COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Services and treatment options for persons with cancer

TUESDAY, 19 APRIL 2005

SYDNEY

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Tuesday, 19 April 2005

Members: Senator Marshall *(Chair)*, Senator Knowles *(Deputy Chair)*, Senators Humphries, Hutchins, Lees and Moore

Substitute members: Senator Cook for Senator Hutchins

Participating members: Senators Abetz, Allison, Barnett, Mark Bishop, George Campbell, Carr, Chapman, Colbeck, Coonan, Crossin, Denman, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Forshaw, Greig, Harradine, Lees, Lightfoot, Ludwig, Mackay, Mason, McGauran, McLucas, Murray, Nettle, O'Brien, Payne, Watson and Webber

Senators in attendance: Senators Humphries, Knowles, Marshall and Moore

Terms of reference for the inquiry:

To inquire into and report on:

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

  (i) the efficacy of a multi-disciplinary approach to cancer treatment,

  (ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,

  (iii) differing models and best practice for addressing psycho/social factors in patient care,

  (iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians, and

  (v) current barriers to the implementation of best practice in the above fields; and

(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

  (i) the extent to which less conventional and complementary treatments are researched, or are supported by research,

  (ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and

  (iii) the legitimate role of government in the field of less conventional cancer treatment.

WITNESSES

Committee met at 9.00 a.m.

COATES, Professor Alan Stuart, Chief Executive Officer, Cancer Council of Australia

CURROW, Professor David, Vice-President, Clinical Oncological Society of Australia

ELWOOD, Professor Mark, Director, National Cancer Control Initiative

LANCASTER, Ms Letitia, Deputy Chairperson, Cancer Nurses Society of Australia

MYERS, Mrs Cheryl, Private capacity

CHAIR—Welcome. Firstly, do you have any additional background information you would like to share with the committee?

Prof. Coates—Yes. By training, I am a medical oncologist. I do breast cancer trial research. For 15 years I was the research director of the Sydney Melanoma Unit. I am here to help with things about the clinical management of cancer and cancer policy development in this country.

Prof. Currow—The Clinical Oncological Society of Australia is the national peak body representing cancer clinicians, including nurses, social workers, allied health workers and doctors. It is an organisation which has been in existence for more than 30 years. It has key responsibilities for the quality of clinical care and for clinical service provision around the country. By training, I am a consultant physician in palliative medicine. I hold the chair of Palliative and Support Services at Flinders University, one of a handful of palliative care chairs in the country. Before my current appointment, I commissioned and ran a comprehensive purpose-built cancer centre in Western Sydney.

Ms Lancaster—I am a registered nurse. I have been working as a cancer nurse for over 21 years in both clinical and management positions.

Prof. Elwood—The National Cancer Control Initiative is an expert group set up as a joint venture of the federal Department of Health and Ageing and the Cancer Council of Australia. Our purpose is to conduct studies and reviews and provide expert advice on all aspects of cancer control, which includes prevention and screening as well as cancer care. By training, I am a public health physician and a professor of epidemiology. In a past life, I have been a general practitioner.

Mrs Myers—I am a cancer consumer.

CHAIR—Thank you. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions. I now invite you to make an opening presentation to be followed by questions from the committee.

Prof. Coates—You have received our very comprehensive submission. I do not intend to waste the time of this committee by going through that in detail. We have also provided various handouts, and these can be made available to you. They begin by looking at the magnitude of the burden of disease from cancer in this country. I am sure other witnesses will have rehearsed this to you: it is the major single cause of death in Australians as classified by the Australian Bureau of Statistics. That is a matter of how you classify the vascular diseases. As a vascular disease survivor myself, I might have a different view on that. But those are the figures. It is about 28 per cent of all deaths, rather more in men than in women. It is certainly the most feared disease in Australia. Having been involved in treating it for the last 40 years, I can understand exactly why that is.

It is a disease which we do pretty well on. After the statistics in the handout I listed some of the things we do well. In Australia we do manage cancer well. By international comparative standards, the survival of people who get a cancer in Australia is right up there with the best in the world, with Switzerland and the United States, and better than most of our comparative countries. Yet we can improve. The burden of cancer is at least half preventable. We are not spending enough on cancer prevention. The treatment of cancer can be improved. One of the reasons I prevailed on Cheryl Myers to come along—I have been privileged to be part of her treatment team—was to talk to you and answer your questions about the cancer journey from the inside. Making that work involves seamlessly bringing together all that the patient needs in the treatment of that particular cancer and making that happen without it being too hard. Cheryl can talk to you about how that worked in her case. But it does not work as well as that in every case, and that is something that we can and should do better.

There are some barriers. Your terms of reference ask us to speak to those barriers. One of the biggest barriers is something that this committee probably cannot address: the multiple layers of government that are responsible for the delivery of health care. We cannot avoid the fact that people will shuffle blame and experts will shuffle costs. Let us face it: doctors are experts at shuffling costs between layers of government. This is inherently inefficient. For the purpose of the cancer patient, though, it introduces difficulties because it implies that there will be different problems in the delivery of care for those entering the private sector and those entering the public system.

The barriers in the public system are mainly to do with staffing. You can get multidisciplinary care in large teaching hospitals, but only if you have enough staff. We have referred in our submission to the AMWAC report for medical work force requirements. There are shortages in many of those medical disciplines. I would say to you also that there are major shortages in some of the paramedical positions. Perhaps one of the most critical is the therapy radiographers, who actually point and shoot the radiotherapy machines. So delivery of care in the public system is limited by resources and by manpower.

In the private sector there is a perverse incentive not to provide good multidisciplinary care, because there is no reimbursement pattern for a multidisciplinary consultation. We have submitted before, and we say again to this committee, that one of the requirements of delivering multidisciplinary care in the private sector is to develop Medicare benefit schedule items that properly reimburse the multiple specialists, and others who need to come together as part of a multidisciplinary team, to provide that. Otherwise the patient is trotted around from one to the other in a sequence where each of them can charge for their own consultation. That is not the best way to do it.

Travel is a problem because of the remoteness of many of our patients. I spent 20 years providing services in north-west New South Wales, based in Dubbo. My medical parish stretched to the Queensland border, across beyond Bourke and halfway to Broken Hill. That is an enormous area. People travelled long distances to see even the local general practitioner and the focal cancer clinic which we set up in Dubbo. But, with the devolution of travel reimbursement from the federal government to the states about 10 or 15 years ago, that has become quite inequitable. Getting to where you need to be treated is a bit of a lottery depending on where you live. That is one of the things that people find a problem, which our studies of cancer in the bush have shown to us repeatedly.

Extending from that, we in the Cancer Council have become very interested in the problems of cancer in Aboriginal and Torres Strait Islander communities. We ran a symposium on this in Darwin last year. We are in communication with the National Aboriginal Community Controlled Health Organisation, NACCHO. We have their blessings to represent their problems at this hearing, although no member of the organisation could be present with us today. We are working with NACCHO to see what concrete steps we can take to address the problems of cancer in the Aboriginal community. I am happy to answer questions on those, because we do have now some quite good information, at least in the Northern Territory, on cancer in Aboriginal populations.

The mission of Cancer Council Australia is to improve control everywhere across the spectrum of where cancer affects people. It might require research, it might require the application of existing knowledge, and it can be anywhere from primary prevention through screening to early detection, appropriate treatment—which is where I spent the coalface years of my career—and support and palliative care, and Professor Currow can talk to you particularly about that.

I see that part of your terms of reference is to look at complementary and alternative medicine, which are sometimes linked together and which I would say are pretty well normal parts of every cancer patient’s exploration of options. I find that it is the norm rather than the abnormal. I guess Professor Currow and I can address those points if they are of interest of the committee. I would now ask some of my colleagues to say something about their own areas of expertise and I stand ready to answer questions on anything in the submission or what I have just said. Cheryl, could you tell the committee what happened to you, what your journey was, and why it might have worked better in your case and why it should work for others.

Mrs Myers—I had a very positive outcome. I had cancer 5½ years ago. At that time it was like a darkness that overcame me because I did not know what to do and I did not know why it happened to me. I had the privilege of having a girlfriend who worked with Professor Coates, and she took me under her wing straightaway. She directed me to the best professional care that I could acquire, which included Professor Coates. My managed care team was everything to me because they knew me as a person; I was not just another number in the system. I could ring Margaret, my surgeon or my oncologist and ask questions. They were there, they knew me and they all worked hand in hand. They seemed to communicate amongst themselves, and the results were always affirmative and positive. I had one of the best outcomes. I hope it continues. I think it was because such a well managed team cared for me. I do not think everyone gets that. It was a very privileged position to be in.

CHAIR—That was a good experience. Thank you for relating that to the committee. You indicated that you knew someone who was in the field and was able to point you in the direction of the best care. Unfortunately it has been described in other areas as the cancer lottery. Professor Coates, you might like to talk to us about how people who are diagnosed with cancer, especially in that time when they feel like a darkness has come over them, as Mrs Myers indicated, take control and ensure that they are going to get the best treatment?

Prof. Coates—I think it is very difficult for the individual without help because, as Cheryl said, they are in shock. I talk to patients and it is obvious that, unless you take a lot of care, most of what you say is not being heard. In fact, we have done studies of this and we have worked out that about one-third of all the facts that are transmitted and recorded on tape in an interview are remembered by the person when they are interviewed later. I think it is very helpful to have someone else present, an extra pair of ears, who is not personally involved, as Cheryl did on several occasions. I encourage my patients to have a friend present at the interview, particularly if they have access to a friend with some medical knowledge or qualifications, so that they can absorb the things that might not be absorbed by the patient. Communication skills have evolved, but there is still some way to go. Doctors need to be trained in getting messages across and confirming that the messages have been received. Too often I think we are guilty of assuming that, just because we have said something to a patient, they have received that message. It does not always happen and, at least theoretically, we know that. In practice we need more implementation of good communication skills.

There are healthy movements, such as the Pam McLean Cancer Communications Centre here in Sydney and other centres around the country, that are fostering good doctor-patient communication. That is something that needs to be more firmly spread. We have through the efforts of various people around the country produced guidelines for the psychosocial care of patients with cancer. They follow a similar publication for patients with breast cancer. Copies of those will be made available to the committee; we have brought them with us. Implementing those guidelines would go a very long way towards improving the journey for patients with cancer. How much people can take control themselves is very much a personal thing and is very badly diminished by the fact and the shock of the diagnosis.

CHAIR—I guess the information that is being put before the committee is that even a patient’s GP does not know how to win the cancer lottery in terms of directing people. I am looking for you to talk to me about that process. There does not seem to be the public information available, even within the medical community with GPs, about where to go for particular cancers and get the specialised treatment that is going to have the best success rate.

Prof. Coates—I should say that one of the other hats I wear is as Acting Chair of the national Cancer Strategies Group which reports to the health ministers through the National Health Priority Action Council. One of the things that we are looking at there in the context of a national service improvement framework is accreditation of cancer centres and the credentialling of the people who work within them. It would simplify matters if the GP knew that the right thing to do with a patient diagnosed with cancer in their practice—and it would be four or five a year, it is not a huge volume that the GP sees—is to refer them to the local accredited cancer centre, where a care coordinator will take care of pointing them in the right directions.

I have been fortunate enough to work with care coordinators for over 30 years and as one of them was involved in Cheryl’s case. But in the Sydney Melanoma Unit, incidentally the world’s biggest melanoma unit, we have had this concept of a care coordinator and multidisciplinary care actively in practice for all the time that I have worked in it since 1978. A succession of oncology nurses in that case has filled the role of care coordinator. Once you are in touch with a system like that, everything works. But, as you say, until we have that sort of thing available for all cancers in all regions then the GPs do not have the information that they need. I think the accreditation of centres will go a long way towards that.

Bruce Barraclough, who works with me in the Australian Cancer Network and is Chair of the Australian Council of Safety and Quality in Healthcare for the federal government, is coordinating the accreditation working party. He is securing a great deal of approval for the processes of accreditation of centres. The credentialling will follow the same patterns of credentialling that apply in other medical areas. We can look forward to seeing both centres accredited and practitioners credentialled within them in the next few years.

CHAIR—I do not really like using the word ‘consumer’ in this context, but will that process involve consumer representatives in the development of the accreditation?

Prof. Coates—All of our processes involve consumers in the development. All the committees that work this up include people who can talk to us about cancer from a personal experience of that journey. We think that is absolutely important.

CHAIR—We have probably gone a bit too far without allowing some of your colleagues to speak.

Prof. Elwood—I would like to comment briefly on the general practitioner situation. We have a program to look at cancer from the general practitioner primary care point of view, because that has been relatively neglected in most of the planning processes. The sort of thing which is happening around the world, for instance in Britain and Canada, and is happening in New South Wales is, firstly, trying to establish a general practitioner lead person in every GP division who will act as the coordinator of things to do with cancer, which includes education programs and also the critical issue of where general practitioners in that area should refer their patients. This is moving ahead quite rapidly in New South Wales. There are moves towards it in Victoria, but it is at state level initiatives. We would like to see that on a national basis and we are trying to get a national network of general practitioners to give us that perspective on this issue. So often it has been seen only from the hospital point of view. In the UK, under a monopoly employer like the National Health Service, you can say, ‘All patients suspected of having this type of cancer should go to this clinic.’ We cannot quite do that under our more complicated system, so we have to work around that.

Prof. Currow—Thank you for the opportunity to speak today. As I reflect on the cancer journey, you have raised the important issue of how do people win the lottery. At a whole-of-system level, we have a couple of options: one is to change the way we deliver health care; the other, in which I believe we can invest substantially, is to have better informed patients. That is to have accessible information specific to each cancer available to people so that they can ensure that the care they are getting is genuinely interdisciplinary, as Professor Coates has outlined, is timely and is credible. We need to complement any change to the health system with ensuring that health consumers themselves are adequately informed—not only the person with cancer, because the effect does not finish there, but the people around them: their family and friends.

I think the late Premier of Tasmania, in consultation with his clinicians, was very happy to convey the enormous amount of information which well-meaning people pressed upon him. I do not think they just gave it to him but pressed it upon him, and, as I would reflect with many people for whom I care, cancer is only second to pregnancy in terms of people giving free advice and expecting you to take it. I do not think we should underestimate that in the patient journey. Cheryl might like to comment on that, but I think it is an enormous issue that we need to grapple with. As we look at whole-of-system change, it is not just about shifting dollars; it is about ensuring that we have better access to quality, credible information for people with cancer.

What are the other gains that we can make today without substantial change in cost or to the system? Professor Coates has already looked at transportation assistance schemes. I do not think we should just limit our thinking on that to rural and remote Australia. Clearly that is where it is most focused, but the peri-urban areas actually fall outside the guidelines and yet the travel you may have to undertake is substantial and overwhelming in terms of hours per day. If you are having six weeks of radiotherapy and you have to travel 70 kilometres across a major urban centre each way, that is an enormous undertaking which is not reflected in any of the patient transport schemes.

The other gain that I believe we can make today is to look at how we bring disciplines together. As well as dealing with cancer, comprehensive cancer centres should be dealing with people suspected of having cancer so that they can guide the process of making the diagnosis, confirming that, confirming the extent of disease and then providing the information that is needed. There are barriers in both the public and private sectors which are not only financial and not only structural; some of them are cultural within the professions and we need to be honest about that and address that in a proactive way if we are going to make a difference.

The challenges in the gains for tomorrow rather than today are around the work force. Again, if we think of a whole-of-system approach, one of our great challenges is, for instance, when a centre puts up its hand and says, ‘We need another radiation oncologist.’ So radiation oncology puts in a bid, but there is an automatic flow-on effect. If you have enough work to appoint another radiation oncologist, then you have enough work to appoint another medical oncologist, probably another cancer surgeon and definitely another palliative care physician. Although the numbers are good—and Professor Coates has relayed that—one in two people diagnosed with a solid cancer will still have their life substantially shortened by that in 2005. So we need excellent support and end of life care. As we pause there for a moment, I would like to reflect on the fact that good palliative care is not a black hole into which we pour money; it is something with measurable health outcomes that are felt long after the death of a person. The care giver impact is positively affected by the involvement of palliative services and that effect has hangover, if you will, that lasts for many years after the death of the person who has had a life-limiting illness. The very small investment that we make in palliative care has an enormous benefit for the health of the whole community when measured in those sorts of parameters.

Professor Coates has made reference to the national guidelines for the psychosocial support of people with cancer. This is largely unfunded. This is almost not available, if we take a national view. Outside a few major centres, your ability to access a liaison psychiatrist, a psychologist or a qualified oncology social worker is almost unmeasurable. Unless we invest in that, again we will pay a huge price for not making that small investment. A small investment would change the health of not only the person with cancer, while on their journey, but also the people who are most directly affected. Cheryl has already referred to the feeling of blackness that descends not only on the person with cancer but on those around them.

The last work force issue I would like to flag is in terms of burnout. Robust data suggest that people working in this area do burn out unless they are specifically and adequately supported. That is not only about competency and care but also about resourcing. Unless we start to invest in ensuring that highly qualified health professionals—in whom we as a community invest a great deal of money, training and support—are supported in their work, we will face significant consequences in the decades to come.

The last gain for tomorrow that we need to consider is the availability and increasing importance of biological agents for the treatment of cancer. These are crucial. They are exciting. They are the best news we have had in cancer for three decades. They need to be targeted very specifically to those people with the particular cancers who are going to benefit from them. They are also expensive, and we do not have processes in place today that are going to adequately support the way we ration the additional resources that will be required for these particular agents. Unless at a whole of community level we start to consider this issue now, it is going to leave us in a very difficult position in years to come.

CHAIR—Professor, I agree with you about having informed and therefore empowered patients as one of the strategies to improve care overall. But doesn't it then follow that patients should also have access to information regarding the frequency of treatment that specialists are conducting, their success rates and the recovery times of people whom they treat? Shouldn't that information be available to patients generally? Will oncologists support that process?

Prof. Currow—An informed and empowered health consumer is critical to good outcomes of care. The challenge is: how do we convey complex information in that setting? An empowered health consumer will ask that question of every health professional that he or she comes across. That checklist of questions is crucial for that person. Publishing league tables, which I think is perhaps part of the question you are asking, is more difficult. As we look around the world, there have been examples where league tables have not been beneficial in helping create better health outcomes for health consumers. For example, if you have a hospital which is a tertiary hospital, or indeed in cancer and other areas a quaternary referral centre, the complexity of case that they take on would by its very nature be greater. Their outcomes may not look as good on a league table, but it would be very unfair to suggest that their outcomes were worse because of that, if you cannot take into account the premorbid conditions, the comorbidities and the stage of disease which they were prepared to treat in the first place. Perhaps Professor Elwood would like to take on that issue from a population health point of view.

Prof. Elwood—The oversimplistic use of league tables and outcome results can be counterproductive, and that has been demonstrated in some of the areas that it has been tried on. For instance, the Sydney Melanoma Unit might well have worse results from melanoma than a small district hospital because small district hospitals will not treat the most severe cases; they will send them all to the Sydney unit. On the other hand, there are measures which, if carefully constructed, can be valid. It is reasonable for people to know, for instance, whether the person they are dealing with or the service they are dealing with has got expertise in that particular disease, which might relate to how many patients it treats and whether as a facility it has got the full range of services and staff which would be expected to provide services at the highest level.

We do not at present have a system—whether you call it an accreditation system or a standard setting system—to apply to that. There would be wide acceptance within the profession of an accreditation system if it was well constructed, if it was responsive and if it was open and transparent. The first steps have been made by the profession and organisations like this to move towards an accreditation system, initially for services to emphasise the point that it should be the quality of the overall service rather than the individual. The safety of air travel depends on the whole airline; it does not just depend on the experience of the stewardess on the aircraft.

CHAIR—We like a good pilot, I can assure you.

Prof. Coates—I do not think we need to be at all defensive about this. The answer to your question is: yes, the public wants that, and we should provide it for them. It should be done properly as part of an accreditation system and it is coming.

CHAIR—Ms Lancaster, I had better give you an opportunity and then hand over to my colleagues because I have been dominating a little bit so for.

Ms Lancaster—By way of background, the Cancer Nurses Society of Australia is the peak national body for cancer nurses. It was established in 1998 and it has also been the nursing group of the Clinical Oncological Society of Australia since 1978. We believe that the contribution of nurses to cancer care has received relatively little attention in the policy debate until now, and thank you very much for inviting us today to present our submission. I will address a couple of points in the terms of reference and then expand upon some of the other issues that have been discussed.

In the area of care coordinators, we certainly support the proposed development but see that often the planning and appointment of such positions to date has not always been conducted in a systemic or organised fashion. In terms of where we go from there, we see that we need to clearly identify the role development and the training needs of the appointees; to support an infrastructure for the role because often there is none—a person is appointed into that position and then very much left on their own to develop the role without much infrastructure or support—and also to look at issues of succession planning which come into work force issues.

There are significant work force issues for nurses across Australia, for nursing in general and particularly in cancer care. Oncology nursing—cancer nursing—has been identified as one of the top 10 nursing specialties for which staffing and recruitment is very much in crisis. The impact on particularly the retention of nurses in cancer care is reflective of an ageing work force. The average age of a registered nurse in New South Wales is 47, so we are no longer the sweet young things that people perceive nurses to be. In fact, we are very much a middle-aged work force and getting older.

Workload pressures and the burnout that results from them contribute significantly to nurses' intentions to not remain in the job and to leave. An Australian study was conducted a couple of years ago of over 200 cancer nurses, and 70 per cent of them indicated their intention to leave the profession within the next 12 months. Workload issues significantly contribute to that, and they contribute to burnout. Nurses also tend to feel unsupported in gaining access to further education and training. That is as a result of the cost of further training and also the ability of the workplace to release you to undertake that, because of the critical work force shortage. So, while you might have an employer who is willing to release you to go and undertake further studies, there are in fact no people to backfill that position.

We very much support the multidisciplinary care approach. It has traditionally been defined by the different medical specialties, but it has more recently come to be defined by the different professional specialties and professional groups that provide care to people with cancer. We believe that one of the key issues is ensuring access to multidisciplinary teams. We have talked about that this morning, but the areas that we see as having a special need are the rural and remote areas and the private sector. Substantial numbers of patients are treated in the private sector across Australia and they do not have access to multidisciplinary teams. They perceive that their care will be better because they are accessing the private system, but in fact there is not the infrastructure that there is in the public system.

I will expand on a couple of the other issues that have been raised this morning. I would like to support what Professor Currow said about travel, especially in metropolitan areas. As he has alluded to, there are people who will spend two hours each way on public transport to attend a radiotherapy appointment for 10 minutes each day for six weeks, and that is to access their closest radiotherapy facility. The other issue is for people who live in rural areas that are not quite within the boundaries of what has been determined as the right distance from the treatment centre. In New South Wales that distance is 200 kilometres. So if you live 195 kilometres from the treatment centre you have no access to any sort of financial support for travel or accommodation while you are in that centre.

The provision of funds for accommodation is woeful. In New South Wales you are entitled to $37.50 a night for accommodation in Sydney. I defy anyone to find any sort of accommodation for that price. There are people who will decline the best treatment recommended for them on the basis of their inability to pay to get there, regardless of the subsidy. The other thing with subsidised travel for patients is that, unless you have an extremely good social worker who will go into bat for you up front, it is all reimbursable. So people have to fork out that money for travel and then submit claim forms to be reimbursed at a later date. Another thing is that you have to have a medical reason for a family member or attendant to come with you. So you have to be really significantly disabled for it to be deemed a medical reason for a family member to travel with you. I believe that that is simply cruel.

Something we have not talked about today is access to services for underserved populations. We have talked about the provision of information. As has been alluded to, there is a wealth of information for people out there; it is just a question of how they find it. It is particularly difficult for people who are not well educated, people for whom English is not their first language and people for whom even access to the internet is not affordable. They tend to fall through a lot of gaps.

While we recognise things such as language barriers, it can be very difficult. Certainly in New South Wales—and I am sure it is the same in every other state department policy—when you are speaking to someone who does not speak English you must have a health-care interpreter present. Sometimes it can take three days to get an interpreter, and that is in common community languages such as Vietnamese, Korean or Mandarin. You then get languages for which there might be one interpreter in Australia who is available by telephone, and that makes communicating with those people very difficult. It is not impossible, but it is difficult when you are doing everything via the telephone and there is only one person in Australia who speaks that language, and I have had that experience myself on a number of occasions.

So, while we talk about the provision of information and the wealth of information that is available, there are populations that, unless they are treated in very big centres, are unlikely to ever have access to that information. Even when they are treated in very big centres, they often cannot get the written information because it is only provided in English. To have it translated into other languages is very expensive and there is no provision in health-care budgets for that to be done, even for common community languages.

The other thing I would like to highlight is the provision of extra services. We have talked about taking on an extra radiation oncologist which means we need an extra medical oncologist and palliative care physician. We also need extra nurses. It has been very common in many of the big centres that you will take on an extra medical oncologist, which means you may treat another 30 patients a week with chemotherapy, but there is rarely any provision of extra nursing work force to go with that. As medical appointments are made, there is rarely any increase in positions even of the allied health professionals who go with that. I think it needs to be considered in future that you are looking at a whole service provision rather than just appointing one extra person. You need to look at the long-term effects of that.

Senator KNOWLES—I will start with you, Ms Lancaster, if I may. You talked about travel assistance and the difficulty with the 200-kilometre zone. If it were a 150-kilometre zone there would be people at 145. If it were 130 there would be people at 125. It does not matter where one ever sets a level—whether it is for welfare or anything else—there will always be people who just miss out. Therefore, have you given any thought to how you would overcome that problem? Because it is a real problem, where someone can be just outside the zone.

Ms Lancaster—Yes. I think what I propose will still have ongoing effects for other staffing levels. If you are looking at means testing it in some way—and that has huge implications for who is going to do that and how it is going to be done—at least some of the people who fall through the gaps might better be able to access that.

The other thing is that lots of people do not know that that scheme is available. People who are treated in the private sector, for example, do not necessarily have social workers or nurses who will automatically see the patients and let them know that those schemes are available. Just because someone is treated in the private sector does not mean that they are affluent or even financially comfortable; it just means they have been referred into the private system. There are many people who are treated in the private system who will take out loans and put a second mortgage on the house to be able to afford their treatment. That is another story in itself. There is an issue about people knowing that that service is available, and I absolutely agree with you—it is a very difficult thing. Means testing it may be a fairer way, but it has huge implications.

Senator KNOWLES—You are a braver person than I.

Prof. Currow—I think we need to get beyond simply geographical distance. What is a reasonable travel expectation for someone undergoing radiotherapy? Six weeks of radiotherapy is incredibly tiring. I do not think we can understate that, and Mrs Myers might like to comment on it. It is phenomenally tiring. So what is reasonable travel? That is then not about distance. If you are an hour away by car, that may be 2½ hours by public transport. It is the same distance, but one person does not have access to private transport and the other person does. I would like to move it from a geographic distance to reasonable travel time accessible to that person.

Ms Lancaster—The other area that comes to mind is the South Coast of New South Wales. There is a radiotherapy facility in Wollongong. Patients from the communities south of Wollongong, all down that coastline, travel up there every day for their radiotherapy. They have a very good community transport system—a minibus that goes to all those small towns and bigger towns down the South Coast—run by volunteers. The problem with that is that it only comes up once a day and goes back once a day. You might come up to have your radiotherapy, which will take 10 minutes, but you are actually sitting in the cancer centre for five or six hours waiting for the bus to go back. So, while it is a free system and a very good system, once again it is very arduous. If you are sitting there for five or six hours a day every day for six weeks having your radiotherapy, it is an added burden on top of your treatment.

Senator KNOWLES—Another case that was put to us in Melbourne was that, if someone on the North Coast of New South Wales needs treatment, their closest treatment centre is in fact in Brisbane or the Gold Coast or somewhere. But, because it is cross-jurisdictional, that creates another set of argy-bargy between the states. The point that you make, Professor, about looking at the actual logistics is probably getting closer to the mark, but it still does not resolve the other problem of the argy-bargy between the states. I think it is something we are going to have to think about. Professor Coates, can I come to you about some of the cancer prevention programs. It worries me that, as a community, we do not see enough about cancer prevention. We see the SunSmart ads; we see pap smears; we see breast examination. But, when we look at colorectal cancer and a number of those other dominant cancers, there is very little that is out there in the public domain about how best to prevent that. How do you suggest that you, the Cancer Council, governments generally or other organisations should best go about that?

Prof. Coates—I think it is a whole-of-community responsibility. I agree with you that we are not investing enough in either primary prevention or in early detection, with the screening programs. All those things have to properly evidence based. We have impeccable evidence of the harm that is done by tobacco smoking. We are slowly winning that—but I emphasise the ‘slowly’. We used to be world leaders in tobacco control. We have abrogated that by not investing enough. We in the Cancer Council have repeatedly called on governments at both the state and federal levels to invest more to counteract the very large investment the tobacco industry makes in recruiting replacement smokers to keep up with the cancer fatality rates from smoking related disease—21,000 a year. That is not a battle that is easily won, and it is not won cheaply. But it is the most cost-effective investment that we in the cancer strategies group identify in looking at bang for the buck in how you can reduce the impact of cancer from a financial point of view. Of course, most of the smoking related cancers are particularly nasty ones, so it reduces the impact of cancer on people and the suffering people have.

Yes, we can and should do more with that. Some of the things are in the field of regulation, such as the Tobacco Advertising Prohibition Act. We find that we are not getting the changes we sought, and we are a little disappointed in that because the tobacco industry is smart and it has learned to drive trucks through some of the loopholes in the rather good act that was brought in 10 or 15 years ago. Counter-advertising—that is, the mass media antitobacco advertising—is a thing that pays off very heavily. We hope there will be more of that. We think the national tobacco strategy ought to invest in mass media antitobacco advertising. We hope that such a strategy will emerge.

Obesity, lack of exercise and being overweight, those things together are preventable causes not only of cancer but also other chronic diseases. Recognising that at the non-government level, we have made common cause with the non-government organisations for heart, kidney, stroke and diabetes in the Australian Chronic Disease Prevention Alliance because the areas of exercise and diet would benefit all of those chronic diseases. At a government level, we have the development of the national chronic disease strategy, which brings together the heads of all of the subspecialist areas from national health priority areas in the prevention of chronic disease. That strategy is due to report to health ministers in July this year. So prevention is coming to be recognised, but nowhere near soon enough or fast enough. In the economic submissions that we make to Treasury we point out that, unless we do something to prevent the preventable, we will not be able to treat the treatable in the next few generations.

Senator KNOWLES—I suppose I also look at prevention as being part of the responsibility of a specialist or a physician or a GP or whoever. I cite a personal case where my mother died of bowel cancer in 1982, and my sister and I went to different GPs. My GP said: ‘You’ve got to follow a diet of this and that and so forth and so on. You’ve got to have tests and so on.’ I said to my sister, ‘Has anything been mentioned to you?’ She said, ‘No, nothing.’ From there on, we both went to the same specialist. Nothing at all was mentioned about diet, lifestyle or anything. It became a bit more obvious to me that there was a gap in that system—albeit 20-odd years ago—so it has been something I have kept up with over the decades and talked to people about. Where there is a hereditary risk of heart disease or whatever, I ask them if their doctors ever talk to the family about that. The general answer is no. How do we solve that simple problem that would lead to prevention?

Prof. Coates—I think you are right except for the word simple. We recognise that and, increasingly, professional organisations are addressing the problems of prevention as seen from the clinical interaction. We know that simple advice from a GP to stop smoking actually is effective, and it is not given often enough. We know that GPs can give advice about nutrition and alcohol and physical activity. Indeed, there is a formal program within general practice law called the SNAP program—the smoking, nutrition, alcohol and physical activity program—which is designed to try and inject a bit of exactly what you are talking about into the clinical consultation. It is a long time since I have done general practice. Even then, when I did, it was pretty rushed. You are dealing with a lot of problems; it is hard to make the time to do this stuff, but it has got to be done.

Senator KNOWLES—But is that a good role for nurse practitioners?

Prof. Coates—Yes, it is. If you can provide for that in the context of the clinical practice, which is not reimbursed, then there is a real role there for the cancer nurses and specialist nurses.

Senator KNOWLES—I look at it more in a general sense. When a hereditary problem is identified in a patient, whether it be cardiovascular disease or something, there should be a role for someone in a practice somewhere to be able to telegraph the shots to the descendants of that person that they are at risk and, to avoid risk, they should do a, b, c, d, e, f and g.

Prof. Coates—We are doing that to some extent. There is recognition that some of these familial things are much more clear-cut than others. In the case of familial bowel cancer, for example, we have a list, provided as a single folding sheet, for GPs to identify the likely family history that suggests that somebody might be at increased risk and to know what to do about it if they are. I will not go into cardiovascular disease, but with other familial cancers, again as part of the guidelines for experts, we provide books about it, but, as part of the crib sheet to make sure that GPs are aware of this and likely to inject it into their contact with patients and their families, we do provide GPs with a simplified summary of the implications. We call it the tricoleur, because we have got mild, moderate and horrible family risk categories. Horrible risks, mercifully, are very rare, but very many people have mild evidence of an increased risk.

Senator KNOWLES—Ms Lancaster, would you like to add anything on the possibility of the extension of the nurse practitioner role?

Ms Lancaster—Perhaps the other thing you might be alluding to is the role of practice nurses, which is an emerging role in Australia in general practices. They do a lot of the screening procedures and a lot of preventative health procedures in general practices. The New South Wales Cancer Institute has started to look at preventative roles in general practice as well, which I believe—I am not absolutely positive—includes looking at things like practice nurses and providing education for them as well.

The other thing that is often quite difficult—and you talked about general practitioners knowing about family histories and that sort of thing—is that people do not often tell you everything to begin with. It is not that they are hiding information; it is just that they forget. They are busy and they know that the GP is busy. They come in and unless you have a very set group of questions around it, people may not volunteer that sort of thing. You have described the fact that you go to one GP and your sister goes to another, so unless you are actually telling your GP that you have a sister and that this is what happened to your mother—which obviously you have, but not everybody does—then sometimes it is actually very difficult to get all the information together. That information might be built up over a period of time or a period of consultations.

We see in the big centres that we work in that patients might tell a doctor one thing, a nurse something else and a social worker something else. That is the benefit of teams: when you get all those people together, you get all the information together. It is much harder in places like general practice. But I think certainly that with practice nurses there are great possibilities in terms of prevention and screening.

Senator MOORE—Professor Coates, one of the things that I am having great difficulty with is getting my head around the number of organisations working in this field at the moment. I have not asked the secretariat yet, but one of the things I am going to ask for is a list of every one in every state. I have a fear that is going to take several pages. Is that the best way to operate? Who is coordinating all this activity? While I understand the limitation of the state and federal responsibilities for health and understand that everybody is working on it and we are in the situation where every state claims that what they are doing is the best and most innovative, who is responsible for making sure that the knowledge is shared and that the kind of genuine goodwill that is there is actually translated into action?

Prof. Coates—It is a complex question. Let me answer it at different levels. At government level—and wearing my hat as chair—the national Cancer Strategies Group is an interjurisdictional working party. It is an expert group with representation not from every state but from some states, and it reports through the National Health Priority Action Council on any matter to do with the government role in cancer, either state or federal, to all health ministers. It may not be perfect but at least there is a mechanism there for bringing together problems from all the jurisdictions and attempting to deal with the mess of having two levels of jurisdictions—not always successfully.

Senator MOORE—Why are not all states represented?

Prof. Coates—It is too big a committee. We have people from some of the states representing state interests. At the next level up, for example, there is a Northern Territory representative who represents us at NHPAC.

Senator MOORE—So the national Cancer Strategies Group—we have this on paper, but from your point of view as an expert in the field—

Prof. Coates—That works as an expert advisory committee to government. The secretariat is provided by the federal government, but the responsibility is to all health ministers through NHPAC.

Senator MOORE—That reports to the minister at the federal level?

Prof. Coates—It reports to the health ministers through AHMAC. Therefore, although it is supported at the federal level, it is multijurisdictional. Because Australians do not always think that governments can do everything that they need to have done, non-government organisations have arisen to support cancer, and they go back to the 1920s, with the cancer foundations of South Australia being the first of the state cancer councils. The peak body in each state is the cancer council in that state. In the case of Queensland, it is called the Queensland Cancer Fund. All the others are now called the ‘Cancer Council’ with the appropriate suffix.

They fulfil functions of education, patient support and research support that reflect the interests that the community, their donors, have in doing something extra for cancer. At a professional level COSA, which is represented here by Professor Currow, is the organisation of full-time health care professionals of all disciplines that have come together. A need for that was perceived in the early 1970s when multidisciplinary care first began to be evident. I have been a member of that since the seventies and was its president some years ago. It fulfils a different role. It works out of our office at Cancer Council Australia, and the coordination between the bodies is, I believe, fairly close. But it adds to the alphabet soup. I do have a PowerPoint presentation which I call ‘the alphabet soup’, which goes through some of these myriad acronyms. It contains a diagram, which looks rather like one that was put to an ALP conference, of the spaghetti connections between various bodies in the cancer universe.

Senator MOORE—I hope with different results.

CHAIR—I am sorry you did not bring it.

Senator MOORE—Can we get a copy of that? It would seem to me that that would provide the kind of thing that I have been waiting for, that I was going to ask the secretariat for. So on their behalf I thank you for that.

Prof. Coates—I think it is a postgraduate exercise to get your head around all those things. I am not surprised that a committee would have difficulty.

Senator MOORE—And there are lots of joint memberships and involvements. With the submissions that have come in, similar names have been popping up with different hats across all the states. There is something positive about that because it shows that people are working together, but it is worrying in some ways that there are so many specialist organisations—specialists in the general sense—operating.

Prof. Coates—It is a concern. We do try to work together. Some things have emerged as joint exercises between two other bodies. We have now got another player on the horizon with the term 'Cancer Australia'. We are waiting with some interest to see what actually emerges under that banner. Having had something to do with trying to promote such an idea, we are hoping that it will actually fulfil some of its missions, one of which is to limit the number of different bodies that have responsibilities in this area. We in the Cancer Council will look forward to cooperating with such a body when it emerges.

Senator MOORE—Is there much competition amongst the different bodies?

Prof. Coates—Because the cancer councils are all charitably supported, there is competition with other people seeking charitable support, both for cancer and for other causes in the community. Australians are very generous with their charitable support, but it is not unlimited. We in the cancer councils do see ourselves as in competition with other charitable causes. We think there is room at the top, and that is where we have stayed since we started. There is no limitation on people getting a new idea, putting it together and seeking community support. That has been the Australian way. The community does support things, particularly in rural Australia, where I worked for a number of years. The community support there is overwhelming and very heartening. At a national level we enjoy the same support through the cancer councils in each of the states and the federal body which I head.

Senator MOORE—Professor Currow, palliative care is an issue which is dear to my heart. We had some evidence in Western Australia about a study that was done on access to palliative care, with some quite concerning results about the lack of awareness and access people have. When I had a look at the work force advisory committee report, I saw that your particular specialty did not get its own jersey in terms of palliative care physicians. What is the situation with that profession? Do you have the same issues that everybody else spoke about in that survey?

Prof. Currow—Thank you for that question. Absolutely. AMWAC has not considered palliative care. Again I would reflect Ms Lancaster’s comments. It is not about palliative care physicians; it is about interdisciplinary care.

Senator MOORE—The whole team.

Prof. Currow—Yes. For us that includes specifically—and I think we need to note them—physiotherapists, occupational therapists, dietitians, pharmacists, speech pathologists, social workers, pastoral care workers and—

Senator MOORE—I hope you have not forgotten anyone.

Prof. Currow—I hope I have not. There is a perception that palliative care is about just the last few days or few hours of life, whereas the WHO model as expounded in 2002 is very much a continuum of care from the time of diagnosis that this is a life-limiting illness. It is not limited to cancer. Looking at the West Australian figures, the thing that most troubles me—and we have done some similar population based modelling in South Australia—is that cancer forms about 80 to 90 per cent of the workload of palliative services around the country. We believe that for every person with cancer we should be seeing a person who does not have cancer as their life-limiting illness. So there are major issues there.

In terms of work force, an enormous issue for an emerging specialty, there has been a training program through the College of Physicians since 1988. There has been a broader professional organisation in existence since 2001 under the auspices of the College of Physicians. Importantly, that is starting to have benefit in terms of the work force developing, but as of today there are positions available in every capital city in Australia for senior clinicians both in nursing and in medicine in palliative care. Again, unless we start to plan for the future in a very proactive way and ensure that every position has the flow-on effects of all of the allied health, nursing and medical needs—and equalling that with the challenge of ensuring that we are providing infrastructure across the continuum of care; so in the community, in in-patient settings and in outpatient settings—we are going to have problems in the future.

One of the issues that does not come through in this document and which I think if we are talking about palliative care we need to be aware of is that palliative care is still not recognised by the Health Insurance Commission as a subspecialty. That has implications for attracting people to it as a specialty. If you train as a physician, it is not a problem. But if you come in through the lateral entry from surgery, psychiatry or general practice then that is a major disincentive to spend the extra time in specialising if you are going to work in any way outside the public sector. The recognition of the fellowship of the chapter varies from state to state and territory to territory. So it would be good to look forward to a time when a determination is made by the body that is currently considering that so that we can take the specialty forward.

Senator MOORE—How long has that body been considering that issue?

Prof. Currow—The first application went in last year and meetings have been occurring. I do not think there has been any delay in that. The body, as you are aware, is considering new guidelines and new formats, so I do not think anyone is surprised by that delay. But, the sooner that determination can be made, the more likely we are to be able to build a sustainable work force into the future. In national planning documents from Palliative Care Australia we have highlighted the fact that we need more registrars at the moment because there is a shortfall, and that has been one of our major platforms: that our registrar numbers for the next five to 10 years need to be substantially more than we would see in comparable specialties as palliative care emerges as a distinct entity where it genuinely value adds to patient outcomes because of the expertise of people who do this all day every day. As Professor Coates has pointed out, the average general practitioner in Australia sees between three and five new cases of cancer a year. Likewise in general practice the average full-time general practitioner in Australia sees three to five expected deaths per year. So it is a very small part of their workload. It is highly valued as part of their workload, but, at the end of the day, the challenge is how to support primary care givers for whom this represents such a small patient load. This has a significant impact on the patient, their family and the practitioner—who is often quite isolated in providing support and care in that setting.

Senator MOORE—I would like to supplement that with a third point. Do you want to say something about rural and regional Australia? Ms Lancaster mentioned that in particular, but for the record could you say something about palliative care in rural and regional Australia—because I know that the situation there it is even worse.

Prof. Currow—It is much worse. The challenge is that the whole philosophy of palliative care is to provide local services locally and so transportation discussions fall by the wayside here. What we find is that we have incredible variation across the nation, in metropolitan, rural, regional and remote Australia, in accessing specialised palliative care services. I do not for a moment believe that every person facing an expected life-limiting illness needs to see a specialist service. Excellent care is provided by lots of general practitioners and community nurses across the country. Having said that, people who do have complex needs deserve to have access locally to services—and that clearly is not the case. The variations of funding, state by state and territory by territory, have about a fourfold difference in the funds that are matched to Commonwealth funds on an annual basis. That fourfold difference is translating into very different models of care with, potentially, extremely different outcomes for patients and their caregivers.

Senator HUMPHRIES—I want to move on to this question of the accreditation of cancer centres and credentialling of cancer workers. I realise the system is still in its infancy but, if that system were in place today, do you have any idea of how many existing cancer centres in Australia would fail that accreditation process and how many individual practitioners would fail the credentialling exercise?

Prof. Coates—The system that is evolving has some similarities to one which has been in place in the United States since 1913. It was established by the American College of Surgeons and has flourished in the United States since then on a voluntary basis, basically, in private sector medicine, because it is good for advertising that a centre is accredited. More than 85 per cent of American cancer patients are treated through accredited centres. There are various levels in that accreditation system and I am sure we will have various levels of accreditation in an Australian system as it emerges. There will be the specialist, comprehensive cancer centres that can do it all—that have a PET scanner, that can look after the surgery, the radiation therapy, the systemic therapy and provide all the palliative and supportive services that a patient needs.

And there will be places like Dubbo Base Hospital, where I worked for 20 years, where some outreach services are available but, for logistic and, sometimes, patient safety reasons, some types of treatment will have to be centralised elsewhere on a hub-and-spoke model. And there will be outreach even further beyond that. The palliative services that I remember in far western New South Wales were provided by nurses based at Bourke, Lightning Ridge or Walgett and places like that, with whom we were in constant contact by telephone, but the delivery was much more local. The area, I guess, that needs to be emphasised—in addition to the question we just addressed—in rural and remote Australia is bringing culturally appropriate services of all types to the Aboriginal community, which, in many cases, requires the upskilling of Aboriginal health workers in the areas, particularly, of support and palliative care.

I do not think that many centres will fail; it is just that they will be accredited for different functions at different levels of service. But it is also fair to say that the very existence of an accreditation system will lift the game, if it is mandatory—as it is the United States—that a certain percentage of all patients are discussed at a multidisciplinary meeting before a treatment plan is decided, and that that is documented in advance. Maybe then that will happen more often here too; that would be a good thing. If it is a requirement, as it is in many parts, that a certain percentage of patients are entered onto approved clinical trials, that would be a good thing. We will probably see an improvement in standard by the implementation of an accreditation system. I would be looking at it as educative and improving standards rather than as people failing.

Senator HUMPHRIES—Do we know what the cost of that system would be at this stage?

Prof. Coates—No. I cannot give you a cost estimate of that. I know the committee is looking at those facts. Maybe that could be provided on notice, but I do not have it here.

Senator HUMPHRIES—I am being a devil’s advocate: if you were saying that there needed to be, say, $100 million spent on credentialling and accrediting practitioners and centres across Australia, one might think that there might be better uses for $100 million than that. That might be a gross exaggeration of what we are looking at.

Prof. Coates—I have no idea whether or not the figure you mention is reasonable, but I would say that there is also a cost of not implementing these systems. We have seen some tragic examples in Queensland recently of systems that have not been adequately regulated. I am not suggesting that is widespread in cancer treatment, but there is a real benefit in making sure that that sort of thing does not happen.

Prof. Elwood—It is interesting how, for instance, the American standard-setting organisation has moved from having 135 standards a few years ago to now having 35. This is really a recognition that you have to balance the cost and, in fact, the workload of compliance with the real benefits. The initial reports that we have done on Australia have this as an up-front issue: we must not invent a system which is counterproductive. We want a system which is responsive, clear and concentrates on the really important things—not on all the details.

Prof. Currow—If we look at the Australian Council on Healthcare Standards we will see that, over the last 30 years, there has been evolution from process through to outcomes. The accreditation process is not a static process; it is a very dynamic process, as outlined by

Professor Elwood. I think we need to look at that evolution and take the first concrete steps in making sure that accreditation is seen as a fundamental part of good cancer care.

Senator HUMPHRIES—I cannot let you go without your commenting on the ongoing contests that are being played out in front of us between complementary or alternative cancer therapies and conventional ones. We had some strong evidence on previous days about why there is not more recognition of complementary medicines at the level of bodies like the Cancer Council. I would like to put to you some of the things that have been put to us as reasons why that does not occur and get you to comment on them. For example, we were told that very few complementary or alternative therapies have been evaluated in a formal sense because the threshold cost of doing that is significant and complementary or alternative therapies do not generally have the kind of money involved to make those sorts of thresholds.

We were told that there is an institutional or educational bias in teaching against alternative therapies. We were told that, when they are mentioned in most medical schools, they are mentioned in a dismissive way and pushed to one side and there is an ongoing hostility towards those therapies among practitioners and so on. An example was given of a wellbeing conference run by the Gawler Foundation in Victoria, and many practitioners in the medical school where it was being held signed a letter to protest about the foundation running a wellbeing seminar in the school. I notice that you have a very compelling case in your presentation about some of the failures of alternative or complementary medicine. What is your response to the specific arguments that have been put to us as to why these things are not being accepted into the mainstream?

Prof. Coates—I think there are only two sorts of treatment: treatment that works and treatment that does not work. If it has been shown to work, it is something that we adopt as part of the mainstream. If in the mainstream we find that something does not work, we reject it, and we are constantly doing that. That is what evidence based medicine is all about: rejecting what does not work and adopting what does. In terms of an alternative—and I think that is a bad use of terminology, and I think a lot of hang-up has arisen around ‘complementary’ and ‘alternative’ things—as I said in my introduction, most of my patients do something else apart from the things that I prescribe for them. I think that is good because it is a part of their personal empowerment and about taking charge of their health, and many of the things that they do—meditation, massage et cetera—have been clearly shown to improve quality of life. So I applaud those things—they are treatments that work, and I do not think there is anything alternative about them.

If you say that amygdalin—laetrile—should be given to a patient with testicular cancer, instead of cisplatin, it is alternative and it is dangerous because we know from evidence that platinum will cure the young man and amygdalin will not. We have done a clinical trial of laetrile in the case of colorectal cancer and it was found to be completely useless. For about five years of my clinical practice it was the flavour of the month of the real alternatives, and the conspiracy theorists were rampant. I do not think anybody in orthodox medicine or in unorthodox medicine has a right to push a treatment for which there is no evidence. I think every patient has a right to look where they like, to see what treatment they think might suit them, but pushing a treatment that does not work, simply because you can claim that you are being victimised and you have not had a chance to test it, sounds to me like charlatanism, inside or outside the profession.

Senator HUMPHRIES—So there are no financial barriers, as far as you are concerned, to getting alternative therapies or treatments tested?

Prof. Coates—In the United States, by congressional fiat, there is a large budget for the scientific evaluation of alternative medicines and there is a whole section of the National Institutes of Health web site devoted to that. It actually proves to be quite difficult to do those experiments. Very few of them have been carried through to a logical conclusion, largely because many of the practitioners are not skilled in the disciplines required to do a clinical trial. The concepts of randomisation and sticking to a treatment that is prescribed—which are essential to the scientific evaluation of any treatment—are not commonly favoured among such practitioners. So there is a difficulty in maintaining the rigorous quality of science to do what is attempted through that highly expensive program.

Where it has been done, the treatments that have been looked at have failed to show advantage over conventional treatments. In every case that I am aware of where a treatment shows that it works—whether it comes from the bark of a tree; we call that Taxol these days in the pharmaceutical industry, but it is a tree bark extract, and many plant extracts are part of regular medicine—herbal medicine is adopted when it works. The purple foxglove is what we call digitalis. Opium comes from another natural product and it is the basis of the palliative treatment of much of the pain that Professor Currow sees. So, if it works, it is part of orthodox medicine. If it does not work, nobody needs it.

Prof. Currow—Senator, I suppose I come wearing two hats to answer your questions. Firstly, I have a complementary care centre as part of the clinical program that I run in South Australia. Secondly, I am in an emerging field, a field for which evidence was certainly lacking 20 years ago, was scant 10 years ago and is rapidly developing in 2005. So I think there are lots of similarities between palliative care and the issues that you are raising. The submission that you have before you today from us makes a clear distinction between complementary therapies and alternative therapies. Professor Coates has alluded to that, but I think we actually need to characterise that very clearly if we are going to have a discussion that compares apples with apples. There are lots of things that complement current therapies, but if you have a practitioner who says that their product is exclusive, is different, will cure and will cure universally then I hear alarm bells ringing. Cancer is a diverse group of illnesses under one umbrella term, and the person who has the ‘universal cure’ does concern me.

In answer to your specific question, ‘Are there financial barriers to evaluation’: no. Anyone can put up a project for competitive funding in order to evaluate a particular hypothesis they have. Whether you start with human experiments or not, or start at an earlier, preclinical stage, may be an issue. That is where the similarities between palliative care and the question you are asking come into play. You have got to get the right relationships; you have got to get the right expertise; you have got to form the right collaborative groups that actually bring the clinical—including complementary care—the research and the ability to attract research dollars together. That is about building collaboration. So I would strongly say that there are no financial barriers to the adequate evaluation of any of these therapies and, as Professor Coates has quite rightly observed, many of the complementary therapies have an excellent evidence base behind them and are being employed. They are employed for five days a week and free of charge to patients in my centre, at great cost to us because, I add rapidly, if you try and get a department of health in this country to fund it, you cannot. So, if there is a financial barrier, it is actually around service delivery, where there is excellent evidence of improved outcomes for patients and their caregivers. We cannot find funding for it. So, there is a financial barrier that we can grapple with and deal with.

The second question you asked was: is there an institutional or teaching bias? Again, I run a busy postgraduate program with 170 students around the world studying by distance up to masters and PhD level. We have this as an integral part of what we offer. So I think the concept that there is an exclusive institutional bias against these areas is not borne out when you actually look at curricula. I am part of a collaboration with the Queensland University of Technology developing the national curriculum for all health sciences in palliative care, not just in medicine but in nursing and all of allied health. It clearly involves adequate and, I think, very positive discussions about the very real benefits of adequately accessing evidence based complementary care. So we really do need to take on the continued assertions that there is a systematic institutional bias against it and huge financial barriers. It is a level playing field. If you want to put a research group together and ask these questions, I think they are difficult studies to do, as are studies in palliative care. That does not mean we should not do them, but it does mean that the lead time and the recruitment time for those studies is often longer, and you need to have multisite rather than single site involvement. However, it can be done, and that is a message that I would very much like this committee to hear.

CHAIR—Thank you very much. As with many of the witnesses in this inquiry, we have not had enough time with you, but thank you for your very extensive submission and your presentation today.

Proceedings suspended from 10.26 a.m. to 10.37 a.m.

[10.37 a.m.]

BERRY, Associate Professor Martin, Private capacity

KRICKER, Associate Professor William, Private capacity

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

Prof. Berry—Whilst initially this submission was in the name of the South Western Sydney Area Health Service, I do not think it should be as that organisation does not exist anymore. It has been amalgamated with a new entity. I cannot fairly say that I represent something which is not a current entity.

CHAIR—So no-one is here representing the South Western Sydney Area Health Services?

Prof. Kricker—We have a lot of experience in that area.

CHAIR—Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be taken in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission. I will ask you to clarify that as well. I invite you to make an opening presentation to be followed by questions from the committee.

Prof. Kricker—I have provided the committee with a handout. Doctor Berry is a radiation oncologist. He has been head of the Liverpool Cancer Therapy Centre since its inception and was director of the South Western Sydney Area Health Service. When he was appointed, he saw a need to get a cancer service that functioned, so out of the earnings of his radiation oncology practice, he funded the Cancer Services Development Project. He is also currently chief examiner of the faculty. I ran the Cancer Services Development Project, on which part of this submission is based. Prior to that, I was involved with health in that I ran the Alfred Healthcare Group in Melbourne and was the founder of the Health Roundtable. Prior to that, I had a pretty successful non-health career in the private and public sectors.

I will go through these slides, which we have in hard copy only. At the bottom of page 1, the point I wish to make is that health is a very young sector. We may think because we have looked after people for thousands of years that it is not, but the reality is that it is. Professor Shortliffe, who has been on numerous commissions, said last year in Sydney that it is the largest trillion dollar cottage industry in the world. Lewis Thomas, who is definitely the cancer guru, wrote an excellent book about medicine, the younger science, and Peter Drucker’s comments were that it is the most complex organisation he has ever seen.

Looking at the top of the second page, we have policy and scientific knowledge. There is an assumption that all the reports, recommendations and implementations are going to impact on the patient and the patient’s welfare is going to improve. Having seen many of these plans over 30 or 40 years—health and non-health—the implicit assumption in virtually all of them is that magic will happen. Magic seldom happens because an enormous number of black holes have not been taken into account in the original recommendations and because the motivated workers, particularly in health, pick up the slack in the system caused by the lack of appropriate organisations and in the end they burn themselves out.

I have some examples from the last four months—and these are not just cancer; they are an amalgam of three projects because care coordinators are the go these days. They are in mental health, chronic heart disease and cancer. All of these areas decided that we will have care coordinators. Some of the black holes are: they cannot identify the patients; the money was only provided for the lowest grade worker; and there was no leave, back-up or anything. Their attitude is: ‘We have funded the award rate for that, therefore the service is established.’ In two cases there was not even a chair. There was nowhere to sit, no tools, no car computer, no phone or anything. In one case they got a phone after six months but there was no credit on it and it took another couple of months to come. Training was nil. In another case, it was: ‘Follow me around for 10 days.’

The common thing was an overwhelming case load because we had a care coordinator—please meet your 200 patients—and so the chances of doing anything was a slight problem. In those three cases, we do not want care coordinators; we want a care coordination service. With care coordinators you wind up with nine to five Monday to Friday, not weekends, not public holidays and no vacancy coverage. You do not have a service; you have individuals. What the patients want is a service. There are many black holes in many areas of health.

How do we remove this dependence on magic? Firstly, one has to understand the health system. The bit where magic is always assumed is that an organisation delivers the health service that interacts with the patients to deliver the outcomes. There is a very strong belief that the outcomes come precisely from the clinician’s patients, when in fact there is an organisation that has to deliver the services. If you look at the next one down and start unbundling the whole health service thing, you will see that there are many departments, even in the one hospital, that will interact with the patient’s cancer journey.

The important thing is on the next page of the hard copy version of the slides. Because this is meant to be on the screen but it has been printed, you cannot see that along the top there are just some of the departments. But if you take any one department and look there, you find that there is not just a clinician, there is a department of sorts and an organisation that reports somewhere—it may report in three or four different places. If the patient and health service interaction is to reflect good practice then there is a need for the department that is trying to deliver that good practice interaction to be constructed to deliver it. If you are going to have a care coordination service, you have got to build a care coordination service and not say, ‘You are a care coordinator, here is a list of patients.’ You cannot deliver a service unless you build the organisation.

In our submission, we comment on how, if you look at Qantas, you do not assume that the check-in personnel and the pilots are responsible for the whole interaction with the customer. If it does not work, there is some belief that maybe the plane was not maintained or the luggage got lost et cetera. The focus is not just on the interaction with the customer. So the complexity of that is never really understood. This is not about the existing organisation, because there is always an organisation there; it is about building that organisation to deliver the service that you want. To remove that dependency you have got to focus on operational management. That is what Qantas does and the health service does not. It is a low priority; it is not confined to cancer or health. It is very much a public sector issue. If you type into Google the magic words ‘implementation/public sector’ it will produce millions of references as to why projects have not succeeded. The complexity in the embryonic state of cancer service just makes it a larger issue. There is very much a denial mentality that says, ‘I don’t want to hear about the problems, just give me a solution. I actually have to deliver something tomorrow.’

You have to understand what is happening and why, what should happen and why, and how we are going to manage the transition. As an example, somewhat out of left field, when I came from the private sector I was interested to discover that, for a whole lot of things about which there was a lot of thinking in private enterprise, there was no forum at all in the public sector, or in health. After a number of attempts, we finally managed to establish the Health Roundtable, which focuses on understanding how the organisations and the services actually work. There is a web reference to it there. The majority of Australian and New Zealand teaching hospital CEOs are members, and some are not for various reasons. You can see from that list that it focuses on how you get an emergency department to triage high-priority patients and how you improve the cancer patient’s journey. Just a comment: given that this is a pretty large sample over eight years, the operational improvement is not helped by the fact that the average length of stay for a CEO member is a little less than 18 months. So that is certainly a problem. It never appears in any of the agendas.

I have previously made the comment that one actually needs to understand what is happening. The cancer patient’s journey really starts at the suspicion and goes to detection, outcomes and death or living with cancer. That is important, because in the few studies that I have seen the most extremely stressful period for patients was when they were saying, ‘I think I’ve got a lump—what is it?’ We do not really have any figures for Australia, but in America that stage took up to a year, because if you cannot find your way into the system it is very hard to get a definitive diagnosis. If you can, you can do it in a very short period. I have had experience of it taking 24 hours—that was not me personally but one of my relatives. I have put the numbers in just so that people can get a feeling for what we are talking about. There are 88,000, but there was talk about palliative care before, and this is a particular hobbyhorse of mine. The system is designed for the straight ahead flow. The fact that 36,000 die is not reflected in the state of development of the palliative care services. It is a crying need.

Apart from one paper that was done in Western Australia—and there may be others—there has been no real attempt to work out how many patients are living with cancer. On those figures, we would think there are about 600,000, and that has all kinds of implications, because people tend to look at the incidence and say, ‘Yes, those are the ones that were detected,’ but quite a number of those people living with cancer wind up with a suspicion and virtually have to go back up to the suspicion stage to get somebody to seriously have a look at that. So it is about understanding what it is that we are trying to deal with.

The complexity of just one cancer service is that you have probably got 10 clinical tumour groups and a minimum of 10 core services and six sectors. That means that, if you want to deliver a comprehensive and integrated service, in that one entity you have 600 organisational entities. If you get bigger, I suspect that number would be somewhere between 600 and 1,500. I will not say that is non-trivial, but it has to be taken into account. Each patient’s journey is more than an event. In fact, there are many providers—public, private, acute and community, treatments, services, locations and visits—so during the lifetime of a patient there will be thousands of interactions. When people quickly say ‘a comprehensive, integrated service’ they actually have to realise that.

So our submission was about the fact that you have to build the organisation, and that is what the Cancer Services Development Project was about. You have got to build an organisation that can deliver a population patient based, comprehensive, integrated good-practice service. It sits across many clinical services, both public and private, and that makes it a very difficult task sometimes. If it is to be integrated, it must have a way of interacting with the private sector. The strategy and principles for magic removal are that you have to understand the journey, not the clinical pathway. The clinical pathway is important, but it is the patient’s journey. When care coordinators were appointed in South West, one of the real reasons for appointing them was to find out what the journey actually looked like, because, as far as I am aware, nobody has tracked the journey so that you can see what the problems are.

Prof. Berry—It may be better if you ask questions but, just briefly, as a cancer clinician going into cancer management as a service director, it was an eye-opener for me. The way clinicians are trained is for one-to-one interaction with patients, and that has been my focus, but looking at things at an organisational and operational level is entirely different. I could not have functioned at all without the assistance of the cancer development project, which applied those business principles to the complexity of cancer and the way it should be managed. I think the bottom line is that, whilst we have a lot of motivated clinicians who want to do well and do good, they still need that guidance, framework and organisational structure to know how to go ahead and implement their good care.

Senator HUMPHRIES—I was reflecting on the slightly dismal picture that you paint of the state of cancer services from the presentation you made. I assume that, in saying that you need to build a patient care model from the ground up, a lot of services have not been built that way and that we have a lot of problems.

Prof. Kricker—I have read all the submissions you have received. I printed them out and read the lot of them. Many of the comments are things that I could certainly relate to. All we are saying is that, if you are to address those problems, you need to build an organisation to address them. Most of the organisations we have are a result of history. It is not a dismal picture at all. I said somewhere in there that people say, ‘Don’t tell us about the problems; we want the solutions.’ That is a very common response. In fact, one needs to understand the situation before one can fix it. I find it interesting that a number of the submissions have picked up work that was done by the Cancer Service Development Project. We basically went around and talked to all the clinicians and then sorted out what the problems were and how we could solve them.

Looking through all the issues that were submitted, there are only three submissions that actually said, ‘This is how you address the issues.’ There are many recommendations for research, but not how we progress it. All we are saying is that you have to build the organisation. In the appendix there is how you go about it—and not just building it for Sydney but for Sydney and Tibooburra. It is totally doable, but there has to be an understanding that sending policy out will have some impact, but if you really want a very beneficial impact you have to do something about it.

I spent seven years running the IR&D board in Canberra, trying to deal with Australia and innovation, the lack of innovation and everything else. The first thing we did was to try and understand what the real problems were—there were some very interesting real problems—and then start to address them. It was a case of: find out the issues, find out where we think we should be and then go ahead and do it. I will make one comment: it took us many years to get any money to understand the issues because we kept being told that it was not in our remit.

Senator HUMPHRIES—So you see some kind of structural overview as being more important than an on-the-ground exercises of the kind the Cancer Council and the Clinical Oncological Society were talking about with their accreditation and credentialling program.

Prof. Kricker—No, what I am saying is that if the clinician that is interacting with the patient in the medical oncology department is spending 50 per cent of his time, because the booking system does not work, putting in everything, finding the documents et cetera then just saying that we will have policies and guidelines is not going to improve that situation. You have to improve the situation from the interaction with the patient back. You have to make sure that the medical oncology department he is working in has good practice. That is not just about clinical skills.

Senator HUMPHRIES—How do you do that? That is the question I am getting to.

Prof. Kricker—That is what we spent three years doing. You have basically got to go through, as we have done here, sorting out what are the key things you want to focus on.

Senator HUMPHRIES—Who is ‘we’ in that context?

Prof. Kricker—In that context, the clinicians and Martin.

Senator HUMPHRIES—In terms of recommendations to this committee, who do you say should focus on that now? Is that a government job? Is it a job for this cancer Australia body that is being set up? Who does this exercise?

Prof. Kricker—It can only be done at an operational level. I am completely serious about that. There can be a framework for it to operate within, but what needs to be done needs to be done at an entity level. In New South Wales there are eight area health services, so essentially there are eight area cancer services. They need to think about and work through how they deliver good practice. I am not just meaning the clinical trials; I am meaning how the entities function. Martin, you should make some comments rather than me hogging the floor.

Prof. Berry—That is on the last page. It says to build one Australian example, as a start, that is an exemplar of what we consider to be a good model practice which uses all those business principles and organisational principles to bring together the skills and the connections to deliver the service that you need.

Senator HUMPHRIES—You mention on page 6 the example of the dysfunctionality of the system at the moment. You talk about a patient who might be admitted to the orthopaedic ward with a fracture caused by cancer. There is no mechanism to flag this patient to the cancer service. Are you suggesting that a patient who is identified as having a fracture caused by cancer would not be referred, or are you saying that he would be admitted to the orthopaedic ward without the cause of the fracture being known?

Prof. Berry—That is right. A lot of patients who are out there with cancer—these are the people with the prevalence, who are living with cancer—commonly interact with the health system without the cancer team actually knowing what is going on.

Senator HUMPHRIES—Is that because the patient does not choose to refer the matter once they know they have cancer or because they are not diagnosed or because it is not followed through? What is the reason?

Prof. Berry—A person with breast cancer may fracture a hip and get admitted under an orthopaedic surgeon. It may be just by happenstance that the cancer team finds out that that patient is in hospital. There is no system in place to identify those patients. The relatives might get back to the cancer team and say: ‘My mum got admitted two weeks ago. Didn’t you know? We assumed you knew.’ The information system is just not there.

Prof. Kricker—You will see in a number of places that have been discussed the assumption that you know who the cancer patient is—you do not. The only patients a cancer service knows about are the patients that have been referred to the cancer service. You have medical oncology, radiation oncology, surgical oncology. I see somebody nodding to this; they totally understand. The concept that an area cancer service would know who the cancer patients are in the area is a major operational problem.

I will give one slight example. The standards say that all patients should have information before definitive treatment starts so they have some idea. One of the area cancer services said that they had put somebody on full time to work out who the cancer patients were. I was really interested in this and said, ‘How do you do that?’ They said, ‘We look at the operating lists and see who was operated on for cancer the day before.’ I do not think that meets the standard that says you wanted to know about them before. It is a very difficult operational problem. I am not saying it is simple. I am merely saying that there are many assumptions about how the service works, but when you go and look there are reasons, and they are not simple reasons to solve. My guess is that most cancer services would know initially about only a small percentage of cancer patients before definitive treatment starts. That number is certainly going up, and one of the benefits of the MDT treatment opinion groups is that patients tend to be brought to them, so the service is now aware that there is this person with a diagnosis of cancer. But that is a significant issue.

Senator HUMPHRIES—Will a cancer registry fix this problem?

Prof. Berry—Possibly. It would go part of the way to addressing it. I think the problems are the privacy issues and, as you say, any unique identifiers. If we can get over that, that would be very good.

Senator MOORE—Where has all the work gone now? The first thing you said was that this particular entity had been subsumed into some other group. You have done the work. It has taken you four years?

Prof. Kricker—At least.

Senator MOORE—So where does it go now?

Prof. Berry—I do not know. They are reorganising health in New South Wales. The philosophy has been that we need more clinicians where they are needed, so we will get rid of middle management—and that means organisational management—and provide more clinicians. I say good luck, because a lot of the operational, practical detail of implementing a cancer service is highly complex. It is all very well to get the clinicians, but they need to have the framework in which they can operate. It is not going to happen unless these organisational matters are addressed.

Senator MOORE—So it is somewhere in the system in New South Wales.

Prof. Berry—Yes.

CHAIR—I am sorry we did not have time for you to go through your full presentation, but we have had the slides in front of us, so thank you for that and for your presentation today.

[11.08 a.m.]

CROSSING, Ms Sally, Chair, Breast Cancer Action Group New South Wales; and Chair, Cancer Voices New South Wales

ZORBAS, Dr Helen, Director, National Breast Cancer Centre

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be taken in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions. I invite you to make an opening presentation to be followed by questions from the committee.

Dr Zorbas—Thank you for the opportunity to speak with you this morning. We have provided a submission to the committee, and I guess it is important for me to lay some foundations about where our submission comes from. Although we all know that the burden of cancer is great, with one in three men and one in four women likely to be diagnosed with some sort of cancer by age 75, the other aspect of that is that about a third of those with cancer will experience clinically significant anxiety disorders and about a quarter of them will suffer depression. So we are faced with not only the medical aspects but also, very importantly, the psychosocial aspects of the impact of the diagnosis, the treatment and the prognosis, not only for the patient but also for their family and carers. Therefore, I was very pleased to see that this inquiry is looking at a patient centred and more holistic approach to care, which, I think we all agree, is what is required.

Also by way of background, this is something we all know, but I think it is important to state that we have unique challenges in Australia. We have a public-private health care mix, 30 per cent of patients live in rural Australia, the distances are vast and population densities are very varied. So equity of access to quality care is a real issue. Continuity of care is very important, especially when you have a very fragmented journey with multiple episodes, particularly for those who live in rural environments.

To describe the experience of the National Breast Cancer Centre, we were established in 1995 in response to an inquiry similar to this. It was a House of Representatives inquiry into the management of women with breast cancer. In the 10 years since its establishment, I think we have seen enormous positive changes in breast cancer treatment. Ten years ago there were no treatment guidelines for specialists or GPs for women with breast cancer. There was no information for women on which to base decisions about their care or what options they might have. Treatment was focused on the technical aspects of care with absolutely no attention given to supportive care needs. Many women were treated by specialists who saw very few cases of breast cancer and had no particular interest or expertise in breast cancer care. And distance was, and is still, an impediment to accessing best care, but was much more so then. So I can reflect on an enormous amount of change in the care of women with breast cancer and I can certainly delineate what those have been in the past 10 years, but, unfortunately, when I reflect on what we have today, much of what I have just talked about as being the case 10 years ago for women with breast cancer is still the case today for many or most people who have been diagnosed with other kinds of cancer.

Much has been gained and there are lots of lessons learnt from the achievements in breast cancer. I would like very much to support the NBCC model and suggest that its achievements be translated to other cancers wherever possible. We have already shown examples of where this has been extraordinarily successful. One of these is the development of psychosocial guidelines for the management of adults with cancer. This was taken from work we did originally for women with breast cancer. For the first time we identified, for clinicians in the area, level 1 and level 2 evidence—gold standard evidence—of where improvements could be made to addressing the psychosocial needs of people with cancer. This also improves their outcomes. The implementation of those guidelines, I think, is vital for all patients with cancer. We have introduced communication skills training. This was, again, an area that was little touched on by the traditional medical profession, but it has been embraced and patients have seen real benefits in the way they have been communicated to about their care.

We conducted a national demonstration project in multidisciplinary care. This has applicability for all cancers and also perhaps for other chronic diseases. Principles have been developed as an outcome of that study, which looked at how it could be implemented in an Australian setting. There is certainly evidence internationally about the benefits of multidisciplinary care, but it was a real challenge to see how you could make that work in Australia. What we have learnt out of that is very much translatable across the board, and we hope to work with the states to implement that more widely.

What we need and what I would like to emphasise is that we have a unique opportunity in time. We have Cancer Australia in the wings. We have the national service improvement frameworks. We have this inquiry. We have some really excellent work being done in breast cancer care. We are looking at taking principles and policies at a national level but implementing them at a local level—and that needs to be locally relevant. I think we have some examples of how we can make that work.

I will go through what I think we need to make that work. We need governments, professional colleges, allied health and health professionals, cancer organisations, consumers and researchers to all work together. We need evidence based recommendations for care to be developed and implemented, and they need to be responsive to emerging evidence and to be updated regularly. This is quite a challenge. Again, breast cancer has led the way here. We need public health campaigns about prevention and early detection that are based on evidence of benefit and of behavioural change. We know we have a long way to go there.

We need models of service delivery which address our unique environment and provide for equity of access to best care and coordination of care. For example, we have seen the specialist breast care nurse model being developed and implemented. For breast cancer patients, competencies are being developed for breast care nurses. Again, this could be a basis for applying the model to oncology nurses more generally.

I think we need an emphasis on quality improvement in both clinician based care and hospital based care. The community needs some measure of assurance of quality. I suggest the credentialling of doctors. This is already being taken up by the Royal Australasian College of

Surgeons, to an extent, where there is some objective means by which consumers can look at the relative expertise, qualifications or way of practice of specialist doctors. That would also assist GPs in their referral practices. We are also looking at the accreditation of cancer services, and the National Breast Cancer Centre has developed a framework for Cancer Council Australia to look at how that might happen within the Australian context. This will also help to ensure safety. I also think we need an environment which supports innovation and research. This would be in all aspects of care, whether it be genetics, complementary therapies, health service delivery, treatment or whatever.

Ms Crossing—Thank you very much for inviting me to speak to this inquiry. I am going to first speak on behalf of the Breast Cancer Action Group New South Wales. I am a cancer survivor, a current cancer patient and one of an important new species: a cancer consumer advocate. I was introduced to breast cancer at early stage diagnosis in 1995. Ten years later I am ‘living well’ with advanced disease. This year I have had three isolated metastases and half my liver removed, as well as one breast—the one where it all began. I have had quite a lot of recent experience of, from your terms of reference, ‘services and options for the treatment of cancer’. I will give a little bit more background about me. After a paid career in banking and government I became a cancer consumer advocate in 1997, when I founded the Breast Cancer Action Group New South Wales. It is the sister group to that which began in Victoria way back in 1994, which was the first of its kind in Australia.

The two BCAGs—that is what we call them—work together on common issues and share an informative newsletter, arguably the best of its kind. We are separate state-level voices because health services are designed and delivered by state governments. But in 1998 we helped found a national group, which is Breast Cancer Network Australia. I came prepared with some overheads but you have got them there so I will just speak to them. Firstly, just to quickly go through a little bit about the Breast Cancer Action Group New South Wales, it is a state-level voice for people affected by breast cancer. It was established in 1997. It has 750 members across New South Wales, of whom one-third are rural. We work to make a difference for those affected by our disease.

Our mission is giving a voice to people affected by breast cancer. Our objectives are: to reduce the impact of breast cancer on the community in terms of lives affected and lives lost; to improve the experiences of women with breast cancer; to encourage those with experience of breast cancer to contribute to all levels of decision making about the disease—and Helen referred to how we work quite closely with the National Breast Cancer Centre; to promote and contribute to research into the causes of breast cancer, its prevention and optimal treatments for people with breast cancer; to work towards ensuring access to the highest quality treatment and support services, regardless of geographical location, social or economic status or stage of disease; and lastly to provide a forum for women and men—because men do get breast cancer—to share experiences and information.

To know how to work on behalf of our members we need to know what their issues, interests and concerns are, so we regularly scope them to make sure that we are on the right track. The second overhead lists the priority issues which are current for our group. They fall under five major headings: information, treatment, research, special needs and general operational—making sure we are where decisions are being made. I can talk about these in more detail if anyone is interested but in the interest of time I will table those.

Senator HUMPHRIES—What is a CALD background?

Ms Crossing—Culturally and linguistically diverse. It used to be—

Dr Zorbas—Non-English-speaking background.

Ms Crossing—Before that, it was ethnic.

CHAIR—We did not receive the memo that told us that had changed!

Ms Crossing—One of my members said we must be up-to-date and call it CALD. I will now refer to our submission and run through the main points of interest to the Breast Cancer Action Group as we raised them in the submission. A very important point raised by our members was getting onto the right treatment path from diagnosis onwards. I have given you each a copy of our Directory of Breast Cancer Treatment and Services for NSW Women (2002). Our members quite early on said that they had a great deal of trouble trying to find out how to get onto the right treatment path. GPs were very often unsure as to who was the most appropriate specialist to refer them to and they were not always referring them in an optimal way. So we sat down and tried to work out how we could address this particular issue.

It became pretty evident that what we needed was a directory of all the breast cancer treating specialists in New South Wales, with quite a lot of information about how many patients they treat annually, what their qualifications were, whether they work with a multidisciplinary team, whether they had access to breast reconstruction and lymphoedema therapy services and so on. This was quite a labour. We did not do it on our own; we worked in partnership, which is the way we try and work. But it is a good example of cancer consumers identifying a gap and nobody else being prepared to fill the gap. Lots of people said, ‘Doesn’t the government do that?’ or ‘Doesn’t the Cancer Council do that?’

Senator KNOWLES—Who provided the information?

Ms Crossing—The specialists themselves. We developed a questionnaire and sent it out to them. Although it relates only to New South Wales at the moment it is in the process of being rolled out nationally. All national breast cancer specialists will receive that questionnaire—and so will the New South Wales specialists, because their information is slightly out of date; it is a couple of years old. It will be published on our web site and on other web sites linked to organisations who are interested in it. It is the first of its kind and we are really excited about it because it can be used for any other cancer or any other disease.

We wanted to raise that matter. Getting onto the right pathway is still a serious issue. Many of us, including me, have experienced not being able to get onto the right pathway. Another way we found out about women’s experience of treatment was to undertake a survey of all our members—the result being the November 2001 report, *Survey of women’s experiences of breast cancer services in New South Wales*.

I would like to move on to the issue of multidisciplinary care and care coordinators, and acknowledge that the National Breast Cancer Centre has been the trailblazer in this area—and we are delighted. There are more breast cancer multidisciplinary clinics around now than there were when I started on this journey and I hope there will be very many more. One of the problems is that many large hospitals, public and private, still do not have them, so a lot of women miss out on the benefits—as do the clinicians, because it is a two-way thing.

We support the use, for long-distance multidisciplinary communication, of teleconferencing. And we think there should be more breast care nurses. That is another area that the National Breast Cancer Centre has done a lot of research on and has shown what a huge difference the assistance of a breast care nurse can make to somebody going through the journey.

Having looked at getting the right treatment path and identifying gaps and systemic problems—and showing how we have managed to address some of these ourselves—I will move on to a couple of areas which are of particular concern, including access to breast prostheses and lymphoedema sleeves and treatment. If you have a mastectomy you no longer have a breast and you need something, not only for cosmetic purposes but also for medical purposes, so that your spinal situation does not become compromised and cause a lot of other health problems and expenses.

Access to breast prostheses after a mastectomy is very patchy. Some states provide them. Victoria is leading the way but in other states it is pretty much hit and miss. We think that they should be regarded as normal medical prostheses—as are limbs, fingers and so on—and be covered by a Medicare subsidy. The same goes for lymphoedema sleeves. Lymphoedema is a painful swelling of the arm or the area where you have had ancillary dissection. That applies not only to breast cancer but to other cancers—melanoma and so on. There is little help for people who need the special sort of therapy that can improve the condition—you can never get rid of it—and it is very hard to get subsidies to pay for these elastic sleeves.

Another area we are particularly concerned about at the moment is access to PET scans for people with recurrent or advanced breast cancer. Although PET scans for most cancers are funded by the Commonwealth government, they are not funded for breast cancer, even though a great deal of evidence has built up over the last few years to show that it is a very important tool for following and staging the course of advanced cancer. It is $900 out of your pocket and that is a huge sum of money for most women faced with this particular situation.

Lastly, we have just undertaken a survey of all our rural and remote women members to find out exactly what their particular issues are. That is a new project, and we will be up to speed on their needs. In the past we have surveyed the needs of our younger women members, which are quite different from those of older women. That is another area where we have a distinct group within our group who advocate addressing those needs. Mammograms post breast screening are also a problem. A number of women become very distressed when they find that their mothers, sisters and friends who do not have breast cancer are able to have free mammograms through breast screening every two years, but they, because they have been diagnosed with breast cancer, have to pay quite a lot. That is the case. It seems completely unfair, but it is another issue we have on our list of things to try to do something about.

The gathering of statistics is a further area of concern for us. Although we know how many people are diagnosed and how many people have died of breast cancer, we do not know how many recurrences there are and how many people develop advanced disease. Without that sort of information, it is very hard to plan health services appropriately. We are really flying in the dark.

As Bill Kricker mentioned, we think 600,000 people in Australia are living with cancer—this is cancer, not just breast cancer. It is not good enough. We had been using the figure of 400,000, because we know 100,000 are diagnosed each year and we were giving it a multiplier of four, but that was a completely back-of-the-envelope figure, and probably 600,000 is the more correct figure. The point is that it is not good enough. I will pause there, as far as the Breast Cancer Action Group is concerned, and I will take any questions you have.

Senator HUMPHRIES—Thank you very much for those very comprehensive presentations. First of all, I have some questions in relation to the National Breast Cancer Centre. I was interested in the comment in your submission about the survey you are undertaking of women with breast cancer to identify commonly used complementary therapies. At what stage is that survey at the moment? Have you any preliminary findings that you could divulge to us?

Dr Zorbas—No. It is about to go out to the survey participants. This came from a need that was identified for us to address complementary therapies because, clearly, so many people with cancer have access to them, many of them are widely available and certainly they are marketed very effectively. Many clinicians have been aware of their patients taking complementary therapies, and perhaps they themselves are unsure about the benefits or risks of doing that. We were going to go down the path of looking at the evidence base for a couple of therapies, and then we thought that we really do not know which therapies people are using and how regularly and for what reasons they are using them. Therefore that was the basis of our thinking that we needed to do this survey initially, and then, on the basis of that, we will look at the evidence which supports those therapies or otherwise,.

Senator HUMPHRIES—So are there concerns in the groups that you deal with about the range of complementary medicines or therapies that might be in use, or is it just a desire to know what is happening?

Dr Zorbas—This comes to us from two sides: both from the consumers who want to know if what they are taking is harmful or advantageous to them and from the clinicians who are not sure perhaps about the effects that complementary therapies may be having on their patients who are currently taking other standard treatments. I am also a practising physician, and I work one day a week in practice, as well as being the Director of the National Breast Cancer Centre. I certainly see lots of women who have had breast cancer who, of their own accord, let me know that they are taking soy products because they believe them to be beneficial. In fact, there may be evidence that it is harmful for those women to be taking soy products.

It is being marketed as a positive well-being thing for women to take soy products, but in fact they may have oestrogenic properties that may be harmful to those women. So I think there is a lot of clarity required by both the consumers and the clinicians. We certainly know that there are some advantages of complementary therapies that need to be widely propagated, known and supported, but we need to be very well aware of the fact that there may be some complementary therapies that may be harmful.

Senator HUMPHRIES—Is it likely that many women would not be revealing to the GP, clinician or specialist who is treating them what other complementary medicines or therapies they are undertaking?

Dr Zorbas—I think it is quite likely. In our guidelines we make a point of emphasising the importance of clinicians inviting the patient to discuss any other therapies that they are undertaking. We know that there are advantages and evidenced based support for things like meditation and relaxation therapies but we also know that there are harms—for example, in taking vitamin C when you are on chemotherapy—that may not be known to a patient. So it is important that the clinician has achieved a comfortable relationship with the patient in order that there is that two-way conversation about what else they are taking.

Ms Crossing—I think people are often of the belief that if the complementary alternative therapy they are taking is natural they do not need to tell anybody, because it is perfectly okay.

Senator HUMPHRIES—Although arsenic is natural, for example, we would not necessarily take it.

Ms Crossing—Yes, exactly.

Senator HUMPHRIES—Can I say to you, Ms Crossing, that things like this are obviously very useful and I commend you for putting these things together. But it does raise the question of how many different organisations there are that a person with cancer—in this case, breast cancer—might need to deal with. We have had some evidence given to the committee of a vast array of both government funded, sponsored or run organisations and non-government organisations. Obviously, it is important to have groups in the community that are directly assisting people with particular types of problems, like breast cancer, but is there a sense that there are too many organisations with which a person who has cancer might interact for them to be able to steer their way through that maze? Is there a case for rationalising or consolidating some of those support organisations? They are questions for both of you, I suppose.

Ms Crossing—Most people, when they are diagnosed with cancer, know nothing about the organisations which can provide them with information, support or even treatment. So I do not think the problem exists at that stage. And it probably does not exist at stages even further along, because most people are just coping with their treatment and the side effects of their treatment. They may reach out and look for information, which usually means turning to either the Cancer Help Line, which is the clearing house for information about a person’s situation, or the National Breast Cancer Centre in the case of breast cancer. Support, of course, is the other main area; people will probably be looking around wondering if there is anybody who can help them through this adjustment, both physical and psychological. That can be very hard to find too, because specialists and GPs are not particularly prone to referring people to the cancer support groups.

Senator HUMPHRIES—Why is that?

Ms Crossing—They say that they do not have sufficient confidence in them being properly run. And yet, Cancer Council New South Wales has just done an enormous study into the effectiveness of support groups—I have the details here—which shows that they are very effective, regardless of whether they are run by a professional facilitator or a peer facilitator. That is a job we have ahead of us; this is one the things that groups like mine need to do—we need to talk to groups like the National Breast Cancer Centre, the Cancer Council and the Cancer

Institute of New South Wales and ask, ‘How can we get the message across to clinicians that they should offer access to support groups to people with cancer as a matter of course?’

From the point of view of the person with cancer, I do not think that there is a great confusion about different sorts of groups. Consumer advocacy groups are another thing altogether and you do not usually want to get involved with them when you are first diagnosed with cancer. If you do want to get involved, that usually happens later on, after you have had a bit of a think about lessons you have learnt and how you might like to make sure other people benefit from them as a group later on. It is a totally different thing. Does that answer your question?

Senator HUMPHRIES—Yes, it does.

Dr Zorbas—We actually have level 2 evidence of the benefit of peer support, or support groups, in our psychosocial guidelines. Perhaps this is an area where I differ with Sally, because I do think that there is confusion out there—there are too many cancer organisations and there is confusion in the community, certainly where you look at organisations with breast cancer in their title. There are about 150 in Australia. For anyone looking up breast cancer on the internet or anywhere else, unless they are steered or guided by someone they trust or an information source in some way, it is very hard for them to ascertain which is the credible information source and which one they can trust. Certainly the internet has a plethora of information, some of which is based on very little evidence at all or on people’s personal opinions. I get very frustrated by the fact that we could coordinate our few resources and our relatively few experts in this country into a more coordinated approach to developing and delivering information, and developing and delivering care. I think that there is a lot of waste in the current situation.

Senator HUMPHRIES—In that respect, do you think it would be useful for this committee to recommend that there be an exercise in developing a common entry point to information for people with cancer, in the form of, say, a web site? Obviously, you have the Cancer Helpline already, but perhaps that could be enhanced to some degree. Maybe an information pack could be developed that could be mailed to people who ring any department of health around the country—a pack that consolidates information about all these things and provides people with information about support groups, advocacy groups and all sorts of things like that. Would you take part in that exercise if it were being developed?

Ms Crossing—Yes, but these things already exist. The real challenge is: how do you corral everything? As Helen said, the internet of course is full of all sorts of obscure things, but you cannot stop that. That is one of the problems. It is absolutely impossible to address that, I am afraid. But we could do an advertising campaign. Perhaps Cancer Australia could take on the job of saying: ‘For telephone help, ring the Cancer Helpline. For reliable web information, this is the one to go to.’ It could really take a major role. There is the Cancer Voices material and also the complementary and alternate therapies issue of information, which I did not address just now. There is a huge crying need for a central, authoritative source. We have been banging on about this for years. I am really getting quite excited because it seems to be such an obvious job for Cancer Australia to take on: to become the credible source of information about cancer, including prevention, treatment, the journey and all the other less orthodox treatments. I like your phrase: less orthodox treatments. At the moment, people just get information from the *Women’s Weekly*, television or the *Daily Telegraph*. It is ridiculous. Strange emails get sent to young women, telling them that they have to stop dyeing their hair immediately because they will all drop dead of breast cancer. It is a bad situation and we absolutely ought to address it. A central, authoritative source would be the way to go, so please recommend it.

Dr Zorbas—I think you are right, Senator. Cancer Australia provides a prime opportunity to have a body with some sort of seal of approval for this kind of information, so it is out there, obvious and visible to people, irrespective of where they live and what cancer they have.

Ms Crossing—The state cancer councils would still need—because you have to sort of disseminate a little bit, I would imagine—the cancer help lines. Although that is done on a national basis, if someone is calling from New South Wales then they will tell them where the help is available in New South Wales. Information is different. Information should be national, but on-the-ground support probably needs to be divvied up.

CHAIR—We took evidence yesterday about the uncooperative attitude of the colleges in making available performance data on their own treatments. There has been a very strong consumer lobby group for breast cancer, and it has really driven that. This is a good start and it is very valuable, but it does not actually go the next step about performance and outcomes, so we are not quite there yet. Breast cancer is really the model we are looking at for all other cancers—it is probably 10 years ahead of where we are everywhere else. We are still hearing about serious problems in psychosocial support, referring to support groups, exchanging information between the practitioner and the patient, and alternatives or complementaries that people are trying. There is still a lot of holes that need to be plugged.

I am just wondering whether you want to comment generally on the information side and what this committee might recommend in order to provide information back to patients. We heard earlier this morning that information leads to empowerment of the patient. Just as an aside, I want to try and use the politically correct term because the committee was chastised yesterday about referring to people as victims. I do not like referring to people as consumers of cancer, either. Anyway, that is an aside. We might finish off with that. How do we actually take that next step? What might the committee be able to do in a meaningful way to break down some of these barriers to information and empowerment?

Dr Zorbas—It is important to say and to emphasise that, although there is lots to be done, so much has been achieved in breast cancer. We have come an enormous way in a relatively short time. To give credit where it is due, certainly the surgeons in breast cancer have been leading the way in terms of accountability, in terms of identifying their members who have an interest and who are willing to take on particular aspects of their professional education which will identify them as breast cancer specific surgeons. That is quite a transparent process. They are currently looking at the data that is provided by those clinicians, and that is provided willingly. This was completely up to the individual surgeons, but it has now become compulsory for membership of the breast section of the College of Surgeons to provide the data around the patients with breast cancer that they treat. This is fed back to those individuals so that they can review their own practice in relation to that of their peers.

We are now progressing that one step further in looking at standards against the guidelines for practice, which the National Breast Cancer Centre has developed, where surgeons can look at their care in relation to what is recommended in the guidelines. We may be going one step further again with a quality improvement cycle in relation to that.

Ms Crossing—We would like to list in our directory those surgeons who have been accredited by this process.

Dr Zorbas—I think that is a huge step forward. It is also an undertaking by people who are doing this in an honorary capacity. All of this is not supported financially at any level. The surgeons who are setting themselves up to review the data provided by surgeons who are looking to go through this process of identifying standards are doing this because they want to see best practice. The clinicians themselves have shown motivation and goodwill in wanting to ensure that their patients have access to best care.

CHAIR—Is it moving outside the area of breast cancer though?

Dr Zorbas—No, I think breast cancer is leading the way. It is taking a while—I acknowledge that—but it is a huge step. The danger is when it is taken out of the hands of the colleges. The colleges themselves need to take this responsibility for their membership. If it is done in a threatening or punitive way then it will not be adopted more widely. The emphasis has to be on quality improvement and providing best care. Clinicians are very strongly motivated in that direction. For example, the College of Pathologists and the College of Radiologists do undergo these processes within their own colleges for their membership to ensure that the standards are at a good and safe level.

But there need to be some resources put into that quality improvement cycle because, to my knowledge, at the moment there are not. It is up to individuals to decide whether they, for example, change their whole database to comply with the College of Surgeons one so that they can provide their data, or whether they have someone available to enter the data—a research assistant or office manager. There are a lot of implications in conducting these sorts of quality improvement activities. To date, as I said, there has been a hell of a lot of goodwill and personal expense put in by a number of clinicians to ensure that this happens. The consumers can help drive this to a great extent, but it has to be done in the spirit of quality improvement and best care.

Senator MOORE—I have found that there is enormous interest and goodwill around the area of breast cancer. It has touched a chord in the community in terms of fundraising, focus groups and even schools getting involved in information sessions, which is a stark contrast to just about every other form of illness, let alone other forms of cancer. I am wondering about the reliance of the activity and the generation of future action on that goodwill—what happens if that community enthusiasm and fundraising dies off?

Dr Zorbas—The National Breast Cancer Centre is not a fundraiser, so I do not think it would be affected by that. But I think what you are saying is that there could be breast cancer fatigue in the community. With the increasing incidence of breast cancer—although there is a decrease in mortality—there are still going to be so many people in the community affected by this disease that its impact and burden will keep it at the fore. That would be my impression. However, it is also important to share what benefits we have seen in breast cancer with other cancers. I could not agree with you more that to see the mortality in lung cancer is just devastating. So many lung cancer patients are not having access to appropriate referral—the initial referral which could make a huge difference in their outcomes. We have also seen that with ovarian cancer—the National Breast Cancer Centre also runs the ovarian cancer program. We know that there is very strong evidence that the initial referral to a specialist gynaecological oncologist makes all the difference in outcomes. There are many other cancers that also require attention, but breast cancer will always have a place, if for no other reason than the great burden of illness.

Ms Crossing—This is very much the reason why I expanded my horizons as a cancer consumer advocate. I learned a lot from breast cancer. It is all completely translatable to other cancers and, in fact, to cancer generically. I think it would be remiss not to use what we have learned from breast cancer. I agree with Helen about the breast cancer fatigue idea. Breast cancer is not going away; it is increasing. If people do not want to go to the latest Pink Ribbon Ball they do not have to.

Senator MOORE—I come from Queensland, where there is some activity going on in the areas of the directory. We will be looking forward with enthusiasm to having something similar there. One of the things we have talked about is exactly what you were talking about: getting people to give you their details, what happens if they do not and what is the message that is given. I am interested in whether you have had feedback between 2002, when this was first published with great fanfare and success, and now and whether any of the people who did not choose to give information then for whatever reason—and you foreword is very diplomatically written—have come to see you. Has there been a bit of a discussion between those specialists and the group that put together the book?

Ms Crossing—A number of people who were not covered by that—perhaps because they did not want to do it, although we had a very high agreement rate of about 95 per cent—have since talked to us. New ones have come up too and we have a list of people wanting to be in the next round.

Senator MOORE—One of the things we talked about was a woman obtaining the first book—and getting the book is an amazing thing—and her own doctor not being in there. We have just been talking in groups about what happens then.

Ms Crossing—That is a very good message to go and get another opinion.

Senator MOORE—That is what we thought. We were wondering whether you have worked that through with doctors and people who are working through the journey.

Ms Crossing—Is entirely their decision. If they do not want to be there, they are not there. The second time around, when every breast cancer specialist in Australia will receive an invitation to be involved, we expect a very high participation rate. It is free advertising. These guys are sole traders. We talk about the problem of multidisciplinary teams, and Bill Kricker was talking about trying to get some business ideas. It is very hard when you are dealing with a lot of people who have been trained for many years to operate as sole traders, but I think they are beginning to realise that we can help them in their business to help us by pulling them together.

Senator MOORE—It is our feedback that women check this out and, if their doctor is in there, that gives them a tick. That is really useful.

Ms Crossing—I am a little concerned about whether GPs use it as much as I would like them to.

Senator MOORE—That is the next step of the process. We talked yesterday with your sister groups in Victoria. The action group has developed a web site with lots of information. One of the questions we asked them is how they are going to maintain it, keep it up to date and retain that immediate credibility which you have achieved. What is your plan for the expansion of this very valuable tool and also the other kinds of centralised information that Senator Humphries was referring to?

Ms Crossing—We would not attempt to cover general information because it is already very well covered by very authoritative web sites. We get back to the point you were making before—hopefully one day people will all be directed to the very best web sites. I do not think new little web sites set up by small groups who would not be able to keep them up to date and even authoritative is the way to go. The idea with this one is to send everybody the questionnaire again every two years, invite them to update their information if they are already in it and, if they are not in it, to give them the opportunity to be listed.

Senator MOORE—Who funds that?

Ms Crossing—The Breast Cancer Action Group and the New South Wales Department of Health.

Senator MOORE—They gave seeding funding for that one.

Ms Crossing—Yes, they gave us $40,000 in the beginning. We have raised about $50,000 ourselves. The New South Wales Breast Cancer Institute—our partner—has also put money in. It is the people who wanted it to happen who have put the money in.

Senator MOORE—But there still is a requirement for that kind of funding.

Ms Crossing—No, what is really expensive is producing a hard copy. Once you have it electronically, which we have, it is not very expensive at all. It is just a matter of sending out roughly 600 letters every couple of years.

Senator MOORE—Do you update as you go along or do you just do one major update every two years?

Ms Crossing—This time we have a clever electronic device whereby they are given a password and they do it themselves.

Senator MOORE—So it is absolutely self-help.

Ms Crossing—Yes.

Dr Zorbas—We have also got a different kind of directory. It is national and it looks at the hospital services and what they provide.

Senator MOORE—Yes, I have seen that.

Dr Zorbas—I think they are complementary tools and resources.

Senator HUMPHRIES—I just want to give some feedback, Ms Crossing, about that issue you raised of breast prostheses being considered for a Commonwealth subsidy. You said in the action group’s submission that this issue was looked at by this committee in examining the National Health Amendment (Prostheses) Bill recently. I do not think the committee actually did look at that issue—I am not quite sure why. I do not recall that there was any evidence before us about that subject.

Senator MOORE—That was before the committee looking at the mechanical devices bill.

Senator HUMPHRIES—So it was before the legislation committee, which is our sister committee. It looked at that issue. It did not look at the issue of breast prostheses, to the best of my recollection. You might want to bowl it up again somewhere else, because it is an issue which, I suspect, if we had looked at, we might have been very sympathetically disposed towards.

Senator KNOWLES—Congratulations on the work that you do. It is obviously first-class and it is recognised around Australia and in various parts of the world as being first-class. The part that gets me is that it is not adopted elsewhere. I just do not, for the life of me, understand why we have to keep reinventing the wheel the whole time when the breast cancer model has been accepted as being almost world’s best practice.

Ms Crossing—Drip, drip, drip!

Senator KNOWLES—When does the flood start? It really is a very serious thing, because we are wasting huge amounts of organisations’ dollars and taxpayers’ dollars. Do you have any recommendations to this committee as to how we could say: ‘Whoa! Everyone just stop. Take a big deep breath. Let’s have a look at the breast cancer model and let’s see how we can replicate that across cancer fields.’

Ms Crossing—This inquiry might do that.

Dr Zorbas—You are certainly speaking my language! I think there are a number of very well-intentioned people, but there is a proliferation of groups who want to take their way forward. I agree: I think we need a very high-level, national approach. That is why I was saying earlier that I think the principles and the policies need to be nationally driven. The way it happens on the ground needs to be locally relevant, but I hope that this is the time that the stars and the moon or whatever have come together and that Cancer Australia and such an inquiry will help bring some balance and clarity.

Ms Crossing—Wasn’t it a Senate inquiry in 1995 that really kicked off the National Breast Cancer Centre?

Dr Zorbas—Yes, absolutely. I am hopeful and optimistic that we can use the lessons learnt and take the models. Certainly with multidisciplinary care, we are currently taking the model and the lessons learnt to each state around Australia. The Cancer Institute New South Wales has commissioned us to provide a forum in each area health service for all cancers, not just breast cancer, because of the recognition of the applicability beyond breast cancer of the lessons that we have learnt and the resources that have been developed in breast cancer. So hopefully that can happen. Also, we know from where we have done work in breast cancer that the clinicians involved have taken that model and used it in their other practices, in lung cancer and brain cancer. So there are opportunities. I think it needs to be driven at a policy level.

Senator KNOWLES—But, if we were to recommend, for example, that the breast cancer model be widely adopted as the best practice, how and who would we get to do that in a practical sense?

Senator MOORE—What does that mean when you say the ‘breast cancer model’?

Senator KNOWLES—The whole multidisciplinary approach.

Senator MOORE—The care guidelines and that kind of thing?

Senator KNOWLES—Yes, all of that. Who do we drive it to and say, ‘Right, you are responsible; we want you to implement that across all cancer types,’ so that all people who are affected have similar opportunities to those who are affected by breast cancer?

Ms Crossing—There must be a role for government—one would hope with the support of the professional colleges.

Senator KNOWLES—Yes, it is a role for government. That is, let us face it, where we are going to try to drive a number of these issues. But someone then has to implement it. If everyone is wanting to push their own barrow and be the first, be the ground-breakers or be this or be that, that responsibility has to be designated somewhere. How would you see that being designated?

Ms Crossing—You can accredit cancer services according to a set of guidelines. I was going to get on to this, although I do not know if we have enough time left for Cancer Voices. In New South Wales we had this wonderful document, which is a sort of blueprint—although it is a green print!—which sets out the standard for delivering best practice cancer care. This has been done in Victoria and it has been done in other states as well. The NBCC has done a massive accreditation project. If a cancer service is not accredited, it will not receive funding. It is carrots and sticks. I think there is a way through here.

CHAIR—Ms Crossing, could you just read out the title of it?

Ms Crossing—It is ‘A clinical service framework for optimising cancer care in NSW 2003’.

CHAIR—That is part of the problem. Things are accredited in New South Wales and Western Australia. Here, there and everywhere there are lots of good ideas and lots of different things, but there is no universal best practice that is implemented across the board—a one-stop shop where we can help anyone who has cancer.

Dr Zorbas—I think what you are alluding to is the railway gauge issue.

Senator KNOWLES—That is right.

Dr Zorbas—I am hoping again—I am being optimistic—that this is the right timing. We have frameworks like this and cancer plans being developed in most states at this time, and they are at different stages of development, because of the appreciated need to coordinate cancer care within the states. There is a need for each of those states to buy into a national framework of some sort—hopefully Cancer Australia will provide this—which sets out policies which are developed with input from each of those states, which sets up guidelines and which is the overarching body from which we all take guidance but which is also responsive to the needs of the states and which the states feed back into. I think that this is the right time to do that. I do not think we have had cancer looked at in a global sense before. It has been very bitty. I think this is the time when the states are taking it on board and the Commonwealth has taken it on board, and it is opportune to look at how to make that work best. I agree with you there are going to be carrots and sticks, and maybe that is accreditation and credentialling at one level. Maybe it is funding at another level. Maybe even the health insurance companies will buy into this in some way. There are the medical defence organisations. There are a whole lot of aspects that might feed into how this will all pan and out and what the carrots and sticks will be. I think the time is ripe, and I have never seen it as optimistic as this.

Senator KNOWLES—So the council of health ministers really needs to be the driver of the train?

Dr Zorbas—Yes. I think they are vital to this. If you do not have buy-in from the states then it is all going to crumble. The Commonwealth can be saying one thing at one level, but if it is not operationalised in the states then it is not going to happen.

Senator KNOWLES—We have the Commonwealth and the states, but what you are describing to me now is that we still have all the states basically doing their own thing and, somehow or other, they all need to be shepherded into the same pen to produce a similar outcome, allowing for the nuances of, say, my state of Western Australia, where there is a huge geographic problem, and the nuances of a small population in, say, Tasmania.

Dr Zorbas—We are saying that there needs to be agreement on really key things—for example, data collection. There is no point in each state developing its own data collection model or items. There is no benefit in states collecting the same items but defining them differently, because then they have no value either. That is just an obvious example of where you need a national, agreed approach.

CHAIR—Even yesterday in Victoria, early in the submission from the Victorian department, they said, ‘We need national leadership,’ but later on in the submission they then said, ‘We developed our own framework with one eye based on the Commonwealth framework that was already there, and it is pretty close.’ To me, if it was pretty close, why couldn’t it have been exactly the same and why couldn’t we replicate the exact same set of guidelines of frameworks in every state? It just seems a bit difficult there. Senator Knowles, I do not want to interrupt you, but Ms Crossing wants to get something from Cancer Voices on the record before we run out of time. I will hand over to her now and then we will finish off with you, Senator Knowles.

Ms Crossing—I have referred to why Cancer Voices was begun. Through my own personal experience, I began to realise exactly what I have been saying—that is, that we could learn a lot from the breast cancer consumer advocacy movement and its achievements. I also realised that very many people with cancer share mutual problems, interests and concerns and that there needed to be an organisation which could provide a voice for those people.

There are two handouts there. I will not go through the details of our mission, objectives and areas of interest, because you have them in front of you. Cancer Voices began in 2000, so we have been going for five years. I have also given you a copy of our newsletter, which is our main form of communication with our member groups. We are a coalition of cancer support and advocacy groups, not individuals. This is how we keep them in touch with what we are doing and it is also how we find out what they want us to do. We have given you our most recent copy. There is our operational plan, which lists all the issues we are working on, what we are trying to achieve and how we are going to do it. It is a very interactive, two-way organisation, which I think is the only way that a cancer consumer group should work.

This year is a particularly exciting year because Cancer Voices is appearing in every Australian state and territory. Cancer Voices New South Wales wrote to all the CEOs of the cancer councils last year suggesting that this was a gap that needed to be filled and inviting them to help establish branches so that every state and territory is able to contribute at the same level as we do here in New South Wales. We had a very positive response. Western Australia already has one signed, sealed and under way. Victoria, Tasmania, South Australia and Queensland are in various stages of progress. This will form a platform for a national Cancer Voices group, which we hope will come to pass this year. It will mean that we will have a very representative basis, because the state level groups are based on local groups. It is a federal model. We have a federal system of government. Some people like it; some people do not, but that is the system we have. We think this will probably work very well too.

I will run very briefly through the recommendations in our submission. With regard to multidisciplinary care, we have the same comments that we made before. Our recommendation is that this inquiry recommend that the broad principles of multidisciplinary care be adopted for the treatment of all cancers, not just simple cancers. Going back to breast cancer: you get multidisciplinary care if you are a complicated-looking case but you do not necessarily get it if you are an easy-looking case. I fell through that gap myself. I will not go into the details, but it happens to people all that time, so that is something that is very important to us.

On the issue of case managers and coordinators, the inquiry's recommendation is that all Australian cancer services make provision for care coordinators and that cancer curricula and training emphasise the necessity for coordinators and case managers for the benefit of both patients and specialist clinicians. I refer here to the fact that this gives the patient empowerment and we know—and I think you hinted at it before—that empowered patients tend to have better outcomes.

Then we move on to physical and psychosocial. Looking at the different models of best practice for addressing psychosocial factors, our recommendation is that the NHMRC guidelines for psychosocial care be implemented at all cancer services and, again, be taught through medical and nursing training. We keep coming back to this. If when they are learning the clinicians know that these things are expected, they are more likely to put them into practice.

The next recommendation is that the inquiry recommend to government that cancer support group funding—which has just come through in the Cure Cancer Australia pot of money of $137 million over four years—be allocated across all cancer support groups and their networks at local, state and national levels. The Commonwealth currently is emphasising tumour-specific national groups, which we do not support because there is no evidence to say that these are the most effective form of cancer support groups.

As requested by the terms of reference, we looked at current barriers. The recommendation was that government support development and implementation of guidelines, accreditation and credentialling systems and that the government legislate—I do not believe this has been put previously to this inquiry—that representative cancer consumers be invited to participate at all levels of decision making. It has been legislated for in the UK and, more recently, in New Zealand. We think it would make it a great deal clearer and easier for people talking to consumers if they were required legislatively to do so. If it were required by legislation, there would not be all this scratching of heads and wondering whether they would or would not.

I have also given you a list of the less orthodox treatments. It is handy to have, and I thought you would find it of interest. There are 21 less orthodox treatments on that list. It gives you a good summary of the sorts of treatments that people with cancer use. I think 56 per cent of people surveyed had used one or more of those treatments. I just bring that to your attention. Our recommendation, as I mentioned before, is that government funds be allocated or redirected to ensure there is a central information authority for cancer, considering the particular uncertainties that surround this disease, its risks and its therapies. This should be based on a process of investigation into efficacy, with reference to existing international sources and so on. I will leave our comments at that.

Senator KNOWLES—I have one quick question, which again is on duplication. The BCN’s kit is fantastic, but why are so many different kits available? Why can’t we all learn from one and adopt that, instead of wasting a huge amount of money on again doing our own thing?

Ms Crossing—They are all completely different. The BCNA’s kit is given to women newly diagnosed; it gives a very broad, comprehensive picture of the journey and what to look for. The directory is something quite different; it is a much more specialised tool for finding the best or most appropriate person to treat.

Senator KNOWLES—But why isn’t that in the BCNA’s kit?

Ms Crossing—It is too big and it only relates to New South Wales.

Senator KNOWLES—I realise that. But do you understand what I am getting at? We have material coming out of our ears and elsewhere, and someone has to pay for it. Money is being frittered away in some respects, when we should be achieving the best possible outcome through consolidation.

Dr Zorbas—And it is not just with this sort of information. As I say, I work in a hospital where both the oncology team and the breast nurse give information to patients. Before a woman has walked out the door, she has a pile—

Senator KNOWLES—A tree.

Dr Zorbas—Exactly. Some information is better than other information. Some is written at a level that is very simplistic; other bits of it are very detailed. However, people have different requirements and some will want to have many different things to review and others will not. I go back to my earlier statement: there is far too much duplication of effort; we have few resources and few experts in this country and they could be used more meaningfully.

CHAIR—Thank you both very much for your submissions and your presentation to the committee today.

[12.22 p.m.]

BISHOP, Professor James, Chief Executive Officer, Cancer Institute New South Wales

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public. But evidence may also be taken in camera, if you consider such evidence to be of a confidential nature. The committee has before it your submission. I now invite you to make an opening presentation, which will be followed by questions from the committee.

Prof. James—The Cancer Institute New South Wales is a recently formed state government based organisation. It was set up under a separate act of parliament: the Cancer Institute NSW Act. Its primary objective is to reduce the incidence of cancer, to improve survival, to improve the quality of life of cancer patients and carers and to act as a source of expertise to government for cancer related matters. The institute represents a new activity for Australia, although models like it in terms of cancer control agencies occur in other places such as Canada, the US and the UK. We think it is an interesting and an appropriate response to the cancer problem.

We have evidence that, over the next seven years, in New South Wales alone, cancer will increase in terms of the number of patients by about 25 per cent. We anticipate that, by 2011, in New South Wales, there will be over 40,000 cancer patients newly diagnosed every year. This brings into stark contrast the ability of services and groups to support such a large cancer population. The good news is that cancer survival rates are increasing. The aim of our institute—and, I am sure, other groups working in the same area and allied groups—is to accelerate the reduction in death rates that is occurring. Each decade sees a further reduction in these death rates, and we wish to accelerate that dramatically but also to reduce cancer incidence.

Our aim is to find methodology so that we could improve the current situation by actually reducing incidence, as well as accelerating that spiral towards a lower death rate from cancer. Approximately 30 years ago, 60 per cent or more of cancer patients dies of cancer. Today 40 per cent or less will die of cancer. While that is a modest improvement, it is a dramatic one in terms of the numbers of people whose lives are saved as a result of activity. The reasons why survival is improving are numerous, and they are to do with screening programs, cancer awareness, prevention of groups at risk, and also the application of research with respect to better treatments and better methodology to improve outcomes. We know the many levers that we could pull that might improve the current situation. It is a question of trying to understand the high priorities that might exist within those levers to see where work can begin first.

There are a number of key areas which might be of interest to this committee. The largest cause of preventable disease in the world and in Australia and the New South Wales is tobacco. If we were able to reduce tobacco consumption to the level that is current in California, it would have dramatic effects on the health burden of services and suffering in this country. In New South Wales at the moment, tobacco consumption is about 20 per cent of everyday smokers. While that is lower than it has been, we are concerned that the downward trajectory has levelled to some extent. We wish to push that down to 15 per cent in the next few years. We know that, from experience in California and Massachusetts and British Columbia, a level of approximately 15 per cent to 16 per cent could be achieved, and we think that is an important consideration.

Other areas of high priority for prevention and screening include the introduction of bowel cancer screening, which is clearly a proven method. If bowel cancer screening were introduced tomorrow in Australia, we could expect, once that program was established, that approximately 1,000 lives would be saved in Australia every year. That is an important consideration for this group. There are a number of pilot programs which the federal government has funded for bowel cancer screening, and they have been successful. They have successfully detected bowel cancer, and the time is appropriate to now move into a general population screening for bowel cancer in Australia. Based on the experience in cervical screening and breast screening, where the networks are already established, New South Wales, in anticipation of a federal government screening program, has pulled together the screening programs. As of 1 July this year, all the screening programs in New South Wales will be part of an integrated approach which the institute is designing currently.

We believe that with the burden of cancer coming towards us, there are much better models and more efficient ways to provide care. We should have an integrated approach between primary practitioners and cancer centres, and a much more coordinated approach. We support the broad cancer patient consumer advocacy, which would suggest the coordination of care is a high priority. That is the reason why we have funded over 50 care coordinators this year alone in New South Wales as new positions in New South Wales hospitals. Those are currently being recruited as a new program from New South Wales. The coordination of care is also important between agencies, and the opportunities that might occur from that. For example, the role of Cancer Australia would be to coordinate care from state agencies, such as ourselves, with ones that are developing in Victoria and elsewhere. This will allow us to use the expertise that exists in state agencies and in the department as well as in cancer councils to provide a national program. We can all reduce the duplication that was talked about before as well.

Efficient models of care also mean that the majority of cancer care is ambulatory care. A review of ambulatory care in New South Wales would suggest the ratio of ambulatory care occasions to inpatient services at about 15 to one but, to be more efficient, it should probably be above 20 to one. If that is the case, the current models do not allow you to provide optimal ambulatory care because many of those patients are privately referred outpatients and therefore part of the Commonwealth government arrangements. Some of them are hospital outpatients within state health systems. The issue is coordination of care, so the funding models, to some extent, make that more difficult.

The second aspect that we would like to bring your attention to is the fact that multidisciplinary care is critical for cancer care. That means that all of the disciplines, not just the medical disciplines, such as nursing, allied health, social support and other disciplines, need to be brought together to provide the best in optimal care for any individual patient. Again, at the moment the funding models available do not necessarily help that as there is no ability, particularly in the private area, to generate a fee from a multidisciplinary meeting or a case conference. While we are focused a little on the public hospital system, it should be recalled that about 50 per cent of all the cancer operations that occur in New South Wales and elsewhere in the country occur in the private sector. If we are looking at an optimal approach to cancer control, we have to look at optimal methods to encourage multidisciplinary care across the whole spectrum of cancer service provision.

The third thing I would like to bring your attention to in respect of treatment aspects are psycho-oncology support or practical and emotional support—whatever you would like to label it. We think it is a right and appropriate approach to all cancer patients that they have the ability to be supported through their difficult journey—from the point of diagnosis and all the difficult decisions that they need to come to. There is not adequate provision for this throughout most of Australia. Not only should the NHMRC guidelines be applied to that, but they should be applied for every cancer patient in Australia.

Another area which I will briefly touch on is the need for strategic work force development and upskilling of staff. Clearly, there is a worldwide and Australian shortage of high-quality nursing staff. We think a lot of effort should be put into skilling the current staff as well as developing new roles in key areas of discipline. One of the things touched upon a moment ago by Sally Crossing which I would endorse is the issue of cancer information. Clearly, there is a lot of cancer information out there—I think that one of the senators raised that issue about the multitude of information. We have done an audit of cancer information available and it fills a large booklet, which we are about to put on our web site. We have done an audit of cancer information and the major finding is that most people wanting to access information say that health professionals did not know what existed. There is a lot of information out there; some of it is good and some of it is not so good. It is being generated at a great rate. There is no easy method by which patients can access that or know where it is, so we are about to put an A to Z directory on our web site which essentially will show where all the information is. That is the first step of what really is required for what I hope will be a national approach, where we could have various groups expert in various areas given the ability to develop information for the country as a whole.

One of the other areas is making sure that the information available to health professionals is up to date. Young doctors, specialists who are not experts in some areas of cancer and people who are not cancer experts do not have ready access to high-quality evidence based information in their daily work. We have attacked that problem. We will be providing a statewide web site of standard evidence based protocols and treatment pathways which I think will become a national site because other states are interested in this. It is a way of getting rid of wasteful treatment as well as putting an evidence base behind what treatment should be used. We would like to apply the same to what is available in complementary medicine, which I will get to in a minute.

Cancer information is also a problem because of state registries. We run a state registry for cancer. The state registry will provide population based information. It does not tell you what happens in individual institutions. To address that matter, the national cancer control initiative has developed a minimum dataset which will provide information on what happens to a patient in a hospital. That has never been applied in Australia, although there is a very good data dictionary and it is a very well-developed model.

The New South Wales Cancer Institute has started a program which will implement the collection of a minimum data set of 45 items on every cancer patient in New South Wales in addition to the population registry. That minimum data set will tell you about the journey. At the moment in Australia there is no way that you can see what a patient’s journey was and what a patient has experienced through their treatment. There is no data set that will tell you that. You will see the death data and the area where they resided, but you will not know what happened in the middle. We think it is terribly important to get high-quality services delivered, so we will be collecting the minimum data set on all cancer patients in New South Wales. We hope to have that rolled out within a 12-month period, and the data collection will occur following that. So within maybe a two-year period we will have that data collection available.

The other thing I would like to mention is that it is important that research drives practice improvement and that the practice is evidence based. We believe that a major issue is making sure that the research culture is alive and well in each hospital. We think that the translation of high-quality cancer discoveries into clinical practice is a major challenge for all of us, and I think it is one that requires some degree of discussion and consideration by this group. For example, in Australia we would expect to be aware of and make about two per cent of the world’s medical discoveries in cancer. That means that we need to be well connected with the other 98 per cent of discoveries that occur elsewhere in the world and we need to be able to apply them systematically.

The cancer institute has made a small effort in this regard in that we are putting out program grants to hospitals and research institutes in New South Wales which are based on the SPORE grants from the National Cancer Institute. They essentially require a basic scientist and a clinical scientist to be the principal investigators and encourage hospitals to put the science together so that a large question can be looked at. The first such program grant that was awarded in last year’s round was to look for new screening programs for prostate cancer and to understand areas of risk for prostate cancer. That went to a consortium of six hospitals and the CSIRO. The grant was approximately $3 million over a five-year period. We are putting out two of those this year in order to encourage the translation of high-quality research discoveries into clinical practice or policy. We will also be looking at clinical trial infrastructure. We will be looking at basic infrastructure in this state so that we can enable research to happen more readily from the researchers in New South Wales.

CHAIR—On the research issue and the clinical trials, do you envisage putting in place a proper ethical structure for approval of clinical trials in a hospital setting? An issue has been raised of pharmaceutical companies effectively funding some of the trials and not necessarily wanting to meet the appropriate standards that some hospitals might wish to set up.

Prof. Bishop—Recall that the great majority of exciting new molecules that might occur in the next five or 10 years in cancer will be owned by somebody. They will not be owned by university researchers, unfortunately; they will be owned by a drug company. The cost of developing any new drug is in the order of $100 million. Research groups cannot afford to develop new drugs. The National Cancer Institute has developed a program for this. They will encourage drug companies to do their trials but they will also have a parallel process where they will find trials which need to be done for academic purposes, for purposes of understanding and developing a drug for cancers that drug companies might not be interested in.

In terms of ethical issues, the act that governs the Cancer Institute New South Wales requires us to set up an ethics committee which will streamline multicentred clinical trials. We are in the process of establishing that ethics committee at the moment with the hope that we will streamline and increase the participation rate in clinical trials—all clinical trials. I do not think we have a bias towards one particular trial, provided that it is good science and the next best thing for the patient. So whether a trial is developed by a drug company, a university group or a surgical group should not be the consideration but, rather, whether it is the best science and the most likely to work for patients, and also whether it is the most exciting thing we could do and more likely to advance the cause of the reduction of cancer deaths et cetera.

CHAIR—That is what I was getting at. I was not necessarily being critical of pharmaceutical companies putting money into this research and development. I know that in the large public teaching hospitals, in particular, there is a very rigid control process for any clinical trials. We heard evidence in Perth about a slightly more bizarre trial being conducted by medical professionals in a private hospital setting. There is no overarching control of the ethical side of that and whether it is a good science or just someone who wants to use the testing process—

Prof. Bishop—I do not think there is any shortcut to having clinical trials done through proper processes which would include scientific review, ethical review and appropriate consent. It would basically be an open and transparent process in which the ethics committee looked at the patient’s best interest. I do not think there is any shortcut in that process, and I would not encourage any experimentation with new agents or new approaches without a proper approach through properly conducted clinical trials including ethics committee review.

CHAIR—You mentioned that you were briefly going to address the area of complementary medicines. If you are going to do that, we probably need to define what complementary medicines are. To me, the term ‘complementary medicines’ refers more to alternative treatments. There has been a problem with a few of the definitions around the place, so if you are going to talk about that you probably need to define exactly what it is you are talking about.

Prof. Bishop—You have raised the important issue of definitions. In our submission we have discussed the issue of definitions. There is a TGA definition, which we have recommended be adapted nationally. There are a couple of other definitions that are worth while having this group consider. There is a definition from the National Center for Complementary and Alternative Medicine or just part of the National Institutes of Health in the US. They add a little bit to the TGA definition. To be fair, I think they also look essentially at manipulative or body based practices such as massage, acupuncture and whatnot. CancerSupportUK, which is part of the National Health System in the UK, also has a very practical definition.

They all differ a little, but they are coming up with a somewhat similar definition. We have recommended that the TGA definition be adapted but that, where it is deficient, reference be made to those other US and UK definitions. So we are talking about a whole range of therapies. Looking at that range of therapies, one of the first issues I think this committee may be interested in is the incredible cost of these agents and medicines. A great majority of cancer patients will use such medicines, as I think maybe perfectly reasonable in some situations, particularly where they have found that the medical approach to their problem has not been satisfactory in various ways. So it is an area which I think requires quite a lot more work by agencies such as ours but also by anybody who is interested in trying to improve the lot of the cancer patient.

In our submission we say that one of the first bits of work we have started, apart from trying to get the definition right—which is your point, Chair, with which we agree—is to allow some information about this area to be made generally available to the public. There are some excellent web sites that we have now got linked into our web site, which provides a fairly complete database on what is available for complementary approaches and what information is known. One of the big difficulties in this whole area is of course that quite a lot of information is just not known. There is a gap in knowledge. Where there is a gap, it is often filled by information which is mainly misleading.

CHAIR—Does the institute actually support complementary therapies in the orthodox treatment setting?

Prof. Bishop—If I may say so, it is a little simplistic to say yes or no.

CHAIR—We could not work that out from your submission, either.

Prof. Bishop—There is a good reason, I suspect. That is, where a complementary approach may in fact improve the quality of life of a patient in terms of counselling, support and some of the physical therapies, no-one could be against such things. Where a pharmaceutical agent is put up as a particular treatment for cancer, we would think that in terms of someone ingesting a product the same conditions should apply to all products. The issues for a group like this, the federal government particularly, would be, firstly, whether it is beneficial and, secondly, whether it can harm. We need to know whether it is actually safe. We have an obligation of care to make sure that these things are safe. As far as the range of things goes, I think most people in this area would say, ‘We do not have enough information to know whether many of them are successful or not, so we have an open mind about whether that success could be there or not.’

I will give you an example. Many of the successful chemotherapy agents are natural products of various sorts. The drug Taxol, that you know quite well, probably, is from the bark of the yew tree. Vinca alkaloids are from the vinca plant. These are very successful anticancer agents. A number of Chinese drugs are used in cancer treatment which have substances which we know are anticancer. We need to look at this as a huge spectrum—some things clearly have no chance of being successful based on evidence that has been generated, other things we know nothing about and have to have an open mind on and things in the middle—and to each agent we should apply as much rigour as we do to everything else and try to test the system. So an open mind and obtaining information is probably our approach. That probably does not answer your question.

Senator KNOWLES—Your minimum data sets will be a very useful tool. Have you got any problems with the Privacy Act in doing so?

Prof. Bishop—Yes. Our position is that we would prefer to have this minimum data set mandated in the same way as the population based collection we currently collect. We collect quite a lot of information already for the Central Cancer Registry of New South Wales. Some of that is the same data that we want in the minimum data set. We think that at the moment the collection of that data is perfectly reasonable within a hospital setting. We think that if it is going to be collected centrally it will, first of all, require an appropriate ethics committee approval process. Second, we would be pressing that there be legislation which would mandate a minimum data set in the same way the population data set is mandated.

Senator KNOWLES—Do you see any role for an opt-out type of arrangement for the Privacy Act? I suppose you know what I am getting at. I would be quite happy for my medical records to go for research if I thought it would be useful.

Prof. Bishop—I think that attitude is a very common one. A lot of the public, patients and carers have the same view. Whenever we have canvassed what the view should be about our data, most people say, ‘Look, if it is for cancer then collect it if you can clearly show that it’s going to be of benefit.’ That is not an area that people have worried about, provided there is a proper process—proper and secure collection, proper custodianship of the data and a proper access approach. Your attitude is one that we have heard in very many forums in relation to how we should go about data collection. It is a sensible view.

Senator KNOWLES—Reading my medical records would be about as exciting as reading *Dick and Dora*. For some people who might have more sensitive issues in their medical history, surely it would not be beyond the wit to be able to excise certain events from one’s medical records?

Prof. Bishop—The way this is handled daily, and has been for 30 years, through the central cancer collections is that the data is collected in a very clear conduit from the source to the custodian centre. Basically, it is never produced in small enough cells that people can be recognised in any way. There are a whole lot of rules around the data that is already collected, as a mandatory data collection on cancer. Those rules can be easily applied to a slightly extended data collection of an extra 45 items, which would then describe the patient journey quite accurately and have all sorts of benefits as a result of understanding how best to treat those patients.

Senator KNOWLES—You talk about universal bowel cancer screening. I do not know—and I should know this—exactly how far we are going with bowel cancer screening, with the latest government announcements. Should it just be a familial connection or should it be right across the community, as you indicated, in universal screening? What is the cost of that going to be?

Prof. Bishop—I can give you a small perspective on this. The current five-year survival rate for bowel cancer in Australia is 60 per cent. So 60 per cent of people who are diagnosed with bowel cancer are alive five years later. The percentage for breast cancer survival is 85 per cent. The difference between those two illnesses is not just screening, although it is partly screening. We think that we can push the survival rate up if we can identify cancers before they are cancers—in other words, prevent them because they are precancerous polyps—and we also think we can diagnose smaller cancers, and that has been proven in large clinical trials. That is not evidence that we need to generate again.

Large bowel cancer, colorectal cancer, as the whole group, is currently the single largest cancer in our community, with about 4,000 new cases per year in New South Wales alone. If you multiply that by three you get an Australian perspective, which is about 12,000 new cases a year. With a 60 per cent five-year survival, we think there is a lot of work to be done. The evidence shows that if you take the age limit—and you can put it at 50 or 45; there is some reduction in benefit as you get to a younger age, obviously—and introduce it into a screening test which looks for blood that is not that obvious in the bowel motions, and this can be done by a general practitioner or a kit can be sent to an individual, then we think that there will be a higher level of uptake and a reduction in cancer. So it is universal. It is age limited but it is universal, and it affects men and women with similar frequency. While we believe that the five-year survival rate is not bad, it is not very good. We think it should be closer to 80 per cent. It is achievable to be closer to 80 per cent. If you were able to get an 80 per cent five-year survival, thousands of patients over the years would be saved.

Senator KNOWLES—So we are talking about a relatively low-cost blood test in the first instance.

Prof. Bishop—It is a test on the bowel motion; it is not a blood test.

Senator KNOWLES—And then, if there is an abnormality, it is followed by a colonoscopy.

Prof. Bishop—Yes. The UK has run a program looking at some of the feasibility issues as well. The difficulty for us is having a sufficient number of staff to actually do the colonoscopies and the assessments. In New South Wales we should get ready because it is coming and there would not be enough colonoscopists tomorrow to do this. Therefore, we feel we need to start work on training people and getting people involved.

This will come one way or another. The cost we do not know but, if you look at the costs of the cervical screening program, it would be somewhat similar because it will be based on a person’s personal approach, probably with interaction with a general practitioner and then going onto some sort of assessment and some sort of data collection. If you look at cervical cancer screening for women, the overall costs are somewhat similar. It is about $70 million for Australia.

Senator MOORE—I want follow up on Senator Knowles’s question about the data that you are going to be collecting. Is that similar to the model that we heard about from Western Australia in terms of the kind of information that is held to monitor a patient across their whole journey?

Prof. Bishop—The advantage of the Western Australian system is that they have actually pioneered the linkage. We think the linkage is fraught with problems because of the privacy and other legislation, but I think the Western Australians have very much been the leaders in the nation in terms of linkage. Yes, the collection would be somewhat similar. We think that about half or maybe a third of the minimum data set could be populated by data already collected through the New South Wales data warehouse—the health information exchange. We would anticipate that the health information exchange, the HIE, would populate a fair bit of what we need to know and then the rest of it would need to be collected, almost by hand, out of the hospitals. So this year we have put in place data managers in five area health services—that will go up to eight next year; we are just starting that work—and the data systems, including an interim IT module, which will start to collect the data.

Senator MOORE—That is public and private?

Prof. Bishop—We are starting in the public sector; we want to do it in the private sector as well for the reason that a lot of our patients are there. We are yet to sort out how we could do it in private, and I suspect we will probably have to provide the data collection apparatus.

Senator MOORE—But it is part of the goal to have a full record of all cancer patients in New South Wales?

Prof. Bishop—It has to be. A lot of the private patients will access the public system somewhere, but we cannot rely on that, so we do need to address how to collect in the private sector.

Senator MOORE—Have you got some information on your claim for that?

Prof. Bishop—We do have an information plan that we could provide you.

Senator MOORE—That would be great—so we can actually see whether it is going to be of common use across the country. I have one more question. I want to clarify this because I come from Queensland and we do not have a similar body to yours. Where are you different from the New South Wales Cancer Council? You are both under state legislation and, looking at your aims and goals, they seem really similar.

Prof. Bishop—They do.

Senator MOORE—Where are you different, why do you need the two of you and do you work together on these aims?

Prof. Bishop—The answer to the last question is ‘yes and more if we possibly can’. The institute was set up more as a government response to cancer and is funded by the New South Wales government, so its funding comes from there. The Cancer Council is a philanthropic body and its funding comes from donations.

Senator MOORE—And they get nothing from the New South Wales government?

Prof. Bishop—Only through the programs that they run for the government, and we will be working with them on certain programs as well. At the moment, the New South Wales government are conducting a review of this issue. They are looking for aspects of role delineation. Our approach to that is quite straightforward: the Cancer Council and philanthropic bodies are welcomed and should be fully supported and as strong as possible in each state. The Cancer Council in New South Wales is fully supported by the institute. Secondly, there are some areas where we can do quite well because we are well connected into the area health services, the hospitals and the research community, and there are some areas where they can do perhaps better than us because they are well connected to their donor base and to the community. So there are some natural demarcations, but a lot of it is overlap and, where there is overlap, our position is that we would like to do things together and we would like to do jointly badged programs. Some obvious areas are in patient information. We talked before about the fact that there is a lot of duplication of information. We do not want to extend that further by having two bodies in New South Wales producing similar information—it is a waste of everyone’s time.

Senator HUMPHRIES—You recommend that credible and accurate information about complementary medicine be accessible to cancer patients, carers and health professionals. But, for a wide variety of reasons which have been put before this committee, that information about a very large number of those therapies and medicines is not generally available. We have heard that the United States has a congressionally mandated program of testing and evaluation of complementary medicine. Are those evaluations generally used in Australia to make assessments about those medicines and therapies? Is it adequate for dealing with the sort of gap that we are talking about here or do we need to do more within Australia and, if so, how do we do that?

Prof. Bishop—That is a good illustration, isn't it, of the fact that, where there is information available overseas—and I said that most of the information on new discoveries will be overseas—we should take advantage immediately of it? And that connection is quite important regarding how we should do that. We have had discussions with the National Cancer Institute about the possibility of being part of their so-called BIO grid and also the fact that any new information on cancer could be available to us through an IT and BIO grid connection. So the first thing is that that information should be made available, and we will try to extract that information and make it available through our growing connection with the National Cancer Institute in the US.

Another aspect is that we could take the view that there should be no research in Australia; we should just take whatever is there. It would be cheaper, wouldn't it? The reason that is not a sensible idea is that it is only by doing the research that one understands the depth of the research overseas and also that Australians are good at research. Although we have two per cent of the research, we are 0.3 per cent of the world's population. We punch well above our weight for research; it is one of our best industries. There are lots of commercial binds and lots of benefits for our citizens by having research. So that is the argument for research, if you wanted it in a nutshell—and you probably did not. I think the important thing here is that we should do our own research, as well as take advantage of the overseas data. We have set up a complementary medicines committee. It is headed by people and has people on it who like to do research in this area.

One of the key priorities we put down for that group is to look at how complementary pharmaceuticals and so-called conventional pharmaceuticals might interact. It is something we know nothing about. If we believe that a high percentage of people are taking complementary treatment of some sort and are also on other drugs, we have no knowledge about what the interactions would be. Are those drugs as effective? Are they harmful by interaction? We think it is a high-priority program, and we will be supporting other research in this area.

CHAIR—Thank you, Professor Bishop, for your submission and your presentation to the committee today.

Proceedings suspended from 1.02 p.m. to 2.00 p.m.

MICHELS, Miss Lauren, Member, CanTeen Australia

SWIATEK, Miss Dayna Leah, National President, CanTeen Australia

YOUNG, Dr Andrew John, Chief Executive Officer, CanTeen Australia

O'BRIEN, Dr Tracey, Head, Stem Cell Transplant Programme, and Paediatric and Adolescent Oncologist/Haematologist, Sydney Children's Hospital; and Acting Director, Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital

SENNER, Ms Anne M., Clinical Nurse Consultant, Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions. I now invite you to make your opening presentation, which will be followed by questions from the committee.

Dr O'Brien—I am a paediatric and adolescent cancer specialist. I am currently the Acting Director of the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital in Randwick. I speak also today on behalf of Dr Michael Friedlander, who is the Head of Adult Oncology at the Prince of Wales Hospital in Randwick. Furthermore, I speak as a New South Wales representative on behalf of Dr Luce Dalla Pozza, who is the Head of Paediatric Oncology at the Children's Hospital at Westmead, acknowledging that this is a New South Wales state-wide issue. I would like to start by thanking the committee for the opportunity to give evidence on what we believe is a critical issue: the provision of appropriate cancer care services for adolescents and for young adults with cancer. Our time today at this hearing is shared with my colleagues from CanTeen, who are in the best position to speak on the psychosocial and holistic needs of adolescents living with cancer. These are unique and they cannot be met by either paediatric or adult cancer services as they currently stand.

As outlined in our written submission, we propose that a specialised, dedicated teenage-young adult cancer care facility be established. This facility is urgently needed to best service both the medical and the psychosocial needs of teenagers and young adults living with cancer in New South Wales and the ACT. Of all young Australians aged between 15 and 24 years, one-third live in New South Wales. Of these, 300 every year will be diagnosed with cancer. Furthermore, published Australian data, which mirrors overseas data, indicates that during the past decade alone cancer incidence has increased by 30 per cent in young people aged between 10 and 24 years. This increased incidence of cancer in adolescents and young adults is higher than in any other age group. I would like to briefly outline to the committee the inadequacies of the current medical model and the impact this has on the survival of teenagers with cancer. I have four main points to make.

My first point is that adolescents with cancer have poor survival rates. This needs to be addressed urgently. Cure rates for both younger children and older adults with cancer have shown a remarkable improvement over time. The same is not true for adolescent patients. The first graph on the top of page 1 of our submission shows the average annual percentage improvement in cancer survival rates as reported in America and Europe over the last three decades. Improvements in the cure rates for adolescents are the worst—they are circled on the graph in red—and they are falling to at least 50 per cent behind those of all other age groups.

My second point is that access to clinical trials is very poor for adolescent patients with cancer. Adolescents with cancer are far less likely to be enrolled in clinical trials compared with paediatric patients and are therefore less likely to receive state-of-the-art treatment. My second graph at the bottom of page 1 is based on US data and it shows this dramatic shortfall. Not only are adolescents less likely to be treated in clinical trials, they are less likely to be treated in specialised, multidisciplinary cancer care units—shown on my graph in green—where it is known that the best results are achieved. Similar results have been noted for Australian teens and young adults with cancer. Turning over the page, the third graph shows results published for young people with bone tumours treated in Victoria. Patients treated in paediatric hospitals were more likely to be enrolled in a clinical trial—shown on the graph in blue—and consequently were shown to have a higher chance of survival.

My third point relates to access to best available care. This does not currently happen for adolescents and young adults with cancer. Currently in New South Wales, there are no guidelines for the referral of adolescents and young adults with cancer to specialist care. As such, adolescents are randomly referred to either paediatric or adult cancer physicians. This can have a devastating impact on survival. For example, there are some cancers that occur in adolescents, such as acute lymphoblastic leukaemia, that are more commonly seen in paediatric oncology. Independent studies in the US, France, the Netherlands and Italy have all shown that, when adolescents with this type of cancer are treated on a paediatric clinical trial, their survival rate is greater than if treated on an adult trial. The last graph on the second page evidences this point. Leukaemia-free survival almost doubled when French adolescents with leukaemia were treated on a paediatric leukaemia trial compared with French adolescents who were treated on an adult leukaemia trial.

On the other side of that argument, there are some adolescent cancers that occur more commonly in the adult population and would therefore be better treated by an adult oncologist than a paediatric oncologist. As such, a specialised teenage cancer unit where there is collaboration between both paediatric and adult cancer specialists is the best and, I believe, the only way to address the unique medical needs of adolescents and young adults living with cancer. Many countries, such as the United Kingdom and Canada—and I have their reviews on this with me—have noted these results, have recognised the need and have allocated funds accordingly. I believe there is an urgent need to provide such a service in New South Wales and, in fact, Australia-wide.

My fourth and final point is that not only are the medical needs of adolescent patients with cancer poorly addressed with the current medical model but psychosocial care is also completely neglected. These needs are critical to the adolescent patient living with cancer and they are very different from those of an adult or child with cancer. Once again, we believe that a teenage cancer care unit utilising a multidisciplinary team is the only way to deliver appropriate medical and psychosocial care to adolescents and young adults with cancer. I would now like to hand over to my colleague, Anne Senner. Anne will elaborate further on our proposed solution and present to you the ideal model as we see it for treating adolescents and young adults with cancer.

Ms Senner—I am a clinical nurse consultant for practice development and research at the Centre for Children’s Cancer and Blood Disorders at the Sydney Children’s Hospital in Randwick. We believe that the solution to this critical problem is a dedicated adolescent and young adult cancer unit based on a collaborative multidisciplinary model of care. We suggest that this model, which is shown in the last slide in your package, would improve the patients’ cancer journey and ultimately improve their survival.

You have heard from Dr O’Brien that adolescent cancer care is in crisis internationally and is receiving attention in many different countries. Universally, the consensus is that adolescent cancer care would be best managed in a targeted adolescent cancer care unit and that that is the best way for them to receive excellence in multidisciplinary care. However, we also submit that the models of care that are proposed overseas are not necessarily easily adapted to Australia because of the unique geographical area of Australia and the need to provide rural and remote outreach services to our patients.

One of the other unique facets of adolescent cancer medicine is that cancers diagnosed in adolescents could either be childhood cancers, as Dr O’Brien has mentioned, or adult cancers. Therefore, collaboration between paediatric and adult physicians is critical to our model of care. This allows for the identification of the best possible treatment for the individual patient and, ideally, enrolment in clinical trials. Clinical trial enrolment is mandatory to provide state-of-the-art cancer treatment for individual patients and is an avenue for data collection and quality assurance from which future research may stem.

But this alone is not enough. Evidence clearly demonstrates that treatment provided through a multidisciplinary team improves the patient’s cancer journey and ultimately improves survival. Paediatric treatment centres are recognised as experts in providing this model of care. The team should include social workers, teachers, nurses, psychologists and less traditional complementary therapists as well. In addition, young people identify peer support as critical to improving their cancer journey. That is where collaboration with organisations such as CanTeen is vital.

In conclusion, we believe a collaborative multidisciplinary adolescent and young adult cancer facility with rural outreach services will provide the best possible care for adolescents and young adults in New South Wales and the ACT with the best available treatment and supportive care. Dr O’Brien and I would like to thank the Senate for this opportunity to present to you what we believe is an important gap in cancer services in New South Wales as well as Australia.

Miss Swiatek—I am a sibling of a cancer patient and I am proud to have been a member of CanTeen for the past nine years. On behalf of CanTeen’s members and staff, thank you for inviting us to talk to you today. As many parents could probably tell you, the adolescent years are indeed a difficult time, with many changes happening to the young person both physical and emotional. It is not uncommon for teenagers to face and struggle with issues of identity, independence and relationships. A diagnosis of cancer at any stage of life is traumatic, but it is even more so for a young person who is already facing these complex issues. Although cancer is not necessarily a death sentence, it usually means the start of a long process of painful treatment and years of uncertainty. Just as challenging is being a teenager and having to watch a family member undertake this process while experiencing feelings of helplessness, guilt and isolation. In CanTeen we believe that no young person should live through their cancer journey alone.

CanTeen is an Australia-wide peer support organisation for young people living with cancer. We acknowledge that a cancer diagnosis impacts not just on the cancer patient but on the entire family. Our definition of young people living with cancer means that our membership is made up of young people aged 12 to 24 who are either a patient, a sibling or offspring of a patient, or bereaved. Offspring are young people whose parent or primary carer has cancer. In CanTeen we refer to all these young people living with cancer as members.

The programs and services that CanTeen provides are vital to help young people face up to the challenge of living with cancer and to link young people with others who, as we say in CanTeen, have been there and done that. This is achieved by providing recreational and educational programs, with an emphasis on peer support. This means members can get together, have fun, support each other by sharing and listening to different experiences and take some time out for themselves away from the stresses of family, school and hospital life.

Our mission to support, develop and empower all young people living with cancer is evident in every program that we run. We involve young people in all aspects of the organisation, including our governance structure, because we know that young people have the ability, the will and the passion to drive an organisation such as ours. This could vary from being on a committee that assists to organise a camp or being on an interview panel during staff recruitment through to being part of the member majority on the national board of directors.

CanTeen was established 20 years ago, after recognising there was gap in support services for adolescents living with cancer. This group has distinctly different issues compared to those for adult and children cancer patients. These young people could not simply be slotted into pre-existing support groups. CanTeen now has over 2,000 members in nine divisions across Australia. Our membership continues to grow in line with our vision of bringing together all young people living with cancer.

We believe, based on our members' experiences of living with cancer, and based on increasing evidence from overseas, that Australia should focus much more on specific treatment and support for adolescents and young people living with cancer, as there is once again a gap in available services for this group. The primary recommendation in our submission is that cancer wards specifically for adolescents and young adults be established in each mainland state capital city. We will support this recommendation with the point of view of our members and with a summary of the evidence for targeted treatment and support for young people.

Lauren Michels has been a CanTeen member for the past four years. Lauren will briefly tell you about her experiences in being treated in both paediatric and adult hospital facilities. Following Lauren's story, Andrew Young, CEO of CanTeen, will provide a brief summary of the evidence supporting our recommendation.

Miss Michels—In October 1996 I was 14 years old. We were holidaying in Queensland. We visited the theme parks and then headed up to Cairns to visit some family friends. I am normally an excited and enthusiastic person and would enjoy rides and things like that but I became very uninterested and tired. We were constantly stopping for rests and thought it was due to the weather or my asthma, which I was being treated for back in Adelaide. I was having night sweats and losing weight. My family friends in Cairns commented on this and they suggested that I see their family doctor, who was within walking distance. He decided it was best that I had an X-ray and a few tests, which showed up the massive mass that was inside me.

It was cancer, and I would have to have chemotherapy. I had heard of this word. I thought that people who were dying had it and it made your hair fall out. I was very scared and confused. I went for a CAT scan at the local oncologist and was diagnosed with Hodgkin’s. I had the biggest tumour in the chest the oncologist had seen and he advised we head straight back to Adelaide and visit the hospital. But we did not cut our holiday short. We went snorkelling on the Great Barrier Reef instead and travelled home on our arranged date. When we got back we headed to the hospital for the first of many more scans and visits to come.

As Dayna said, being a teenager is about becoming an adult—having fun with your peers, learning from your mistakes, facing issues like identity, responsibility, independence and relationships and deciding on a career path. It is not that easy for any teenager, but, having the huge extra issue of cancer dumped on me, I felt like my world was going to fall apart. Firstly, I was an outpatient in Ronald McDonald House. I wanted control over my life, which was hard, as I was not in control of the situation. I did not want to be in that situation. I felt guilty, and I wanted something or someone to blame. I wanted to be normal and fit in. I wanted to be able to do the same things as my teenage friends.

I was invited to join CanTeen but decided that I was not interested because I did not want to be sitting around with what I thought were other sick and dying people, talking about cancer and reminding me of what I had—hospital already did that for me. A few months later I got better and thought the cancer was out of my life forever. For cancer patients, life does not return to normal or the way it was. You are now a survivor of the disease and you are no longer the same person.

In August 1999, I relapsed. I was older and finishing high school. I was crushed. Being 17, the opposite sex was now a greater issue. I was devastated thinking that no boys would ever want to go out with the girl who has cancer. How could this happen to me again? My chemo was increased and changed. I was an inpatient in the haematology and oncology Brookman Ward. I also experienced radiotherapy. My hair fell out and I looked different. I was asked on many occasions if I was a boy.

The women’s and children’s hospital has a toy room, a great resource for little kids. The walls are painted with huge bright murals of clowns, fairies and under-the-sea themes, all directed at small children. The prints in the rooms are of kittens and Peter Rabbit, and the video collection had much to be desired. Once you have sifted through the Wiggles and stories like that, you might get to view something like *Toy Story*. I wanted a couch to sit on and play music that I liked listening to. I found myself spending a lot of time in the ‘quiet room’, which is a room with two couches and no bright paintings or anything. The small children did not go in there as it was not exciting.

I found the doctors and some nurses directed their conversation to my parents and talked about me, not to me. Towards the end, I stopped bringing my parents to the appointments. Eventually, something made me join CanTeen. I was not in denial and I felt better about the situation and myself. I found out it is not about sick people sitting around and feeling sad; it was young people like me. We had something in common. We had a great time. We were all the same age and felt comfortable amongst each other. We do not even have to talk. We can just relate to each other.

In June 2002, at my next regular check-up, I was to find I had relapsed once again. I had to face cancer again, as it was back. I felt the lump and knew instinctively. I ignored it, hoping it would go away, until my appointment where I pointed it out to the doctor. When my doctor got a second doctor to feel my neck and the CAT scan was planned earlier than scheduled, my mind raced. I felt hatred towards this doctor. I did not get it: how long was this going to go on for? I did not want to be in the room anymore and I was really angry. I had a blankness and a bursting feeling but there was also a void. My brain rushed with so many thoughts as I thought my life was over. Again, I was no longer feeling in control.

Countless types of tests were run to check and recheck. The process and planning had to start again. I really believed I could not go through it again: the nausea, the needles and missing a social life. I would no longer be able to go to university and I would have to quit my part-time job. I had to go through this again, or did I? I had a decision to make whether to have chemotherapy treatment again for the fourth time or choose not to have it. I felt so much emotion ranging from confusion to anger, violence, frustration, helplessness, sadness and numbness. It had been planned that I would start intensive treatment in the following week. I received a letter from my friend that said:

> You don’t drown by falling in the water, you drown by staying there.

As many people are faced with challenges in life, it is what you do once faced with them that makes people amazing. As I considered giving up and not going through with the treatment, I cried, and thought, ‘I’m not going to let myself drown, I’m going to face and beat this challenge.’ I knew what I was up against. It was a challenge I had to decide to overcome.

I had to go the Royal Adelaide Hospital, as I was 20 years of age. I had had six years of treatment and check-ups at the Women’s and Children’s Hospital and now I was being sent to the old people’s hospital. I had to see a new doctor. This intense treatment would mean something different again. I was no longer in the safety net of my school where they knew my family, my situation and me. I was at uni and I had a job. I was to lose my hair again and I would not be able to go out to the pub with my friends. Although the hospital was new and scary, I was excited because I got to see a new doctor. I felt nothing for my old one and I had moved on from the children’s hospital. I knew nothing about this hospital, and it was something new. It was good because I had no memories or expectations.

On my first visit I was shown around the outpatients’ room. It was full of old fogies, and I forgot that I was wearing an Offspring t-shirt with a few song lyrics on the back with a swear word or two. If the chemo was not going to kill them the heart attack they had as they read it would. I definitely gave them something to talk about. I was admitted to Ward D6, and that was an experience in itself. I met a lot of lovely people and their families but I struggled a lot because of the age gap. I was lucky to have friends from CanTeen and other places visit me and have some people my own age around. I found that the Royal Adelaide Hospital, in comparison with the children’s hospital, stuck to rules and guidelines and was less willing to make adjustments with things like visiting hours, the menu, timetables, showering and choices. The waiting around in the adults hospital was a lot more boring and sombre, and there was more seriousness to the whole deal.

I was put in bays with men where I think they were actually more uncomfortable than I was. It was not the greatest thing listening to them hawk up their lungs or urinate into a bottle. One occasion was quite distressing. I was in a room with Mrs Chitty, who had not only cancer but also dementia. She would wake up and yell for somebody, wondering where she was. She would not want the food she was given, saying, ‘I didn’t want this,’ forgetting that she had ordered it a few hours earlier.

Although we all had TV, I found myself spending a lot of time in the TV room as I could hang out with my visitors. I did not feel like we could not talk about stuff that teenagers talk about in front of adults and I did not feel like a sick person with people visiting me at my bedside. It was hard for my friends too to stay positive around me as I was surrounded by sick and older people lying in beds.

I had intense treatment after two rounds of chemotherapy not working. Two more cycles of different chemo were given. It was then time for a bone marrow transplant where very high doses of chemotherapy are given over a few days and then bone marrow is replaced in the body to give it a chance to recover from the treatment. The transplant would take about a month in hospital. I was devastated. My hair had started to fall out and any type of social life I had was soon to be over. These visits and periods in hospital seemed to last a life time, and I longed for the day that I could get out and leave when my visitors left. Following that, I was to undergo four weeks of radiotherapy.

The needs of adolescents are different to those of both children and adults, as there is this middle ground. We are not dependent, like children are on their parents, but we do not have people dependent on us. We have all different issues. By having adolescent wards you would be surrounded by people where you fit in, you feel like you belong and you are not alone. You could have the same interests. Friendships would naturally form and support would be given. Adolescents would be surrounded by others that are dealing with similar situations in and out of hospital. They can relate to what is going on, as they are going through the same things. There would be a positive environment with others who they can feel comfortable and relaxed amongst. We can share, listen, have fun, joke, be ourselves, relax, learn, heal and grow throughout this. Talking is a great healer for cancer patients because it releases disturbing thoughts bottled up inside. It is proven beyond a doubt that the mind can help heal the body when you are thinking positively. Cancer patients and other young people living with cancer have a genuine understanding of each other’s situation and what we are going through.

Dr Young—I will finish with a couple of quick points about our recommendations and then try and summarise. My first point is that adolescents and young adults are the forgotten group in cancer research, treatment and support, and have been for some decades, not only in Australia but also internationally. In Australia there are children’s hospitals all over the country. If I asked you to name some cancer charities, I am sure that you would come up with 10 or more that relate to children. There are not many that relate to adolescents and young adults. I think you would struggle to name more than one or two. It might be surprising, in that case, to learn that in Australia there are twice as many 12- to 24-year-olds diagnosed with cancer every year as there are children 12 years and under. Internationally, as we have already seen from Dr O’Brien’s presentation, research and clinical trials forget almost completely about the adolescent and young adult age group.

Second, as Dr O’Brien has also described, substantial improvements can be made to survival with targeted treatment and support. It is no longer a case of choosing to make an investment in young people and hoping it might make a difference. Now there is real evidence that shows that this investment will substantially increase survival. In saying that, as Anne and Lauren have both said, it is not just about improving survival; it is also about improving the experience of living with cancer. A major study published in the USA in 2003 proved that patients accessing effective support services not only had better outcomes in the psychosocial sense but also accessed health services between seven and 17 per cent less than other patients. So it can also reduce the burden on the health system. Targeted support services not only improve outcomes but also reduce the cost of health care.

Third, internationally there is an increasing recognition of the need for greater attention for adolescents and young adults living with cancer. I will give you a few examples. In the United Kingdom there is an organisation called the Teenage Cancer Trust, which is probably CanTeen’s closest equivalent there. It runs eight adolescent cancer wards and has done for some years. It is looking to establish, over time, as many as 20. In addition, a comprehensive manual for the treatment of young people with cancer is being developed there. It is due to be published this July. New Zealand recently published their cancer control strategy. Objective No. 4 was ‘improving the quality of care delivered to adolescents with cancer and their families’. In the United States doctors are now trialling extension of paediatric treatment for some cancers, up to the age of 30 in some cases. In Western Australia the Princess Margaret children’s hospital is now developing Australia’s first adolescent cancer ward. While it might fall well short of the sort of model Anne has presented, it is our first step in that direction. The international focus on better treatment and support for the adolescent and young adult age group is now growing, but it is still very new.

Our fourth and final point is that CanTeen’s experience and, more importantly, the experience of young cancer patients and their families demonstrate the need for a new approach. Lauren’s story is just one of many. CanTeen’s submission to the committee recommends that a specific cancer ward for adolescents and young adults be introduced in each mainland state capital city. We agree with the Centre for Children’s Cancer and Blood Disorders that these wards should be a collaboration between children’s and adult specialties, should utilise a multidisciplinary model incorporating psychosocial support services among others and, as much as possible, should incorporate participation in international clinical trials specifically designed for young people.

To summarise, adolescents and young adults with cancer have been the forgotten group of cancer research, treatment and support. More than ever before clinical evidence now supports the need for a more targeted treatment and support program and shows the magnitude of the difference that this can make. While global attention is now turning to this area, Australia still has the opportunity to be a global leader. On behalf of CanTeen and our members, and on behalf of all young people living with cancer, we commend our recommendations to the committee.

Senator KNOWLES—Dr Young, why can’t the PMH initiative be replicated in other children’s hospitals around Australia?

Dr Young—I think it can. The trigger was a $3½ million donation given to them by the mother of a girl who died from cancer a few years ago. She had the means to do it, but that is unusual. The funding for the capital costs of developing a ward is one part of the puzzle but by no means is it the only part. My understanding is that the ward will not be the sort of model we have talked about here, involving collaboration between adult and paediatric oncology. I think it is a new ward in a children's hospital, so it is a lot simpler than what we are talking about. These guys have already talked about the fact that encouraging that sort of collaboration could be a very difficult thing to manage, but I think it is fundamental to what we are talking about in a bigger model.

Ms Senner—With the PMH model, only young people still at high school—that is, 16- or 18-year-olds, depending on their age when they leave school—will be admitted to that service. That does not capture the group we are talking about—those up to 24 years old—which is the frequency and diagnosis. We believe the model of collaboration between adult and paediatric physicians is a critical part of that process so that we capture that larger group—also with the different diseases. That is why we do not believe the PMH model is the best model.

Senator KNOWLES—Why is that restricted? Is it purely and simply because of the logistics?

Dr O'Brien—Yes, it is because of the logistics. And it is political because the funding has been allocated to a paediatric hospital. It is not ideal in delivering medical care. I think every country that has looked into this has shown that. As I said, there are some cancers that are better treated by paediatric oncologists and other cancers that are better treated by adult oncologists. That is the uniqueness of cancer in adolescents, and that sets it apart from cancer in children and cancer in adults. There has to be a collaborative effort for there to be an impact on survival in the longer term.

There also has to be a means for transitioning care into adolescence. We see a lot of children with cancer and we are now very good at treating cancer—85 per cent of children are cured. That is great, but they grow up and in 10, 15 or 30 years they need follow-up of their treatment. Lauren has just articulated beautifully one of the problems that can happen if you are a young adult of, say, 15 years old and you have a relapse. You need somebody to be following up this care. Adult oncologists are not used to looking at late effects 10 and 15 years down the track. The majority of patients they treat are 55 to 60. They are not interested in sequelae 25 or 30 years from treatment, which is critical when you are treating young people with cancer. You want to know that their heart is functioning well at the age of 35 because of the treatment they have received. You want to know that they are going to go through pregnancy okay and not have any pressure put on their heart because of the treatment they have received. There are a lot of longer term effects that set apart the medical uniqueness of adolescents—not just the treatment they need there and then but also the longer term effects.

Senator KNOWLES—With whom have you discussed this model?

Dr O'Brien—I have discussed it with paediatric oncologists throughout Australia, and we are all in agreement. I have also discussed it with our adult oncology colleagues. As I said, I am speaking on behalf of the adult oncology unit.

Senator KNOWLES—I cannot imagine there would be any dispute among your peers. I am asking more particularly about how far you have taken it with governments and so forth.

Dr O’Brien—Within Australia we have been trying to lobby for some time—

Ms Senner—Because we are in New South Wales, we have been lobbying with the Cancer Institute New South Wales. We have proposed to them that adolescents and young adults fall through the gaps—that is where we have taken it politically at this point.

Senator KNOWLES—What has been the response?

Dr O’Brien—There is recognition now that this is a problem. We have been slow to bring it to a head because we primarily represent paediatric people, and the adult oncologists primarily represent adult people. So the adolescents and young adults have literally fallen through the gaps and there has not been a great advocate. I think that is the simple truth of it.

Senator KNOWLES—What response have you had from the Cancer Institute? When you have taken it to them, where have they taken it and what response have they had?

Ms Senner—I believe their focus this point is more on prevention—tobacco and other things. We are currently looking at the New South Wales survival data, as Victoria has done. We do not yet have that data; it is still being analysed. One of the things the Cancer Institute said was, ‘Once you have that data, come back to us,’ but it has not been a priority for them.

Dr Young—At CanTeen this is relatively new. We have a new direction which involves more in the advocacy area, and that is something that Luce started with over the last 12 months or so. Having said that, I have talked to a couple of doctors; besides Dr O’Brien, I have spoken to another one from Randwick. The view tends to be that a lot of doctors have talked about this and think that it is a good idea, but there really is not a very coordinated approach to it yet. Hopefully, we can get that over time, as we bring more people into the conversation.

Senator KNOWLES—Have you spoken to the state Minister for Health?

Dr Young—No.

Senator KNOWLES—What are you envisaging as the final product? Will it be a completely separate, stand-alone facility?

Dr O’Brien—No. I do not think we need to do that. For example, in New South Wales we could have a ward at the campus with the children’s hospital, the adults hospital and the women’s hospital, which would cover the gynaecological cancers. All of the medical facilities are there and established. Costing would not need to be done. We would just need a unit that is set up and is environmentally appropriate for adolescents. We would need a head of that unit, either a paediatric or an adult oncologist, and there could easily be cross-appointments, with my going across from the children’s hospital to treat the more paediatric cancers, with the adult people coordinating. You would need a dedicated team of nursing staff. Again, support and allied health care could well be cross-appointments between the hospitals.

Importantly, in that model, nurse practitioners from Sydney Children’s Hospital who have the ability to be rural outreach nurse practitioners would go out to remote areas and teach the GPs to give chemotherapy and educate the schools, if they need to, about various things. It would be a coordinated facility which would be referral based to target the best available medical treatment, whether it be an adult protocol or a paediatric protocol. A lot of treatment these days is outpatient, as you well know, so that would involve educating the outreach people and having services go to the adolescent patients. We service all the ACT, for example. Some set-up costs are involved in getting this, but it should be at a centre that is already established and has access to medical, surgical and imaging needs.

Senator KNOWLES—Has anyone been charged with the responsibility of doing the economics of it?

Dr O’Brien—Yes. As our own initiative, we have started gathering some numbers for that, and the nursing unit manager is putting together some figures based on the campus at our set-up at the Sydney Children’s Hospital and the Prince of Wales Hospital that we would be happy to submit to the committee as a guide at least.

Senator KNOWLES—But there has not been any formalised economic study done?

Dr O’Brien—No. As I said, we are just gathering some initial costing data.

Senator MOORE—Just following on with the practicalities in terms of the medical knowledge in the area, does anyone in Australia specialise in this area?

Dr O’Brien—There are people like me who are paediatric and adolescent specialists. As far as I am aware, no stand-alone person is trained solely in adolescent oncology because there is no discipline. It crosses over between paediatrics and adolescence.

Senator MOORE—Between paediatric and adolescent specialists, there is an understanding of the need to do it.

Dr O’Brien—Yes, absolutely.

Senator MOORE—And people are studying that.

Dr O’Brien—Yes.

Senator MOORE—Is that in all states?

Dr O’Brien—I cannot speak well for all states, but certainly in most of the states in Australia there is a recognition and people are taking that initiative. The Children’s Oncology Group in America, whom we collaborate with, as do most of the children’s oncology groups, have really taken this on board and extended many of their protocols to age 30. They are trying to educate their colleagues to try to have a consensus approach to treating this age group. It is the same in the UK.

Ms Senner—I think it would be safe to say that in every state there is a paediatric oncologist who has recognised that this is a gap in therapy, and there are paediatric adolescent oncologists. So there is a recognised person at every centre in the country.

Dr O'Brien—It is usually the youngest consultant who gets involved with the teenage kids. It is hard work. Teenage years are very difficult anyway. Put cancer into the mix, and as a physician I have issues such as compliance, acting up and the normal teenage behaviour which can make curing cancer really difficult. It cannot be done with medical services alone; you need the spread of full psychosocial support and services available to help get through the journey of having cancer in your teenage years. It is a difficult one.

Ms Senner—One of our colleagues who sees second opinions on some adolescents and adults who are treated in adult facilities finds that one of the troubles that young people have is that, because adult oncology is such a big system, if you do not come yourself nobody tracks you down. It gets tiring, as Lauren was talking about, and you just get sick and tired of being at the hospital.

There is a way of making sure that young people's needs are being met so they feel like it is actually worth staying on track. One of the things that this really collaborative model does is there are support people for those young people to say, 'It really is worth it. Let's figure out how we can get you to your dance, to finish your university exams and to do all those things that are really important to you. But you stay on treatment because, in the end, that is what is going to make it a cure for you.'

Senator MOORE—Dr Young, Miss Swiatek and Miss Michels, is the advocacy for this particular process now going to be a focus of CanTeen?

Dr Young—I believe so. We developed a plan for our organisation and this approach is very much a part of that. The sorts of things you were talking about—more study and developing the recommendations further—are something I think we will focus on in the next year.

Miss Swiatek—We did identify that there is a gap for an appropriate group to advocate on behalf of young people living with cancer, and we are sitting around saying, 'We are probably in the best position to do that'. We are increasing our resources to make sure that we can do young people justice and be the voice for this area that has been missed out for numerous years.

Senator MOORE—As I said to you earlier, I think this particular stream is something we just did not know about. So it is very useful that you have been able to come and tell us about it and see what we can do.

Dr O'Brien—One reason why we do not know about it is because we do not collect the data as well as we do in, say, paediatrics. Exactly what happens is that they are falling through the cracks and the data is not centrally collected like it is in paediatrics, so we did not have an appreciation of how poor survival was and of the lack of clinical trials. If we can have a collaborative approach and have adolescents treated in various centres then we can track the improvements that we make, we can target therapies, we can minimise side effects and we can make some real changes and improvements. If we keep doing what we do, things are just going to get worse.

Senator HUMPHRIES—I can understand the psychosocial needs of an adolescent with cancer but, for a lay person, what are the main differences in the clinical treatment of paediatric cancer as opposed to adult cancer?

Dr O’Brien—This is a very good question. As you know from reading all of the cancer documents for the paediatric oncologist role modelling that we implement, this multidisciplinary thing, why that has worked so well is that we collaborate nationally and internationally, and we do it through clinical trials. The clinical trials are executed with military precision and we get the children through their treatment. Children’s cancers have very aggressive protocols, as do adolescent cancers. They are usually very aggressive and therefore the treatment must be very aggressive. That is a very different mind-set than to a lot of adult cancers, where it is often an indolent process. They are not rapidly growing, so it probably does not matter if you do not get your radiation therapy for six or eight weeks. It can be life or death in an adolescent or a paediatric disease. So there are biological differences in terms of how aggressive the treatment must be. That is the first big point.

In terms of the outcomes when you look at the difference between success in paediatrics and adolescents, clearly that has been dictated by the use of clinical trials. Because these cancers are rare—they are rare in children and in adolescents—they have to be studied with some sort of cohesive approach. That is the only way to build on the results that we have. That has happened beautifully in paediatrics, where 80 per cent of children coming into the ward are put on a clinical trial that is usually international. We get numbers quickly and we make improvements year after year. That does not happen with adolescents because they could be treated out in somebody’s office, not even in a cancer centre. So biological differences are the big ones—aggressiveness of treatment, lack of clinical trials and lack of improvements because we have not studied adolescent cancers in the same way that we have studied paediatric cancers. We do not get, say, the bone marrow of every child who comes in with leukaemia sent to our cancer institute and studied for biological properties and for drugs that could be targeted to be a new drug in five years. That does not happen in adolescents because they are all treated scattered throughout the place and on different treatment protocols. So we are not making any improvements.

Senator HUMPHRIES—What is the main reason that more adolescents are not on clinical trials?

Dr O’Brien—I do not think adults utilise clinical trials as much as paediatrics do. If you are under the age of about 14, you usually end up being referred to a paediatric hospital. It does not always happen. I know of 14- and 13-year-olds that are treated in adult hospitals. But, by and large, most of them will end up in a paediatric cancer centre.

If you are 16 or 17 then you end up being referred to any adult cancer physician at any centre. So there is not the collaborative effort that there is nationally and internationally like there is in paediatrics. Every Australian oncology group belongs to the children’s oncology group in America—we use the American protocols, we submit our data and that is used in improvements. It is the same with bone marrow transplants—all of my data goes to the European bone marrow data registry. That does not happen in adult medicine—there is just not the same sort of cohesive or collaborative approach.

Ms Senner—One of the other limitations about young people’s age and where they are referred to is that in each state the department of health has established the cut-off for who is allowed to be at a children’s hospital. In New South Wales, if you are aged 15 and 11 months then you can go to a children’s hospital. If you are 16 then you cannot be admitted to a children’s hospital for a new diagnosis of cancer. So we literally have an age criterion.

Dr O’Brien—Even if you have paediatric malignancy you will be sent to an adult hospital under an adult oncologist who has probably not treated that disease or has only seen it half a dozen times.

Senator MOORE—Even if it is a recurrence?

Dr O’Brien—If it is a recurrence, the policy is that your treatment has to be finished by the age of 17.

Senator MOORE—So there is a little bit of a grey area there?

Dr O’Brien—Yes.

CHAIR—So really the wards you are talking about ought to be in specialised cancer facilities?

Dr O’Brien—Absolutely, specialised facilities where there are adult facilities, paediatric facilities and also, very importantly, gynaecological facilities—because that makes up some services. Our centre at Randwick where we have the adult paediatric services and the Royal Hospital for Women is an ideal set-up—and all of the money has already been spent. There are surgical services, there are imaging services, there are laboratory services all there. We need a ward and we need staff in the ward to deliver the service. Once that is established and that initial costing is done, it will then be a bit of a cost-shifting exercise because we will just be moving to a centralised area to deliver specialised care, not getting a whole lot of new people that we have to service.

CHAIR—What you are saying is that that has many flow-on benefits, not just for treatment of the individual but also in terms of keeping the knowledge, skills and treatment together.

Dr O’Brien—Absolutely, and we will then have the opportunity to improve on that—to study, to learn and to improve.

Senator KNOWLES—Miss Michels, are you back at university?

Miss Michels—Yes, I have a year and a half to go studying junior primary teaching.

Senator KNOWLES—Well done.

Senator HUMPHRIES—Although you have explained the gap in services very well, in my experience CanTeen does a great job in helping support people in that age group, so congratulations.

CHAIR—At the end of your presentation you talked about the importance of having a positive frame of mind and that the fact that you had some friends and support through CanTeen around was useful and necessary through your treatment. Outside of that, did the hospital or your treating physicians ever offer psychological type support in that area or did they ever offer any complementary treatments, such as meditation or other treatments we know are out there such as those offered by the Gawler clinic?

Miss Michels—At the Women’s and Children’s Hospital there were teachers who came in and psychologists and things like that. But I found at the Royal Adelaide Hospital that you had to go to them and make another appointment—they were not just constantly visiting the area and in and around the ward.

CHAIR—Thank you very much for your valuable contribution to our inquiry.

[2.50 p.m.]

MARINE, Ms Franca, Executive Officer, Medical Oncology Group of Australia

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission and I now invite you to make an opening presentation to be followed by questions from the committee.

Ms Marine—Firstly I would like to thank you for this opportunity. There is always room for improvement in the provision of cancer services given that it is such a complex disease and has so many different features. Just as background, the Medical Oncology Group of Australia is a national professional association for medical oncologists. We have about 300 members Australia wide, which comprise fully qualified medical oncologists as well as trainees.

I will briefly summarise the main points of our submission. The first point is that the Medical Oncology Group strongly supports an integrated, patient focused, multidisciplinary approach to cancer care. Given the complexity of cancer care, input is required from a full range of professionals—specialists, medical practitioners and allied health practitioners—because you need to make sure that you are developing a treatment plan which offers the best range of opportunities for treatment for the particular person. If you can ensure that you get a multidisciplinary approach with input from all the relevant people that will be involved in treating that patient then you can help to ensure that that treatment is coordinated and delivered in a timely fashion. That is very important. Basically, multidisciplinary care is very important.

Having a case coordinator working as part of a multidisciplinary team can really improve the experience for the patient because it gives them a point of contact for any queries and it is someone who can help to guide them through the maze of what is a very complex delivery of treatment, particularly in some of the more complex cancer cases. There is considerable evidence to support this. I gather that you heard from the National Breast Cancer Centre earlier this morning. They did a demonstration project on multidisciplinary care in breast cancer and they found that having a case coordinator helped to increase the number of referrals of patients to psychosocial services, which most of them really need because it is a very stressful experience. About 66 per cent of cancer patients require some sort of psychosocial support. I do not know what the rest of them do, but that is certainly a very high percentage. Multidisciplinary care has broad support and it is encapsulated in most of the clinical care guidelines that are relevant to cancer. It is also broadly supported by patients. But it is still not implemented in a comprehensive fashion in Australia and there is certainly scope to improve that.

The issue that I would like to focus on today is the importance of work force shortages in the provision of multidisciplinary care. I am sure you have heard from other presenters that there are work force shortages in just about every category of cancer support and every professional area. Lack of personnel in those areas is a bit of a barrier to implementing multidisciplinary care because it is hard, particularly in a rural area, to find the appropriate practitioners to be part of your multidisciplinary group and also because many of these people are very busy anyway and trying to schedule in additional meetings can be problematic. I have members, for example, in certain regional areas of Australia who are working 80-hour weeks and cannot take more than a week off at any one time because they cannot find a locum to fill in. Trying to find time to provide multidisciplinary care and attend meetings is difficult under those sorts of circumstances.

You are probably aware that the Medical Workforce Advisory Committee looked at the medical and haematological work force a couple of years ago. They reported that there was a quite a significant deficiency in medical oncology. That is still the case. I think it is probably going to get worse because, particularly in medical oncology, there is a lot of research in the area and it is a fairly new specialty. There are increasing indications for chemotherapy treatment and second- and third-line treatments now because the first-line treatments are improving survival. The increased survival of a patient means that there is actually more of a workload in the field of medical oncology, and that is just going to increase. So I think that, unless something is done to address the work force shortages that are here at the moment, things are going to become quite difficult in the future.

The work force shortages are particularly problematic in rural areas, because they are the ones that suffer. Eighty-five per cent of my members are in either a large regional centre or a capital city, which leaves just a handful resident in rural areas to provide oncology services. That means that most people in rural areas are receiving services on an outreach basis, where an oncologist comes in for one day a fortnight or one day a month and they do a clinic for that day and fly back to their home town. The patient has to rely on the local medical practitioners to provide care if there are any complications or any problems with the treatment. As you can imagine, that can create quite a few challenges for the coordination of care. It also creates a lot of educational challenges, because these people need to know the complexity of the treatments that are being given to these patients and the sorts of complications and the life-threatening nature that some of these things can have if they go wrong. So there is a requirement for coordination and education in those areas.

The best model for delivering cancer services in rural areas obviously depends on what resources are available. I think the hub and spoke model is probably the most appropriate one. That is where a large referral centre has a link with a rural based service so that, for cases that are more complex or require input from a broader range of people than those available in the regional or rural centre, that input can be provided through that link. That link can also assist in the delivery of multidisciplinary care.

I would like to highlight briefly, in addition to the work force issues, some of the issues in getting access to best practice treatments in Australia. We have the very good Pharmaceutical Benefits Scheme and registration system, but sometimes, especially in an area where research is ongoing and new treatments are being developed or amended quickly, there seems to be a bit of a delay in making sure that patients in Australia have access to the internationally proven best practices. It seems to be related to the complexity and length of the registration and listing process within Australia.

As a result of that, you find that there are some anomalies on the Register of Therapeutic Goods and the Pharmaceutical Benefits Scheme. The one that has been brought to my attention most often is the fact that one particular drug, cisplatin, which is a major component in chemotherapy regimens for non-small cell lung cancer, is not registered in Australia for use in that indication. I do not know that the sponsoring company for that drug is likely to apply for that indication to be registered with the TGA, because it is already registered for other use. The additional use is small, and there may not be the financial incentive for the company to do that. It would be very useful to have some mechanism whereby there was increased flexibility in the listing and registration of drugs, particularly for things like changes of indication, broadening of indications or changes in dosage schedules. That would mean that the available treatments could keep up with the new evidence as it arrives.

I will talk briefly on the complementary and less conventional cancer treatments. They are usually not part of conventional treatments because there has not yet been enough proof provided of how effective they are. That is normally the reason. It is probably worth making the distinction between complementary and alternative medicines. A complementary medicine that is used in addition to a conventional treatment is one thing; an alternative treatment is used instead of a conventional treatment. I am sure that distinction has been made for you a number of times—

CHAIR—And blurred as well.

Ms Marine—And blurred as well. It is a classification. The main concern with an alternative treatment that has not been proven is that it could delay or replace a conventional treatment that has been proved to work. In cancer treatment there is usually a very limited window of opportunity in which to treat that cancer, either for curative or life-prolonging effects. So there is a very small window, and if you do not get it then there is a chance that, six months down the track, that cancer may no longer be curable or treatable with what is currently available. I suppose there is a concern where an unproven therapy replaces a proven therapy. You could argue about why things are proven, but we will not go into that. So that is the concern about alternative therapies.

With complementary therapies, especially if it is a dietary supplement, a vitamin or herb or something, there are sometimes indications that those particular things can interfere with the conventional treatment or aggravate particular conditions. It is important that the patient feels comfortable enough to discuss their use of complementary medicines, because we know that it happens. We know that a very large number of cancer patients are using complementary therapies, and that is fine where it can improve their quality of life and not interfere with their treatment. But I think the important thing is to encourage an open dialogue between the treating doctor and the patient.

CHAIR—The evidence we have had is that patients are scared of your colleagues.

Ms Marine—Yes. It does not surprise me. I probably should not say that—can we strike that from the record! But I think you will find that a lot of people are willing to consider something that gives a patient quality of life, but we are talking about treatment in a narrow window. You want something that is not going to interfere with what has been proven to work. There may be a whole range of reasons why something has not been proven—there have not been the clinical trials to prove it or there has not been the commercial incentive for someone to undertake a clinical trial to make sure that it works—but I think at the end of the day you need to make sure that what is used is what has been proven to work.

Senator KNOWLES—But isn't it too easily dismissed? We had evidence yesterday, for example, from someone whom we know who was seeking complementary therapies and was up-front enough with the oncologist to say that he was taking melatonin. The oncologist said, 'That's a whole lot of mumbo-jumbo.' Then the evidence was provided to the oncologist and the oncologist said, 'Okay, then—that's okay.'

Ms Marine—I think that highlights the need to make sure that there is some sort of comprehensive information base on these complementary therapies available to both the practitioners and the patients so that they do not become dismissive about it and so that they say, 'This might be something that's worth looking into.' You have got to look at the most promising treatments and do some research into them.

CHAIR—That comes back to something that you picked up on in your submission, and I thank you for it because I think it is a fairly well balanced one. A lot of the evidence we have is that everyone accepts the multidisciplinary approach. People seem to say: 'Everything is fine—what are you worried about? Why do you keep asking us about it?' But you have identified that there is resistance to change and you have said here that it has not been universally accepted and put in place.

Ms Marine—Are you talking about complementary medicine?

CHAIR—No, the multidisciplinary approach. There is resistance to change, particularly from the medical professionals at the top of the food chain.

Ms Marine—Is that what I said?

CHAIR—You did not talk about the 'top of the food chain', but you referred to one of the barriers to the development of multidisciplinary care being resistance to change. I wonder if you might like to expand on that.

Ms Marine—That has come out of the National Breast Cancer Centre's multidisciplinary demonstration project. It is understandable and natural that there is going to be resistance, particularly in an environment where people are very busy. As I said, you are looking at very large caseloads. People are going to say, 'Do I have to make time for another meeting?' I cannot speak on behalf of individual members about why there is that resistance to change, but I know that it is certainly more difficult in the private sector to get a multidisciplinary care arrangement in place. And any change requires time to settle in, get bedded down and become part of the normal paradigm of practice.

CHAIR—The next change that may well be coming would be about the accreditation of cancer treatment facilities and the credentialling of those specialists who work in them. What are your members' views on those proposals?

Ms Marine—We do not have a specific policy on it so I would need to take that on notice, but we have certainly been supportive of a general move to credentialling. The actual details of how such a process would be conducted obviously need to be worked out, but I do not think there is any resistance to a credentialling process.

CHAIR—It comes back to what you also indicated earlier about ensuring that best practice is applied.

Ms Marine—That is right, and giving patients an idea of what level of services they can expect in a particular area. I think you need to make allowances for resources, particularly in rural areas. You need to take into account the level of services that can be provided in those areas.

CHAIR—That is one of the great dilemmas, isn't it? Say we want to provide services in rural Australia. Do we give patients people that do not have the same turnover, flow-through and knowledge for treating people? Shouldn't the patient have the absolute right to understand that they may in fact be trading off expertise for the convenience of not having to travel?

Ms Marine—Exactly. A lot of patients will also undertake to have their chemotherapy given in their home or by their local general practitioner, who may not have much experience in that area. There are a number of difficulties and complications that can arise through giving chemotherapy in those circumstances.

CHAIR—As long as the patients are well informed.

Ms Marine—Exactly. I think an accreditation process will help to inform a patient about what they can expect from that area.

CHAIR—Looking at the breast cancer model, we have the professional saying, 'We absolutely endorse accreditation, credentialling and best-practice models with five stars,' or whatever. But then we have what are described as consumer groups that are saying, 'No, they are absolutely resistant to make that information public and really provide it; it is too subjective.' So we hear two different things about this sort of stuff.

Ms Marine—I think the other point relates to what information is available. For example, I know that the College of Surgeons have developed a reporting mechanism for outcomes for treatment in breast cancer surgery. I might not have that 100 per cent. If you do not have a reporting arrangement on what people's outcomes are, that is the sort of thing that needs to be addressed by a credentialling program. We do not have that information. In fact, we do not even have information on stages of treatment for cancer and what treatments are provided to people, let alone what the outcomes are for those particular treatments.

CHAIR—That is right. That problem has been identified many times. That is something we will have to turn our minds to.

Senator HUMPHRIES—I want to come back to this problem that you identified with the PBS and the TGA. As I understand what you are saying, you feel that drug companies see certain drugs that are produced elsewhere as not being profitable enough to seek registration for in Australia. Is that right?

Ms Marine—I will give you a small example. I do not know enough about cisplatin, so I will take the example of Herceptin. I know that is under a separate arrangement for funding, so it is not part of the Pharmaceutical Benefits Scheme list at the moment. For the sake of argument, let us say that it was. There is evidence to show that a different dosing schedule is achieving better results than the dosing schedule that is listed under the current funding arrangements. If you wanted to change that dosing schedule and it was under the Pharmaceutical Benefits Scheme, you would have to get that new thing relisted on the Pharmaceutical Benefits Scheme, so you would have to resubmit the whole proposal. It is a fairly expensive and long-winded affair. For a company where there is only a small incremental gain, there may not be the incentive to do that. We would love to see an alternative for getting some of these changes made to the list, because it does put a treating doctor in a difficult situation—'I'd love to be able to prescribe this for you, but I can only prescribe under these circumstances.'

Senator HUMPHRIES—Has a pharmaceutical company actually sought that inappropriate dosing?

Ms Marine—Their submissions are based on what they know at the time. Twelve months down the track further research becomes available. It is not an issue with what the company chooses to present so much as the fact that information changes; research goes on and more clinical trials come forward with improved results and different evidence. There is not the flexibility within the scheme to actually adopt those quickly.

Senator HUMPHRIES—And there is a cost to the company, presumably, in going back and asking for a re-evaluation of the dosing of that.

Ms Marine—Yes, of course.

CHAIR—The biggest issue you are identifying is that it is only a small group that it affects.

Ms Marine—Exactly. Particularly with out-of-patent drugs and orphan drugs, there is not often the commercial incentive for those companies to sponsor a submission. There are not alternatives. We would like to be able to sponsor some of these things, but we cannot. We do not have the financial background to do it but also we do not have the option. We have been talking to the Pharmaceutical Benefits Advisory Committee and the TGA trying to get some sort of understanding of the difficulties involved. We are still trying.

Senator MOORE—Senator Marshall asked you a question about credentialling, and that is coming up a lot. We spoke with the breast care people this morning.

Ms Marine—Who do you mean by 'the breast care people'?

Senator MOORE—We spoke with the action group and also the—

Ms Marine—And the consumer groups, yes.

Senator MOORE—This little book is widely valued. A lot of your members are in there, but I bet there are a lot who are not. Does the organisation actually have policy on becoming involved in things like that or is it purely an individual choice?

Ms Marine—I am not aware of that. Is it a directory of breast cancer services?

Senator MOORE—Yes, the directory of breast cancer treatment services that was put out in 2002. They have just updated it. They are going to keep it online.

Ms Marine—I think they approached us about that and we supported that.

Senator KNOWLES—It is to do with all the doctors.

Ms Marine—It probably covers more than just medical oncologists. It probably covers radiation.

Senator MOORE—Yes.

Ms Marine—My members would definitely be in there.

Senator MOORE—Yes, you have got your own little bit. Of course anyone in that specialty is one of your members. It is unique but it is widely valued. It is something that other groups are looking at. They are saying, ‘It would be really good if we could have something that came out.’ I was interested in whether the organisation had looked at it as a whole to see whether something like that would be favoured.

Ms Marine—Let me have a look.

Senator MOORE—What we were told was that they developed a survey form, and the doctors were all sent the form to fill in. Some people filled it in and responded straightaway. They did a couple of follow-ups and gave people full warning about what they were doing. But we know that that is not a full list of all the practising people in New South Wales.

Ms Marine—From what I can gather, it would be a very valuable thing for patients. We have no problem with that. It depends on what sort of information is involved. One of our ongoing concerns is that some of our members deal with more lung cancer than other members, and some of them deal with more breast cancer, but there is no credentialling process for that at present. They can say: ‘Yes, I have an interest. I do a lot of my work in this area and I see a lot of patients in that area.’ But does that mean that we can recommend them as a breast cancer surgeon when our philosophy is that all medical oncologists can treat most cancers? The issue is how far you stand behind what you include in these sorts of things. Something like this would be very valuable. We do try and provide something within our membership—who provides services in what areas, particularly for rural referrals and stuff. It is usually an in-house document because not everyone wants everything put out.

Senator MOORE—The other thing we were talking about this morning was that, while this is very valuable for consumers, one of the groups we have identified is GPs. The GPs just do not know what is available. Is the information that you as a college keep the kind of stuff GPs can ring up and ask about?

Ms Marine—We have a listing on our web site, for example, of people who have agreed to be listed publicly. That indicates what their self-expressed areas of interest are, whether it be lung or breast cancer, and a contact point. That is really all that is available. Certainly if I ever get any GPs ringing me up about things I will try and find out whatever I can for them. We are willing to help. As for the best methods of doing that and what we can vouch for under the current systems, it varies.

CHAIR—Thank you very much for your presentation and your submission.

Proceedings suspended from 3.15 p.m. to 3.25 p.m.

PAGE, Dr Susan, President, Rural Doctors Association of Australia

STRATIGOS, Ms Susan Mary, Policy Adviser, Rural Doctors Association of Australia

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission. I now invite you to make an opening presentation, which will be followed by questions from the committee.

Dr Page—I thank the committee very much for the opportunity not only to do the written submission but also to present verbally. To me, cancer services are probably the most heart rending of all the services which are currently not being done well in rural areas. I am sure you are aware of a recent *Medical Journal of Australia* article stating the increased rate of mortality. Just to refresh the committee's memory on that, for overall cancer mortality in rural areas you are now 35 per cent more likely to die within a five-year period after diagnosis than a person with the same cancer living in a metropolitan area. For certain cancers, such as cancer of the cervix and cancer of the prostate, there is a 300 per cent difference—you are now three times more likely to be dead in a five-year period. I note that these figures are not related to the increased mortality figures of our Aboriginal and Torres Strait Islander people, who by and large do not live long enough to reach cancer ages.

CHAIR—I think we need to clarify that, because I do not think that is consistent with some of the information we have. Are you saying that the improvement in treatment in the metropolitan area is not being reflected in the rural area so the gap is increasing, or are you saying the mortality rate from cancers in general is increasing?

Dr Page—The mortality rates from cancers in general are worse in rural areas than they are in metropolitan areas. I think a lot of those differences relate to earlier detection and better access to treatment in metropolitan areas but also to differences in risky lifestyle behaviours. I have brought an article with me which, for me, typifies a lot of the problems in the current cancer system. I will give you a copy of it. The article was recently published in *The Breast*. It is called 'Surgical caseload and outcomes for women with invasive breast cancer treated in Western Australia'.

As a basic summary, in this article they looked at the mortality outcomes for women who were treated by higher caseload surgeons—defined as doing more than 20 breast operations in a year—compared with those who were treated by low caseload surgeons. As you might expect, the high caseload surgeons were predominantly Perth based, in and around Perth. There were nine of them over the follow-up period. They obviously do not provide services to the vast majority of Western Australia. However, it is interesting to see the trend in the number of women being treated by those nine surgeons. It started off at around one in three and has ended up being slightly over 80 per cent of women with invasive breast cancer being treated by these surgeons.

The researchers looked at a number of different aspects of cancer surgery. I can take you through those. The first was that the women who presented to the breast cancer surgeons were much more likely to have come through a screening process and were much more likely to be younger. We know that our breast cancer screening services, while provided on a theoretically national basis, do not make it out into rural and remote areas in a consistent fashion and are particularly poorly attended by Aboriginal and Torres Strait Islander women. The uptake for breast screening services in general tends to be better amongst high socioeconomic groupings—women who have high levels of education and women who are in the major metropolitan cities. So you automatically have a skewing of the caseload, which the researchers say that they have corrected for by using different statistical methods.

A lot of cancer studies have found that the presentation of the women is when they are more advanced in their cancer stage. This particular study did not find statistically significant differences at the time of presentation. However, it did find significant differences in the rate of what happened thereafter. If the women were attending a high caseload surgeon they were almost twice as likely to have radiotherapy and almost half as likely to have breast conserving surgery. The implication at the end of this was that you were more likely to have a better outcome because of your longevity, your use of adjuvant therapy and so on.

The big difficulty is that your rates of radiotherapy are appallingly low in rural areas not because your surgeon is incompetent or does not know that it is good. For example, adjuvant chemotherapy is more readily available in rural areas and the rates for using adjuvant chemotherapy were statistically the same in both the high-volume and low-volume groups in Western Australia. What was different were the rates with radiotherapy, which is predominantly only available in metropolitan centres.

If I use examples from my own personal clinical career, I have women with the nearest radiotherapy unit being an hour and a half down the road. But the idea of spending three hours on a daily or two-day basis for six to eight weeks, at a time a woman has been newly diagnosed with cancer and wants to be with her family and friends, is appalling. I have had women refusing to travel for radiotherapy when they have to travel only an hour and a half. Certainly if you have to travel more than an hour and a half, you are not talking about something you can do in a round trip in one day, particularly if you are feeling so unwell that you are unable to drive yourself and so you are pulling a second person away from work.

I have a colleague in the state who, at the moment, has a patient with prostatic cancer. That man is in Sydney now having radiotherapy, and he will be having it for six to eight weeks. The radiotherapy is being given in a 15-minute dose on a daily basis for that six- to eight-week period. After taking into account his travel and accommodation assistance package, which is provided, it is costing him $85 a night in accommodation. This is not an amount of money that an impoverished low-socioeconomic and particularly low-educated rural person can afford. Having services like radiotherapy only available in metropolitan areas and expecting people to have to travel to them and to pay for their accommodation in order to be able to attend them—quite apart from the social aspects of depriving them of their family and social supports at that time—I really think is not okay. It is shifting the costs of medicine to the people who are least able to afford it, those who are sick and those who come from low-socioeconomic groupings.

Ms Stratigos—Mr Chairman, just getting back to your question, we use terminology a little loosely and perhaps with different meanings. By using the word ‘increased’ in connection with rates of mortality in rural as opposed to urban areas, we do not mean ‘excess’. I am afraid this is jargon, and we have something about it here. Excess mortality does not necessarily mean an increase. It means that a standard expected rate of mortality for a certain reason, in a certain age group, is taken as a standard and then in some areas, if there is lower mortality in that group, that is not excess. But a question of excess would be: is there more mortality in a particular group? It is not necessarily increasing; it could be constant or, in fact, decreasing. I just want to make it clear that we are perhaps using 'excess' not in the sense of increasing but simply as a proportion.

CHAIR—Thank you.

Senator MOORE—Dr Page, just so I can visualise it, whereabouts do you practise?

Dr Page—My home town is Knockrow. My practice is at Lennox Head on the far north New South Wales coast. I come back to this particular article. Researchers, having made the point that a woman is half as likely to have radiotherapy, also report that the woman is half as likely to have breast conserving surgery, as if those two were independent. If somebody with breast cancer has the lump out only and has radiotherapy, their five-year survival prognosis is every bit as good as if they had radical surgery. If they do not have radiotherapy, they have an unacceptably high rate of recurrence. So surgeons who are unable to access radiotherapy for their patients no longer have a choice as to what is the best surgical cosmetic result, because they are talking about what is the best surgical longevity result. For these researchers then to assume that a patient's interests are better served by seeing a surgeon, when the research is saying that a patient's interests are better served by having the full range of cancer care—of which surgery is one component—means that there is a new gold standard in terms of defining how breast cancer should be managed. This then leads into how we train our future surgeons and what their expectations of safe practice are.

We live in a medical world where we have increasing rates of medical litigation. The surgeon is faced with two working environments. In one he is able to offer his patients the full range of cancer care, including radiotherapy and chemotherapy. He is able to do what he knows is gold standard surgical treatment. In the other he is offered a position where he will be socially and collegiately professionally disadvantaged because he is living in a remote area away from a metropolitan centre and he has to offer what he knows in his heart is not gold standard treatment for his patients. It becomes extremely difficult to try and entice surgeons further away from metropolitan areas. Yet we cannot afford to have a state as large as Western Australia clustering 83 per cent of its breast cancer treatments in the capital city in that state and think that is a good thing.

Cancer is perhaps unique in that it does usually require a whole range of different services. It requires not just surgical services but also chemotherapy, radiotherapy, psychological services, the network of family and palliative care. Palliative care and pain management is becoming an increasingly specialised field which, again, translates very poorly into rural and remote areas. I am very distressed to say that the worst palliative care services are often for children's cancers. An example from my own personal experience is a four-year-old who was diagnosed with leukaemia. The only place he can access treatment is in a capital city. His family lives in a country town. In this case they are a second generation family in that country town. Sometimes they may be fourth and fifth generation families. All of their social supports, all of the children's school friends, if they are school age, will be in that town. Yet the only treatment option we are offering that family is to live in a capital city for two to three years while they have cycles of chemotherapy. They can now come home to their family for short-term holiday treatments.

CHAIR—What are you suggesting is the answer, because in a country as diverse and large as Australia we are not going to have a specialised cancer treatment hospital within 100 kilometres of everybody?

Dr Page—I do not think we can spread radiotherapy bunkers around in a lot of areas. It is enormously expensive to build the actual building, which is all shielded. You also have the expense of the equipment and a very limited number of people who are radiation oncologists in Australia. However, every radiation bunker that we have in Australia should be attached to free-to-patient accommodation units where preferably the family can move in, like the Ronald McDonald House scenario. It should be something that is part and parcel of providing the radiotherapy service. In addition to that, we need to look at the financial supports we can give to these families because, in a lot of families, they are also dropping their income. It splits families. The husband, who may be a farmer, for example, has to stay behind in order to get crops in. It breaks the family in half. One of the GPs in New South Wales has a child with cancer who is in Sydney at the moment. It has split his family entirely for that scenario. For families to also have to pay out of pocket for travel and accommodation is not okay.

I see no reason why chemotherapy cannot be done more freely across Australia. We have a couple of quite successful pilots in New South Wales. Quite ironically, the two most successful pilot sites have been giving chemotherapy for more than a 20-year period. But they were relegated to pilot status when an oncology specialist in Sydney determined that it was unsafe to be giving chemotherapy outside of a dedicated oncology specialist unit. Looking at the component pieces of what is involved in giving chemotherapy, there are risks to the technicians who are mixing up the medications. You can absorb them through your skin, in a number of cases. You obviously have to have staff who are trained in the use so that a chemotherapy agent that is meant to be given intravenously is not given through a wrong access site, for example. And you need to have the dose exactly right and so on. Those are all pieces of training that can be delivered in rural and remote areas.

Places like Moree, for example, have oncology sisters who are well trained in giving the chemotherapy. It was determined that Moree did not have a surgeon who would be able to deal with the tissue damage complications of the chemotherapy should it extravasate out of the vein and then damage the tissues around it. Moree actually has three surgeons. These types of decisions were being made at a central level without consultation with the rural area. It would have denied all of the people in the central west access to chemotherapy services within remote travelling distance of their families.

There is no reason that I can see why you cannot have GPs and nurses trained up with advanced skills, specialist oncologists linking in by videoconferencing or teleconferencing and the individual patient perhaps doing a once or twice a year visit back to the metropolitan centre, if that is required. But the component pieces can be delivered in rural areas so long as you do not say that it needs to be a teaching hospital specialist oncology service—we cannot get around that one in a rural area. If you say you need to have the trained nurse, the trained doctor, the trained oncology specialist, access to these types of things, the place the medications are mixed up and all adherence to protocols, the component pieces can be delivered—so long as that is the way it is phrased. But if you tie it up as one parcel we cannot do anything with that except close the unit.

Palliative care is something which should be available in every country town. A number of palliative care units have been GP run in the past. The one at Lismore, which is now specialist run, was GP run up until a couple of years ago. There are a vast number of GPs out there with palliative care skills and advanced-level pain management skills. In addition, there are five college collaborations delivering a diploma in palliative care. As we speak they are writing the different curriculum modules. They have been working on it for about 18 months. There is no reason why those modules cannot be delivered across the rest of Australia.

At the moment we only put our attention, our funding and our research dollars into the teaching hospitals. When we look at, for example, the Commonwealth planned roll-out for cancer screening services—I have a publication here from the AIHW called *Rural, regional and remote health: a study on mortality,* which was published at the end of 2003. It looks at the leading specific causes of excess deaths in the years 1997 to 1999. These are higher death rates occurring outside major cities. On that list it pulls up prostate cancer, colorectal cancer and lung cancer but it does not mention breast cancer or cancer of the cervix. The reason for that is that, by and large, the national breast screening service with the screening clinics has reached rural and remote areas better than some of the other screening services. Currently, in New South Wales if you are female your chances of having a pap smear is higher in rural and remote areas than it is in metropolitan areas. It means that where those screenings are done in a systematic fashion we are losing the excess deaths in those particular types of cancers in our rural and remote areas.

On the other hand, if we look at things like lung cancer we know that country people are much more likely to smoke and to drink to excess. They are less likely to be regularly exercising. They are more likely to be overweight. They are more likely to have diets that are high in animal fat. All of these things are associated with increased rates of developing cancers in the first place, yet we very rarely see public health screening programs. You cannot walk into your local 7-Eleven store in a country town and have somebody offering to do a cholesterol or a rotary bowel screening test the way that you can in metropolitan areas. Bus shelters do not have the Quit lifeline numbers posted up in them.

We have a paucity of public health education in rural and remote areas which means that our rural high school kids, for example, are not being exposed to the same modules. It should be borne in mind that rural people on average will leave school at an earlier age. If we talk about Indigenous Australians the average age of school leaving is year 9. They leave with an average literacy level of year 7. This means they are leaving before most of the major health modules are delivered in a high school, which usually happens in year 10, on safe sex, drinking and smoking and so on. Up until that level you are dealing with things like Healthy Harold and eating fruit and vegetables but the gutsy modules tend to drop in after a lot of these people have already left high school.

If we are going to have a major roll-out of colorectal screening nationally, as intended by the Commonwealth government, the first thing I see happening is that we are going to have a large number of people who will be having positive tests without access to follow-up services. In my area, we had a real block in trying to get colonoscopies done. We have been able to turn that around by using access to the private hospital. I would have patients who would cheerfully pay anything up to $250 to have their procedure done privately so that they did not have to join the six, eight to nine months waiting list at the nearest public unit. They could not even do that within our state. They had to cross the border into Queensland in order to get on the shorter waiting list a couple of years ago. We now have a good service in my area based at Lismore, but that is not the case for most rural towns—there are not the services there. I see no reason why we should not be training a lot more of our GPs to do endoscopies. We have people like Dr Peter McInerney who does endoscopy lists at both Scone and Coonabarabran who is a GP who has been trained in that.

We are finding that a number of our specialist colleges are very focused on doing the training within their own specialty college and not making that education freely available. With the increasingly subspecialisation pathway that we are going down, we are making it more a more a case of: the gold standard looks like this, and the only people who can do this safely are these ones. And then we will go down the pathway where not only do they have to be specialists but they need to be professors before we are really happy that it has been done properly.

These are services that impact on people’s lives and we need to have them spread as widely across Australia as we possibly can. They are no longer things that people might access only once in a lifetime. We have a considerable number of people who will be hitting the cancer age group. Year by year, we have an ageing population. By the year 2025 one-quarter of Australians will be over the age of 65. We need to build up our resources now to have a much greater cohort of health care providers who can provide these types of services. We need to have that training on the ground before we start doing our mass screening programs and then have a whole lot of people in rural areas who are given a positive bowel screening test and have nowhere to go because the service is not available in their hometown.

Ms Stratigos—I just want to add that the whole business of the bowel screening program really highlights an issue in Commonwealth funding and programming. It was piloted—and it was really good that it was piloted—and it was very thoroughly done. The methodology was great in a clinical sense. The one problem was that it was piloted in five areas, and the rural area was Mackay. Mackay has three hospitals and seven specialist surgeons who deal with this; it has more GPs—and I have spoken to them—than can fit into two quite large rooms if they come in at lunchtime. With Mackay, we are not talking about rural Australia.

Senator MOORE—And they have radiation and chemotherapy.

Ms Stratigos—Exactly. And this is the rural pilot. The people who are running it in the department are given a certain amount of money to pilot things. I think we have to look at the price of not doing something in this area, as well as the cost of doing it. Because the pilot was done in this way, the scheme, as it is about to be implemented, has a vulnerability in it for rural Australians which Sue has pointed out. If there had been enough money to trial it in the areas of Oodnadatta, West Wyalong or somewhere like that, this problem would have been seen in the planning of the program, but the funding to take the pilot out to a totally different part of Australia where different people may have had to be involved was not there. We would like to point out that you can have some really good programs, and we do, but they are not equitable if they are not trialled and designed for the 36 per cent of Australians who do not live in urban areas.

Senator KNOWLES—Dear oh dear—where do we start with rural medicine!

CHAIR—Move to the city, Senator!

Senator KNOWLES—I'm okay Jack—I live in the city. But my constituents live all over Western Australia. I hear what you are saying about putting so many facilities into every town. I do not know whether you are talking from a New South Wales perspective or an Australian perspective, but we can whistle Dixie in a west wind and we are not going to get all those facilities in every town. So how best do we give people facilities on their doorstep while supporting them when they do have to go away? I have listened to all that you had to say about supporting people to go to accommodation and everything else, but then you said that we have to provide palliative care in every town in Australia.

Dr Page—Most palliative care takes place in the community rather than in a hospital.

Senator KNOWLES—That is exactly right.

Dr Page—I have an Aboriginal patient at the moment. We do outreach services to an Aboriginal primary health post in my area, at Cabbage Tree Island near Wardell. This particular lady is dying of metastatic breast cancer. She is very unwell. She has not had a hospital admission. She has refused to have a lot of the treatments. For example, most recently her blood count sat at around seven haemoglobin and she was refusing to have a transfusion. She would rather stay in her community. She has everything that she needs in the way of medications, wheelchairs, different foam mattresses in her bed and people to assist her with her shopping. Centrelink is providing services. When she moved onto the disability pension, Centrelink staff actually got in a car and drove out to the community. These are all things which are technically possible but require an enormous personal effort on behalf of the clinician—in this case, me—to arrange things, because they do not happen naturally or in a coordinated fashion or spontaneously. We need to change the way that we deal with health so that that becomes normal and that it is abnormal for people to come into hospital.

As for what that means for things like chemotherapy, there are some types of chemotherapy where, for example, if somebody had a brain tumour you would be injecting it directly into their faecal sac—basically going into their nervous system. That is very unlikely to be something that you could give safely in a rural hospital. It would be happening so infrequently that it would be hard to maintain your trained staff. But intravenous chemotherapy is something that is certainly able to be done, if not in every small country town then certainly in enough regional centres that you can get there and back in a day.

Senator KNOWLES—But, you see, sometimes that is not possible. In a lot of cases—say, in Western Australia—it is easier to go Perth than it is to go to a regional town.

Dr Page—Yes, all planes go to Perth.

Senator KNOWLES—Yes, that is right—you do not have that crisscrossing of aircraft services. Do you then try and utilise facilities such as RFDS or other sources of transport?

Dr Page—I think you do. I think that there will always be a point at which you have to ration your services. As with the example before, you cannot have a radiation bunker in everybody's backyard. There will always be some services you will have to travel for. At the moment we expect people to travel without considering the impact on them, their family or their finances. We make the assumption that the isolated patients travel and accommodation assistance scheme with serve it. The amount of money that IPTAAS allocates for accommodation is something quite small—less than $50 a night. I am not sure of the last time you stayed in a hotel in Sydney, but you would be really pushing it to find one for that amount.

Senator KNOWLES—If you did, you would not want to stay there.

Dr Page—That is right, and certainly not when you are feeling sick and your hair is falling out and you are vomiting—it is really not fun. Yet most of the accommodation blocks that we used to have attached to hospitals have either turned into hospital administration or disappeared altogether. We do not have nursing accommodation. We are hitting a problem with the number of students, for example, that are wanting to stay in hospital grounds. We do not have hospital services available. If we do, we charge for them. Sometimes it is cost recovery but, still, you are asking the individual sick person to pay for the cleaning of the room and all of those different expenses. If they lived in the city, they would just be at home with their family and those costs would balance out, but we are asking people to leave their home and their family. That is putting a financial impost on them that they should not also have.

Senator KNOWLES—We know the problem; what is the answer?

Ms Stratigos—Can we look at the other end of this for a minute? Prevention, as our grandmothers all taught us, is better than cure—and it certainly is. In a fiscal context, there is no doubt about this at all. But if you look at health promotion or public health initiatives, they are designed in cities for cities. Just look at some of the programs that run on television sometimes or some of the billboards. They are not going to attract a 13-year-old Aboriginal boy or a 15-year-old girl, Indigenous or not, in a rural town. There are some things that we could do that will not have an impact for a while. We use peer group pressure as a PR way of cutting down smoking and alcohol consumption. We use those things, but I do not think we necessarily design programs that will assist people or convince people it is a good idea to cut down on binge drinking or smoking or something like that.

Senator KNOWLES—But how do you get that message out there?

Ms Stratigos—I think we have to design new programs—though I am not sure who 'we' is. Maybe the health care system has to call in PR advertising people to design programs that really catch what makes younger rural people tick.

Senator KNOWLES—No-one would disagree with what you are saying. It is the methodology of doing it. We have gone to a whole range of areas—trying to get people to eat more healthily to avoid diabetes, trying to get people to reduce alcohol consumption and things like that. We have seen some results, but there is a limit to which you can get the message out. If anyone has greater ideas—

Dr Page—Part of the limit in the rural areas is that the message actually does not get out there. You obviously have greatly limited television transmission and things like that, you do not have the billboards, you do not have the people going out to the schools and you do not have the people in the local supermarket. It just does not happen out there. But one of the things—

CHAIR—A lot of things you are talking about relate to state infrastructure and it is very tempting for a Senate committee to recommend that the states spend several billion dollars more on doing all these things, but it is pointless to do that. You were talking about the design of programs and having that rural uniqueness put into that. We have had this with the consumer groups too—they say consumers should be represented when people are developing programs. Is one of the things we could do as a committee to recommend that there be regional or rural representatives—whatever terminology we would like to use; ‘regional’ might pick up Mackay—on the bodies that develop pilots and programs so that your direct concerns about how the message is going to get out, how it is going to be accepted and how the program is going to work in rural towns can be taken into consideration?

Dr Page—From a research point of view I would probably go even more hard-line. I would say that you should not be giving research funding out unless there is a subsection in the project that asks: ‘And how will this address the needs of rural and remote Australians?’ The year before last there was a review of the National Health and Medical Research Council—forgive me, I did not bring it with me and I cannot remember it exactly. You would need to check the figure, but off the top of my head it said that two per cent of the previous 10 years worth of National Health and Medical Research Council funding had gone on rural health topics. It was enormously low, and that is partly because the researchers who have the credibility needed in order to attract the large grants were all based in major teaching hospitals and major universities and are all metropolitan—and they forget.

To use an example, I was on one of the working parties for the New South Wales alcohol summit. In the working party we were looking at how research dollars might be allocated in the state of New South Wales for alcohol. The main proposal that we were being asked to consider was gene research that was going to be delivered through one of the major teaching hospitals in Sydney. I was cheeky enough to say that, when the highest rates of risky drinking were in small countries towns of less than 5,000, I could not quite understand how gene research at one teaching hospital in Sydney was going to help that. In the course of that workshop it was then turned around so that, instead, the research funding was going to be allocated to developing community education programs. That was from one question in the course of a two-hour meeting. It was a really simple process for me to say, ‘How is that going to help rural people?’

CHAIR—I think that is a very fair question that ought to be asked with all these projects. I am surprised that there is not a check list of those questions to be asked before programs are developed and put into place.

Ms Stratigos—It is surprising.

Senator KNOWLES—Can I come back to what you were saying earlier, Dr Page, about some of the Aboriginal youngsters leaving school at year 9. What is wrong with bringing forward some of those educational health aspects?

Dr Page—Personally—I do not know that I would run this past my committee of management—I think that the biggest gains in health outcomes for our Aboriginal and Torres Strait Islander people will be delivered through education and not through health systems. I think we need to be looking much more aggressively at those things that impact on the social determinants of health. If they complete their education then they are more likely to get employed; if they are more likely to get employed they are more likely to have higher incomes. Automatically, you are starting to skew the health outcomes associated with each of those different risk factors. They are more likely to have adequate housing, which then impacts on health. We have had, for example, health for housing programs in the Northern Territory which have reduced the rates of glue ear just by living in a house—simple things like that. I absolutely think we should bring those programs forward earlier for all rural people.

Senator KNOWLES—Look at diabetes. You are trying to teach children at a very young age that unhealthy eating and so forth could lead to the loss of their sight et cetera.

Dr Page—And teeth.

Senator KNOWLES—Yes. It almost becomes a fear, depending on how it is put forward with young children. If there is accepted knowledge that they are missing out because they are leaving school too soon, it just seems too obvious to me that you should be bringing it back a bit—about three notches, maybe—to start earlier.

Dr Page—I personally think that would make a big impact, not just for Aboriginal and Torres Strait Islander people but for all rural people, who on average tend not to complete their schooling.

Senator KNOWLES—We have heard evidence today and in other places that there are a number of people who miss out on patient assisted transport purely and simply because they are just under the distance. My argument to that is that it is never going to be an easy subject because you set a distance and no matter what that distance is there will always be people just under it. What is your answer to that?

Dr Page—In my area people from Lennox Head can get it but people from Byron Bay cannot, and there is a 15 to 20 minute car trip between those two. Whatever limit you set you are going to have problems. If we are making the decision as a nation that we will provide certain healthcare services in certain places, you could set the amount of travel—by public transport or whatever—as being reasonable, but we need to do it.

Senator KNOWLES—When you say an amount ‘as being reasonable’, are you talking about distance or are you saying, as it was put to the committee this morning, that maybe it should be considered in time?

Dr Page—For my people at Cabbage Tree Island, they do not go to Lismore unless the travel is provided. Out of our budget, we pay for a community driver to pick them up and take them. There is no public transport off the island; they cannot get anywhere. For them, half an hour is too far because there is no physical way of getting from point A to point B. It needs to be flexible enough to allow those different things so that you can apply for it. As a doctor, I can say, ‘This person can get upgraded travel for these reasons,’—for example, they can fly instead of taking the bus—but I cannot say: 'This person is five kilometres short but there's no-one to drive them. There's no public transport and their husband is in hospital with a hip replacement.' That is an example of one patient I had. We have pulled in, in some circumstances, quite extraordinary ways to get people to their appointments—next-door neighbours taking alternate days off work so that they can drive them on different days—but again it all comes down to making it easier. You need to make it easier for country people to access the services in a different centre.

Senator KNOWLES—But how do you do that? You are saying to me that maybe you should do it on an individual basis or the doctors put a case for an individual patient, but then every doctor will put a case for an individual patient, regardless of the distance, regardless of the time. There has to be an end to it somewhere along the line, because, after all, it is taxpayers' money. How do you come up with a good solution to the problem?

Dr Page—Each radiotherapy unit can only take a set number of patients a day. As a minimum, there should be that amount of accommodation attached to the radiotherapy units so that rural people can come in and at least the accommodation can be taken care of. From the travel point of view, there is such a variation on the way that people travel. What we see at the moment is that the money is given to the states and the states come up with quite idiosyncratic ways of developing it. We already have differences in one state compared to another. Having a flexible program where that is concerned is probably not going to be a difficulty thing to achieve. There are so many varieties of transport. There are so many different types of public transport, but there are also community drivers and so on who might be paid petrol money. That flexibility is built in. Accommodation is one that you know in advance you can budget for because a set number of patients a day is the case load for that machine.

Ms Stratigos—I do not wish to be controversial in raising this phrase—we have not talked about it as a policy matter—but you have talked about time and distance as markers of support. Another way would be a sort of, dare I say it, safety net approach. Some people have to get taxis for example for enormously long distances and in the cases where this was paid, if your expenses were more than $50 or $100 or something—

Senator KNOWLES—But then someone will opt for the more expensive option.

Ms Stratigos—They may, but is the need of the patient outweighed necessarily by that? Is a little margin for human error or skulduggery or greed perhaps something that should be factored into a program in helping people with an illness like this?

Senator KNOWLES—I am not a state treasurer, so I will not answer that.

Ms Stratigos—Neither am I, as you can tell, but I just wondered. I am looking at health outcomes in rural communities. If there are five per cent of patients somewhere across the country who are so sick that they need radiotherapy, and they decide they will rort the system by taking a taxi when they could take a bus, might it be worth while just allowing that cost to be paid in order that the other 95 per cent of patients, who really needed it, got the support that they need?

Senator KNOWLES—I am sure the state treasurers would be delighted to hear your evidence.

CHAIR—I am afraid it was very inappropriate to use those ‘safety net’ words.

Ms Stratigos—I do apologise and I ask Hansard to expunge them immediately. Wait till I get the transcript.

Senator KNOWLES—At least we have one.

CHAIR—Thank you very much for what was a very forthright and frank presentation. It has given us some significant food for thought about general public policy issues as well.

[4.07 p.m.]

KHOURY, Mr Raymond, Head, Herbal Medicine Department, Australian Traditional Medicine Society

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera, if you consider such evidence to be of a confidential nature. The committee has before it your submission. I now invite you to make an opening presentation to be followed by questions from the committee.

Mr Khoury—The Australian Traditional Medicine Society is a professional body of complementary medicine practitioners, which was formed 21 years ago. The society accepts into its membership those practitioners who have undergone training—usually of a four-year period—in complementary medicine. Once admitted into the society the members are expected to undertake continuing professional education. The society publishes a peer review journal, and some 40 health funds pay for the services of our practitioners.

The inquiry has used the term ‘less conventional and complementary treatments’. I respectfully suggest that that is an incorrect term. In Australia, the term which is used by government departments is ‘complementary medicine’. ‘Complementary medicine’ refers to the practice of those therapies and the term ‘complementary medicines’ refers to the actual therapeutic products used, such as vitamins, herbs et cetera. In Australia, complementary medicine is a highly organised structure whereby, according to a University of Sydney survey, our members alone conduct 1.9 million consultations a year with the community. I suggest to the committee that in Australia there is no such thing as alternative medicine. Unfortunately, ‘alternative medicine’ was a term used in the 1980s, early 1990s. Alternative medicine may be applicable in some Asian countries, but certainly in Australia there is no organised alternative medicine.

One of our recommendations to the committee is that research funding for complementary medicine be considered. Since 2001 the National Health and Medical Research Council has allocated $850,000 to complementary medicine research which, compared to the $1 billion allocated to pharmaceutical drug research, is a very small amount. Compare it with the situation in America: in 2002 the American government allocated $14 million to complementary medicine research.

There are numerous studies on the use of complementary medicine in a wide range of conditions, including cancer. The view of our society is that the complementary medicine practitioner can play an important role, as part of a multidisciplinary team, in the management of cancer. There is no way in the world that a complementary medicine practitioner would take sole responsibility for the treatment of a person with cancer—that is totally inconceivable—but, with our training and using our medicines, we believe we can contribute in quite a significant way as part of a team.

I have been in clinical practice as a practising herbalist for 24 years. Like all practitioners, I have seen cancer patients from time to time. It is certainly not my role to be the prime practitioner—absolutely not. The people we see have undertaken chemotherapy, have adversely reacted to it and are seeking assistance. According to the information I have received from my patients over the decades, that sort of assistance is not available in the current health care system.

All complementary medicines in Australia have been scrutinised for safety and quality by the Therapeutic Goods Administration. Any notion that complementary medicines may adversely interact with pharmaceutical medications used in cancer needs to be put in perspective. In Australia every complementary medicine on the market has been assessed for safety and quality. The mechanism used by the Therapeutic Goods Administration is second to none by world standards.

Senator KNOWLES—How about the contraindications?

Mr Khoury—Safety would include contraindications as well.

Senator KNOWLES—In conjunction with other medication?

Mr Khoury—In conjunction with all pharmaceutical drugs. Where problems are detected, the Therapeutic Goods Administration is well known for its swift action in publicising such results to health care practitioners. There may be a theoretical problem associated with complementary medicines and interactions with pharmaceutical medications—in this case, with anti-cancer medications—but the reality is that we have a highly regulated system and if there are problems they have certainly not surfaced to date. Given that an estimated 60 per cent of the population are using complementary medicines, I would reasonably expect that those complications would have risen by now.

We would like to congratulate the committee for embracing the use of complementary medicine in your terms of reference. It was interesting to note that none of the submissions today mentioned the practitioners of complementary medicine. Any mention of complementary medicine was specifically about the medicines themselves, as though the practitioners do not exist. Our society has 10,000 members. Our society represents about 65 per cent of the total practitioner population. So we certainly do exist.

Senator HUMPHRIES—I commend your organisation for making a very clear distinction in its philosophy. I will summarise it by what you say on page 3 of your submission:

> The view of the Society is that complementary medicine practitioners must never engage in the primary treatment of cancer, but rather complementary medicine practitioners, using complementary medicines and practices, can contribute in a significant manner as part of a healthcare cancer management team.

That is the kind of approach which has been commended by conventional or orthodox practitioners and advocates in evidence before the committee. I do, though, wonder about the comment you made that there is no such thing as alternative medicine being practised in Australia. I think you need to qualify that by saying ‘organised alternative medicine’, by which I assume you mean there is no umbrella organisation like yours for alternative medicine. I assume you are not saying that there is no alternative medicine being practised or administered in Australia at the moment.

Mr Khoury—Listening to the comments today I gained the impression that the meaning of ‘alternative medicine’ as used in this forum meant a system whereby a person would go out and self-manage or self-treat their cancer.

Senator HUMPHRIES—I do not think so, with respect. I think it is broader than that. It is delivery of therapies or medicines which are an alternative to conventional treatment, where a person would replace conventional treatment with one of those alternative treatments. A list of them, many of them, have been referred to in evidence before the committee—and often by practitioners or people who profess to be expert in the provision of these sorts of therapies.

Mr Khoury—Certainly within our training and certainly within the society’s code of ethics there is no way that we would use our medicines as a replacement or as a substitute for pharmaceutical drugs.

Senator HUMPHRIES—I am not suggesting you would, but I am coming from the point that you said that there were no alternative therapies being administered in Australia, although you did not say that. I assume you are aware that there are many alternative practices and medicines used in Australia. We have been trying to understand what role they play within cancer treatment in Australia.

Mr Khoury—Perhaps I should clarify that by saying that there is no body of practitioners who will take cancer patients off their medication and put them on substitutes. There is no organised body of practitioners that will do that. I have come across many patients over the years who choose not to undertake chemotherapy, radiotherapy. I have come across patients who do not even want to have the lump on their breast examined. This is an individual choice. Unlike complementary medicine as represented by our society, which is organised and structured and works within the health care system, there is no body of practitioners that say: ‘Come off your chemo. I’ll give you this instead.’

Senator HUMPHRIES—That presents a problem for us in looking at this issue, because we know that many Australians are choosing to use both complementary medicines—which is a good thing, I think most people would accept—and alternative therapies or medicines, which may not be good in certain circumstances. Although the figures presented to the committee suggested that the majority of people do consider or use complementary and/or alternative medicines, we do not know exactly what the break-up between those two categories is. There is probably a significant number of people who are eschewing conventional medicine for the sake of some form of alternative medicine. How do we try to bring the people using those sorts of medicines into the tent to engage in a dialogue about what is efficacious, what is effective and what is beneficial and to examine areas where they might actually be harmful to a patient’s regime in other respects? How do we do that? You obviously do not represent that sector. But what do you suggest we might do to engage that group in some kind of dialogue?

Mr Khoury—I would suggest public education is probably the best way to go. My concern, and the concern of colleagues, is that many cancer patients are self-prescribing over the internet. To me, this is a very big problem. Firstly, they do not know what they doing; secondly, the medicines they are importing from wherever could be nothing more than placebos; thirdly, there is no regard to dosage; and fourthly, when I hear of some of the costs involved, these people are clearly being ripped off. To me, this is a major problem. The internet, with all of its positive value, is unfortunately proving to be somewhat of a demon to a class of people who, I can safely say, are rather desperate to resolve a potentially life-threatening situation. We have the personal import scheme, which is run by the Commonwealth to allow personal importation. Whilst I acknowledge the positive virtues of the PIS, perhaps a review of the scheme may be one step forward to addressing this problem to some extent.

Senator HUMPHRIES—The problem for us is that many people who use those sorts of avenues also to some extent subscribe to conspiracy theories about why they cannot access those drugs in a mainstream way within Australia. Unfortunately, you cannot necessarily educate people that those conspiracies are not true. You can try to but you probably will not succeed in all cases.

Mr Khoury—Senator, I am a victim of the conspiracy theory. Hardly a week goes by without a conspiracy theory.

Senator HUMPHRIES—There are a fair few in our line of work as well, I might say.

CHAIR—On our side of the table there are a few that go on too, don’t worry.

Senator MOORE—We have heard evidence in three states about various state government initiatives to raise the awareness of cancer and to look at the way cancer is being treated. I know that in New South Wales they now have quite a focus within the state government level, with cancer institutes and a minister in the state. Is your organisation involved in a formal way in consultations or discussions with the government on treatments?

Mr Khoury—We have not been involved. In fact, much to my embarrassment, I was not even aware of these developments. After today’s meeting I will certainly be contacting the relevant bodies. If I may make a recommendation to the committee, it would be for bodies such as Cancer Australia and others to perhaps consider the involvement of properly qualified complementary medicine practitioners as part of an overall multidisciplinary team. But certainly, we will be making contact with these bodies.

Senator MOORE—Good. Thank you.

CHAIR—Things like shark cartilage therapy are used by critics of complementary therapies. There may be something very valuable in shark cartilage and I am not making a judgment, but it is presented as shark cartilage therapy in order to draw us to a conclusion that we should dismiss this sort of stuff as quackery. Do you use shark cartilage therapy and, if you do, what are the benefits of it? We may not be able to prove these things because of the expense, and we have heard evidence about some of the difficulties in getting tests done that will actually mean anything. People may feel that they are doing something positive that is making them feel good and giving them a positive state of mind. We have heard plenty of evidence from cancer survivors that a positive state of mind, feeling that you are somewhat empowered and that you are doing something to help your illness all make a positive result better in conjunction with conventional medicine. I wandered off the track there a little bit, but tell us about shark cartilage therapy.

Mr Khoury—All I can tell you is that a book came out of America—and the Americans just love to write about the virtues of shark cartilage in cancer treatment. It was totally unreferenced and published by a publishing house that I think publishes comics. In our democratic society where people have the right to read, this is what happens. The biggest problem I see is that there is a lot of junk material coming out, especially from American, with all these ridiculous claims being made. Unfortunately, when you are desperate—when you have a loved one who is virtually dying—you tend to clutch at straws.

CHAIR—So you would view the people who promote this sort of stuff as quacks, just as more orthodox conventional Western medicine would?

Mr Khoury—People who prey on those who are vulnerable are quacks. They are charlatans and they should be kicked out of our society.

Senator MOORE—Has that happened?

Mr Khoury—We live in a democracy, fortunately.

CHAIR—You are not talking about your society as a professional body?

Mr Khoury—No.

Senator MOORE—I am sorry, I took that to mean your professional society.

Mr Khoury—No, I mean the community at large. For example, I had a cancer patient only recently—a 33-year-old with two young children—who had about two weeks to live. His neighbour told him about a Chinese remedy from Hong Kong, and he rang Hong Kong. It cost something like $1,800. Out of desperation this person actually was going to spend that sort of money. Unfortunately a lot of these charlatans or quacks are not in Australia—they are overseas—but they target Australia. Australia has a reputation as being a country with high socioeconomic standards and high living standards so we are targeted. As far as the society is concerned, we have our code of ethics and duty of care is No. 1. If you do something which is not towards the patient’s highest good then you are in trouble. We spend something like $10,000 to $15,000 a year in legal costs to get rid of people. If you do not do the right thing, you are out. If a sexual offence or a criminal offence is committed then it is referred to the police. We let the police handle that because they are much better geared towards dealing with that than we are. It is in no one’s interest to have those sorts of practitioners. They are charlatans.

Senator KNOWLES—I am a supporter of complementary medicines, I have to say, but how do you regulate the health food shops where people just wander in, have a read of what is on the shelves and say, ‘That is for me’?

Mr Khoury—In Australia, medicines are regulated by the government and complementary medicines are regarded as therapeutic goods. In America, complementary medicines are regarded as foods so therefore the standards in America and other places are a lot less stringent than our standards. So the consumer can safely assume that what they are buying is at least safe and of a certain quality.

Senator KNOWLES—That is not the point I am getting at. I am interested in where it can sometimes contraindicate, where it can have an effect on other medication a patient is taking—not necessarily cancer medication but other medications that they are taking.

Mr Khoury—Unfortunately some members of our community tend to over self-prescribe, whether they over self-prescribe complementary medicines or whether they over self-prescribe analgesics. It is a common problem. How do we address it? Again, the answer is education. If there is an adverse reaction between complementary medicines and pharmaceuticals, it would be picked up.

CHAIR—It has been put to us—by whom, I cannot remember—that high doses of vitamin C affect some of the conventional treatments.

Senator KNOWLES—Chemotherapy.

CHAIR—Yes. That has been put to this committee by conventionally qualified people. And you are saying there is no evidence of that.

Mr Khoury—Listening to the submissions today, I got the impression that there are a range of complementary medicines out there which are causing harm. What I am saying is that everything out there has undergone safety and quality testing by the regulators. If there is a problem it is picked up. Regarding the vitamin C situation which you have just cited, there is no definitive information that there is a clash. There is a lot of information on vitamin C, and a lot of it conflicts. I can assure you that if there were definitive information the Office of Complementary Medicines and the Adverse Drug Reactions Advisory Committee, ADRAC, would put out public warnings. At the very least there would be a warning on the label. What concerns me is that high profile academics and researchers are coming out with blanket statements which are not factually correct, thereby creating a false impression that these other medicines—which are called ‘complementary medicines’—are or could be a danger. If there is a danger, for heaven’s sake, where is the evidence? If there is not a danger, stop bagging them. Many people in our community rely on complementary medicines for their wellbeing. It is not just people with cancer but also people with arthritis, respiratory problems and women’s problems who rely on the them. Complementary medicines cost the government nothing: it works on a user-pays system. So why bag them? Why would you want to get people off these safe medicines, which have been tested and assessed, when it is doing them good and costing the government nothing? What is the rationale for that?

CHAIR—I think that is a question that needs to be answered. We had Dr Ian Gawler before us yesterday. Complementary medicine practitioners do what they want to do and believe they are helping, and the people who go to them believe they are being helped. So why do they need to prove to the conventional world that what they are doing helps, and why do others need to try to prove that it does not help? It is a bit confusing. Maybe there is a conspiracy theory—I do not know.

Senator MOORE—The problem with vitamin C and chemotherapy is one of the few issues that has been itemised in discussion with this committee. Could your society have some discussion and consultation on that with the college of radiographers—or whoever it is that does chemotherapy—and put out a definitive statement? It is one of the few cases we have come across, in evidence given to us, in which the use of a complementary medicine in conjunction with conventional forms of treatment is an issue.

Mr Khoury—Our society subscribes to 32 journals—we do monitor the literature. If there were a problem we would contact the Therapeutic Goods Administration with our recommendation.

Senator MOORE—I have not seen anything on it from the TGA.

Mr Khoury—And we would also contact them if there were not a problem. If we felt it was necessary or there was value in contacting another health care group, of course we would. However, we would think it proper to first go to the regulator with a recommendation. We sit on a couple of committees of the TGA, so we are quite familiar with their processes.

CHAIR—Thank you. We are very grateful for your submission and for your well-presented evidence today.

Committee adjourned at 4.34 p.m.