and gynaecologists so that we can reinforce the issues of gynae-cancer generally. We hope that that will help as well. We do also supply them with all of our literature, at least in Queensland. That does help.

Senator WEBBER—I would like to ask about the psychosocial support that women and their families need. We spoke with some people about the supports that they put in place. Do we know enough about the support that people need, particularly given the cultural differences and what have you, or do we need to do a bit more research? Are the current guidelines good enough or do we need to do a bit more research to make sure we have got the support in place for these people?

Mr Gower—I think we know enough. I think it is actually making it happen that is the issue. Since we started our emotional support helpline we have taken over 5,000 calls. So I guess we are as well placed as most to comment on what appears to be needed from what our callers are telling us. We also run a chat room on our web site, and have done for eight years. The reality is that what women want is to be able to pick up a phone and talk to another woman in their age group who has had their particular sort of cancer. That is why we have spent a lot of time and expended a lot of effort in setting up a helpline that offered just that.

Senator CAROL BROWN—So amongst the society's membership are patients who have had gynaecological cancer.

Mr Gower—Yes.

Senator CAROL BROWN—How many members are there?

Mr Gower—Do you mean how many members there are in the entire society?

Senator CAROL BROWN—No, I am referring to patients.

Mr Gower—We would have about 30 patient members. About 15 of those are actively involved in counselling at any one time.

Senator CAROL BROWN—What is your total membership?

Mr Gower—About 45.

CHAIR—We did have this discussion a little bit at the roundtable, but I would like to put it on the record. Is your association focused mostly in Queensland?

Mr Gower—Yes.

CHAIR—It has such a noble title, but how does it fit nationally? The services you provide seem to me, from my understanding of working in Queensland, to mainly work through the state government and Health letting people know about your services.

Mr Gower—Yes.

CHAIR—We heard evidence yesterday from people in New South Wales about their system of having centres, having telephone support and having a lot of networking through their geographically based centres. From your knowledge, how does this kind of thing operate nationally? You can talk with authority about what you are doing in Queensland, but the issue is national. So how does it operate in other places and how do you link in together?

Mr Gower—Effectively we set up to operate state wide in Queensland.

CHAIR—Why? What stimulated that?

Mr Gower—Effectively the Gynaecological Cancer Society was the brainchild of Professor Alex Crandon, who is the clinical head of gynae-oncology in Queensland. For my sins, I had been doing some work running research establishments. That is how it all came about. We use a 1800 number, and because it is a 1800 number we get calls from anywhere. As near as we can figure, according to our phone bills about 25 to 30 per cent of our incoming calls come from states and territories other than Queensland. Because we use a telephone system it does not matter. The only thing that hurts me is when we make return telephone calls and I have to pick up the bill.

The system is that when a caller rings us we then contact one of our counsellors with their name and telephone number and the counsellor rings back, so that we are not actually inflicting that cost on the patient. That has been working very effectively for a lot of years. Because it is phone based it does not really matter where the person is.

CHAIR—For about how many years, Mr Gower?

Mr Gower—Our telephone system has been operating for seven years.

CHAIR—So you would have built up a considerable amount of knowledge in those seven years of service.

Mr Gower—We think we have, and we think that there have been some interesting things that have come out of that. The supporting partners program was a direct result of the information that came in from our callers.

CHAIR—What kinds of national services are you aware of? You could talk about Queensland but I am really interested in finding out what is happening for women across the board on this basis.

Mr Gower—There is a cancer helpline which is extremely good. It is national. When they get gynaecological cancer calls, they send them to us.

CHAIR—From anywhere in the country?

Mr Gower—Yes. The reason they do that is that they like what we do. They recognise that we have a system that works. They do not have at the moment—they may have it in the future—women counsellors who have been there and done that in all of the age groups. That is effectively what the callers want.

CHAIR—Is there a formal link between you and the central cancer number or is that an informal arrangement that has built up with experience?

Mr Gower—It has just been happening.

CHAIR—What association has your organisation had with the National Breast Cancer Centre in terms of the whole process around ovarian cancer?

Mr Gower—Not a lot, but where it has happened it has been very good. We have absolutely the highest regard for the national organisation. They are wonderful people. There has not been a lot of interaction because effectively there has not needed to be, but where there has it has been at the best possible level.

CHAIR—Is there anything that you would like to add—often there is—on record?

Mr Gower—I do not think so. I think our submission speaks for us. We think that this is the best opportunity that gynaecological cancer has had in a long time or will have for a long time, so we certainly support your work. We thank you for coming to Sydney—I was looking at the weather reports for Canberra and they were a bit frightening. We wish you the very best of luck and imagine what it must be like to sit through hours and hours of this sort of thing.

CHAIR—I have a last question, Mr Gower. What relationship, if any, do you have with GAIN? That is also one that started in another state and it is very much focused in one state. I am wondering whether there has been any link.

Mr Gower—There has been over the years. Our association has been over the last few years a little at arm’s length. That was caused by a slightly different philosophical view as to how you achieve change and the methods used. Our version is that it is much better to cooperate and coordinate. In fact, you do better with honey rather than with a brickbat—and I mean that in the nicest possible way. Our view is that you approach things systematically and methodically and you achieve what you want through a reasoned argument. We have a little bit of a problem with some more emotional, high-powered, confrontational approaches.

CHAIR—Thank you very much for your evidence and thank you for coming to Sydney to meet with our committee. We appreciate that.

Proceedings suspended from 12.59 pm to 2.01 pm

MELLON, Mrs Anne Marie, Clinical Nurse Consultant, Hunter New England Centre for Gynaecological Cancer

PERRIN, Dr Lewis Charles, Secretary and Treasurer, Australian Society of Gynaecologic Oncologists

PROIETTO, Associate Professor Anthony Mark, Chairman, Australian Society of Gynaecologic Oncologists

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

Prof. Proietto—I am the Director of the Hunter New England Centre for Gynaecological Cancer and I am also the Chairman of the Australian Society of Gynaecologic Oncologists.

CHAIR—Have you given evidence to government inquiries before?

Prof. Proietto—Yes.

CHAIR—You have received information on parliamentary privilege and the protection of witnesses. If there is anything you would like to take in private, let us know and we can work that out. We have your submissions. If any or all of you would care to make an opening statement, that would be fine, and then we can go to questions. Do you wish to make an opening presentation?

Prof. Proietto—Anne would like to make an opening presentation on behalf of the Hunter New England Centre for Gynaecological Cancer.

CHAIR—Dr Perrin, do you want to make a statement?

Dr Perrin—No. I am happy for Tony to, unless any statement is required.

CHAIR—No, not at all.

Prof. Proietto—I would like to make a brief statement on behalf of the Australian Society of Gynaecologic Oncologists.

CHAIR—Absolutely. Let us start.

Prof. Proietto—As I have mentioned in my submission, gynaecological cancer in Australia is a significant problem in that something like just under 4,000 women per year are diagnosed with a gynaecological cancer. Of that group, a significant number, especially of those diagnosed with ovarian cancer, will eventually die of their disease. We feel as a society that it is very important that we aim to provide the best possible care for our patients and ensure that as many of them as possible are offered the most up-to-date and best practice that is available currently.

There are certain issues that we feel are important. As a society we believe that one way of furthering our care of women and our investigation into the causes and possible prevention of this disease is to have a national gynaecological cancer centre that is adequately staffed, funded and resourced to have a coordinating role in trying to improve the level of communication, cooperation and care that is already available. We feel that such a centre could have a role in collecting and analysing data on a national basis so that we could have a very accurate picture of the current situation with gynaecological cancers, how well women are treated, the survival rates and, equally importantly, how many, in what proportion and what groups may be missing out on the best possible care. It could act as a resource centre for clinicians and for the general public and be involved in the coordination and production of, say, clinical guidelines, public education campaigns and the education of health professionals to widely disseminate the principles of gynaecological cancer care.

Also, we would see such a centre as having a function in coordinating research into gynaecological cancers, especially in the field of clinical research, where it may coordinate and help to coordinate clinical trials across states and gynaecological cancer centres. We would see it cooperating with other groups that are involved in research for gynaecological cancers, such as the Australia New Zealand Gynaecological Oncology Group and the Trans-Tasman Radiation Oncology Group. It may also profitably have a role in promoting and encouraging basic research into gynaecological cancers and in endeavours such as finding tumour markers and finding screening strategies and screening methods for cancers other than cervical cancer, for which a screening program already exists. Obviously such a centre would require adequate funding and resourcing.

We see our role also as promoting improvement in the service delivery that is currently available. Australia has in every state, though not in the ACT and the Northern Territory, dedicated gynaecological oncology centres which have expert gynaecological oncology practitioners in all fields—medical, nursing, psychosocial, data managers et cetera—and these act as central referral centres and centres of excellence. We feel that, although they function very well and have very good results, within such centres there are individual gaps that perhaps could be filled with a little bit of extra funding and encouragement. We would also see it as important to try and improve the access of rural and remote communities and women who are in disadvantaged groups to the best care that is available in such centres. For a country like Australia, with such huge distances, this provides a real challenge. Our challenge is not only to bring them into our centres to receive up-to-date treatment but also to then support them, follow them up back in their own communities and have adequately trained and dedicated staff—nursing, medical and paramedical—to make their cancer journey as close to the best that is possible.

The follow-up of women with gynaecological cancer is very important. Often some of the worst or most stressful and difficult periods for women with such a diagnosis are not so much during the whirlwind phase of their treatment but once things have settled down a little bit and they have a chance to reflect and perhaps start to feel the enormity of what has happened to them. I think improvement in the provision of psychosexual and psychosocial care is then of great and critical importance. We should have adequate resources to ensure that every woman gets the best in that field. That is all I would like to say at this point.

Mrs Mellon—Thank you for giving me this opportunity. The Hunter New England Centre for Gynaecological Cancer is situated in Newcastle. Our area health service currently covers an area the size of the United Kingdom. Our service has one visiting medical officer and a 0.4 full-time equivalent staff specialist in gynae-oncology to cover that large area, so access for women can be quite difficult. They have to travel a long way to our centre to get diagnosis, surgery and their adjuvant treatment. This means that they spend a lot of time away from their families and community support.

There are four main types of gynaecological cancers. The one that we hear about the most these days is ovarian cancer, because of its associated high mortality rate. Also, most of the research goes into trying to find a screening tool and improved treatments for patients with this cancer. But a gynaecological cancer like endometrial cancer has a higher rate of occurrence and can be helped through health promotion—that is, looking at things such as nutrition and diet, especially with the increasing rate of obesity in our communities these days. We need to improve the education of both the public and the medical profession about gynaecological cancers so that women can receive early referrals to specialist centres—and it has been proven that women receive better treatment in a specialist centre—we receive appropriate referrals to our centres and gynae-oncology specialists can utilise their specialist skills to treat the women that require their services.

Equity of access for rural and remote women in our area can be quite difficult. As I said, they travel quite some distance to the centre. People in lower socioeconomic groups also have a problem in getting transport to the centre and in being able to find the time to be away from their families and their jobs, especially if they are the main source of income for their families. Another disadvantaged group is women with mental health issues. A lot of other issues go along with that. New South Wales is lucky in that it has six gynae-oncology units. Associated with those units are clinical nurse consultants, who provide services that help in the comprehensive and coordinated care of those women. Unfortunately, the rest of Australia is not in quite the same situation.

As more women with gynaecological cancer are surviving longer, there are issues of survivorship. These include long-term follow-up and the side effects of their treatment, surgery or radiotherapy, such as lymphoedema. Once those women are back in their rural and remote communities, treatment is not always easily found and access to services is not always gained easily. There are also the associated psychological and psychosocial effects of having treatment for gynaecological cancer, especially for young women who have been put into early menopause and who have had their fertility taken away at a time when they may not have thought about that as something they would have to face.

Also, when there is follow-up in rural and remote areas, patients have to come to the major centres to have their treatment. It is often quite difficult for them to come back to those centres to have their treatment every three to six months so that they can be assessed for ongoing problems or recurrence of their cancer. It is very important that the practitioners in the rural centres are able to follow up with these those women, so they do not have to spend a lot of time travelling backwards and forwards, and that the rural centres have the resources to deal with the problems those women may face.

In the Hunter New England centre one of the major difficulties is access to adequate theatre time, and the waiting list for surgery at our unit at the moment is approximately eight weeks. According to the Cancer Institute plan, women are supposed to have surgery within two weeks of a diagnosis of gynaecological cancer being made. It is quite appalling that women have to wait eight weeks to have their treatment done. After that, in the Hunter New England they are then waiting approximately six to eight weeks to see a medical oncologist or radiation oncologist to have their adjuvant treatment. A lot of women travel from rural centres to Sydney to have that treatment because they cannot get it in a timely fashion. In the Hunter New England we require funding for increased medical professionals, gynae-oncologists, medical oncologists and radiation oncologists so that women can have treatment in a timely fashion.

The Hunter New England centre recommends that we have a national gynaecological cancer centre that can coordinate all aspects of gynae cancer care, including education and research—that is, education of the community as well as the medical profession—so that rural and remote medical professionals can follow up patients and have the resources to assist women when they go back to their communities following their treatment for gynae cancer.

Dr Perrin—Anne has brought forward the problem with waiting lists. At the Queensland centre, we see over 600 new cancers a year and we have only four gynae-oncologists available to do public work. Again, we have a problem with waiting lists. Fortunately, our waiting list at the moment is not eight weeks—although it has been up to eight weeks—but approximately five or six weeks. Again, I think that is appalling. One of the problems we as clinicians and clinical nurse managers have is that we have to prioritise cancers. So, when someone is diagnosed with a cancer, we have to say one cancer becomes more urgent than another depending on the type. We often find that someone will be booked in to have a cancer operation but then we will have to delay the operation because of a lack of available theatre time. That lack of availability of theatre time is not necessarily just a medical issue; it may be due to a lack of theatre staff or appropriately trained theatre staff. It may also be due to a lack of intensive care space, as it is not unusual for a major operation to need intensive care backup. That can cause, obviously, stress for the patient.

The other problem we have in Queensland as well as in Newcastle and the Hunter Valley is the tyranny of distance. With the lack of concentration of population, you do not have the expertise. You cannot get me or Tony to fly in, do a major operation and then fly out again. These patients need to come into a major centre. That brings with it stress, including financial stress. Hospital management say they will not fund travel unless it is arranged prospectively. As you can imagine, patients with the stress of a cancer are not going to try and organise travelling funds first up; they want to get them but only after they have been treated. That is a significant issue from that point of view.

CHAIR—I am going to be very rude and ask the first question, because you press my buttons when you say Queensland. You mentioned four gynae-oncologists. Do you mean across the whole state?

Dr Perrin—That is correct.

CHAIR—How many places do you operate in in the public system?

Dr Perrin—At the Mater Medical Centre in Brisbane, the Royal Women’s Hospital, Royal Brisbane and Townsville.

CHAIR—So it is only in Townsville and Brisbane that you offer these services at the moment?

Dr Perrin—Correct.

Senator ADAMS—I am a rural senator from Western Australia and I have a nursing background. The Patient Assisted Travel Scheme is one of my big bugbears. As a breast cancer survivor from a rural area, I am fully aware of what is going on, but if I had had to wait the amount of time that your people are waiting there would have been a lot of chaos in WA because I would not have put up with it. I think this is appalling. What about the budget? I was waiting for you to say that theatre constraints might have been budget driven as well. What is the story there?

Dr Perrin—It is budget driven. We are told our access to theatre is limited. We make ourselves available and we would like to have extra sessions, but we are told that there is no theatre time for us to do it.

Senator ADAMS—That is with Queensland Health, is it?

Dr Perrin—Yes.

Senator ADAMS—What about for the Hunter? Is it budget driven for you as well?

Prof. Proietto—It is. The area sets surgical targets, and patients do not always follow the surgical targets or they are just not set correctly or whatever. Our problem also is that we are available to do cases, but no times are given to us.

Senator ADAMS—In this day and age, that is absolutely unacceptable. Cancer is not something that can be pushed aside like any of your elective surgery; this is a very different ball game. That will be well and truly noted. Getting back to the Patient Assisted Travel Scheme: can you highlight the biggest problems for your patients coming in from rural and remote areas in both Queensland and New South Wales?

Dr Perrin—With Queensland, the problem is that the patients, both public and private, are meant to try and organise this prospectively. There seem to be a lot of hoops that patients have to jump through and that are not insignificant, like getting the right people to sign the letters and that sort of thing and the fact that it is made difficult to do retrospectively. Obviously patients’ priorities change. The other thing is that for these patients it can be quite a harrowing experience but you often need another reason to get a support person to come down with these patients, who are often elderly. You write these things, but it is not guaranteed. Whether or not a support person will be funded to come down often depends on who the administrative officer is.

Senator ADAMS—They will not accept psychosocial support; it has to be medical support. It is very difficult, and I can see it from your point of view. I get a number of constituents coming to me about this in Western Australia as well. It certainly seems to be a national problem.

Dr Perrin—A lot of our patients are quite elderly as well.

Senator ADAMS—That is right. In the Northern Territory, the Indigenous patients are allowed an escort and the others are not, so there is quite a lot of angst up there. As far as accommodation for them goes—and perhaps we will just go through Brisbane first and then the Hunter—when they come for radiotherapy and their chemo, what is available?

Dr Perrin—There is a combination of hospital based, relatively cheap—although it depends on who you are talking to—budget accommodation close to the hospital that is privately run. There is some limited hospital-run accommodation, and the Queensland Cancer Fund also has some accommodation.

Senator ADAMS—So there is enough accommodation?

Dr Perrin—Not always, no. For instance, the Mater is close to the Gabba, and if there is a big football or cricket match on accommodation can be extremely hard to get.

CHAIR—Like last weekend.

Dr Perrin—Yes.

Senator ADAMS—What about with Newcastle?

Mrs Mellon—It is the same. We have on-site accommodation for families when patients are having surgery but, again, it is only limited. There is an Indigenous cottage, as well as two other cottages. If that is empty then sometimes we can utilise that, but there are never usually enough beds. For radiotherapy and chemotherapy, there are villa units at the Mater hospital where they do that treatment. But, again, they are not supervised and a lot of our patients are quite elderly when they are having treatment. They are unwell. They are actually supposed to be self-sufficient in those units. There is also budget accommodation close to the hospital, but it is not very nice for patients and it still means they have to travel at least 10 minutes in an area they are not used to. With the travel allowance scheme, in New South Wales there is the 200-kilometre rule—they have to live more than 200 kilometres away.

Senator ADAMS—They have just changed that.

Mrs Mellon—Yes, they have just changed that, so hopefully that will start to make a difference, but some women who are perhaps travelling from the Central Coast up to us and who are not out of that 200 kilometres still find that quite difficult. Again, it depends on what you write on the form as to whether you receive the refund.

Senator ADAMS—My other question concerns lymphoedema patients, especially your rural ones. What access have they got? Do they have any way of having their condition treated in Queensland?

Dr Perrin—It is very ad hoc. We have some dedicated lymphoedema specialist physiotherapists and the Lymphoedema Association, which does provide a good service, but it is mainly in the city centres.

Senator ADAMS—So once again rural women are very much disadvantaged. What about with the Hunter?

Mrs Mellon—We have two dedicated physios in our hospital that do lymphoedema treatment. I have also done the lymphoedema course and am qualified to do that as well. Rural women often do have to travel back to the major centre to have that treatment. There are not many physios in the rural areas that specialise in lymphoedema.

Senator ADAMS—Where I come from you can get a physio appointment probably in five weeks, but you can only get one; you cannot get a physio appointment every day to have the treatment, as you need to. That is obviously a problem everywhere else.

I have another question on PATS. You did mention that some of your patients are bypassing the Hunter, because of the long wait, and going to Sydney. How are they getting on? Normally, to be able to get patient assisted travel, you have to go to the nearest specialist. How are they getting on bypassing the Hunter?

Prof. Proietto—The patients who typically bypass Newcastle to go to Sydney are not so much the surgical patients as patients for radiation therapy. That is because we have had a six-week wait between the patient being seen and the patient having radiotherapy. In Sydney they can have their radiotherapy within a week.

Senator ADAMS—Can they still get their PATS, though, because they are going past you?

Prof. Proietto—None of my patients have actually tried to get PAT.

Mrs Mellon—I am not aware that there have been any problems.

Senator ADAMS—I just wondered, because that is another problem for rural people—you have to go to the nearest specialist; you cannot go to the best person or the best centre. That is an anomaly with the system. You may be going to a GP specialist in a regional town rather than being able to access a proper multidisciplinary team and centre in the city. There are all these issues. Somehow we have got to fix it.

Senator ALLISON—I want explore some of the funding issues that you talk about in your submission. I put on the record that you note in your submission that at the beginning of December 2005 the waiting time for cancer surgery was 10 weeks per patient, which seems extraordinary. The recommendations you make are all about the Commonwealth providing funding so that the number of gynaecological oncologists and so on can be increased. What are the determinants at the present time of how many gynaecological oncologists you can have within your hospital? Who decides? Is it the hospital manager or is it the state government and, if that is the case, what point would there be in the Commonwealth being involved in this?

Prof. Proietto—The hospital management in conjunction with me as director of the unit have worked out that we would need three to run our service. On that basis we have negotiated with the area that another person should be advertised for.

Senator ALLISON—This is something that happened recently, is it?

Prof. Proietto—Yes.

Senator ALLISON—What is the EFT number?

Prof. Proietto—It is 0.4.

Senator ALLISON—So you will go from that to 1.4?

Prof. Proietto—Yes.

Senator ALLISON—Again, is this a matter that is determined by the management of the hospital?

Prof. Proietto—Yes.

Dr Perrin—In Queensland, when we are going through the same process, we need to do a business plan, which is then presented to the hospital.

Senator ALLISON—Doctors do a business plan?

Dr Perrin—Yes. You can imagine how bad that would be.

Prof. Proietto—That is what we have been asked to do, yes.

Dr Perrin—It is a business plan; a business case. I have to put that forward with a number of case loads and waiting lists and that sort of thing, along with the estimated operating time et cetera. In our submission from Queensland, one was put forward. That is then presented to the hospital and the hospital then forwards that on to Queensland Health. There are many layers that it has to go through. Then the funding has to work its way back through the layers—it may actually eventuate.

Senator ALLISON—So you do not have a casemix funding arrangement like Victoria does?

Prof. Proietto—No, we do not.

Senator ALLISON—So these are all negotiated in an ad hoc way with business plans that have to stack up against other business plans. Is that how it works?

Dr Perrin—Yes.

Prof. Proietto—The typical reaction we get is: ‘Yes, you can have the other staff member, as long as you make savings in your other areas so that you can pay for it.’

Senator ALLISON—You are asked to put your hands up for savings. I understand. If I can come back to your recommendations about the Commonwealth, how could the Commonwealth intervene in this process? Are you suggesting that the Commonwealth-state housing agreements be somehow modified to do this?

Prof. Proietto—I am not a great expert in the differences between the Commonwealth and state funding arrangements. One of the issues that we looked at is whether a national gynaecological cancer centre with funding could perhaps provide a salary for a position, be that a staff specialist position or a training position, for, say, an oncology fellow. That could ease the load on the clinical service.

Senator ALLISON—Yesterday we were told, in the context of being told that half of all patients are not receiving multidisciplinary care and not seeing a gynaecological oncologist, that there is some room for there to be an increase in the number of patients seen by such surgeons, who typically also do a whole range of other surgery that, if this were the case, they would not be involved in. But it sounds as though your shortages mean that your gynaecological oncologists are flat out doing just that. Would that be a fair assumption?

Prof. Proietto—That would be a fair assumption. If you look at our submission and the numbers for the Hunter-New England area, the service started 15 years ago and until 2003 there was one oncologist—me. Over that time, our major procedures—

Senator ALLISON—Pretty much everything has doubled.

Prof. Proietto—Yes. We started off with 187 in 1993 and that went to 318 procedures in 2004. The numbers keep going up; they are not going down. There is a fairly heavy case load. To some extent, we have been forced—as they have in Queensland—to streamline our procedures so that we concentrate more on patients who either have a definite diagnosis of cancer or for whom there is a reasonable suspicion that there may be cancer. They are the sorts of patients who we tend to see. Every gynaecological oncologist in the country will also see a certain proportion of women who may not have cancer but who have quite complicated and difficult surgical problems that are best dealt with by the kinds of surgeons who have our training. All of those numbers add up, and we need to see them all.

Dr Perrin—I will add to that. I think there are two issues. One is the number of gynae-oncologists but the other one is giving to the gynae-oncologists that we have access to perform the surgery. As we said earlier, the theatre times are curtailed. Even if we are available to do extra operations, we are not allowed to do those, because we have not been allocated adequate theatre time.

Senator ALLISON—Again, whose decision is this?

Dr Perrin—It is the administration of the hospital that say they have to budget. I was informed that I had to cut back one operation a day. Even with a waiting list of, say, six weeks, I have to cut back one major operation on my all-day list because we are going over budget.

CHAIR—Is that at Royal Brisbane or Mater?

Dr Perrin—That is at the Mater. But the Royal Brisbane is the same; I have recently changed from the Royal Brisbane. In fact, they have been told that, if they are looking at going over their allocated theatre time, the last case will be cancelled. So they are doing it in another way.

CHAIR—On the day?

Dr Perrin—They are doing it on the day.

CHAIR—So the patient is ready, having been told they are going to have the surgery?

Dr Perrin—Neither situation is satisfactory.

Mrs Mellon—That happens in our centre as well. I was told yesterday that, if they did not put knife to skin by a certain time that afternoon, surgery would be cancelled and that last patient—who was already in, who has had the preparation that they need prior to surgery—would have to go home and come back again for whenever we can fit them in next time.

Dr Perrin—For them to come back again, you have to bounce another patient who is already booked, because you cannot really get that first patient to wait another eight weeks—that is, to go on the end of the waiting list, if you know what I mean. The problem snowballs.

Senator ALLISON—How has it come to a situation where there is obviously a shortage of theatres?

Prof. Proietto—It is really an issue of funding and staffing. Our hospital runs 10 theatres at a maximum, but they have a finite budget. They allocate X number of lists to our service and we are not able to increase those lists, because they do not have the funding, so they tell us.

CHAIR—Who tells the patient?

Mrs Mellon—Me.

CHAIR—The nurse, is it?

Dr Perrin—It is normally a team approach. On the phone, it is definitely the case manager. That is what I was talking to Anne about. We have different names, but it is the case manager. That can be a very stressful job. Often, one of the most stressful things—and I was saying this to Tony—is when you see a patient in outpatients, you tell them about the treatment and they ask, ‘When is it going to be done?’ You say, ‘Oh, the 24th—’ and they say, ‘Good, that’s only three weeks.’ Then you say, ‘I’m sorry, you didn’t hear me; I meant 24 September,’ or something like that.

Mrs Mellon—Only this morning I spoke to a woman and said, ‘Your surgery will probably be done early to mid-September.’ She said, ‘Oh, has doctor decided that my surgery isn’t that urgent?’ I said, ‘Well, actually, no. That is just the next available date that we can get you in without moving somebody else.’ It is hard to say to somebody, ‘You need to be moved because there’s somebody more urgent.’ To them, they are the most urgent person and they want it done yesterday.

CHAIR—There is someone sicker than you.

Mrs Mellon—That is exactly right, and that is really hard to tell them.

CHAIR—I wanted to know who actually had to tell the patient that they had been bumped.

Prof. Proietto—It is often whomever they ring. Sometimes they will ring me or my secretary, and they will speak to them and tell them, but most often they ring Anne.

Senator ALLISON—Is the position of your hospital different from that in any other major hospital in any other region outside metropolitan Sydney?

Prof. Proietto—Probably not outside of Sydney. Earlier on, when we were at a very critical stage, we did ring around Sydney and try and find out what the waiting times were. Most of the major centres in the city of Sydney would have waiting times for surgery of two to three weeks, as opposed to our eight weeks.

Senator ALLISON—But your hospital would be typical of those outside the metropolitan area? That is what I am asking.

Prof. Proietto—Yes, it would.

Senator ALLISON—Are you a member of RANZCOG, Professor?

Prof. Proietto—Yes, I am.

Senator ALLISON—Are all of the gynaecologic oncologists also members of RANZCOG? I think I might have asked this question, but I will ask again.

Prof. Proietto—I think we are all invited to be members of it. I do not know that we all attend all of the meetings, but all of the units are members of RANZCOG, yes.

Senator ALLISON—Thank you.

CHAIR—I want to ask just one more question, because I am fascinated by these location things. Your area is Hunter-New England?

Prof. Proietto—Yes.

CHAIR—So you go as far north as where?

Prof. Proietto—Tenterfield.

CHAIR—So if I were a woman in Lismore, where would I go?

Prof. Proietto—You would go to Queensland.

CHAIR—Across the border to Queensland—that is what I thought the answer was going to be.

Dr Perrin—That is where a lot do go, but Gregory Robertson flies to Lismore once every month or six weeks and does some work there.

CHAIR—We have a very nice little list with all the names of the members of ASGO. So Gregory Robertson is the mobile one from New South Wales who flies over here.

Dr Perrin—The gynae-oncologists from the Royal Hospital for Women go to Canberra—

CHAIR—And they go to Wollongong as well?

Dr Perrin—Yes, and Greg flies to Lismore.

CHAIR—And who flies around in Queensland?

Dr Perrin—We all fly to Townsville.

CHAIR—You take it in turns?

Dr Perrin—Yes. Another example of what we do in Townsville is one of us does one week a month. We now have another gynae-oncologist—

CHAIR—You do your country service?

Dr Perrin—Yes. Because there are significant demands on the service and last year we had another gynae-oncologist join the state and we said, ‘Why don’t we now go once every three weeks instead of once every month?’ They said, ‘Thank you, but no thank you,’ because they would not be able to give us theatre time to do that.

CHAIR—In Kirwan?

Dr Perrin—Now it is at Townsville General Hospital. Kirwan has moved to Townsville.

Senator ALLISON—This is probably a fairly obvious question, and a difficult one to answer, I am sure, but if someone needs to wait 10 weeks, how many people die or have their condition made much worse in that time?

Prof. Proietto—That is a difficult one to answer accurately. The situation is that if we have a 10-week waiting time, as Dr Perrin said earlier, it means that we have to prioritise which cancer patients get done at what time. For example, if we have a patient with an advanced ovarian cancer who clearly cannot wait 10 weeks because she would be dead in that time, then we have to either negotiate on an ad hoc basis with the operating theatre to do that case at a time on an urgent list outside our normal allocation or rearrange our lists to try to fit that person in and put other people back.

Senator ALLISON—So some wait longer than 10 weeks?

Prof. Proietto—Yes.

Senator FERRIS—You would not think about sending them down to Randwick?

Prof. Proietto—That may be possible, but the time saving would perhaps not be as much as one would think. By the time you got an appointment for them to see the oncologist there—you could not just send them for surgery; they would need to go and have a consultation with the gynae-oncologist—they would then have to be put on a list at the Royal Hospital for Women. If their delay is three weeks and it takes two or three weeks to get down to Sydney to be seen, then the amount of time you are going to save is really very limited. It is a major disruption. Why should patients, when the expertise and the services are available in the Hunter, have to travel 250 kilometres to have their treatment?

CHAIR—Do you operate privately as well?

Prof. Proietto—Yes, I do.

CHAIR—So—and this is a question to both doctors—it is an option for some patients that, if you could not fit on the public schedule, there is a possibility through negotiation to fit wherever you operate privately?

Prof. Proietto—That is an option. There are occasional patients who have the means to be able to pay and do that if they are not insured, but that is really out of the reach of the vast majority.

CHAIR—Dr Perrin, does that work for you as well?

Dr Perrin—It can do. I must admit I do not encourage that, because I feel as though it is almost blackmailing a patient with a terrible disease and the cost for them is not insignificant. It may be $12,000 or $15,000 with hospital fees, theatre fees, disclosable instruments—

CHAIR—That is the kind of costing we would be talking about.

Dr Perrin—That is the sort of figure I tell them. It may actually be $10,000. I would much rather do that. I paint the picture. We looked at survival patterns for patients that had had their operations delayed six weeks compared to those of patients that had had theirs urgently. The trouble is that that is a retrospective look at it. All those ones with aggressive cancer are the ones who are squeezed in, as Tony said, so statistically we could not show a difference. We wanted to present that to Queensland Health and say, ‘Look, what’s going on?’ But we have corrupted the data, because all the urgent patients—

CHAIR—You have fitted in somehow.

Dr Perrin—we fit in. The ones which may get bounced are those with low-risk cancers. The ones which would wait 10 weeks would be those with an endometrial cancer, I would imagine. That is well differentiated. Though we know that waiting 10 weeks will not have a statistical difference in survival, for the patient it is a very hard pill to swallow, even though you tell them you are delaying them because you have another lady who, if you do not operate on, could well die in that period.

Senator WEBBER—Once you have told these patients that they have to wait, for any of these conditions a degree of psychosocial support is needed. Obviously there are a few added issues there as well. Do we know enough about the kind of support that we need to give women going through this cancer and their families? Are the guidelines good enough? Do we know it all, particularly given some of the cultural differences we have in our society?

Dr Perrin—In summary the answer to that is no. That is an area which needs an awful lot of research. When I counsel my patients I say that when you get a diagnosis of cancer it is similar to being on a plane that is hijacked. You may get off the plane, but unfortunately the terrorist has got away and while he was getting away he yelled out, ‘I’ll be back to get you.’ They always have that in the back of their mind. I feel that if someone was on a plane that was hijacked they would automatically be sent off for counselling. At the Mater we do not have a psychologist. We have a social worker, but they are part time.

CHAIR—At the Mater public?

Dr Perrin—At the Mater public dedicated for breast cancer or gynae cancer. That is one of the things in the business plan we have submitted. I think what you are alluding to is a huge issue, and we do not deal with it well. The other thing is, as you can see, we have two gynae-oncologists here and we are both males. We are trying to encourage our female trainees to do it, and we are succeeding to a degree. But to become an obstetrician it is already six years; to do gynae-oncology it is another three years on top of that, remembering they have done six or seven years of medicine and three years before they got in. So, if you go straight through, you are well into your 30s or almost 40 by the time you become a gynae-oncologist. It is not surprising that a lot of women find that unattractive. That is another issue that came out from the psychological point of view. We do have a female trainee from Queensland going through at the moment, so our next one coming through will be female.

CHAIR—Your next ‘one’.

Dr Perrin—One, yes.

Prof. Proietto—To add to what Dr Perrin has just said, the majority of the emphasis in terms of psychosocial care understandably has been on patients who are going through either treatment or post-treatment surveillance rather than who are in that window between seeing their oncologist and having their operation. I think it is not only an issue for those women who have an obvious and diagnosed cancer but also a major stress for women who may have, say, a mass in their pelvis and do not know whether it is malignant or not. They are often the ones who get pushed back in further because they do not have a definite diagnosis. They really are chewing their fingernails until the surgery is done and a definite diagnosis is made. I do not think we really have much of a handle on the scale of that sort of problem or any really good resources and strategies to deal with it.

Mrs Mellon—We have a full-time social worker and a half-time psychologist in our unit. They both meet the patients at their initial diagnoses and try to stay in contact with those women during the waiting time, but that is often just by telephone and it can be quite difficult to really help at that time when they have not had the time to establish a relationship with the women and get to know the full psychosocial circumstances. The worst time is the waiting time, when they have been told, ‘You’ve probably got something but you’ve still just got to sit there and wait.’

Senator WEBBER—Given that a lot of the evidence that we have had in this inquiry has been about late diagnosis and, in some cases, a 10-week wait for surgery, and therefore obviously the need for early detection and early intervention, should we be looking at raising public awareness? What would be the best way to do that?

Prof. Proietto—I certainly think we should be raising public awareness. If we look at some of the other cancer sites, cervical cancer has a reasonable public profile, breast cancer certainly has an excellent public awareness profile and the profile of prostate cancer is getting better and better. We see this with our own patients. They often say: ‘We didn’t know anything about ovarian cancer. We didn’t know it could exist. We didn’t know that there were symptoms. We didn’t know anything about it.’ It is not talked about by the media, it is not talked about among women themselves and there is an awful lot of ignorance about some of the other sites, like ovary endometrial, vulval et cetera. From the point of view of encouraging women to present with symptoms early, raising the profile and raising awareness would be good. One would not want to raise it to the point of panicking and finding that every woman decided that she had ovarian cancer and had to have tests, but a much higher level of awareness than currently exists would certainly be very beneficial.

Dr Perrin—The other point is that gynaecologic oncology is a relatively new specialty and that is one of the reasons we are having trouble keeping up with the workforce, but other doctors are not aware of the benefits of going to a gynaecologic oncologist. As well as patients knowing that there might be something wrong, effort needs to be made to educate doctors who are not in this specialty of the benefits of going to a gynaecologic oncologist. We are able to document significant improvement in patients who are managed by a multidisciplinary unit compared to those who are not. I documented that in our report. But still only 50 per cent of ovarian cancers are treated by gynaecologic oncology units; the rest are treated elsewhere, and I think that is because of a lack of knowledge. I do not think the practitioners are deliberately poorly treating their patients, but they are not aware of the now documented evidence showing significant improved survival going into one of these units. Of course education is needed for the public, but I would say it is mainly for the medical profession.

Senator WEBBER—That was going to be my next question, so that is obviously not good enough at the moment either.

Dr Perrin—No.

Prof. Proietto—No. That is why we have suggested in our submissions that medical education is as important as public.

Senator ALLISON—Professor, would anyone disagree with you on that point? Is there a group out there that says, ‘It’s a load of nonsense; we can do it just as well as you guys’?

Prof. Proietto—I do not know. Certainly in the past there have been. As gynae-oncologists we have all come across individual practitioners who, perhaps because they have been doing this kind of work for a long time or they are in areas where they do not have access to greater expertise, have done it themselves and feel that they are as good as anybody and that they do not need to send their patients off. I would have to say that in our area that is a real rarity.

Mrs Mellon—I want to make a point about community education. Firstly, there has to be public awareness of what tests they are having and what they pick up. Often women come to our clinic and say, 'But I've always had my pap smear,' not realising that a pap smear is not going to pick up ovarian cancer. We need to get that sort of information out to the general community so that they know that when they have their pap smear they need to have an internal examination and have their abdomen palpated and things like that. They need to be aware of what needs to be done, rather than just think, 'If I have my pap smear I am not going to get any of those sorts of cancers.' I think gynaecological cancer is not looked on as being a very attractive cancer to get—not that any cancer is attractive to get. But breast cancer is out there in the public eye and people do not see that as a horrible thing, whereas gynae cancer is not talked about as much publicly because it is stuff that happens 'down there' and people do not want to bring it up. I think it needs to be brought out so that people can talk about it a little bit more.

Senator FERRIS—I notice that you as a society have recommended the establishment of a national gynaecological cancer centre. There is a divergence of opinion about this, and we have picked it up in the last two days from various witnesses. Are you confident that a new body would still be able to work with the same efficiency and effectiveness on gynaecological cancer as the National Breast Cancer Centre is now? Leaving aside the public education aspect of it, how do you think the states would go handing over to a new body, for example? Do you think there would be territory issues?

Prof. Proietto—There may be territory issues. Gynaecological cancer, even though the number of practitioners may not be large, involves quite a large group of women. If I were a member of the public it would not occur to me, if I or a relative had gynaecological cancer, to ring up the Breast Cancer Centre to get information. I think that it is an imbalance in a sense, because breast cancer has such a high profile and gynaecological cancer has no or very little profile effectively. To lump gynaecological cancer with breast cancer tends to swamp the gynaecological cancer aspect. That is one issue.

The other very important issue is that the only thing in common between breast cancer and gynaecological cancer is that they both occur in women predominantly. Their treatment is vastly different. The kind of surgery that is involved with advanced ovarian cancer or an advanced vulval cancer is nothing like what would be needed for treating a breast cancer. The issues are different as well. Breast cancer is very visible. Gynaecological cancer and the sorts of surgery and the sorts of treatment that are needed for it I think in some ways are an even more fundamental threat to women in terms of their view of their femininity and their view of what is happening to them. I do not think there is necessarily a natural integration of breast and gynaecological cancers. They are separate. Breast cancers are generally dealt with by general surgeons, medical oncologists and radiotherapists, and gynaecological cancers are dealt with by gynaecological oncologists. We really are not in the same grouping. I think that we would tend to lose our identity if lumped with another group.

Senator FERRIS—What about the turf issue?

Prof. Proietto—I am not sure about the turf issue. As a society we have not ever been funded in any way by government or anything. I am not sure how the states—that is, those that are currently running it—would feel about a new body. Just as gynaecological oncology separated itself and became a distinct group from gynaecology within our own college, with certain stresses and territorial conflicts, the same can and really should be done in terms of having a national gynaecological cancer centre.

Senator FERRIS—Can you explain to me what sort of relationship AGSO has with Cancer Australia, the newly formed overarching body, and how you expect to liaise with them?

Prof. Proietto—One of our concerns with Cancer Australia is that we have no representation on that body at all. We as a society have never been asked to make any sort of submission. I really do not know anything about Cancer Australia.

Senator FERRIS—But, presumably, you would see the national gynaecological cancer centre working in conjunction with them?

Prof. Proietto—Indeed.

Senator FERRIS—As you understand it?

Prof. Proietto—Yes, as I understand it. Then, yes, it would be a relationship with mutual representation.

Senator HUMPHRIES—I want to make sure I am reading correctly the figures on what is happening with gynaecological cancer at the moment. I might be comparing apples with oranges here, but you mention in your submission that uterine cancer is now the most frequently diagnosed form of gynaecological cancer in New South Wales.

Prof. Proietto—Yes.

Senator HUMPHRIES—You say it represents 3.8 per cent of all female cancers. The Cancer Council submission includes a table with comparisons of instances of these diseases across the whole of Australia. Your figures are for 2003 and theirs are for 2001, so that might account for some differences. They say, for example, that uterine cancer accounts for 1.7 per cent of all new cancer cases versus your figure of 3.8 per cent in New South Wales in 2003. Is that just a difference in the way they are counted or is there some evidence of an increase?

Prof. Proietto—I think it is the former. My figures are for the percentage of cancers in women and I think the Cancer Council's are for the percentage of cancers in both sexes overall.

Senator HUMPHRIES—But men do not get uterine cancer.

Prof. Proietto—No, that is true. It is just a denominator.

Senator HUMPHRIES—You say that uterine cancer represents 3.8 per cent of all female cancers. They say that it accounts for 1.7 per cent of all new cancer cases—I see. I have got it.

Senator WEBBER—We are happy to share that cancer with you if you would like!

Senator HUMPHRIES—No. I am very pleased that these are not problems that I am sharing in a personal sense. You do say in your submission that the total number of women treated for gynaecological cancer in the Hunter New England centre between 1993 and 2004 increased by 75 per cent. That is a much larger increase than population growth in that area. Is there a reason for that?

Prof. Proietto—It is partly because we are looking really at occasions of service rather than at individual women. A significant number of those represent the follow-up patients that we see.

Senator HUMPHRIES—You actually say 'the total number of women treated' has increased but you really mean occasions of service.

Prof. Proietto—Yes.

Dr Perrin—I will clarify that. It is a relatively new specialty. We are starting to make inroads into who gets referred to gynae-oncologists. In the past—say, 15 years ago—a lot of endometrial cancers were treated by general gynaecologists and, say, 50 per cent by gynae-oncologists. In Queensland, for instance, approximately 90 per cent are now treated by gynae-oncologists because education has got out. As well as achieving that with endometrial and cervical cancer, with education we will hopefully increase our numbers and also increase appropriate referrals of ovarian cancer to gynae-oncologists. I think that would be part of the reason that, as your service improves—as Tony's has—and as his reputation improves, the referring GPs will start to refer more doctors to the specialist units.

Senator HUMPHRIES—Following up Senator Ferris's question about the National Gynaecological Cancer Centre, you say that in the merging of gynae cancer and breast cancer there is a tendency for the former to swamp the latter. Is there an argument that says that the enormous interest in breast cancer that there seems to be at the moment might actually be helpful to gynaecological cancer, as you bring that into a mainstream debate about cancer in Australia? In your answer, with respect, you seemed to be saying that the professional structures would not make that easy to accommodate if you were to merge the two areas, but what about from the patient's point of view?

Prof. Proietto—No, I was really looking at it from the patient's point of view. It is not the professionals or that I have a demarcation dispute with breast cancer; I think they do a wonderful job for breast cancer patients. I just think that gynaecological cancer, being different, would benefit from having its own structure, its own infrastructure and its own way of doing things. I do not see that the talk about breast cancer has in any way stimulated interest in other gynaecological cancer. It has remained in breast cancer, and that is appropriate. That is what breast cancer advocacy is about. But the fact that there is a lot of information out there and a lot of interest in breast cancer has not—at least not as far as I can see in my clinical practice or in what is coming across our area health service—stimulated any additional information, talk or conversations about other gynaecological cancers.

Senator HUMPHRIES—But isn't there an argument that if you brought the two forms of cancer together in that national centre then you might get a productive relationship? It is a strange thing to say, perhaps, but you might get more women who were entering it to find out about breast cancer and give them access to information about gynaecological cancer that they might not have had the chance to see before.

Prof. Proietto—I am not sure that it would work like that. If people want to find out about breast cancer, that is what they will find out about. Really, we are talking about a different issue with gynaecological cancer. It is not one cancer; there are many different ones, and I do not think a generic female cancer approach is necessarily going to improve gynaecological cancer care, which after all is what we are after.

CHAIR—I have got a couple of questions about the workforce, both for the medical professionals and for the nursing case manager staff. I asked these questions of the cancer nurses yesterday as well. I have got the list of the members of ASGO, and you have identified that you are a relatively new specialty. How old are you? Not you two personally; I mean we hear that a workforce issue is that it is one thing to have the numbers, but in many medical professions the profession is ageing and people are choosing to leave the profession earlier. I am looking at the list; we have got all the names, and I saw the quite clear gender bias. I know the new one in Queensland is going to be a woman, so that is possibly one in Queensland.

Dr Perrin—That is the only one we have got.

Prof. Proietto—Can I just address that? Currently, something like 40 per cent or more of the gynae-oncologists—I think it was 44 per cent when we last surveyed it—are over the age of 45.

CHAIR—Comparatively that is not bad.

Prof. Proietto—Partly because it is a new specialty. It was set up initially in the late seventies, early eighties. There have been a number of trainees, and certainly there are a number of female gynae-oncologists in Australia now, and there are more trainees coming on.

CHAIR—I can see about four.

Prof. Proietto—It used to be zero.

CHAIR—So that is good.

Prof. Proietto—The professional lifespan of gynae-oncologists is relatively shorter because of the long training period.

CHAIR—So you would be in your mid-30s, even if you do it straightaway?

Prof. Proietto—Even if you do it straightaway, it is late 30s.

CHAIR—So you are in your late 30s by the time you have the full qualifications.

Prof. Proietto—Yes.

CHAIR—So your ‘operating period’, which I suppose is the right term, is not that great?

Prof. Proietto—No, it is not.

CHAIR—So you need to be refreshing all the time with new recruits. How do you get them? How do you attract wonderful medical students? There are shortages in every profession. No matter which inquiry this committee has done, we have identified a shortage. It does not matter what it is. How do you encourage any medical person, not just young students, to choose to be a gynaecological oncologist?

Prof. Proietto—Partly it is because all the trainees in O and G do go through the gynaecological oncology unit, so they are exposed to it.

CHAIR—So everyone going through basic gynaecological training would go through your unit?

Prof. Proietto—Yes, they would go through the unit.

CHAIR—So they would get a sense.

Prof. Proietto—People will find that particular line of work very attractive, very challenging and very good. Until very recently we really had no trouble in getting trainees, or people have been keen to train. My impression is that that has changed over the last three or four years. The reasons for that may be legion. It may be because there have been changes in the way that general obstetrics and gynaecology are structured and the way that obstetrics has changed, and a whole lot of other things may be the case. A significant number of the trainees who have gone through the system in the last few years have in fact been overseas graduates who have come to Australia for gynae-oncology training and a significant number have stayed on.

CHAIR—With this specialty people can stay on in Australia. You can encourage immigration processes and so on if they choose this.

Prof. Proietto—You can.

CHAIR—In terms of specialist case management work, which is particularly challenging, is there an attraction for people with your qualifications to move into your field?

Mrs Mellon—Firstly, there is probably a lack of numbers of people who go on to do specialist oncology nursing training. The nursing profession is ageing. We as a group of gynae-oncology and clinical nurse consultants do have an education day once a year, and we have done a survey and looked at the ageing of people who are working in gynae-oncology, whether it be in the metropolitan or rural centres, and the average age of nurses was over 50. There is a lot of burnout in nursing because oncology is such a stressful area to be working in, so it is quite difficult. The way to get people to want to be in these positions is a matter of selling what it is that we do. Personally, I love the job that I do, and I find it quite a privilege to be working with these women right through their journey. On a personal note—I am wanting to go on long service leave in two months time—it has been difficult to try to get someone to do my job for just six weeks, whether that be because of the unknown of what we really do or because people do not feel that they have the knowledge to be able to fit into that position.

When we looked at the increasing ageing of the gynae-oncology nurses—and these are nurses who have worked in oncology, perhaps without specialist oncology qualifications, for over 20 years—what we found they feel confident in talking to women about really surprised us, because they are nurses who have worked in this profession for such a long time. It is a matter of selling what we do and encouraging junior nurses who are coming through to see that oncology nursing can be a challenging and rewarding profession.

CHAIR—We had detailed evidence yesterday from the cancer nurses, and they went through those kinds of things—about people’s comfort levels. Senator Allison asked questions about where people train and those things.

Senator ADAMS—With regard to these long waiting times and the community being disadvantaged, do you have any consumer groups that have been revving it up in either of the states? It is something that I think should be highlighted. Secondly, have you been to see your local politicians?

Dr Perrin—From Queensland, we have the Gynaecological Cancer Society—John Gower has been very supportive—and we write letters on a frequent basis to the Director-General of Queensland Health, so they are aware of it.

Prof. Proietto—Our consumer groups seem to be fairly silent on this sort of issue; they have not taken it up. From the point of view of talking to politicians, as an employee of the area health service I do not think I am in a—

Senator ADAMS—Yes, a bit tricky, I suppose. You have your consumer advocacy groups to do that.

Mrs Mellon—Often some of our individual patients have taken it up themselves.

Senator ADAMS—That is why I am surprised. If I were in that same boat—I was very fortunate in that I did not have to wait for my surgery—I would have been making quite a lot of noise. I think that it is unacceptable in this day and age that that is happening. Having come from a hospital administration background—and I can see what they are trying to do—it is just not on.

Mrs Mellon—In those circumstances, when individual patients make a statement or write a letter it helps them only to get their surgery date; it does not help the gynaecological cancer patients as a whole.

CHAIR—Someone else gets bumped.

Mrs Mellon—Someone else gets bumped so that the person who made a complaint can get in there and get things done.

CHAIR—You have given us the information from Queensland and New South Wales. To the best of your knowledge and with the interaction you have across your association, are there similar issues in other states—it would not just be Queensland and New South Wales?

Prof. Proietto—I think that it is right to say that, but I suspect you happen to have gynae-oncologists from the two worst affected units in Australia.

CHAIR—Your case is identified in your submission—and we acknowledge that. We in the committee have expressed our outrage at that situation—for any patient to be in that process. We are taking evidence in Victoria and Western Australia, and we will follow up with the other states as well, so that we can get a snapshot across the board. Thank you so much, particularly as, Dr Perrin, you have had to travel from the best state, and Associate Professor and Mrs Mellon, you have had to come from the Hunter. We do appreciate the fact that you have taken the effort to come to share your knowledge and experience with us. If there is anything else you would like us to know or things that come up—sometimes you leave and that is when you remember what you have would liked to have said—we are not reporting back until October so there is still an opportunity to provide supplementary information to us. If you think there is something we should know as a committee, please let us know. Thank you very much.

Prof. Proietto—Thank you for giving us the opportunity.

[3.19 pm]

LICKISS, Professor J Norelle, Private capacity

STRUTT, Dr Rebecca, Private capacity

CHAIR—Welcome. Have either of your appeared before Senate or government committees before?

Prof. Lickiss—I have had a fair bit to do with committees, though I have not appeared before a Senate inquiry.

CHAIR—You have information on parliamentary privilege, the protection of witnesses and how the process operates. If you have questions please let us know.

Prof. Lickiss—Yes.

CHAIR—Would either of you like to open with a statement or something of that nature? Then we will go into questions. Dr Strutt, we have your submission. Professor Lickiss, we have yours, but we got it today and so we have not read it yet.

Prof. Lickiss—I appreciate the courtesy of the committee because my initial submission was made under considerable difficulties after quite a nasty bit of trauma. I did my best, and I am pleased to be able to follow up. I did prepare a few informal notes this morning with regard to matters I wanted to raise, I hope more intelligently.

CHAIR—That will be very useful. We will table that.

Prof. Lickiss—There are some specific suggestions I would make. What you are getting in front of you gives some background to these suggestions. We should pay much more attention to the whole cancer trajectory, the whole journey from the time of diagnosis, and the difficult circumstances around diagnosis, right through the treatment phase and the post-treatment phase, with all its uncertainties—the so-called period of survivorship. It may be survivorship if cured, or survivorship with persistent disease. There is also the period of disease progression, if that occurs. In the focus that one sees on television, even advertising this committee, there is a great deal of stress on the need to improve early diagnosis, with which I absolutely agree, and also some other matters. There is talk about mortality rates, there is talk about cure rates, but there is not enough stress on the personal experience, the whole story of that woman's experience, which can go on years. It also occurs in breast cancer. I have obviously had experience treating patients with breast cancer, sometimes for years, and the chronicity of the disease is not appreciated. So I think the focus needs to be on the whole field, with more emphasis on an understanding of morbidity.

The point of view I bring to this complements that of my colleagues. I am not a gynaecological oncology surgeon. There needs to be more focus on the morbidity and the experience of that long continued story, rather than just bits and pieces of it. I see the need for increased research in clarifying what is at stake. We do not have enough descriptive research and descriptive studies of the lifetime experience of people with this disease. We just do not have it. We have patchiness. There is one doctorate, as I am sure you know, done by one of the nurses who presented some material to you yesterday, but there is not much. So there is an area of research that is needed, particularly in the area of symptoms—understanding symptoms, clarifying symptoms, treating symptoms. That area of research is missing. Psycho-oncology is going ahead well. The issues of anti-cancer treatment are being researched well. But the issue of the understanding of the subjective and the symptom side of things is really not there. There is some hard-nosed clinical medicine at stake there which, over the last few decades, I have tried to teach.

Secondly—and I move on to a couple of quite specific points—there is need for surer funding of training positions. The funding for training in people who understand this area—the symptom relief area, the continuing care area—is very haphazard, and it is not adequate. As my own submission mentioned, we have had many registrars in Sydney—Sydney has been the focus of that—training in gynaecological oncology for a short period of their palliative medicine training, for example, which goes for several years. But the funding is very precarious. This cannot go on. There is need for much surer funding with regard to those positions, preferably tied to the cancer centres themselves, so that a gynaecological oncology centre has a tied registrar position in palliative medicine/continuing care.

The other need that I see quite specifically is for skills enhancement training. As you heard, it takes years to train in gynaecology oncology. It takes at least 12 or 14 years to produce a palliative medicine specialist. Meanwhile we need to provide opportunities for short-term fellowships for people who already have some of the knowledge—general oncology, radiotherapy etcetera—so they are able to enhance their body of knowledge in the area of gynae-oncology. I think that would be a short-term measure that would have high yield. That would be my view on that.

I personally think another thing that is needed is that we should set up strategies for much better continuing care and surveillance of women survivors of gynaecological cancer. We have many times seen tragedies happen because the symptoms of relapse are just not appreciated by whoever the woman goes to, and they have gone round and round and had unnecessary delay and unnecessary pain—which happens to be my particular area of expertise—whilst a situation is being brought under control. We do need to do better on the surveillance side. It is very haphazard, and I see a lot of thinking and intelligence needed there to do something about that. Part of it will be woman initiated and part of it will be of course be related to public education and people becoming aware of what it is possible to do. But part of it does need to come from the health service to get something better—nets that people do not fall through, because that is happening. There are no easy answers there. I just want to earmark that that is an area of need.

I do support the concept of a national centre for gynaecological cancer for several reasons. One is that I think the time has come. The breast cancer focus has helped us see what can be done. The chicken and egg thing is real. If there is a resource injection you get injection of intellectual energy, you get interest of young people in the field and you do start to see a take-off. I think the example of breast cancer has been magnificent, and I think the time has come when the gynaecological cancers should be given that kind of boost. Not being a gynaecological oncologist I can say—and I do have international experience in several relevant matters—that

Australia has been a leading light in gynaecological oncology. There is real talent in this country and this really needs to be harvested now. I think it is a great pity if we do not.

As I have mentioned, the symbolic value of creating a centre is important also. It would give us a way of stimulating interest in the situation of women with cancer, and that would not hurt in our region. The status of women is precarious in some countries in our region and the incidence of gynaecological cancer is very high—I have personally done some work in Indonesia and places like that. The women who get some of the worst of the cancers are often the underprivileged women, not the middle-class women, particularly with cancer of the cervix. The whole issue of a nation prepared to put a spotlight on gynaecological cancers is, I think, symbolically very important. I do not think symbols are worth nothing. I think symbols are very important at this time.

I am not sure that I want to say anything more than that as my introductory remarks. I am very pleased Rebecca Strutt is here. She represents one of the several trainees—we have had a couple of hundred registrars in Sydney but some of them have ended up as specialists in palliative medicine. We have had over 20 of them—often heads of departments, heads of services—and, of those, some did special training in palliative medicine in gynaecological oncology. Rebecca is one of those people. It is a handful and it should have been much more common than that. That is what I would like to see for the future: more specialist training available in palliative medicine; that it is not such a lottery that you just get that position. That is all I want to say, unless there is anything else that you want me to volunteer.

CHAIR—We will ask Dr Strutt whether she wishes to make a statement then we will go to questions. I am sure there will be questions from the senators. Thank you for that opening statement.

Dr Strutt—I want to stress the point that Professor Lickiss made about the morbidity associated with the disease. Although we will be looking for screening tools we have to remember that in the case of, for example, ovarian cancer, 70 per cent of women will present with late-stage disease. It may be 10 years before we have an effective screening tool. That is the area in which I work: women having maybe three, four or five cycles of chemotherapy, going through different stages of their illness and understanding the complex set of symptoms that they get. Because I work in the community I fear the lack of understanding by medical and nursing practitioners in this field.

Professor Lickiss has talked about the concept of having a clinical fellowship in continuing care, which I see could be very useful for someone like me, whereby GPs and clinical specialists could maybe get three months experience and take that back with them. I always feared discharging a patient to a rural area. I know, in my heart of hearts, that it is a lottery as to whether they get the right treatment, even in Sydney. The reason is that a GP may see only one palliative care patient per year, so they do not have the experience. I do want to stress the morbidity rate, that many women will still fall into the category of late diagnosis and that is a real concern for me looking after women in the community.

Senator ALLISON—Professor Lickiss, can I start with what you said in summarising your points: there needs to be increased funding for research concerning complex factors involved in causation. We have not heard a lot about that so far in this inquiry.

Prof. Lickiss—I presumed that you would have had a discussion on causes of gynaecological cancer. You haven't?

Senator ALLISON—Apart from HPV, which is the most obvious one. Do you feel that this is an underresearched area just in Australia or world wide?

Prof. Lickiss—The answers are not clear. In my younger life I was a little interested in the causes of cancer. There is some evidence, for example, that obesity is tied up with uterine cancer—corpus uteri. We know that there are some viral associations with cancer of the vulva, not in all of them. We know that HPV is accompanied by smoking as a risk factor for cancer of the cervix. Cancer of the ovary is a mystery. We know there are genetic factors, but we also know that anything that you can show genetically in the way of genetic markers is responsible for a very small amount of the incidence of ovarian cancer, and that is the big mystery. Anyone who is working in this field knows that ovarian cancer is the great challenge. Cancer of the cervix is much more understandable; it is a much more comprehensible form of cancer. There is light now that we may be able to prevent it. We also know how to diagnose it early and we do know some of the things that cause it. Most of it is a mathematical association with viruses, but it is also aggravated by smoking.

We have done a little bit of probing at the Royal Hospital for Women with regard to why some of those patients with very early cancer of the cervix do progress and do not get cured when, statistically, they should. There is some interesting research there, and we have to try to understand that more. The generic answer is there is certainly more need for research into causes of gynaecological cancer—there is no doubt about that whatsoever. The taunting one is ovarian cancer. The others are more understandable, even though we cannot beat them all.

Senator ALLISON—Ovarian cancer is not positively associated with smoking?

Prof. Lickiss—No; nor with obesity. There are some genetic factors. My surgical college would not want me to go on about this because I am not a surgeon, but I am still a paid-up oncologist. One form of ovarian cancer is a little associated with endometriosis. There are some associations. But the field is not clear. Even with breast cancer, too, the field is not clear about its aetiology. Cancer is a very multifactorial disease. When I was young I used to grow cancer cells in the medical school laboratories at the University of Sydney—so that is actually 53 years ago I was trying to grow cancer cells.

As one moves on one realises that it is not quite as simple as that. We are dealing with very complex interpersonal relationships and physiological complexities with regard to the aetiology and progression of cancer. Keep in mind that the issue of the cause of cancer is not only the cause of the initiation but the cause of progression to a metastatic state. There is a lot of biology there. There are very fundamental basic sciences there. I used to be very well up on my reading on that when I was very interested. I happened to be interested in the aetiology of lymphoma. That happened to be my particular area of interest in the seventies, and I was much more aware of that. The complexity is great and the need for research is right and pressing. Australia has the ability to contribute in this area.

At the moment genetics is the flavour of the month. There is no question that genetic aspects of ovarian cancer are important. The mileage will come from trying to find any environmental triggers that are critical. You cannot change your parents, you cannot change your genetics. But if we knew, for example, that people with a particular genetic predisposition should never eat honey or they will get ovarian cancer we would be on pigs' backs. But we do not know that kind of thing. We do know that certain people with genetic predispositions should not smoke because there is a much higher risk of lung cancer. We do know that. But smoking does not have any tie-up, to my knowledge, with ovarian cancer.

Senator ALLISON—Dr Strutt, we have heard throughout this inquiry that up to 50 per cent of women with ovarian cancer in particular, but not only ovarian cancer—other gynaecological cancers as well—are receiving inadequate treatment. That is, they are not seeing gynaecological oncologists and they are not being treated in a 'multidisciplinary'—that seems to be the jargon for it—environment and that in some circumstances there is too great a readiness to see patients as needing palliative care rather than some sort of surgical intervention. Since you work in palliative care, do you ever see any incidence of this?

Dr Strutt—Palliative care is a specialty that comes in when needed. I may come in at a diagnosis if someone has a lot of pain associated with their diagnosis or has a lot of post-operative pain. I may then not be involved with a woman for many years but then at relapse I may see her. Palliative care—and I will take Norelle's term—is not a cigarette-butt approach where you get it at the end of your illness. This is particularly so in gynaecological malignancies, because these women have ups and downs and they have relapses. We may become quite involved at one point in time with somebody's relapse if they have pain or symptom control. That need for continuing care is very important.

Palliative medicine is really involved often from the onset of a woman's disease. Some women get cured. Some women have a very long disease-free interval. I am needed on the basis of need in terms of patient symptoms; I am not there just at the end for terminal care. I may see a patient for five, six or seven years who is having relapses in their malignancy. Sometimes they have surgery; sometimes they may have another course of radiotherapy. It is definitely a specialty that is really involved almost from the beginning of their illness.

Prof. Lickiss—There are some patients where there is not an aggressive enough approach taken to the possibility of a dramatic level of control of the disease. I have certainly seen a patient like that. The importance is that anyone involved in patients like that should have enough knowledge and skill to understand the opportunities. I could actually tell you anecdotes that are quite important where people would be thought to have absolutely no chance of being retrieved and brought into remission but who are alive and well. One woman in Sydney today is running around doing some sport. It can happen.

You are pinpointing the need for a very sophisticated level of understanding of the possibilities of response of disease, rather than a nihilistic approach that such and such a disease is not going to be controllable. That needs to be balanced with a very realistic view that (a) we are all mortal and (b) there are some times when the truth needs to be absolutely accepted. To get that balance is an issue of wisdom, and it is very difficult. But you have pinpointed something quite important that happens to be a very special interest of mine in the training within our registrar system, where we have insisted that oncology as such is a very important part of palliative medicine training.

Senator ALLISON—Are there any gynaecological cancers which are particularly difficult in the palliative care phase and are there gaps in our knowledge with how to deal with them? I gather the end stage—if that is the right terminology—is very different depending on what condition you have.

Dr Strutt—Certainly, and Norelle has trained us in that. I would like to talk about our international focus. I recently attended an Oxford symposium on gynaecological malignancies and I was surprised that things we had been talking about for the past 10 years were only being put on the agenda now—such as the difficult bowel obstructions that women often get in the terminal phase of their illness and how complex this is. I was absolutely astounded at the lack of education. We are lucky to be ahead of that field, and that really comes down to Professor Lickiss's interest. There are particular scenarios where a lot of input is required in the terminal phase in ovarian cancers. For example, I may not be required by the nurses on more than a weekly basis for some patients with terminal care, but in somebody with an ovarian malignancy I am more often involved on a daily basis. I do not want to push other malignancies aside and say they are not important, but there are some instances where I know I am going to be needed on a daily basis for the management of that woman's care.

Prof. Lickiss—I will come in again because you are asking a very important question. I have pinpointed, and have discussed with Professor Hacker, instances where very serious symptoms associated with relapse have been completely misinterpreted, leading to unnecessary pain for several weeks. I want to document that expert understanding of the symptoms related to gynaecological oncology should be part of the armamentarium of clinicians involved in surveillance so that they pick it quickly, instead of having somebody going round in circles, with nobody wondering what is wrong. So there are instances where knowledge is lacking with regard to some serious situations that can arise. The variability of gynaecological cancers is both one of the most interesting things and a never-ending source of amazement.

Senator ALLISON—It is not so much research as training and imparting that knowledge.

Prof. Lickiss—Understanding it and documenting some of these instances. The thing that I did not raise as one of my final points because it sounded a little vague was number 2, the documentation of some cases where there has been delay in diagnosis of recurrence or failure of appreciation of the severity of symptoms in women in anticancer programs. We have heard some very bad anecdotes of women having very serious symptoms in the course of treatment—radiotherapy, for example—with pain to almost suicidal levels in people afraid to complain because there was not enough active surveillance. I will not forget some of those things, and they should not occur. This is in the best of circles, and it should not occur. So there are instances, and there are gaps in appreciation of the severity of things.

Senator WEBBER—I want to reassure you that the Garvan Institute yesterday presented what they saw as some of the research challenges. They said that ovarian cancer remained one of the least well understood of all human cancers and that therefore there needed to be priority funding for research into the causes and mechanisms of the development of the disease, leading to prevention. You talked about the prevention of unnecessary pain with relapse. Earlier on we had evidence of the unnecessary pain associated with early diagnosis. Usually it is very late, and it is a severe cancer, as you would both know. It is obviously that overall lack of sensitivity to the symptoms of the disease right from the beginning, and perhaps the conditioning of the women concerned that this is going to be painful, that means that it takes them months and a degree of assertiveness to get through the system in the first place. Perhaps they become conditioned to accepting unnecessary pain.

Prof. Lickiss—There are countries where, for example, analgesia is basically not available. I have taught in places where the drugs are there but not used and are very difficult to get. You are absolutely correct in that the only way that a woman can cope is by just bearing the whole thing and putting up with it. I was told that one of the sad things is that it is presumed that if a woman gets cancer of the cervix in a country like Iran at the moment, although things are fortunately moving, she sits in a corner of a house and dies in pain. It is very hard for us to understand that. In some cultures the only way of coping with symptoms is, in fact, by repression, conditioning and adaptation. It is an ethical issue if we say that that is the optimum for the human race. In our society, on the whole we would say that we should not expect our women to have to have that means of coping with that level of distress. This is a very big issue; it is a very deep culture.

One of my concerns is that, in a multicultural society—and I have made very brief mention of the fact that I worry about women whose language is not primarily English—it is very hard to understand their symptoms, because symptoms are intrinsically subjective. It is not just a question about interpreting language; it is actually about understanding the mindset and trying to understand their experience. I worry that we may have a lot of buried distress in our own society with regard to culturally slightly alienated women or women who are outside the torchlight. Keep in mind that I am still a paid-up medical oncologist, even though it is about 20 years ago that I gave chemotherapy. I have just lost track of what I was going to say. It must not have been very important. I will leave it. The cross-cultural thing is very deep and very dear to me.

Senator WEBBER—Do we know enough about the psychosocial support that we have to give women from culturally diverse backgrounds.

Prof. Lickiss—What I was going to mention was that in all of the research in the anti-cancer treatment area—the randomised control trials et cetera—anything that I have seen in the way of protocol positively excludes women who do not speak English, because getting data is very difficult, as is filling in all the checklists. It really is a very strong trend in oncology. It is something that we need to react against, not only ethically but practically. We of course know that diagnosis is often delayed in those groups, so we have a lack of preventive things, but also we may be missing some serious levels of distress and putting people into the kind of pattern that you were talking about.

Senator WEBBER—Could I go on, and I promise that I will then finish because it is getting to the end of the day, when time is of the essence. We are told that we have guidelines on the kind of support that we need to give women who are diagnosed with some form of gynaecological cancer. Do we know enough? Are the guidelines sensitive enough to take the cultural differences into account?

Prof. Lickiss—I will opt out on answering that because I have not seen the written guidelines. I have seen the ones on breast cancer, of course, I am aware of the nurses initiatives going on and I have been to some presentations, but I am not prepared to answer on that. My suspicion is that they usually do not adequately cross the cultural bridge. Culture is not just about ethnicity—

Senator WEBBER—That is right.

Prof. Lickiss—it is about geography, occupation, educational attainment and sometimes attitude. You will even see some problems with the cultural gap between the professional staff and people living a rather alternative lifestyle, where the serious symptoms are completely misread because communication is very difficult across that divide.

Senator ADAMS—My question is for both of you. I am from a rural area, and I am very interested in the Patient Assisted Travel Scheme, especially for those who have to have oncology and radiotherapy. Would you both be able to comment on how you feel the scheme works here for your rural patients, and also their follow-up when they go back? I note there have been a few comments in your submissions.

Prof. Lickiss—I cannot answer on specifics. I cannot answer on that. I am prepared to say that I do think the future should have more of an exchange situation. I spent one year of my life flying one day a week to Orange to run a clinic with general practitioners in the morning, to meet the nurses from the surrounding towns at lunchtime, to see patients in the hospital in the afternoon, and then get on a plane and come back. I was a consultant going into the situation just to bring some technical expertise to enhance their already superb quality of practice and care. But with regard to the patients, I cannot answer.

Dr Strutt—There is the funding to get people to and fro, but the problem is actually treating people in their area. My problem is I send someone home knowing that there is not somebody who will be able to visit them every other day, for example, if they have terminal bowel obstruction or, if there is someone, that person is covering a huge area and may not have the expertise. You tend to maintain some sort of phone link with them, because a lot of the patients I see are not well enough to keep coming back, and that is when you see some problems arising. That is why I keep coming back to the teaching hospital, because it is really at that stage, at a later stage, that their care needs to be where they live. That is something that is an issue with a number of GPs and nurses in rural areas. It cannot be got by coming back to the centre, and that is why we feel that training people to go back there with some expertise would go some way towards alleviating the problem.

Prof. Lickiss—We both agree that skills enhancement, and even strengthening of the travelling consultant, does have a place, as long as it is focused on exactly meeting where the gap is and not downskilling local people.

Dr Strutt—Your telephone consultation is only as good as the information you get, and it still relies on the interpretation of the person at the bedside. My interpretation may be completely different to that, so it has got to be someone either going there or somebody who we can enhance. There are some wonderful community nurses who I am sure would be absolutely chomping at the bit to enhance their skills.

Prof. Lickiss—I noticed in Orange, where I used to go, that the general practitioners were above average in their comprehensive care and their capacity to understand people. The psycho-oncology, family support et cetera, that is not where it was needed. We just needed to bring more technical assistance into the pudding to assist in improving care. Once one had personal relationships established with the doctors—not letters, ringing—then it was possible to keep telephone contact during the intervening weeks. That helped them with their next problem. The concept of exchange is just as important, whilst making certain that there is enough travel money for patients who truly will benefit by coming back to the city. The sorting out of which ones really will benefit by moving is an art form. It is very difficult.

Senator HUMPHRIES—I do not know if it is possible to rank illnesses or cancers according to how seriously they debilitate their victims and how painful they are, but is it possible to do that when comparing gynaecological cancers with other forms of cancer?

Prof. Lickiss—It is, even within the gynaecological group. Pain with cancer of the cervix can be a very, very serious issue. With patients with recurrent disease that is not responding to chemotherapy, we have got an increasing complexity of the pain problem the longer that person lives. In ovarian cancer, pain is of a different type and is usually more easily controlled. In uterine cancer, it is usually bowel and tummy symptoms that are the biggest battleground. The cancers vary very much across the spectrum, even within the gynaecological cancer area. I do not think I could say that gynaecological cancers are more or less symptomatic as a group than other cancers.

I want to make it clear that I have not been talking about palliative medicine or palliative care; I have been talking about my experience across this whole spectrum. It just happens that I was asked to concentrate on palliative medicine for about 20 years and to try to teach it.

Most of us think that advanced melanoma is one of the most difficult things that you could have to die of, but every cancer has patients with problems that are easy to manage and problems that are difficult to manage. One of the issues is to train people so that they can handle that broad spectrum. Does that help at all?

Senator HUMPHRIES—Yes, it does.

Prof. Lickiss—Cancer of the vulva is always a very difficult cancer to die of, if the disease locally is not controlled. That is why it is a good example of a cancer where sometimes one would do local treatment—operate on the local cancer—even if there was metastatic disease present, because dying from what we call a local cancer, a primary cancer, is sometimes a much more difficult situation to cope with than from systemic cancer.

Senator HUMPHRIES—Do you mean psychologically or—

Prof. Lickiss—No, I mean physically—the symptoms from local disease. We see it in, for example, head and neck cancer and things like that. Symptoms from local disease are much more difficult to control, from a symptom specialist’s point of view, than systemic symptoms—say, a few secondaries in the lung or something like that. That is a breeze compared with some of the local problems. Dying of locally invasive cancer of the vulva is terrible. Those are very subtle things that influence judgments of what best to do in an individual case and why it is so complex.

Senator HUMPHRIES—In what percentage of gynaecological cancer is effective pain management not possible?

Prof. Lickiss—Very trivial, very minor. I think that both Dr Strutt and I, looking back over years, would have great difficulty in thinking of patients that we could not control the pain of. We might have had to use our brains more with regard to some percentage of them, but these days, fortunately—we could not have said this 30 years ago—we can usually get on top of it. It is just that it requires more knowledge, more expertise, more experience and different approaches. Pain is very complex. I used to teach a sort of slogan that 90 per cent of the pain is controllable for 90 per cent of the time in 90 per cent of the patients by fairly straightforward palliative medicine techniques. The other 10 per cent is what you really need your specialists for.

CHAIR—Thank you very much.

Prof. Lickiss—Thank you for the privilege of trying to take this further forward.

CHAIR—Absolutely. If you think of other things you would like us to know, particularly when you go away and review what you have said—

Dr Strutt—There is one thing that Norelle has taught me which she did not bring up. We were talking about the longevity and the chronicity of disease, and I think it is important that people understand that we see women who may have pain for weeks, months or years before CT scans or MRI scans show anything. In that case, you have got to say, ‘This person has a recurrence,’ and you have got to say it before a scan shows it. We see problems there. Doctors do not want to give bad news, especially when they do not see it on scans, and that is some of the delay sometimes as well. You can have pain 18 months before you see something that is that big on a scan.

Prof. Lickiss—Rebecca is putting her finger on something there: the clinical science of symptomatology, which I decided to focus on—rather than psychosocial support and all the rest, which I happen to be rather interested in. In the science of symptomatology, one of the issues is that symptoms clearly understood—and that requires a very experienced capacity for communication, understanding and crossing cultural barriers—and listened to and watched over time are much more accurate than imaging techniques. That is what she is actually referring to there.

We have seen some patients who I was absolutely certain, on the basis of the symptoms, had a recurrence. You might think that that is unintellectual. Ten or 15 years ago, in Sydney, I had an instance where I was certain somebody had a recurrence and somebody objected to my use of morphine to get hold of that pain in the patient, on the grounds that the person did not have proven recurrent cancer.

Dr Strutt—That can still occur in the eastern suburbs. People want to know. People are frightened of prescribing opioids unless there is a recurrence clearly documented—and we do not see clear documentation. Norelle has put it in a better way, but I do want to highlight that point.

Prof. Lickiss—It is not just academic.

CHAIR—No.

Prof. Lickiss—The issue of diagnosing recurrence is actually very important, as is taking away the uncertainty and getting clarity with regard to treating. I have fortunately had available to me PET scans, CT scans and all the rest, so the imaging is available in Sydney. But the knowledge of symptoms is actually more accurate. This is hard to teach.

CHAIR—And hard to prove.

Prof. Lickiss—Part of my discussion is that I think there should be clinical fellowships in improving understanding of symptoms alone. Leave out all the rest of it. If we had those we would actually get some advance, because that is the bottom line. The rest can build on that. If that is faulty and the care system has shaky foundations, we are in trouble. I am overreacting there because I see a gap. But my time in this has passed—and here is the future—so I am allowed to say these things.

CHAIR—Thank you very much, Professor Lickiss and Dr Strutt, for making yourselves available.

Prof. Lickiss—Thank you very much.

Proceedings suspended from 4.01 pm to 4.13 pm

CARTER, Professor Jonathan Robert, Gynaecological Oncology, Royal Prince Alfred Hospital

CHAIR—I welcome Professor Carter. Have you given evidence at parliamentary committee hearings before?

Prof. Carter—No, I have not.

CHAIR—You have information on parliamentary privilege and the protection of witnesses. If there is anything you are unclear about, let us know. There is a standard way of doing things. You have given us a submission. You now have the opportunity to make an opening statement, and then we will go into questions. That is the sequence. Do you have anything to add about the capacity in which you appear?

Prof. Carter—I am professor of gynaecological oncology at the University of Sydney, the area director of gynaecologic oncology services for the Sydney South West Area Health Service and the head of the Sydney Gynaecologic Oncology Group at Royal Prince Alfred Hospital.

CHAIR—Do you have an opening statement you would like to make before we go into questions?

Prof. Carter—Yes. It is unfortunate that one in three women in this country will develop cancer, and a disproportionate number of those will have a gynaecological origin. Of the women who die from cancer, a disproportionate number will have gynaecological cancers, primarily ovarian cancer. This has been a problem that we have ignored for far too long.

I lead the Sydney Gynaecologic Oncology Group, which is an integral part of the Sydney Cancer Centre at Royal Prince Alfred Hospital, and we represent a collaboration in comprehensive cancer care between Royal Prince Alfred Hospital and the University of Sydney. My group, the Sydney gynae-oncology group, provides gynaecologic oncology care for women from the city all the way through to Bowral, which is a very large area of the Sydney South West Area Health Service. We have our tertiary gynaecological care facility at Royal Prince Alfred Hospital in the city and our secondary care facility at Liverpool Hospital in the western zone.

Together we call ourselves the Sydney Gynaecologic Oncology Group. We share our available funding, which has been partly given to us by the Greater Metropolitan Clinical Taskforce. We have shared treatment protocols and shared research. We have some staff that is shared. We share our patients. As a team, we provide good care to patients in our area. Our area, like the country, unfortunately, is a very large area. Sometimes our patients do have to travel to one of our treatment facilities. We think the area is too large and our resources too limited. We think that our model certainly could be one of the models envisaged for tackling the problem of gynaecologic cancer care in rural areas.

Our submission like other submissions highlights a number of things. While we are all providing good care, we are hampered by a number of resource, personnel and financial constraints. We are all trying to do a good job to a greater or lesser extent but we are doing it in a disjointed fashion. I think what we are lacking in gynaecologic oncology in this country is a national task force or a national gynaecological cancer centre.

That cancer centre should really have a clear and accepted plan for delivery of gynaecological cancer care that would include screening, treatment and management of post-treatment morbidities. It should also, within its jurisdiction, develop a national gynaecologic oncology database to accurately measure data for planning and outcomes assessment to oversee the development and distribution of educational information and treatment protocols to our consumers, the public, general practitioners and allied health workers. It would develop strategies to help minimise the cost and burden for those patients who indeed have to travel to get access to our services. It would recognise and support vital research into gynaecological cancers and ensure that all tertiary units providing gynaecological cancer care are adequately resourced and staffed. I thank you for allowing me to present on behalf of the Sydney Gynaecologic Oncology Group.

CHAIR—I am sure there will be questions, Professor Carter, but I want to open by asking if you are adequately staffed and resourced now?

Prof. Carter—No.

CHAIR—In your submission you actually list some of the key personnel at the end of the submission. How many more do you need?

Prof. Carter—How long is a piece a string?

CHAIR—I know.

Prof. Carter—The unit at Prince Alfred, which is the tertiary unit, lacks a number of personnel. The unit at Liverpool, which is really the apex of a huge growth area in south-west Sydney, lacks a significant amount of funding and resources. They are really behind the eight ball out at Liverpool.

CHAIR—And you share those resources between the two centres?

Prof. Carter—The GMCT has allocated $300,000 to our group, of which we have $150,000 each. That is not a lot of money.

CHAIR—No, it is not.

Prof. Carter—Our $150,000 goes to a group data manager. Our data manager looks after both the eastern and western zones. We have a clinical fellow who we train on a yearly basis to try to get into gynaecologic oncology. The western zone employs care coordinators and clinical psychologists with part of their $150,000. It does not go nearly as far as required. Some of the resources that we are missing out on are access to appropriate imaging such as PET scanning and MRIs and access to an ever decreasing amount of beds and theatre time. As far as personnel, all tertiary units really should have a gynaecologic oncologist because, without a gynaecologic oncologist, there is no gynaecologic oncology unit. There are workforce issues there, which I am sure you have heard about. We need care coordinators, psychologists, social workers, data managers, research and trial assistants and a variety of other personnel without which I do not believe any unit in this country is fully resourced.

Senator ADAMS—With the Patient Assisted Travel Scheme, can you give me an indication as to how you feel the New South Wales scheme works for rural women who are coming into your area?

Prof. Carter—People are referred primarily from the other side of the Blue Mountains to the city units. There seems to be a lot of paperwork and a lot of hassle involved. There are always forms to be signed. They are always chasing up on their reimbursements and so on. They do have to spend a long time away from home, as you are well aware, and not only to see me. I might just be the tip of the iceberg. If they have chemotherapy, that might go on for three to five months. Radiotherapy goes on for six weeks and they are continually away from home. So it is not just the problem of getting them to the city; it is actually making their stay less traumatic while they are down here. It is not just the patient; it is the family, and also what they have left behind. It is a huge issue, and I don't have the answer to it. I am sure the answer is not that straightforward, but just giving them $100 and saying, 'Get in a taxi' or 'Get on the train'—the CityLink or the CountryLink train—down to Sydney is not the best way to approach patients who have cancers and who do not have direct access to one of the tertiary care facilities.

The answer is not putting a tertiary care facility out the back of nowhere, because you will never be able to staff it or provide the quality that you need. So unfortunately, in this big country of ours, like the big area we have that I look after, you have to allocate your resources where you think they are best placed. Unfortunately, people have to travel, but how do we minimise that and minimise the trauma while they are away from home and while they are down here? I don't have an answer to that.

Senator ADAMS—With your unit, as far as accommodation is concerned—

Prof. Carter—We have no accommodation for country people.

Senator ADAMS—Right—so there is no accommodation anywhere?

Prof. Carter—No. We have plenty of hotels, and we have a social worker who is not assigned to our unit who may help, but usually that is after the case. Usually he helps with the partner. But when the woman comes down from Dubbo to see me or to see our team, she will often have to seek primary accommodation off her own bat, and that could be from a hostel down the road to a hotel or whatever.

Senator ADAMS—They have their treatment at your unit for their radiotherapy?

Prof. Carter—Assuming they come from Dubbo, which is 300, 400 or 500 miles away, they would primarily have their surgery, radiation and/or chemotherapy, whatever they require, at Royal Prince Alfred Hospital. If, for instance, they have seen me and they have come from somewhere else within our area, they might have their surgery with us but have their further therapy at Liverpool, or there is a medical oncology unit at Campbelltown. So their access to medical oncology and radiation oncology is a little bit easier sometimes than surgery. That is what would normally happen for patients coming from areas not specifically next door to Prince Alfred or Liverpool hospitals.

Senator ADAMS—And the back-up for them to get from A to B for their treatment and all of that sort of thing—

Prof. Carter—Is poor.

Senator ADAMS—Are they supported?

Prof. Carter—Not well supported by the hospital. There are interhospital buses available. It is an area we are sorely lacking in. We are unable to effectively transport patients from Campbelltown to Liverpool Hospital for treatment or for follow-up or for X-rays. It is an issue that we have addressed at our cancer centre executive meetings. It all comes down to finances, and finding a way to do it in a smooth and streamlined fashion. But we are poor just with patients in our area, getting them from Bowral to Campbelltown, let alone from Dubbo to Sydney.

Senator ADAMS—We heard from the Hunter earlier about their problems with a lack of theatre sessions and also having to cut down. Is that happening in your area as well?

Prof. Carter—At Royal Prince Alfred Hospital we have ongoing, rolling—every 10 weeks 15 per cent—theatre reductions. While I was waiting in the audience I was called by a theatre director, the head of theatres, to put in my next 10 per cent cut of theatre time. That is across the board.

One of the resource issues that we all face—and it is not just in gynaecological cancer; it is in all cancers and all medicine—is the decreasing resources, access to theatre time and access to beds as well. It is not an uncommon occurrence that, while there might be theatre time, there might not be beds or vice versa. You can have patients who are able to get to theatre, but if there are no beds in the hospital that theatre is closed. If that patient’s operation is cancelled she then gets delayed. If you have a two, three, four, five or six or 10-week waiting period everybody just gets pushed down the line.

CHAIR—I do not have Senator Adams’s medical background, so could you just explain that percentage cut to me again in terms of rolling reductions? I do not understand that. It is like an efficiency dividend. It is almost like a cut.

Prof. Carter—We have a 15 per cent cut in our theatre time.

Senator ADAMS—You are saving money, in other words.

Prof. Carter—Yes.

CHAIR—And every 10 weeks you cut another 15 per cent?

Prof. Carter—No. Every 10 weeks we allocate theatre sessions. I operate all day Tuesday and half a day on Thursday. So that is three sessions a week. Over a 10-week period I have to pull it down 10 per cent. I will cut and close 10 to 15 per cent of those theatre lists for them to save money. They can put the nurses and all the other staff that go with theatre time elsewhere, to save money.

CHAIR—So you are not cutting 10 per cent off, 10 per cent off?

Prof. Carter—No.

CHAIR—In my mind I saw you shaving off that much.

Prof. Carter—It is actually a 15 per cent theatre reduction. At this time of the year in particular the hospital is often full of patients coming through accident and emergency with coughs, colds and sore throats. When the hospital is full, elective surgery—which is what cancer surgery is considered to be; it is urgent but it is still elective—has to give. In all fairness, our hospital goes to great lengths to avoid cutting cancer surgery.

CHAIR—That would be a priority.

Prof. Carter—Yes. But I cannot say that that is the case for every hospital.

Senator ADAMS—How many patients would that 10 or 15 per cent be? I know it is hard because they are all at different times.

Prof. Carter—I operate on a Tuesday and I do two to three cancer operations each Tuesday. Over a 10-week period of 30 lists, you are looking at 10 to 15 per cent of those. The patients still get operated on but they get operated on later rather than sooner.

Senator ADAMS—Which is not the ideal situation for them.

Prof. Carter—It is not the ideal situation for an early cancer. It is not the ideal situation for a woman who in fact does not have cancer but who is thought to have cancer. It is not ideal to tell that woman: ‘You might have to wait for a month,’ when she thinks she might have cancer. It is not the ideal situation when you have an advanced ovarian cancer. If it is advanced it can certainly make surgery more complicated, and psychologically and for other reasons it is not good when you have an advanced cancer.

Senator ALLISON—We have not had much discussion about the training that is provided to gynaecological oncologists—except that we heard that it was a three-year time frame.

Prof. Carter—I trained in this country and I also trained and worked in the United States for six years. The problem that we are facing in this country is a workforce issue across the entire country. It is particularly evident in medicine, obstetrics and gynaecology. I am trained primarily as an obstetrician and gynaecologist but I do not practise obstetrics—never have—and I do not practise general gynaecology. To get where I got I had to go through four or five years of general residency and registrar training.

Senator ALLISON—In a general hospital?

Prof. Carter—Yes. I was then accepted onto a training scheme to become a specialist for five years. During that training I realised I wanted to be a cancer surgeon. I had to wait to get onto a training scheme, so I waited for another year and then had a three-year training scheme. So I was in my mid to late 30s before I actually finished studying.

Senator ALLISON—And then you started paying off your HECS.

Prof. Carter—I am a little bit before that. The problem is our graduates coming through now are looking at people like me and saying: ‘Why would I do all that training? Why wouldn’t I do something a little bit easier and practice general obstetrics and gynaecology?’ We are having a lot of difficulty training the new cancer surgeons, because nobody wants to go through that pain of training. While a lot of things that we do in our day-to-day work help a lot of people, unfortunately some of our patients die and it is a stressful occupation. So why would you want to do it? There are those of us who have always wanted to do it, but to encourage the new generation is an issue.

Senator ALLISON—What are some of the ethical issues that you deal with on a day-to-day basis?

Prof. Carter—What do you mean?

Senator ALLISON—It seems to me there are some ethical issues associated with prioritising patients, for one thing. We heard this afternoon a bit about palliative care, and we also heard about patients being treated by surgeons who are not part of a multidisciplinary team. How much discussion is there about the ethics of these situations? Do ethics committees from hospitals become engaged in this dialogue?

Prof. Carter—Ethics committees generally will look at research protocols to make sure that they are ethnically sound and not at whether a doctor in the periphery or a non-cancer surgeon should be operating on such and such a patient. There are internal mechanisms in larger hospitals. At the Prince Alfred—and I say this because I am head of gynaecological oncology, and another hat that I wear is that I am the head of general gynaecology—we are able to keep a tight rein over who does what. We have a fairly robust credentialling and privileging process. But for all intents and purposes, as a qualified obstetrician and gynaecologist, anybody can operate on cancer, although they should not be if they have not had that training. Unfortunately, many patients who have gynaecological cancers have their surgery performed by non-gynaecological oncologists.

Senator ALLISON—What do you think should be done about that—a bit more education?

Prof. Carter—I think education is important. I have just published a paper in our Australian journal on 12 young ladies with ovarian cancer to highlight the fact that, while ovarian cancer tends to occur in older women, a large percentage can appear in young women, so younger women can have ovarian cancer. It is an ongoing educational process. Educational processes take a long time for that to sink in. Indeed, it may be appropriate for a higher authority, a state or a federal authority, to say to patients who have suspected gynaecological cancer—because the outcomes are so much better if they are operated on or cared for by a team—that those patients should be directly referred to a gynaecological oncology unit.

Senator ALLISON—Are there any other instances where that takes place, where there are some conditions where the law or the regulation or a dictum of some sort says that you cannot treat this person because of inadequate qualifications?

Prof. Carter—I am not aware of any off the top of my head, not a law as such.

Senator ALLISON—Even a direction or someone on-high saying, ‘From now on, you have to have both—

Prof. Carter—It is understood in breast surgery that patients with breast cancers have a better outcome when they are cared for by a qualified breast surgeon in a multidisciplinary approach. It is the same with colorectal surgery.

Senator ALLISON—So by ‘understood’, do you mean it is has become the common practice and so now it is understood?

Prof. Carter—Yes, but that is not to say there are still not dabblers out there who, for financial and/or other reasons, feel themselves as amply qualified as the qualified breast surgeon, and who refuse to refer on. That is an issue, with them saying, ‘I can operate on a pelvic mass; why should I send that patient along to Professor Carter?’ So those patients are operated on by a general gynaecologist, often to the detriment of the patient. How you legislate or force that person to refer on, I think that would be difficult. That is where education comes in.

Senator ALLISON—Has it ever been taken to a court of law?

Prof. Carter—I am aware anecdotally of a patient in Western Australia who was operated on by a non-gynaecological oncologist, who found out that in fact the care would have been better had she been operated on by a cancer surgeon. It is my understanding, and it is hearsay, that the patient actually sought some medical legal advice. I am not sure what happened to the case.

Senator WEBBER—Professor Carter, can you provide the committee with a copy of the paper that you referred to—the one that you had published? I am sure we would all enjoy it.

Prof. Carter—Yes.

Senator WEBBER—We may not understand all of the medical terminology, but we are getting better at it.

Prof. Carter—It is a series highlighting the cases of a dozen young girls, over a six-month period of time, who were referred to me with issues about their management. Some of the management was quite appropriate, but many of the things that occurred had a detrimental effect on those women and, unfortunately, many of them are now dead.

Senator WEBBER—I cannot speak for everyone else on the committee, but I for one would find that interesting. You mentioned before, as well as in your submission, that we talk about the lack of resources and then about the lack of national coordination. To what extent do you think that is? As decision makers within the wider community, we are only just becoming aware of the significance of gynaecological cancers. As a shorthand way of putting it: is it due to gynaecological cancer being the poor cousin of other cancers that perhaps have a more established network?

Prof. Carter—I think that is largely true. Also, our predominant cancer—the deadly one—is ovarian cancer. Unfortunately, many of those patients do not live as long as patients with breast cancer or other more fashionable cancers, who can then become advocates for those cancer groups. Gynaecological cancers such as vulval cancer or vaginal cancer are not things that people would want to stand up and say that they had. Cervical cancer also may have a connotation with the mode of transmission of the HPV virus, which is by sexual transmission. Our biggest group of patients have ovarian cancer. That is the one cancer that most of us deal with on a day-to-day basis. While one in five women will be long-term survivors of this cancer—I saw a lady in my rooms today who has been perfectly well for six years—more commonly those patients do not survive.

Senator WEBBER—If the committee were to recommend national coordination through a national body that specialised in coordinating research and treatment of gynaecological cancer, would that be a step towards proving to some of the people whom you are trying to attract that we do value the profession and that it is a legitimate career path, rather than everyone having to be as persistent and patient as you to get to the other end of the training?

Prof. Carter—Absolutely.

Senator WEBBER—If we were to establish something like a national centre, to what extent should it look at raising public awareness and increasing public education? We have had some mixed evidence on this. There is the view that what we are doing is a step in the right direction, but it is probably enough because we do not want to make every woman who has consistent pain and is bloated think that therefore she has ovarian cancer and she should rush off and insist on the test, versus the view that women overlook symptoms and put up with discomfort. Do we need to raise awareness, and what is the best way to do it? Does it need to be public awareness or does it need to be, in the first instance, within the wider medical profession?

Prof. Carter—It needs to be both, but it needs to be done in a coordinated fashion. The gynaecological cancer centre would be best able to think of a strategy on how to spend the allocated bucks appropriately—whether it is to be done this way, that way or another way—so as to get the best value for money.

There is no doubt that public awareness is low. We all have abdominal distension and bloating, but that does not mean we all have ovarian cancer. The last thing we want to do is have every woman on her GP’s doorstep saying that she has ovarian cancer and using those valuable resources. Usually by the time they have those symptoms, they have advanced cancer anyway. That is where the larger body can say: ‘We need to have education. We need to put some money into research. The research for the next five years that we think is going to give us the best value for money is going to be ovarian cancer or cervical cancer research.’

At the moment everybody is doing a little bit of everything and it is just not coordinated; it is quite disjointed. That is the issue that I see that we all face. Some of the more prolific units or the units with more go-get-em leaders are doing well, but there are pockets elsewhere where the care is suffering because of that. When patients are put on clinical research protocols, it usually implies the next step in cancer care. If you are not attached to a major teaching hospital with access to those trials, those patients will miss out. That is where we need a coordinated approach, where indeed everybody can have access to a clinical trial, whether you come from Sydney or Bourke.

CHAIR—Which is not the case now.

Prof. Carter—No, that is not the case. I must say, when I was in America, every person was put on a clinical trial. In this country, a lot of our patients still consider it an experiment. Awareness and education need to be increased to emphasise to patients that, in fact, it is not an experiment but an advance. It is usually gold standard treatment against what we think is the next available and best line treatment. So participation in clinical trials is very important, and that was one of the highlights in our submission. There needs to be support of a national clinical trials group. The Australia New Zealand Gynaecological Oncology Group is really the one involved and with which we are involved as well regarding clinical based, advanced cancer trials which are often of international significance.

CHAIR—We are getting mounting evidence about access to clinical trials. I have a final question, if I may be permitted. Regarding the patients that your centre deals with, do we know enough about the psychosocial support that those women need? We have had some mixed evidence: evidence that there may be a need to do more research, particularly into some of the cultural differences that we now have in our community, versus evidence on the guidelines and that we know what we need to do; we just need to make sure that we do it. What is your view?

Prof. Carter—We have a large unit—one of the three tertiary units in Sydney. Although we do not know nearly enough, in association with the University of Sydney’s School of Psychology we are doing some very basic and rudimentary studies into vaginal dilator therapy, patient satisfaction, CA125 monitoring, anxiety levels and a whole lot of other things. We believe that we are doing a great job, but it is the tip of the iceberg. Again, it is a huge area that is under-resourced. I do not think that there is any unit in this country that has adequate resourcing in the area of psychosocial effects of cancer. We do not have an assigned social worker or an assigned psychologist. We are using circuitous methods through our associations and our research to do it, but we do not have a clinical arm in our unit for that sort of thing. It is a huge void in the way that we deliver care to our patients. We are one of the tertiary units in the country.

CHAIR—That is a budget issue.

Prof. Carter—It is a budget issue as well as a resource issue for those people. You do not just pick up those people off the side of the street, but if we had the money I would find one. I am sure that every department head of every unit in the country would say the same thing. It is also about allocating resources to where you think they are most appropriate. There is no point in having a social worker, a psychosexual counsellor or a psychologist if you do not have a cancer surgeon or if your cancer surgeon has just left or if you do not have a care coordinator. It is a big group and, unfortunately, the psychosexual component is always the last thing—not quite the last—because we do not have the money or the resources.

CHAIR—You have operated in the multidisciplinary team model at your organisation for a very long time.

Prof. Carter—The multidisciplinary team was actually first introduced into this country by Malcolm Coppleson, my predecessor. I was his registrar at the Royal Prince Alfred Hospital.

CHAIR—So you have actually had the model which celebrates the multidisciplinary team approach for that long but you do not have the budget to effectively resource it, and yet there is clear evidence that that is the way to go.

Prof. Carter—That is right.

Senator ADAMS—Coming back to GPs and diagnosis, how can we improve that? GPs are the first place someone goes to when they have a problem. Unfortunately, there are a lot of records of misdiagnosis, and by the time they get to you it is getting to crunch time.

Prof. Carter—If you are talking about ovarian cancer specifically, I would not be too hard on the poor general practitioners. I would hate to be in their shoes with people coming in with non-specific abdominal symptoms. Only a very small percentage of those patients will actually have anything wrong with them. To do a CT scan or something on every single person is truly not cost-effective, and if they do have those constitutional systemic symptoms then they do not have early disease. The thing with ovarian cancer—and I am sure you have heard it before and you will hear it in future submissions—is early diagnosis and picking it up in its pre-cancer phase. That would be the goal, like we have with cervical cancer, and everybody is well aware of what has happened to cervical cancer in this country because of the pap smear. Again, education is important for general practitioners, but the symptoms of ovarian cancer are so non-specific that, other than awareness, I would not be too hard on them specifically.

Senator ADAMS—I wanted the evidence. I am not being hard on them; I feel sorry for them.

Prof. Carter—I feel very sorry for them. It is very easy for me to sit at Royal Prince Alfred Hospital and say: ‘The diagnosis was easy because a woman walked in with abdominal distension and non-specific symptoms, she had a CA125 and the ultrasound or the CT scan had shown an abnormality.’ But what I have not seen are the 100 or 200 other women who have had wind pain. To sort those out with the tests that we have available, with the access to tests in the periphery and with the cost of everything would be an extraordinarily difficult job, and that is where the research is so critical. It is not just in this country; every developed country in the world is looking for the blood test or test for ovarian cancer. That is not what we have available, which is a CA125 and an ultrasound, unfortunately.

CHAIR—So your advice to us is the summary at the front of your submission where you list eight things, in order of priority, that you would like to see happen. Is that it?

Prof. Carter—Yes.

CHAIR—Thank you very much.

Committee adjourned at 4.48 pm