COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Services and treatment options for persons with cancer

MONDAY, 18 APRIL 2005

MELBOURNE

BY AUTHORITY OF THE SENATE

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Monday, 18 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, Tierney, Watson and Webber

Senators in attendance: Senators Humphries, Knowles, Lees, Marshall, 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.

BOYD TURNER, Dr Mary Josephine, Senior Medical Adviser, Programs Branch, Metropolitan Health and Aged Care Division, Department of Human Services

SCOTT, Ms Leonie Anne, Manager, Quality and Performance, Cancer Coordination Unit, Department of Human Services

SMALLWOOD, Professor Richard Alan, Chair, Ministerial Task Force for Cancer, Department of Human Services

THOMAS, Professor Robert John Shedden, Chief Medical Officer and Director, Surgical Oncology, Peter MacCallum Cancer Centre

CHAIR—The committee is continuing its inquiry into services and treatment options for persons with cancer. I welcome the witnesses. Do you have any comments to make on the capacity in which you appear?

Prof. Thomas—I also chair the clinical services working party of the Ministerial Task Force for Cancer in the Department of Human Services.

CHAIR—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. You will not be required to answer questions on the advice you may have given in the formulation of policy or to express a personal opinion on matters of policy. 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.

Prof. Smallwood—Victoria has always been proud of its cancer services and research, but it has acknowledged that a lot needs to change to do things better. So Victoria has embarked on a major reform of cancer services, and you would see that embodied in the government’s Fighting Cancer policy and in the adoption of a new cancer services framework. It is trying to achieve a number of things: better integration and coordination of care, better access to services when and where they are needed, and a more uniform approach across the state to care and services. It is acknowledged that there is variation in the care of individuals and the accessibility of services. So to get a more uniform approach and to have that approach embody best practice on the best evidence base that can be brought together, there need to be agreed standards of care for all the major tumours—and of course the standards would include multidisciplinary care, the continuity of care, excellent psychosocial care and a range of things that I am sure you will be hearing a lot about.

To help achieve these reforms, the government has established a cancer coordination unit within the Department of Human Services and it has established the Ministerial Task Force for Cancer, which first came together about 16 months ago. The ministerial task force is essentially an advisory group. It is the link between government and the cancer community outside. It has as its members people from the community, from health administration and from various professions, including social workers, nurses, others in the medical profession, researchers and clinicians. It numbers about 25. It is a very substantial and comprehensive group.

The new cancer services framework, which you would have learnt of in our submission, embodies a number of integrated cancer services. There are three metropolitan and five regional cancer services—the so-called MICS and RICS. They have been put together to try to ensure that, within a geographic area and a geographic population, there is coordination of services and to ensure that the roles that various institutions play are appropriate for the skills and resources they have. This is a notion of role designation. So there is coordination within an integrated cancer service and then appropriate referral—for example, to a tertiary centre within a metropolitan area. The notion is very skilful and appropriate networking to make sure that people have access to the level of care that they need when they need it.

The other concept that is important has been called the notion of tumour streams. What that is saying is that the 10 most important cancers are being considered as individual entities and that care from prevention right through to care at end of life is being considered in detail. Bob's committee has auspice of a group of workshops which are looking at patient management frameworks in those 10 tumour streams. There is a document which, if you have not seen it, might be worth trying to get hold of. It is a draft report of the first of the workshops on these patient management frameworks.

Two other major entities need to be considered in bringing up the standards of services and care. One is the coordination of research. The research committee of the task force has that as its major focus, and Dr Turner might enlarge on the work of the research committee. We see research into practice as an area that is very important. It is patchy at the moment, and that is true in other jurisdictions. Given the rate of change of information that is coming in through research via a whole range of new technologies—for example, the much more detailed classification of tumours—and the rate of change of information about the genetics of cancer, all of this is likely to have an application which is direct to classifying cancers and to the sorts of treatments that patients will need inside the next five to 10 years. It is going to be crucial to have a very close juxtaposition between research and services. That is bringing in not only basic science but also health services, research and clinical trials. Again, it is perceived as very important to foster clinical trials and to have more patients coming into clinical trials, given that there is fairly solid evidence that the outcomes for people in trials are, on average, better than those for people who do not make it into trials. So research is another critical area for us to bring into the thinking.

The third major area of activity, certainly of the task force, relates to health data and information. It is fair to say that the sort of data that is available now, which is good, is on the incidence of various cancers and on mortality. We do not have good data on how our interventions alter the outcomes for patients with those cancers. One of the major pieces of work of the data group of the task force is to look to how we can collect the sort of data which will allow us to say how we as a health system are travelling and how our interventions in these various cancers are helping or not helping. The NCCI minimum data set—the way we are taking that forward—is something that the data group of the task force have in hand at the moment.

So the task force itself, about 16 months on, has embarked on a major work program with three working groups: the clinical services group, which Bob chairs; the data group, chaired by

David Hill, who I think you are seeing after us; and then the research group that Paul Mitchell chairs. In specific terms, the activities that we are undertaking are in our work plan, which I gather you have seen. It tells you what we have been up to to date and what our plans are for 2005 and 2006. Perhaps I should leave it at that, other than to say that this is a major and complex exercise in the reform of cancer services and I think the work from the task force's point of view—in our three or four years of existence—will be to set all of this in train, but there will be a lot of work to do beyond the life of this task force.

CHAIR—Thank you. You talked about the importance of clinical trials. I was wondering what involvement the department actually has in the clinical trials in terms of funding or infrastructure support.

Dr Boyd Turner—The Department of Innovation, Industry and Regional Development has a comprehensive infrastructure support program for the biomedical research institutes in Victoria. These include the Walter and Eliza Hall Institute of Medical Research, the Ludwig Institute for Cancer Research and others that are major nationally and internationally recognised research institutes. They certainly have a considerable investment in research into cancer. The Department of Human Services also provides funding to the Cancer Council Victoria for data managers to support rural patients' access to clinical trials. So they are the main areas where government provides infrastructure support for clinical trials.

CHAIR—I am also interested to know whether you encourage hospital based cancer registries. Are they part of your data collection program?

Dr Boyd Turner—A number of the hospitals do have databases for patients with cancer. It is certainly something that has been picked up by the data working group mentioned by Professor Smallwood—looking at how the cancer patient data that is kept by hospitals can be more effectively integrated with the information kept by the Cancer Council for the state-wide Cancer Registry.

Prof. Smallwood—I would just add that the National Cancer Control Initiative's minimum data set is the way that we hope to capture across the board the sort of information that will say how what is being done actually impacts on the course of the cancer of a particular patient or group of patients, and their outcomes. I think that the various registries that are set up have their value, but they do not necessarily give you a sense of how things are tracking across the board.

CHAIR—How do you manage it in the private sector?

Prof. Smallwood—That is something that has to be worked through. In all of this, bringing the private sector into the thinking and ensuring that its data collection and cancer care meet the standards that are being set are things that we have to give very careful thought to. I am not sure that we have a solution which would reassure that this was all set fair.

CHAIR—Thank you.

Senator KNOWLES—I am a little bit perplexed about all of this. We have only had one hearing in Perth thus far. It was in Perth that we counted up some 137 organisations doing the hard yards for people with cancer. But there just does not seem to me, as a lay person, any pulling together of the data so it can be of benefit to those who are yet to be diagnosed—in other words, prevention—those who have recently been diagnosed and those who are long-term sufferers. Is the task force able to make any recommendation whereby there can be some national information put together that is usable across the board, as opposed to usable only in a particular setting?

Prof. Smallwood—I am not sure that I can answer that question exactly as you have asked it. There are a couple of points I wish to make. What we are setting up in the patient management frameworks and what we are setting up in collecting the National Cancer Control Initiative's minimum data set is our attempt to do exactly what you are asking. I know New South Wales is also involved. As a concept, what we are doing aligns well with the national service improvement frameworks that the Commonwealth has put together. We are keen to learn what Cancer Australia is going to see as its major initiatives. There is discussion between us and New South Wales. There is, I hope, going to be very useful interaction with the Commonwealth. But it is not something that can be turned around quickly, in my judgment. But Professor David Hill is going to be talking with you later. He is probably someone who could give you some more explicit and detailed thinking on data.

Senator KNOWLES—What is worrying me is that there is a whole lot of money being thrown at a whole lot of areas: we have the task force getting money, we have New South Wales getting money and we have the various support groups getting money. But at the end of the day we do not seem to have a coordinated approach for someone who, say, is diagnosed today with a specific cancer. We do not know the best way in which to deal with that. I am just wondering why it has been beyond the wit of a smart country like Australia to have pulled all that together a long time ago—that here we are now, talking around in circles.

Prof. Smallwood—The way it could reasonably be looked at, if we just take Victoria for the moment, is that it is not so much that we do not know what should be done; it is actually getting it to happen. That is really what this new framework is all about. It will set standards that everyone understands and can adhere to.

Senator KNOWLES—Can I interrupt there. Once you have set those standards, though, is there a possibility that those standards will be adopted nation wide, as a consequence of your good work, as opposed to people sawing sawdust in Western Australia and Queensland and reinventing the wheel?

Prof. Smallwood—I think the answer is yes. I do not think that this task force is in a position to solve the usual problems of a federation but the work that we have done initially in liaising with New South Wales is a good start. Our links to those in the Commonwealth who have been watching what we are doing and who are interested to make sure that the Commonwealth is in tune at least with the major moves that are going on in New South Wales and Victoria are also good. I think that is an excellent start. If those three entities can be seen to be getting it right, I would have thought that would be a very powerful stimulus to spread across the country.

Senator KNOWLES—How long a time frame do we have to allocate to expect to get it right where the perception is that it has been achieved in the correct fashion whereby it would then be adopted? Are we going to have a situation where there is a long time frame and, meanwhile, everyone else is going off and doing their own frolicking and, in essence, repeating the work that you have done?

Prof. Smallwood—I will start with Victoria. I would hope that in Victoria there would be a perceptible and evident change for the better in the coordination and the general level of practice and the way the whole system is planning to work. It will be evident and really off and running in the next three to five years, let us say. I do not think that is unreasonably optimistic. You might check with one or two of the others. While that is happening, I would hope that our processes in New South Wales are well aligned—and we have spoken with Jim Bishop at length. There are a number of areas of collaboration that we can see. It does also depend on national leadership from the Australian government. There is a lot that could be done if the Australian government and the two major jurisdictions are working alongside each other. That would be my thinking on this business of trying to get it right nationally.

Senator KNOWLES—Is there anything that you could suggest to the committee that could be done now to ensure that that outcome is achieved?

Prof. Smallwood—I hesitate to give direction to the committee. I think whatever you can do to work with and assist the Commonwealth authorities to align with at least the two major jurisdictions that are putting enormous thought, energy and resources into cancer services would be much appreciated.

Senator KNOWLES—I suppose I am being fairly direct, and quite deliberately so. I know from your previously lofty position within the Commonwealth department that you might be able to give us a bit of a hint as to where you think we should be going. I know you are disinclined to point the committee in a specific direction, but I ask you to kindly put aside your disinclination for a moment and just say, ‘Maybe these are the shortcomings that we’re hitting at the moment; these are the barriers that are obstructing our progress,’ and give us a bit of an indication about how best we could go about it.

Prof. Smallwood—I would like to give that further thought. A lot of the barriers are ones that we are going to be tackling intrastate. The way the Commonwealth can often be most helpful is to understand rather better than sometimes they do the needs of the front-line in actually bringing services to people rather than high-level, broad policy thinking—to actually come down and see what the barriers are here in Victoria or in New South Wales and where the resources are needed. The astute application of Commonwealth resources after detailed discussion with jurisdictions, particularly Victoria and New South Wales, might be an excellent step forward.

I should say that the Commonwealth’s national service improvement frameworks do show that the thinking is along the lines of what we are grappling with. So the next step for the Commonwealth I think is resources, and how the Commonwealth chooses to work with its resources in health. But it is also getting a much closer feel for the front-line with the Commonwealth. In the first instance, it is working with jurisdictional groups—maybe it is Victoria, New South Wales and the Commonwealth—to nut out where the Commonwealth can best intervene. It really is difficult to say, from my point of view, that all the Commonwealth has to do is that and we are off and running. There may be some other views about it but I think the possibility is there. The thinking is along the same lines but it is then a next step in a practical sense.

Senator KNOWLES—I will ask one more question about the 10 major tumour streams. Is that your baby, Professor Thomas?

Prof. Thomas—I think so, yes.

Senator KNOWLES—I think Professor Smallwood was referring to part of that work—the patient management framework—stretching from prevention to end of life. Could you please explain the prevention aspect of it? I can understand diagnosis to the end but I am just interested in the prediagnosis stage.

Prof. Thomas—We are producing—and we will have this, we believe, in place by the end of this year—a description of an optimal patient journey. We have defined the nine critical points along the patient's journey with cancer. You indicated the situation where a patient might develop cancer and embark on something that goes off into the ether somewhere. If we are concerned about the patient journey then we have to be concerned about the processes which occur right at the start of the patient's journey, which include prevention and, of course, screening. I suppose screening is the easier element to put into the patient journey and prevention is a bit harder. Prevention implies a lot of issues that affect the whole community and health policy. That is perhaps a bit beyond the scope of quite a specific tool, which the patient management framework will be, to guide the patient through a program of treatment and offer that patient some information and support as they go through their journey. Prevention is included, in a way, to avoid it being excluded in the process. In all these areas you have an opportunity to get close to both communities and on-the-ground health systems. Anywhere you can put a prevention message into that program is very helpful.

CHAIR—Professor Smallwood, you mentioned the national service improvement framework. Do I take it from what you have said that Victoria has adopted that framework?

Prof. Smallwood—Not as such, but, in thinking through the patient management frameworks, they look awfully similar. It has not been a deliberate case of: 'There are national service improvement frameworks. Now we must set our patient frameworks according to the national service ones.' The process and the thinking has been the same: where are the critical intervention points along the path that the patient follows and what is needed at those points for that person? That is what the national service improvement frameworks are focused on, and that aligns very happily with our patient management frameworks. I guess our frameworks were started with one eye on the NSIFCs, but I think it turns out that they are very much the same entity.

Senator LEES—I refer to page 2 of your submission, where you talk about issues surrounding less conventional and complementary cancer treatments. You go on to say that the current Victorian cancer reforms do not directly address these issues. Maybe regarding research with Dr Turner as well, could you look at the ways you are addressing the issues of patient well-being and particularly in assisting them and their families to cope with what they are now facing?

Prof. Smallwood—Again, I might ask Bob to elaborate in terms of patient services. One of the approaches has been to set up a workshop, which is coming up on 2 May, on psychosocial and supportive care. It is an area which, we are very aware, has in many instances been lacking or less than optimal. It is a critically important area. It is not just the science of the right technical intervention at the right time. It is clear that, for anyone who has to deal with cancer—the carers and the patients themselves—it is a huge area for improvement and it is very much a focus of the work of the task force. Bob might like to elaborate.

Prof. Thomas—Professor Smallwood alluded to a workshop that is coming up very soon. We are having a major workshop looking at the impact of supportive care and palliative care on the ‘patient journey’ program that I have talked about before. The second point I should make is that both the original patient framework processes and this current one are very much consumer driven. Within what we are calling the Supportive Care Workshop, the issue of complementary therapies will be raised, I am sure.

Senator LEES—Who is coming along to this particular workshop?

Senator MOORE—Is it by invitation?

Senator LEES—Which groups have you invited?

Prof. Smallwood—It is restricted in terms of numbers to make it workable, but it is also fairly open. As far as possible, everybody who might have an interest in the process is coming to that meeting. The way it is being worked is that there will be about 10 or 12 people in each section. They will be looking at it slightly differently from the other patient management frameworks. They will be looking at each of the sections and deciding, for example, at the time of diagnosis, what support mechanisms are required for a patient who has been diagnosed with cancer or, alternatively, at the time of recurrence of disease or at the end of life, what support systems are required for that person. Everybody from conventional medicine to allied health to pharmacy to those who offer spiritual support is coming to that workshop.

Senator LEES—Is the Victorian government looking at supporting, encouraging or in any way coordinating research into the area of what effect this has? Looking through our submissions, a lot of people are very thankful that they are able to access some of the alternatives, particularly those that reduce stress for them and their families. What is happening in Victoria on the research front?

Dr Boyd Turner—Another event we are having is a psychosocial research seminar. That will cover the range of personal support, as Professor Thomas has referred to, for the patient care component. We see that the research into supportive and psychosocial care is perhaps less well developed or is something we know less about than the scientific aspects of cancer services and care. We are planning to have that in July this year. That will hopefully be attended by some international researchers. We are hoping that Professor David Kissane, who used to work in Melbourne and is now working at the Sloane-Kettering Institute in New York, will be able to attend and tell us about not only his own work here but also work that is going on in the US. We are hoping to get people from the UK as well so that we get an understanding of what is going on internationally. Of course, we will also be asking people nationally to attend.

The seminar will also include consumers. They will play a major part in planning for it so that we ensure to the best of our abilities that the questions that they are keen to see considered get addressed. The target audience for the seminar will be researchers, service providers, policymakers, consumers et cetera, so it will be broad based. The outcomes are to ascertain what is happening nationally and internationally in psychosocial supportive care research to inform how we could best support that in the future.

Senator LEES—Are you working in any way with other states and looking at what they have already done or are planning to do in this area?

Dr Boyd Turner—Certainly we will be looking to researchers from other states to help us plan this seminar. In terms of working with other states, as Professor Smallwood has alluded to, we have spoken with Professor Jim Bishop from the New South Wales Cancer Institute and are looking at mechanisms or joint projects that we could undertake. I guess we are yet to specify psychosocial research and supportive care as an area, but it is certainly an area where there is work going on in New South Wales. We would be looking for opportunities for joint work—firstly, so that we maximise our capacity and, secondly, so that we do not duplicate.

Senator LEES—You are looking at July, so I realise not all the details are finalised at the moment. What particular areas have you got planned at the moment? For example, will diet and specific programs that try to assist people with cancer to address stress be areas that you will be looking at?

Dr Boyd Turner—As you have suggested, we have not got down to that degree of detail. But certainly we want to look at the spectrum of people, from those who do not need a lot of counselling but perhaps need some supportive care in terms of spiritual care or whatever to people who suffer major stress and distress from cancer. They clearly require quite a different type of intervention. We will be aiming to look at the breadth and depth of types of support that could be given to people with cancer. I need to highlight that we are planning to focus on the psychosocial component, so at this point we have not considered looking at things like diet.

Senator HUMPHRIES—There was reference earlier to the 10 major tumour streams. I assume these are the 10 most common types of tumours that one would encounter clinically. Do you have a list of those that we could have?

Prof. Thomas—Yes.

Senator HUMPHRIES—Thank you. I have heard it said that cancer is a catchall phrase, which really conceals the fact that there are 80 or more quite different diseases which have quite different manifestations, treatment regimes and so on. Is there a dramatic problem in administering a system, like the one you are setting up at the moment, educating practitioners about that range of variations in cancer?

Prof. Thomas—To an extent, yes. Each tumour stream is basically organ or system based. Take urology, for example: there are obviously two entirely different sorts of cancers. There is testicular cancer, which we are concerned about, and there is prostate cancer—two very common and important tumours. And there are many other cancers. So there is a limit to how far you can expand a commonality of concept into multiple different cancers because, as you rightly implied, they are all managed in a slightly different way. Essentially, we have gone for the issue of the significance and frequency of these diseases in the community, so we are making sure we are covering the common and important cancers as affect us widely in the community. Then we will deal with another group, probably by lumping them into a group of rarer cancers which have to be managed much more individually.

Senator HUMPHRIES—Professor Smallwood, you mentioned that there are enormous resources going into the reforms happening in Victoria at the moment. What kind of resources? How much extra spending is going on in Victoria at the moment as a result of these changes?

Prof. Smallwood—I will ask Dr Turner to give you the numbers. Looking at the overall resources going into cancer now is one thing; the resourcing of the task force and its workers is something else. The setting up of the integrated cancer services is something else again. I think the task force is doing a lot of pro bono work on a modest budget. The overall resource to cancers is reasonably substantial, but perhaps Dr Turner will give you the numbers.

Dr Boyd Turner—I will defer to my colleague Leonie Scott to give you the numbers for the task force and the cancer coordination unit. I will supplement with more about some research.

Ms Scott—The overall budget that is spent on cancer is over $350 million in direct care. In addition to that, in 2003, the government made a commitment to the cancer service reforms and allocated $20 million over four years plus $4 million for the work of the task force plus $4 million specifically around paediatric cancer services.

Dr Boyd Turner—As indicated previously, considerable infrastructure support goes to biomedical research institutes. If my memory serves correctly, that is in the order of $23 million annually. Additionally, as of last Friday, the Department of Industry, Innovation and Regional Development announced $7 million for the development of a statewide tissue-banking initiative, which will include both the public and private sectors. That will enable cancer tissues to be collected in a systematic way with common procedures across lots of sites in Victoria, which will inform research. The government also set up the Victorian Breast Cancer Research Consortium. That is funded to the tune of $3 million annually. Additionally, money is provided to the Cancer Council, which Professor Hill will talk about, and also to various other initiatives such as the Victorian Cytology Service and BreastScreen Victoria. The government has also provided funding—I do not know the quantum of this—for a broad based prevention program which includes dietary elements known to prevent cancer or to assist with the prevention of cancer.

Senator HUMPHRIES—I have not seen recently in other parts of Australia any cancer education programs being run. I recall a few years ago there was a program around breast examination for women, but nothing very recently. Is there anything being run in Victoria at the moment in the way of preventative education?

Dr Boyd Turner—The Cancer Council Victoria runs comprehensive education programs, and it would be more appropriate for Professor Hill to discuss that when you meet him in the next session.

Senator HUMPHRIES—I was thinking more of things like public education advertisements on TV, in newspapers or whatever.

Dr Boyd Turner—The Cancer Council runs public education for SunSmart et cetera.

Senator MOORE—Through this inquiry and through the submissions, which I am sure you have pored over, lots of terms are thrown around. It is really difficult sometimes to get a clear focus on whether people are using the same kind of terminology. I am interested in the focus on the multidisciplined approach to service and, through the papers you have put out, there is a great concentration on the term ‘integrated approach’ to cancer treatment. I am trying to find out whether those two things are the same, similar or whether they are partially the same. It would be useful at this stage in the inquiry to have a definition of those two things. You can take it on notice and send us something. I think they are similar, but they are confused and people throw them around.

Prof. Thomas—I can say that there are even more terms than that.

Senator MOORE—Yes. I have focused on those two.

Prof. Thomas—We talk about multimodality treatment planning, which is a critical issue for me in the early management of the patient with cancer. There is a growing almost science, discipline or research effort going on in this area, and Leonie has some information about that.

Ms Scott—When we talk about integrated cancer services, we are looking at integration across disciplines, settings and time. For coordination and integration of patients within the health care system you need those three elements, and that is what an integrated cancer service is. We are looking at settings that are both outpatients and in-patients. We are looking at the care that they receive initially and at the end and how that can be more integrated so that the flow of information is quite clear and at no point in time does the patient miss out on the type of care that they need across that type of continuum. In contrast to that, we consider the multidisciplinary approach to care to be more around the multiple disciplines that are necessarily involved in the care planning for a patient. In particular, we know that the research shows that if there is multidisciplinary care planning initially for patients with cancer those patients are going to have better outcomes. From our point of view, that is a priority. Multidisciplinary care by its nature because you are getting disciplines together will facilitate more integration, but integration is a much broader term that goes across time, disciplines, and locations.

Senator MOORE—But there is general acceptance that the multidisciplinary approach is the way to go.

Ms Scott—Yes. There is evidence that it decreases the morbidity in people in terms of their psychosocial morbidity. There is evidence around better outcomes for them and there is evidence around making good decisions—better decisions when they are made in a multidisciplinary arena than individually by clinicians. There is good evidence, and the NBCC has done some very good work around multidisciplinary care. That is a priority for the cancer services reform, and we have got a two-year project around multidisciplinary care that we are going to be rolling out across the state.

Senator MOORE—Another recommendation or hope that is coming out in some of the submissions is that there will be some formal accreditation of services that have reached a certain standard. I am interested in whether Victoria has looked at that. The theme of the information that we have received is very much about setting standards and having equity across the state so that, as a consumer, you could go somewhere and find out that X service has been accredited as one that would provide certain treatments. Has the Victorian government considered that process?

Ms Scott—The Cancer Services Framework actually talks about accreditation and role designation of services and that role designation will be based on the capacity to deliver services for particular tumour streams. The work that we are doing around the patient management frameworks is preliminary work to determine the standards and capacities of services needed to provide care to a particular level. Credentialing is potentially involved in that, and that has already been raised through the patient management framework workshops—not in terms of credentialing but in terms of people’s experience and skills to undertake particular types of surgery. We are embarking on a literature review at the moment to look at the evidence around that, particularly related to high-volume type surgery, in terms of better outcomes. That will certainly inform us but our long-term plan is to have some form of accreditation process.

Senator MOORE—State based?

Ms Scott—Yes, state based.

Senator MOORE—But on agreed criteria?

Ms Scott—On the agreed criteria, which the patient management framework will be the start of.

Senator MOORE—I know there are other people who want to talk on that.

Dr Boyd Turner—We have been actively involved in a process that is being carried out by the Australian Cancer Network to look at accreditation. A number of Victorians have been actively involved in that work. Secondly, as part of the Radiation Oncology Reform Implementation Committee there is a quality working party. It is a jurisdictional committee that is run by the Australian government. I chair the quality working party. One of the key projects of the quality working party is to look at a quality program for radiation oncology. Clearly, that will have national application. One of the key points I would like to make is that we are looking at the Victorian work in the context of other national work that is occurring as well.

Senator MOORE—My reading of the workforce issues is that, of the three working groups that have been identified, it would be your work group, Professor Thomas, that would be looking at workforce issues. Is that right?

Prof. Thomas—They will become apparent as we work through our program, yes.

Senator MOORE—I come from Queensland, and they are looking at the same stuff. One of the things the paper mentions is that radiography services is an area that has to be looked at. In the submissions we have received from across the country, specialist services, radiography and a whole range of things—and we have a submission here about social workers—have been mentioned. What is the plan for looking at developing people studying the various disciplines? Your program says that you are establishing the gaps and that will come out. Whose responsibility is it to ensure that people who are looking at working will be able to identify areas that are needed, and what support will be given to people to choose working in various areas where there is a need?

Ms Scott—The department has a whole unit which looks at workforce planning.

Senator MOORE—Is that human services?

Ms Scott—Yes, the Department of Human Services. There is a range of priority areas within that, and obviously cancer is one of them—particularly related to radiotherapy. In terms of the work that will be done, although we will identify the gaps in the workforce, we will need to take that work to the workforce planning unit and look at how it fits within the overall plan for the state with respect to incentives in particular areas.

Dr Boyd Turner—Specifically, in terms of radiation oncology, the government has provided funding to support radiation therapists. As you may or may not be aware, there was a shortage, which has been caught up with over recent years.

Senator MOORE—Is that through the state government?

Dr Boyd Turner—Yes. The Victorian state government provided funding for educators and also to assist with some overseas recruitment of radiation therapists. Also, once again Victoria is contributing to the work of the Australian Health Workforce Officials Committee, AHWOC. They are undertaking work force planning for the radiation oncology work force. So that is the medical and non-medical work force for radiation oncology. That work is being done now to inform where to go in terms of radiation oncology.

Also, the work force working group of RORIC has looked at a number of initiatives to assist the Australian government to spend the money from the cancer budget measure of $72.7 million, which I think was in 2002-03, and in the more recent Strengthening Cancer Care coalition policy for the election late last year.

Senator MOORE—So you are feeding into that national program from a state level.

Dr Boyd Turner—Correct. The only other thing that I would add is that one of the key areas that we are seeking to look at in Victoria is clinician scientists. Clearly, we need to build human capital in this area so that we have clinicians for whom research is more embedded into their way of practice and their way of thinking so that we can implement and support research driven services.

CHAIR—Ms Scott, given your very clear support for the multidisciplinary care approach, can you comment on this. It has been put to me that it is there in name only, and the people at the top of the food chain—the oncologists—do not really support it. Are the medical colleges proactive enough, in your view, in pushing the multidisciplinary approach?

Ms Scott—I cannot really comment on the colleges, but, prior to the cancer services reforms, we undertook redevelopment strategy around breast services. That was where we found that there was a gap in multidisciplinary care and we did a lot of work facilitating that. Our experience was that there was some resistance initially from medical practitioners towards that approach but, once they participated in the approach, they saw real value in it for themselves personally and professionally and for their patients. Then they became great advocates and supporters of it. In the patient management framework workshop, with nine tumour streams we had 120 clinicians, medical oncologists, radiation oncologists, surgeons and nurses all sitting together in a room, they all said that multidisciplinary care was one of their areas of priority. I believe that is because they had seen the value of all the work that had been done around breast cancer. They considered that that was best practice and they now want it for all patients across all the tumour streams. In this state, there is very good support for multidisciplinary care. Yes, there still may be some resistance in some areas, but my experience so far of discussing it with clinicians is that there is very strong support for multidisciplinary care.

Prof. Smallwood—It is one of the areas where the private system needs to be thought about carefully in bringing multidisciplinary care on board. My perception would be that it is happening effectively in various areas in the public system. There is still a way to go. I suspect that it will take more time to ensure that public and private systems are integrated in their thinking. As so many cancer patients move between the two systems, I think it will take some working through but the general sense that, yes, this is the way to go has filtered out.

CHAIR—Thank you for your presentation and your submission today.

[10.00 a.m.]

BELL, Professor Richard, Senior Clinical Consultant, Cancer Council Victoria

HILL, Professor David John, Director and Chief Executive Officer, Cancer Council Victoria

KELLY, Ms Karen Mary, Private capacity

SNYDER, Dr Raymond David, Chairman, Victorian Cooperative Oncology Group, Cancer Council Victoria

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

Ms Kelly—I am here as a cancer patient who is taking part in clinical trials.

Prof. Hill—I am the director of cancer services in Geelong. I am also the chairman of the board of BreastScreen Victoria. I am here in my capacity as senior clinical adviser to the Cancer Council.

CHAIR—Information on parliamentary privilege and the protection of witnesses in 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.

Prof. Hill—Thank you very much for the opportunity to be here. The Cancer Council Victoria is of course a member organisation of the Cancer Council Australia, which has provided you with a lengthy submission. We have been involved in the creation of that submission and of course fully support it going to you. We plan to bring out a few additional points, if we may, and pick up on some of the terms of reference that we understand you are interested in.

You have heard from the Department of Human Services and task force representatives a moment ago. The Cancer Council Victoria was mentioned several times. We are an active player in the cancer environment in this state and the organisation has existed since 1935. I thought it would be valuable to profile our organisation very briefly for you to give you an idea of our scale and range of activities, and then perhaps move to some of the particular things that the inquiry is interested in.

A PowerPoint presentation was then given—

Prof. Hill—We are incorporated in an act of parliament, the Cancer Act. We actually function more as a charity though. We do not have any by-right funding streams from government, either state or federal. We essentially think of ourselves as operating as a charity which attracts government funds. I am sorry for the misprint on the slide; that should be ‘grants and contracts’ not ‘events and contracts’. You can see that in our budget of about $40 million or so per annum we are raising more than half of that from the public of Victoria and we are raising a fair proportion through grants and contracts. Grants can be competitive grants from the usual funding streams.

We are an interesting organisation in that we are both a funding organisation for cancer research and a grant-getting organisation. We have two in-house research groups in epidemiology and behavioural/psychosocial aspects of cancer. They are funded both from our resources and from the winning of contracts and grants from the National Health and Medical Research Council or the US National Institutes of Health. We are actually an accredited medical research institute within NHMRC. The slide shows the breakdown of proportions spent in different areas.

We have programs. Senator Humphries mentioned health, education and prevention programs. You can see that our programs are split: 66 per cent for health promotion—that is the QUIT program, SunSmart promotion pack, cancer screening and cancer education more generally—and then about a third for information and support—for instance, our helpline, which I will come to in a moment.

Senator KNOWLES—Professor Hill, could you just expand on what ‘et cetera’ covers?

Prof. Hill—‘Et cetera’ would cover general information about cancer, some of the cancers that were not listed there, bowel cancer screening—this is something that is now coming onto the agenda much more—diet and nutrition and physical exercise, which are not so large in our repertoire at the moment but are becoming so. So we would see ourselves as a very general resource for cancer information for interested people.

I anticipated and I have certainly picked up today that one of the interests of this committee is in psychosocial programs, so I will talk a bit about what we are doing there. We have a computerised database—that is not people’s names; it is in fact information and resources—which our oncology nurses who man the helpline can look up as a person rings in. Callers can ring in—anonymously, if they choose, and usually they do unless they want information posted out to them—and speak to a trained oncology nurse. So when the call comes in the nurse has a computer which can get into all sorts of information, such as the cancer support group nearest to where they live, other sources of information and so on. Per annum the helpline is now getting about 12,500 calls from patients and about 6,300 from carers and families of patients and about 400 calls from people who want the interpreter service made available so they can make their inquiry in a language other than English.

I thought you might be interested in some of the topics that callers commonly ask to be dealt with. About 80 per cent of them talk about management and treatment; 45 per cent, diagnosis; 30 per cent, side-effects; 45 five per cent are interested in psychological and emotional support issues and 35 per cent are interested in recurrence and advancement of the disease. We have very detailed statistics available in a paper that has just been published internationally which shows six years aggregate experience of the helpline and which I could make available to the committee if desired.

Senator KNOWLES—That would be very helpful, thank you.

Prof. Hill—Okay. The other programs here are Cancer Connect, a program which connects by telephone people who have had cancer two or more years ago and have been trained by the Cancer Council in supportive techniques, listening and so forth. A person can call the helpline and very often they will be offered a connection with another person who is a Cancer Connect volunteer for us. They all work in a voluntary capacity. Living with Cancer is a group support program, so people can come together. We have welfare grants; we can actually make money available to people to plug holes in a particular situation. We would say that is flexible and enables us to act decisively with a minimum of red tape.

A particularly interesting program we have in Victoria is the Cancer Clinicians Communication Program. Patients often say, and doctors themselves admit, that doctors have not been trained in communication skills and are not necessarily very good at communication. They are trainable skills. So we now have this program in Victoria which began with a kind of stone in the pond technique, by getting very senior clinicians to come along and be trained in clinical communication skills. They then are not only champions of the training but become trainers of other clinicians in their work environment. That has been taking off in the last 12 months or so and is, I think, one of our flagship programs.

In the clinical domain, we would argue that we are an organisation that is extremely well connected. Dr Snyder is going to talk in a moment about the Victorian Cooperative Oncology Group. That is a network of clinicians and consumers which comes under the auspices of the Cancer Council. It comprises nearly 350 medical clinicians, 85 non-medical clinicians, 13 consumers and the 18 sites where we support clinical research—we have data managers funded in 18 sites around Victoria.

At the moment, there are about 7,000 patients in trials in Victoria. The work that is done is funded mainly by Cancer Council money but also by the Department of Human Services' contribution to support clinical trials in rural and regional areas. We are putting in a bit over $0.5 million and the department is putting in about $170,000. If I may, I will be coming back with the slides in a moment. Ms Kelly will now speak to the slide we have up there and give you the perspective that the patient has on participation in clinical trials.

Ms Kelly—I was diagnosed in 2003. I live in Geelong. The doctor set up a specialist for me to see, so I went to see a general surgeon in Geelong. He said that they would do surgery in a couple of day's time. Things were happening very fast and I really needed to take a step back, which I did. I rang around some friends to find out what alternatives there were and whether they knew anyone in Melbourne. I was then given the name of a surgeon in Melbourne. There was a wait of about 10 days, I suppose and then I went to see him. He came with good recommendations. I was pleased to see him and spent about an hour or so talking to him. I decided then that the first diagnosis and treatment program was probably what would have to happen anyway. But he then sent me back to Geelong and I had a meeting that day with Professor Richard Bell.

Out of talking with him on that day I discovered that there was a clinical trial running which I fitted the criteria for. I must admit that at the time I was really not thinking about clinical trials. When it came up at the end of an hour of discussion I thought about it and it kind of made sense to me. It was really the order of the treatment program that made me choose it. People have surgery, then follow that up with chemotherapy. They then have radiotherapy and perhaps hormone treatment. But I could have it another way with chemotherapy first. The reasons he gave me actually made some sense.

I did not decide then and there; I had some time, because I did not really remember all of what he had said. There was a nurse who was attached to the clinical trials. Her name was Ann. I went to see her and speak with her after I had time to think it through. It appealed to me. We have three daughters so going on a clinical trial seemed a good way to contribute something for future research so that in 10 or 20 years time people might not have to be in the same position. I have subsequently gone on another clinical trial, but that was my entrance into clinical trials.

How was it presented? It certainly was not presented as the first thing but was presented after quite a long discussion about the state of play. I certainly did not feel any pressure. In fact, the first person I saw made me feel quite pressured. Things were going to happen and I was going to actually lose control of the process. Being on the clinical trial gave me some control in a way. Who decides? I suppose it is a two-way thing, because a person has to actually meet the criteria. The clinical trial has to pertain to the individual. There is decision in that way but there is also plenty of decision from the individual.

CHAIR—Has anyone ever put to you an opposing view, that you should not go on the trial?

Ms Kelly—I asked about the possible side-effects and things like that, so I knew that was probably a stance—that I need not go on the trial, not that I should not—but I would still have treatment. I always felt that was an option.

Senator KNOWLES—So you did not have surgery in the end?

Ms Kelly—Yes, I did, but I had chemotherapy first, followed by surgery.

Prof. Hill—The psychosocial research that is done at the Cancer Council comes under several headings. One absolutely vital area—and I would be interested to see whether the hearing will pick up on this—is patient needs assessment. We have done one study so far in which we tried to contact two samples of patients—one from a public hospital and one from a private hospital—sourcing the information about who to contact from the cancer registry, so it was a fully enumerated sample base, and interviewing them about their unmet needs for whatever. They were interviewed by telephone soon after their diagnosis, as soon as we could reach them.

What is absolutely striking about the outcome of that research is that the most commonly mentioned unmet need is for information. The top seven of the unmet needs, from a list of about 30 or so in the questionnaire, were for information and about 20 per cent of people had unmet information needs. In comparison with the bottom end of unmet needs, the care given by the hospital staff was rarely mentioned by people as an unmet need, or even the psychological and daily living needs. I think a very big message from that is that there is still a lot of work to be done in providing cancer patients with the information that they need.

Senator LEES—Do you have a copy of that survey so we can look at some of the issues that patients are raising?

Prof. Hill—Yes, absolutely. I have a paper here which I will leave. The finding about unmet information needs has been found by other people working in this area. We do caller surveys on the cancer information and support line. That is really a quality control measure. I will spend a moment on out-call studies. Although we have large numbers of patients calling the cancer help line, it is still a minority of patients. When we do caller surveys, services like that—and ours is one of them—get rave reviews. The people who have called in have said, ‘That was fantastic. If only I’d known earlier. What a shame I didn’t ring earlier.’ All of this kind of information comes back, and yet it is not happening.

We have a controlled study funded by the National Health and Medical Research Council in which men—because men are underrepresented, so we thought we would go where it might be more difficult—are proactively referred to the service. This means that when they first meet their clinician, if they meet the inclusion criteria, they are told, ‘Unless you disagree for some reason and opt out, I would like to give the service your telephone number and they will call you within a week.’ This is proactive referral. We are getting a very high percentage of people accepting that offer—80 per cent or so. We do not know what the results of that study will be. We are measuring psychological outcomes, not disease outcomes, of course, and people will be followed up for a year. The volunteer support study is another NHMRC funded one in which we are looking at using volunteers to connect up with newly diagnosed patients, doing a needs assessment and then helping refer them to where those needs might be met.

Regarding the whole area of complementary support, I think I have shown that, if you define complementary therapy as psychosocial support, we are involved in it. Building knowledge in that area is the same as building knowledge in any area. You have to do a study, whether it be an experiment or some other type of research design, get findings that other people can replicate and make a case that (a) leads to (b)—cause leads to effect. You have to use valid research methods, which are methods that have been developed by methodologists. They cover a whole range of different disciplines, but they have to be used. Then you have to get data which you can interpret that makes theoretical sense and postulate plausible pathways that fit with the data you have generated.

Finally, with regard to my slides, you have asked about barriers to research on less conventional complementary treatments. I am not sure that there are really systematic barriers to this. You can get funded through the conventional systems to do research, but I think that some of the difficulties arise because proponents do not really engage with the ways in which research can be funded in a way that is going to give them a chance of succeeding. Sometimes I think there is an unwillingness or inability to use valid research methods, and studies will not get funded by scientists on panels who look at a research design and say, ‘The question they are postulating cannot be answered with this study design.’ It will not get funded.

Sometimes grant applications—and I have seen some of these; I am involved in assessing research as well as doing it—just fail to take account of existing knowledge. There is nothing worse for a possibly very good idea from somebody who wants to test it than, in the first paragraph of a grant application, finding a statement which is simply not true because there is knowledge that exists that this person is unaware of. I suppose inevitably some people are a little trepidatious about having their therapy put to the test. Those comments are speculative. They are based on some experience that I have had and knowledge I have gained in talking to others.

Senator LEES—We have had evidence, and as you read through the submissions it seems, that there are barriers. Some of them revolve around actual patient response, in that if you are, for example, looking at a complementary treatment such as diet you might find that patients themselves have taken off and decided that they will take vitamins or do something else that, at the end of the day, might actually have quite a bearing on whether diet had any impact. And there are other treatments, from massage on, where there are so many variables that if you try and home in on one area and restrict or not consider the others you end up with research that people are still not going to take in any way as something worth while.

Prof. Hill—I think in principle and practice, if you try hard enough it is possible to design a study that isolates the effect of one variable and controls everything else—everything else is the same—and see whether it makes any difference. I think in principle it can be done. I absolutely agree that, for much of the work that is out there claiming effects for full complementary and alternative therapies, if there was a research design at all it was a very flawed one.

Senator LEES—Does the Cancer Council get involved in supporting people to do the research? You said that you are involved in sorting out who should do research and who should get funded. Does the Cancer Council play a role by saying: ‘We really do need this looked at. Here are three people in the area. We will get them together and support them as they set up their methodology’?

Prof. Hill—As I have said, within our in-house research, the behavioural psychosocial group is already doing some research of that sort. We are also a research funder, and I will turn to that now. There is no bar at all to somebody applying to the Cancer Council for the competitive grants to work on any aspect of cancer research. If it is for addressing a cancer problem, they are eligible to apply. From then on it will be peer reviewed and assessed by a committee in the usual way. So there is no bar in principle to getting involved. It is not easy to get funded, and you may have heard from people who claim that they could never ever get funded, it was so difficult. Four out of five established scientists fail to get funded after any given attempt to get funded, so it is very common not to be funded. Young researchers have to be trained that they are not likely to get a grant in the first go. They have to be mentored and eventually the good ones will get funded. I will hand over now to Dr Snyder.

Dr Snyder—I am going to continue the theme of clinical research and to first make the point that both physical and psychosocial areas can be investigated by clinical research, and I will give you some examples of both of them. We think that it is important that patients such as Karen are entitled to make informed decisions about their treatment. ‘Informed decisions’ means having sufficient information. In general, sufficient objective information really only comes from clinical research.

Clinical research can be a variety of different things. It has been very common for people to say, for example, that meditation can influence the outcome for people with cancer. Two major studies have been done—one by David Kissane in Melbourne, funded by the NHMRC—which have now looked at this in a prospective, objective fashion. They were both randomised trials which failed to support that contention. On the basis that there has been no objective support for that contention, I think we need to move on and start looking at other areas that we might turn our attention to which may be more benefit.

In the area of drug treatment I want to mention Trastuzumab, which is a drug designed to treat a known abnormality in some breast cancer cells. It is a designer drug. It is an example of where clinical research and basic research is going. As a result of trials which were done world wide, including in Victoria, the place of Trastuzumab in treating advanced breast cancer has been clearly established. When you establish something in late cancer you then investigate it in early cancer, and those studies are now under way. We hope within the next 12 months to have results from three studies which might indicate whether or not this drug has a place in this area. It is an expensive drug, it is not easy to give and we need to have very clear evidence that it works before undertaking it widely.

Slides were then shown—

Dr Snyder—We also need to recognise that, although cancer treatment is nowhere near perfect, we have made some progress. I have some data here from the WHO web site looking at survival in breast cancer. The red line is 1990, which was about the time that screening was introduced, and it took a few more years before it was introduced widely. In fact, screening in itself does not prevent cancer for some five to 10 years after you have actually had the screen, because that is how long it takes to die from your cancer if you do not have the screen-detected cancer treated.

In this slide you can see two things: firstly, that Australia does better than two other countries, certainly better than the United Kingdom; and, secondly, there has been a steady reduction in death due to breast cancer in that 10-year period. We believe that that is as a result of clinical research done in the 1980s which was then introduced very widely throughout the state and in fact throughout the country which has influenced survival of women with breast cancer. So we are making some progress.

Senator KNOWLES—You are pausing because we are looking perplexed—so why is the incidence so high in the UK?

Dr Snyder—This is not incidence; this is death.

Senator KNOWLES—Deaths, I mean.

Dr Snyder—I think the UK people have answered that question in the results of their cancer plan. Medical services in the UK in the mid-nineties were quite a shambles. It took something like two or three months even to get a CAT scan to investigate where you were with cancer. They were a long way behind the eight ball, and we do not want to measure ourselves against them in that sense. If you look at us as against the United States, various accesses to treatment there might explain some of those differences. We do not have that problem to the same extent in this country. But you can see in all three examples death rates from breast cancer have been going down through the 1990s. I think this is really a result only of clinical research done prior to that time.

Currently in Victoria about six per cent of cancer patients take part in trials. Many successful international studies have accrued somewhere between 5,000 to 9,000 patients. We are looking at very large groups of patients and we need to make a contribution to the accrual of those patients. If you accrue a large number of patients quickly you get your results quickly, therefore you can change cancer treatment quickly and the outcomes can be affected positively. There is no doubt that patients who go onto clinical trials have the capacity and the potential to benefit from those treatments, if they prove to be beneficial, much earlier than if they had to wait for them to be introduced into standard practice, so there is already a benefit from patients in cancer trials.

What are the barriers to implementation of what we consider best practice, which in fact is through clinical trials? Ethical approval does present some problems. The first thing we need to recognise is that patients do have a right to take part in clinical trials, and I think the ethics process should reflect that right. The ethics process therefore needs to be supportive of clinical research and it needs to be efficient of time and resources. This is a real problem in large trials which are being done in a number of institutions throughout the state or throughout the country or as part of an international effort. We need to find mechanisms to make those processes as efficient and as effective as possible.

CHAIR—When you are testing drugs—I think Ms Kelly’s example was about the timing of treatments—how do you deal with the fact that a number of people in the testing process are not getting the drug and therefore are probably not getting any treatment in terms of their cancer during the clinical trial? Is that how it works?

Dr Snyder—No, I do not think that is the case. In most cancer situations we have gold standard therapies available. The experimental arm in such trials would compare a new drug, perhaps plus the standard treatment, as against the standard treatment alone. We do not subject patients in most situations to a no-treatment control arm unless there is in fact no treatment at all for that particular situation. That is part of the process of protecting the patient interest so that nobody on the clinical trial hopefully will get substandard therapy. There is a potential that some patients will get better than the standard therapy, but we do not know that in advance.

The second thing that we have a real need for is infrastructure. One of the ways of achieving this would be to recognise that non-commercial cancer research should be part of any quality cancer program. This means that you are not necessarily doing stuff that is dictated to you by a pharmaceutical company but may be an investigator driven study on a state-wide or country-wide basis. It does give the patients within that program the potential to take part in useful clinical research. We need to recognise that this research often requires support over a very long periods of time. In the adjuvant breast cancer situation, for example, we are following large groups of women for decades. We have been following large groups of women for more than 20 years in some instances. This requires a lot of resources, a lot of time and a lot of effort, but that is the way you work out whether these treatment are effective over a very long period of time or just a short period of time.

As David has mentioned, the Cancer Council provides three-quarters of a million dollars a year to support data managers in institutions. But off that we are able to leverage five or six times more data managers in institutions to promote clinical research, so having seeding funding is extremely important to the long-term development of clinical research in institutions.

You have heard a bit about data this morning. I think there is no doubt that we have inadequate data to know which patients receive best practice treatment because we do not collect that, although it is a goal of the current cancer framework. We do not know how quickly significant new changes to therapy spread throughout the community. We have some data from surveys of cancer treatment which have been conducted in a variety of organ-specific areas over a period of time, but it is fairly limited and it is only intermittent. I think it is very important to know if we do get a new treatment how effectively the population gets to benefit from it.

If we had more data, then we would be able to answer some of the questions on this next slide. You can see that older patients with bowel cancer do not do as well as younger patients. We do not know whether that is because patients who are older present with more advanced disease, are affected by comorbidities—other illnesses that they already suffer from—or if we treat them as efficiently and effectively as younger patients. I think these are important questions that we can only obtain the answers to if we collect the appropriate data.

Finally, all of the barriers that I have been talking about are the responsibility of a wide variety of different groups. There needs to be some way of coordinating—certainly between the state and federal levels—to make sure that we do overcome the barriers that we have been talking about. In considering this presentation to you today I reflected on the fact that there was an inquiry into breast cancer treatment 10 years ago, in 1994, by senators. A lot of the things that were in that inquiry still resonate today as important issues—things like multidisciplinary care and adequate communications. We think it is very important that the messages that come from this committee will continue to reverberate as long into the future as that inquiry has to improve cancer outcomes for patients in Australia.

CHAIR—We heard the department in Victoria say that multidisciplinary support is their preferred model and the model they support. We have psychosocial care out there that is accepted by everybody. Why is it all taking so long? Why, in Victoria, are we just now having workshops and doing literature reviews in 2005? Surely there is a bigger problem.

Dr Snyder—There are a lot of big problems. In the breast area, multidisciplinary care has really been provided for quite a long period of time, certainly in the major academic institutions. The question is trying to extend that into the smaller institutions, where perhaps people are not full-time on-site and people have to come from outside to attend meetings, and also into the private practice area. In areas like lung cancer, for example, we have really only had the tools that can influence outcomes for patients with lung cancer in the last four or five years—for example, the use of adjuvant therapies and the wider use of palliative chemotherapy, which is now effective. So the need and the drivers for multidisciplinary care have not really arrived until those improvements have been made.

Another good example is the provision of PET scanning for the proper staging of early breast cancer so you can decide who is going to benefit from aggressive treatment and who is not. There are a variety of things going on and everybody is working in this area. With respect to psychosocial care, I think we really do not have any resources at present to provide psychosocial care on a routine basis to cancer patients in our institutions. I think that is one of the grim realities of life at present.

CHAIR—Are the oncologists on board for multidisciplinary care?

Dr Snyder—The oncologists have always been on board. I was chairman of the Medical Oncology Group in the late 1980s and we were pushing this process even then. But it is one thing to believe that as a philosophy it is a good thing; it is another thing to actually have the tools to provide to patients that can achieve some outcome changes through the provision of multidisciplinary care. I think that is a process that is much more recent.

CHAIR—Is the medical indemnity insurance issue still with us?

Dr Snyder—This is actually a serious problem. We had a meeting with the major medical defence organisation in this state the day after I had made that slide. We have resolved some of the issues, certainly the medical defence issues, for private patients in the state. But I think that indemnity keeps coming back at both the public and private hospital levels. We do not have solutions for that across the board, although we will have intermittent solutions which will solve the problem for one or two trials. But we do not have a global solution. I suggest that one global solution would be to have a non-guilty process whereby patients were covered to a certain amount without having to go through any litigation, and therefore patients would be covered across the country. A no-fault system might resolve some of those issues.

Senator KNOWLES—You have given a very comprehensive presentation. Thank you very much.

Senator HUMPHRIES—This dichotomy between conventional therapies and non-conventional or less conventional therapies is a great concern. There is a flavour in other submissions of almost a hostility between these two approaches towards treatment. For example, you mentioned that you have SunSmart programs that you spend money on to promote reducing access to the sun. The Gawler Foundation emphasise in their submission that a reappraisal is going on of exposure to the sun and suggest that there should be less emphasis on avoiding the sun. What mechanisms for dialogue are there between those two sides—not just in respect of cancer but in respect of those two approaches towards treatment of illness and disease in a state like Victoria? Are there forums where you regularly get together and talk about the different approaches that you take?

Prof. Hill—I would say probably not. Certainly a number of conferences occur which are publicly advertised and anybody can register for and come to. I am aware that people who are, as you have characterised them, on the other side do attend and are able to participate and sometimes present papers. At that level, which is not a deep level, there is dialogue. I have met with Ian Gawler—not recently, but we have had discussions. I am not particularly thinking of the Gawler Foundation, but sometimes there are quite significant barriers if groups propound, and they often do, a range of techniques which include ones which doctors regard as dangerous. I think there is a difference between interventions that are dangerous—injecting something, eating something, swallowing something or being irradiated with something—and those such as massage, aromatherapy, meditation or whatever. It would be really nice to measure the effects of the non-invasive types of interventions. I think there is some work being done on that. Being realistic and honest about it, sometimes there is a falling out because there is something in the repertoire of an unconventional therapist that creates a medical problem.

Prof. Bell—There are dialogues. Cancer occurs in the community. Clearly the people that we look after in our parish are the same people that are looked after by alternative practitioners. I think in the area of complementary therapies there is a lot of common ground. Conventional medicine has moved away from the paternalistic process of saying: ‘Here is cancer X; the treatment is Y. We will do it,' to saying: 'Here is a person, an individual, who has cancer X. Here are all the circumstances. What is the best plan and how do we get this person and their family through the journey that has now begun?' That is quite a different sort of mind-set.

It is difficult. You can go on the web and find out almost any piece of information. A specific example that you quoted—the research that says that sun is good for you—comes from countries that are at a much higher latitude than the country of Australia. We have a predominantly fair skinned population living in a highly solarised environment. That research comes out of places like the UK, which are far from being highly solarised environments. So the dose, if you like, of sun exposure is quite different. You are talking about a population that has a very low background dose and looking at variations down at a low level versus the potential here for very high personal doses. To really connect those dots would take a lot more research.

I think we are often more similar than we are different. But to give an example from some of the alternative treatments, laetrile has been scientifically put to the test not once but twice and failed both times, yet there are practitioners out there who are pushing that medication. It does contain cyanide, and people do get toxic effects from it. It is very difficult for us, as medical practitioners, to have warm and fuzzy dialogues with people who do that.

Senator HUMPHRIES—The Australasian College of Nutritional and Environmental Medicine says:

> ... the conventional practitioners and researches should play only a minimal role in the research, teaching, and practices of less conventional cancer treatment …

They would suggest that there is a cultural or educational bias in the way that conventional practitioners are trained that leads them to disregard or even be hostile towards these sorts of alternatives. Do you accept there is any truth in that?

Prof. Bell—I doubt that there is truth in that. It would seem to me that that is a policy that will ensure even more separateness. It is really driving a wedge into a gap—if there is a gap—to make it even wider by saying, 'No, that group of people can't have any insight and can't have anything to do with it.' What we need are much closer relations. We are dealing with the same individuals. We know from research that probably as many as two out of three of our patients will do something for themselves. That might be stopping smoking, trying to get a bit more fit, cutting down on booze, changing diet or spending more time with friends.

There are lots of different things that different people do, but cancer often does change people's lives. It makes them reprioritise what they are doing. As you have heard from Karen, there is no doubt that taking charge and being empowered, which often means altering lifestyle in some way, is a very positive thing that patients can do. There are lots of things in our lives which are annoyances to us, and if we really had a good reason to do a stocktake every now and again we would probably change many things: relationships, work, jobs, bad habits—all sorts of things. Cancer tends to be one of those things that make people re-evaluate, but you cannot make decisions without good information. That is the most important thing, and good information does not necessarily come from a web site in Nebraska. You need good solid information from reputable sources.

Senator MOORE—Professor Hill, one of the things we talked to the last series of witnesses about was the need for a register and appropriate data resources. Your comrades referred to you at all stages on that issue—I am sure you are very grateful for that. Our first hearing was in Perth—it was coincidental that it was there—and some of the people from the state government there were quite passionate about developing improved databases and having a good computer system that covered public and private with the points along the way. I am trying to find out whether the proposal you have here in Victoria is similar to that and whether it has the same basis of information so that we can build up some kind of national register. Also, one of the issues raised in Western Australia was a recommendation that the federal government have a larger role in providing funding to support this information gathering. I would like your comments on those issues.

Prof. Hill—I would love to comment on that. I am in that particular area because the Cancer Council has a cancer registry for the state. We have terrific cancer data. We count everybody who has cancer. We know their age and sex; we know where they were treated; we have information on the pathology, although it is not very well coded; and we have very good mortality data—for everybody who dies there is a pretty accurate death certificate. We have those bits of it. What we do not have is the information in between. I just do not believe it that if you walked out into the street and asked a few people: ‘Is it true that they can’t tell us what’s the staging profile of cancers of the breast or whatever, and they can’t tell us across the state how people are treated?’ the answer would be yes. There is a great urgency to fix all that up. The data exists but is not connected. It exists in clinicians’ offices, hospital registers and fabulous data collection systems that individuals such as Richard Bell and Ray Snyder have built up over many years.

The National Cancer Control Initiative Minimum Dataset in Victoria was referred to. That is the bare bones of what you would want. We have a plan to collect that in Victoria, with the registry as the centre of the wheel and all the spokes going out and bringing in the information that is there. We could start with a completely new system, which would be lovely. We could try to change everyone’s work habits, give them fantastic technology and let everyone do it the same way. But we do not think that is practical in Victoria at the moment, or nationally for that matter. So we are wrestling with the way to extract electronically from the existing data sets the key information that comprises the core data. Then we will be able to answer questions such as the one Dr Snyder alluded to with a colon cancer. We can create those graphs and time trends and so on and we can look across hospitals at what proportion of patients are being treated according to best practice guidelines in hospital A versus hospital B. Then we can start to make system changes that will really have some bite.

We know that, as soon as we get out there trying to get this information in, the hospitals will say, ‘Where’s the money to do this extra bit of slog that you are asking for to get the data from here to here?’ We are trying to minimise that with electronic collection, but that will certainly be a resourcing problem. But if I could put in a bit of a plug, I suppose, the cost of doing this well is absolutely trivial compared with the cost of treating cancer. It is nothing. It is millions but, in the scale of things, it is very small. We would certainly like governments to get their minds around the fact that it is going to have to be resourced.

Senator MOORE—Would the kind of bases on which you would be working be similar to that which the Western Australians told us about?

Prof. Hill—Western Australia is already the envy of the rest of the country.

Senator MOORE—They said that.

Prof. Hill—They have this wonderful data linkage project. It is quite interesting to look at where NHMRC funding goes: it goes to Victoria for certain reasons and it goes to WA above the proportion you would expect. That is partly because they have an infrastructure there for doing terrific research. Jurisdictions are different. I do not think it will matter whether they achieve the end result the same way or not. We are all talking to each other and trying to feed off each other. There is one other thing that keeps coming up and I think it is worth the inquiry thinking about, and that is privacy legislation. I am not sure whether this has been mentioned to you.

Senator MOORE—It was mentioned, yes.

Prof. Hill—Again, the opportunity costs of letting privacy concerns stand in the way of what could be done through data linkage in the cancer area, and indeed much more generally across health, are not understood by the public. They need to know what could be done—for instance, picking up much earlier on the Vioxx bizzo; sorry, bizzo is not a technical word. I am talking about the connection between a prescription and an outcome quite different from expected.

I do not think the public understands the opportunity costs that are consequent upon not connecting up data systems. To illustrate that point, I was in the country giving a talk and a woman in the audience who had had breast cancer basically said: ‘The cancer registry is silly. They contacted me to take part in a study on early breast cancer and I do not have early breast cancer; I have late breast cancer.’ I had to tell her that we are not allowed to actually connect that up at the moment. So there is a consumer interest in this.

Senator MOORE—Thank you.

CHAIR—We are, unfortunately, out of time. Thank you for your submissions and your presentation today.

Proceedings suspended from 11.00 a.m. to 11.11 a.m.

ARANDA, Professor Sanchia Kaye, Director of Cancer Nursing Research, Peter MacCallum Cancer Centre

ZALCBERG, Professor John, Director, Division of Haematology and Medical Oncology, Peter MacCallum 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 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.

Prof. Zalcberg—Thank you very much for the opportunity to appear before the Senate inquiry. We have put in a submission to the inquiry, which we will make some reference to, but we do not have a PowerPoint presentation this time. We are happy to take questions. The first issue that the terms of reference deal with is the value of a multidisciplinary approach to cancer treatment. The point we are trying to make in our submission is that there is some confusion over the term ‘multidisciplinary’—what that means and when it is to be applied. We propose a somewhat simple way of thinking about this. For an individual patient there is a stage of illness. That stage of illness may be curative, defining a diagnosis, defining curative therapy, providing support or how best to keep that patient comfortable if they are dying.

For each stage of illness, there are goals of treatment—that is, the goal is to come up with a diagnosis or a plan of initial therapy et cetera. So for each stage of illness there is a goal of treatment, and for each set of goals there will be a different set of disciplines required to manage that situation. For example, if you are trying to define curative therapy for a patient with colon cancer, it is perhaps highly appropriate at that time to have the surgeon, the radiation oncologist and the medical oncologist present. If, on the other hand, the patient has a tumour that has recurred in the abdomen and their particular problem is pain, you are not trying to define the antitumour therapy; you are trying to define how best to deal with pain. Then the persons who need to be present may well be a palliative care physician, a psychologist to help deal with the way they are coping with the situation, if the situation is incurable, and so forth. There are many examples like this.

It is a model I use conceptually when I think about the issues of multidisciplinary care. There are many disciplines involved in cancer management. There may be 20, if you started to list them all down. They cannot all be present at a single meeting, but if you define the stage of illness, the goals of treatment for that stage, then you can define the disciplines that need to be present. A multidisciplinary approach is the bringing together of the relevant disciplines that can address the goals of treatment for that stage of disease. As I say, that is a statement of how we think this works. That is what we try and do at Peter Mac in terms of bringing the expertise together around the table when patients are being discussed. As a corollary of this is the evidence that multidisciplinary care is the way we should be practising. I think there is no question that consumers like it and patients like it.

I often tell patients personally, for example, that I am not going to make a decision about the right treatment but take their case details to a multidisciplinary meeting—often this is the time of diagnosis when you are trying to come up with a treatment plan—and discuss that with a range of people from different disciplines, all of whom have expertise and interest in the particular disease. There is no question that patients and consumers like this approach. They feel confident with it and feel that the best care is being delivered.

The other important thing about the multidisciplinary approach is that it is a corollary of providing a critical mass. There is no question that high-volume hospitals or institutions and high-volume clinicians have better outcomes in their management of patients. It is not actually high science—if you have rectal cancer and you see a doctor who has operated on one patient with rectal cancer in the last two years then it would not be surprising that his or her outcomes are not as good as someone who has operated on 10 in the last week. I am not just saying that; the evidence is absolutely clear-cut with a range of different tumours. What we are talking about is a critical mass. I guess we may come to this later, but talking about critical mass in terms of Australia and Australia’s geography is more complex than it is when talking about a single institution. Nevertheless, critical mass leads to better outcomes. Institutions, organisations and centres that are in a position to provide this critical mass invariably practise the multidisciplinary care that I have just been referring to. That relates to item 1 of what we talk about as a multidisciplinary approach. I will now hand across to Sanchia to talk about the case coordinator.

Prof. Aranda—The issues around nursing and care coordination or case management kinds of roles are fairly complex and I think they are well-covered in the CNSA submission, whereas in our submission we touch on the highlights. I think it is true to say that the evidence does support the concept of the role, specifically coming out of breast cancer treatment, but that many of our education systems have not supported that role development. At Peter Mac over the last three years we have implemented a system of having 10 nurses in key coordination roles in the various tumour streams. Our struggle has really been with the basic preparation for cancer nursing not actually preparing nurses for taking population based roles. For example, they might do a very good job with an individual patient but do they understand the care pathway for the 400 patients with GI cancer who are under their auspices, and what is the specific kind of training that they need to do that? There is a lot of role confusion across the country.

Recently Patsy Yates from Queensland and I put forward a submission for the spending of the Strengthening Cancer Care policy money that was promised to nursing last year that really emphasises the development of a national framework for these things. It is important that this does not happen state-by-state in a piecemeal way, which we have made the mistake of following in most other areas of nursing, and that we get some common language and some common definitions—and therefore some common role preparation—developed for these roles, because they can make a difference—but only if they implemented in a very strategic way.

Our own evaluations through the Victorian Centre for Nursing Practice Research of the breast cancer nurse role suggest that there really are significant problems with the implementation of the role when it is undertaken outside of a common framework in that nurses begin to see themselves as one-stop shops meeting everybody’s needs. They are not very good at referral to other health professionals and they do not place a major emphasis on looking at the pathways of care. So if you can in any way influence the spending of that money, that would be fantastic because it has not rolled forward yet.

Speaking specifically about the psychosocial care issues that arise from that, a large part of what the nurse coordinator does, in our institution anyway, is to identify psychosocial issues and engage in appropriate referral to other health professionals. We have very strongly supported the NHMRC guidelines for psychosocial care, but the implementation of those guidelines is very difficult in the absence of funding systems that support the employment of the necessary people to whom you can refer patients.

At Peter Mac we are very lucky. We have managed to employ psychologists and we have a strong bank of social workers and limited psychiatry, but that would be unusual in most hospitals across Australia and certainly across Victoria. Implementation of the guidelines is hampered by the absence of positions funded either through state health systems or through Medicare. Under Medicare, the rebate for psychosocial health professionals is limited and does not meet the needs of the chronic population; they often have quite complex needs, including the need for ongoing support. The current model supports referral to psychiatry more strongly than to other health professionals who might be able to do an equally appropriate job with many of the patients at a lower cost. So we have a model that drives us towards the expensive end of the market rather than looking at what can be put in place and how, from other levels of practitioner, very complex patients might be referred to a psychiatrist.

I note some interesting models in the CNSA submission. In our own submission reference is made to the C-Care demonstration project undertaken in Victoria, and I would commend to you the evaluation report of that project. In Victoria there are plans to research that further, beyond the breast care model, and we are working currently with DHS on a proposal around that.

Prof. Zalcberg—The third part of our submission to the inquiry relates to models and practice in delivering services to regional Australia and Indigenous Australians. I suppose you would be aware that the rate of survival of people with cancer in rural New South Wales is less than it is in the city. Indeed, we are aware of much worse data for Indigenous Australians.

We are here representing the Peter MacCallum Cancer Centre and we are fortunate in the sense that essentially we are a comprehensive cancer centre with a brief to deliver the same quality of care to all Australians but clearly to the people who present to us. However, within the state of Victoria—you may have heard about this earlier this morning—a framework model has been established, which is clinical pathways, if you like, saying that if you have a lymphoma, a colon cancer or a lung cancer, there is a clinical pathway for appropriate intervention and decision making. At least in part, that is one way that regional and rural Australian issues can be identified.

Having said that, no matter what the pathways are, I think it will be difficult without specialist support—and many areas of the country are without adequate specialist support. I have made a comment about critical mass. Looking up, on a web based page, what you should do—‘This is the pathway for lung cancer’—while not having much expertise or knowledge in the area will be a big ask when the time comes, although it remains to be tested. Whether these framework models can address these deficiencies, particularly ones brought about by geography, remains to be seen. As I say, I believe that large areas of the country are not adequately supported not only by appropriate medical staff in particular but also by all other types of staff required for a proper cancer care model.

Those points were the essence of our submission to the inquiry, and we did attempt to address issues around barriers to implementation. Would you like to ask us questions at this point?

CHAIR—We are happy to move to questions, if you are ready.

Senator KNOWLES—I note your reference to the absence of Medicare rebates for specialist case conferencing. At the moment who pays for those case conferences?

Prof. Zalcberg—In public hospitals—for example, Peter MacCallum is a public hospital—I suppose, through the Medicare agreement, the Victorian government pays. We have case conferencing that occurs around patients in almost every tumour stream. Whether you have colon cancer, melanoma, lung cancer or head and neck cancer, a multidisciplinary case conferencing meeting is held weekly.

Senator KNOWLES—Is one patient or are multiple patients discussed at that meeting?

Prof. Zalcberg—No, there will be multiple patients. The principle—and of course this is partly a workload issue—is that all new patients presenting with disease X will be discussed at the appropriate multidisciplinary meeting. The meetings that I am talking about now tend to be ones about defining the treatment plan. So if you said there is a patient with pain and the issues around pain need to be discussed, there are different levels of meetings occurring. If we take the example of defining a first line treatment plan for a new patient presenting for the first time with a diagnosis of cancer, in each tumour that I described there is a multidisciplinary case conference. However, the people who attend are either full-time, salaried members of staff, who attend because they believe this is best practice and this is how they should spend their time, or they are visiting medical officers—as I say, this is the diagnostic treatment paradigm, so this is the more medical end of the discussion—who attend because they believe this is a useful use of their time and this is how they can best manage their patients.

Senator KNOWLES—So they are being paid for their patients' service to start with. I am trying to get to the bottom of this. Is this all about the doctors just wanting to be paid for this particular conference, or is there a broader subject to it? I am looking at it from a patient's and a layman's point of view. I would have thought that specialists who are being paid for their services to start with, through either the public or the private system, would not resent or begrudge having a case conference that is not funded by Medicare that decided the process by which a patient was treated in a comprehensive way.

Prof. Zalcberg—As I said, I would like to separate it into public and private, but you may not feel it needs to be separated at the end of the day. At a hospital like Peter MacCallum Cancer Centre there is no begrudging doing it that way, because it is seen as the optimal way of doing it. Having said that, a visiting medical officer who is basically there for a clinic that starts at 1.30 but who needs to come at 9 a.m. or 12 that day to attend the case conferencing is doing that when they may be supposed to be somewhere else. They do that when they have other commitments as well. At the end of the day the question is: do you look at it as rewarding the doctors, or do you look at it as encouraging best care?

Senator KNOWLES—I look at it as though it is part of the care for the patient.

Prof. Zalcberg—Yes.

Prof. Aranda—Putting my hospital administration hat on, hospitals in Victoria get funded in essentially two main ways: through the weight of in-patient activity and through the Victorian Ambulatory Classification System, which funds medicine. If Professor Zalcberg and Professor Thomas, who are the surgeon and the medical oncologist and GI, see a patient together we can only claim for one of those doctors. So the whole way in which the hospital is funded does not support that. It would be much better for the patient to see Professor Thomas today and Professor Zalcberg tomorrow, because then we could actually claim for both of them in terms of supporting the hospital. But if they are seen together in an ideal patient management framework we can only claim for one under the rules. So there is no ambulatory classification for a multidisciplinary meeting to manage that patient. Our entire income is based on counting all of the activity. That system is slightly different from that in most of the other states, where I understand there is block funding to hospitals that covers the medical staff salaries. Also, there is no facility if the nurse attends that meeting as well. As cancer care is moving more and more into the ambulatory system, our capacity to fund the complexity of care is simply not there.

Senator KNOWLES—What discussions have you had with the state government about the way in which you are treated vis-a-vis the other states?

Prof. Aranda—It has been on the agenda of the ministerial task force in the sense that the limitations to the WIES funding and VACS funding for the delivery of cancer services came up at the first workshop, but it has not got back on the agenda as yet.

Prof. Zalcberg—The other thing I would say, Senator, is that I think you are right that, if we leave aside the funding models for a moment which Sanchia has referred to, at the end of the day you have to run the hospital and it has to run on budget and the funding models in a way prevent or restrict the financial modelling around this sort of activity. From a clinician’s point of view, clearly, treating patients optimally is exactly what everyone is about, but we are talking about a work force that in Melbourne, let alone in regional Australia, regularly does 60- to 80-hour weeks. People who go home have not had time to order their drugs and dictate their notes before we are saying, ‘By the way, optimal care means getting together with your colleagues and spending an hour talking about patients.’ It absolutely does.

In an ideal world, if there were time to do the things that needed to be done, this would be top of the list. But you do have to dictate a letter to the GP and you do have to order the drugs that are required for the patient’s next treatment. I am arguing that, in the public sector, it is complicated but it is a resource issue, and I do not necessarily mean the money coming in. If the federal or state government funds things differently through VACS, we will put more person-power in to try and resource those services, but it will not make any difference to individual doctors. No-one will get paid any more, but what it might mean is that we have enough people to actually do the work.

In the private sector, though, which does not affect us directly, I would argue that it is quite different because what you have is a financially driven system whereby, basically, you get paid for what you do. If you are doing a case conference and not seeing more patients, who are waiting to be seen and complaining about the waiting list, when do you have the time to see those patients? Yes, it is about optimal care, but you have to try and balance it. I do not question the wishes of the clinical community to try and provide best practice care, and case conferencing is an example of that, but the system does not easily lend itself to do that, for different reasons in the public and private sectors.

Senator KNOWLES—Moving on to the statement that you made about poor recognition in state government funding for outpatient services, would you like to expand on where you are at with that?

Prof. Aranda—If you look at Peter Mac’s separations, we have gone from having about 25 per cent of our separations being same-day to the current situation, where more like about 75 per cent of our separations are same-day. All of those patients then require supporting in an ambulatory system. John could speak to the issue of chemotherapy, but there is a single payment for chemotherapy regardless of whether it takes 10 minutes or five hours. So the system is already stretched. It used to be the assumption that patients who were at home and just coming in for day treatment were reasonably well, and that is no longer the case; they are as sick as the people who are in hospital. The support systems that you need to put around that are much more complex than they were before, and the funding systems just have not kept pace with that reality.

Prof. Zalcberg—I would add that, in Victoria—and I guess it is an essential fact of life—we work under capped systems. One issue is how much money is received in order not to compensate but to provide the resources required for an intervention. Remember I was talking about writing up the chemo and writing the letters. There is also the counselling of the patient and the communication with the relatives. There are a lot of aspects to looking after a patient properly. So there are two problems: one is that it is capped. For example, we are currently running 35 per cent over our patient targets. That means we do not get paid for it. And yet you need to provide the same level of resources that all patients need. The second problem is: what do you get for an actual intervention? Clearly, the complex end of outpatient treatment is quite different to what might be—dare I say it without a surgeon being here—a simple surgical procedure where you have had the surgery, you are recovering well and you go home. That is a bit different to someone who is coming along for initial diagnosis of cancer when all the issues are required to be dealt with.

Prof. Aranda—I will give you a really concrete example. We have just done an evidence review of how fast you can feed somebody who has a gastrostomy tube inserted into their stomach for feeding. That project has resulted in patients, instead of having a 10-day stay in hospital, having a five-day stay in hospital. But they have to be seen on a regular basis by a dietician. Our overall ambulatory services are over capacity by 35 per cent; in allied health it is even worse. So we are getting those patients out of hospital, which is making the system much more efficient, but they are actually quite ill and need a lot of support in the community. That group of patients in our organisation is growing because of the multidisciplinary head and neck treatments that we can offer, and we have really no way of expanding the support. And people are so committed to what they are doing that they just keep doing more and more unpaid overtime. So there is a recognition that the kind of service that used to have to be provided in hospitals and is now being provided in the community is just not part of how the system sees its funding strength.

Senator KNOWLES—Where are the negotiations currently with the state government about the overruns?

Prof. Aranda—The response from the state government at this point has been to do an audit of VACS, the outpatient classification, which is really to see whether we are accounting appropriately. There has not been any widespread response to the issue of complexity.

Senator KNOWLES—How long has that audit been under way?

Prof. Aranda—Peter Mac was audited the week before last, so it is in progress across the system.

Senator KNOWLES—When is it due to be reported?

Prof. Aranda—I am not sure. We have not been given a reporting date, but presumably it will be prior to the funding allocations for this year.

Senator MOORE—I want to follow up on Senator Knowles's question. Professor Aranda, shouldn't that issue be worked on with the working groups that we heard about this morning from state government? It would seem to me that particularly that first working group, as I have read it, should be looking at exactly those kinds of issues.

Prof. Aranda—The Clinical Services Working Group?

Senator MOORE—Yes.

Prof. Aranda—I am on the Clinical Services Working Group—

Senator MOORE—So you will be feeding it to yourself—that is good.

Prof. Aranda—We have certainly been talking about it at every juncture. The problem at the moment is that the energy of that working group is going into defining ideal care so that you can then assess the extent of the delivery of that care across the system. We are struggling because we are attempting to meet ideal care. At the moment you could not see a dietician at most public hospitals as an outpatient; you would have to be admitted, because that is the only place where the resources are. This is coming out in our conversation partly because we are ahead of the game on a lot of those issues, in terms of recognising their impact on patient services.

CHAIR—Does Peter Mac offer any complementary therapies in cancer treatment?

Prof. Aranda—Yes, we do.

Prof. Zalcberg—It depends on what you mean by 'complementary therapies', which is a whole Pandora's box.

CHAIR—Tell me what you offer.

Prof. Zalcberg—Currently in managing patients, we have an absolute belief in managing the whole patient—patient and family. If we just go through some of the disciplines: social work services, occupational therapy, physiotherapy, music therapy and psychology. Issues that are often referred to as 'complementary', for example meditation and relaxation—I do not believe music therapy falls into quite the same category; it is a communication approach—are routinely available. I do not even call them complementary therapy anymore; I just call them part of the way we approach managing patients.

We have probably learnt from people who have been labelled as alternative practitioners about things like meditation, hypnosis and so forth—we certainly have to be grateful for that—and now understand in our practice that the types of modalities that improve patients' wellbeing, their coping strategies and their stress levels, and those of their families, are an integral part of patient care. I do not even call them particularly complementary.

When you get to the other end of the spectrum of what is called 'complementary', which perhaps others will call 'alternative therapies', that is a slightly different issue that I would be happy to address in a moment. With respect to things that are directly about improving the welfare of patients from a psychological, emotional, social and indeed physical point of view—and I am not talking about the treatment of the cancer per se—those types of modalities are routinely available and provided to as many patients as possible.

CHAIR—When you say 'routinely available and provided', how is that done? In Perth we heard about the Brownes centre, so we understand how it is delivered there. How do you deliver it?

Prof. Aranda—We would love to have a Brownes Dairy service at Peter Mac.

CHAIR—We understand that you have an area within the hospital that is empty.

Prof. Aranda—We have a patient information and support area for which we are currently seeking philanthropic funds to run more programs. We already run what would be considered complementary programs in terms of exercise, diet and relaxation in that environment. It is a little open. Our meditation classes are run in the occupational therapy department. We have a program in place to routinely make information available to new patients about those sorts of services, and we are making quite a strong effort to increase the number available within our current service provision. We have the support of the board to look at making a wider range of therapies available. The program is such that it relies on lots of volunteers, and getting volunteers to give up their time to do the things they would normally be paid for is relatively difficult in the long term. We do have some volunteer masseurs who come into the hospital and work with patients but it is of limited capacity. It is just another one of those things that compete for funds.

We also provide evidence based information to patients about the kinds of therapies they would seek. We promote programs that are offered in the community through the information centre, but we step back from promoting anything that might suggest that it is modifying the disease, because I think that is the point where we begin to separate from what would be alternative versus complementary. We would be very encouraging of people to take up things that enhance their wellbeing, but all of us have seen too many patients sell the family house to take the latest complementary therapy—it is labelled complementary but it is actually alternative therapy—give up treatment and, basically, ruin the family. It is with those issues of separation where we come unstuck.

Prof. Zalcberg—The critical issue is that there are therapies that improve patient wellbeing but are not intended specifically to change the course of the cancer itself, as opposed to therapies that are directed at the cancer. Radiation treatment and chemotherapy are treatments that are designed and intended to change the natural history of the cancer itself. We do not call those alternative; we call them conventional or standard approaches to management of the cancer. The so-called complementary therapies—the ones we are talking about—are not about trying to change the natural history of the disease but improving patient wellbeing. When a treatment is unproven—at least, from a scientific point of view—in changing the natural history of a cancer, that is where the concept of alternative therapy comes in; at least, as I see it.

CHAIR—To extend on that, to prove something, do you go through a clinical trial process?

Prof. Zalcberg—Correct.

CHAIR—Do you do that at Peter Mac?

Prof. Zalcberg—Correct.

CHAIR—Do you essentially supervise all the clinical trials at Peter Mac?

Prof. Zalcberg—Absolutely. All clinical trials need to go through a very rigorous evaluation at a clinical level, a service level and a divisional level and then go through an overall clinical research committee and an ethics committee, and that is true for all trials whether they are qualitative or quantitative and whether they are a modification of existing treatment or the implementation of a new treatment.

CHAIR—Do you fund them all?

Prof. Zalcberg—How long do you have?

CHAIR—I am interested in the breakdown between the trials that may be funded by pharmaceutical companies and the ones that are publicly funded directly either by the hospital or by others.

Prof. Zalcberg—Approximately two-thirds of our clinical trials are not funded by the pharmaceutical industry and about one-third of them are funded by the pharmaceutical industry. The major sources of funding for clinical trials are pharmaceutical industries, which have been identified, national cooperative groups and institutions, although the capacity for individual institutions to fund clinical trials is very limited. So the major sources of funds for clinical trials in Australia are as I said, the pharmaceutical industry—and that may include other industries; if it is a new device, then it may be the manufacturer of the device, for example—and cooperative groups. There are also networks—for example, there may be a psych oncology network that has government grants. When I say cooperative groups, I mean that they in turn derive .their sources of funding from two places: one is industry and the other is competitive peer review grants. Some of those cooperative groups are well formed and some are not so well formed. That is the way the trials are funded in institutions such as ours.

Senator MOORE—Professor, when you say ‘institutions such as ours’, do you mean the hospital itself?

Prof. Zalcberg—Yes. So the capacity of Peter Mac to fund an individual trial from beginning to end, while it is possible for very small trials, is not usual and is quite limited because the hospital is essentially funded through the state government. It receives some philanthropy, which goes into research, but clinical trials per se are quite expensive and not usually funded specifically from an individual donation. So Peter Mac does not usually fund—I am not saying there are no examples—individual clinical trials on its own. Would you agree, Sanchia?

Prof. Aranda—That is right.

Senator MOORE—Would cooperative groups include the Victorian Cancer Council?

Prof. Zalcberg—There are about nine national cooperative groups. I am chair of one of them, just to declare that. The one I chair is called the Australasian Gastro-intestinal Trials Group. There is the Australian Leukaemia and Lymphoma Group, the Australia-New Zealand Breast Cancer Trials Group and a gynaecology-oncology trials group. These are national networks of clinicians interested in the management of cancer that conduct trials around Australia and often New Zealand.

Prof. Aranda—With the group of witnesses from the Cancer Council, the question of differing world views arose as to whether you can actually have people who come out of medical training overseeing the research of another group. There is a really interesting model in Hull, in the UK, where many complementary therapies, although still looking at survival as one of the end points, are researched by a group—reiki, psychotherapy, neurotherapy, immunotherapy. The interesting thing there, regardless of what world view you come to, is that there has to be relationship between the therapy research and the outcomes that you want to derive from that, in that the research process is about measuring the outcomes and ensuring the integrity of the relationship between what you are doing and the dependent variables that you are looking at; and that the robustness of that does not differ depending on your world view.

The people in Hull have quite an alternative world view in terms of the therapies that they are providing, but they can equally rigorously evaluate them in the same way as the supportive-expressive group therapy in Professor David Kissane’s research on women with advanced disease can be evaluated, where survival is one of the outcomes but wellbeing and the experience are also measured along the way. Clearly, analysis of the survival benefits has not yet been run. But the research process has to be as rigorous in one world as in the other because that is about the protection of the public, in that the claims made must be substantiated by the process through which the treatment has been evaluated. I think that is the position that orthodox medicine takes. It is interesting, because the National Institutes of Health in the US funds the study of alternative therapies through that rigorous process. Laetrile was certainly evaluated in that way.

Prof. Zalcberg—So, if the question about clinical trials is related to clinical trials around complementary therapies, for example, then they go through exactly the same process. As Sanchia just said, we had a previous head of psychiatry run a trial asking whether various coping strategies improved survival rates of people with breast cancer. It was a very reasonable question. It was funded by the NHMRC. It went through exactly the same process that all other clinical trials went through. The trial was completed and will be reported on.

Senator LEES—You mentioned reiki. Does your hospital offer that opportunity?

Prof. Aranda—We have on staff someone with reiki knowledge who can provide information to patients, but we do not provide it as a funded service, mainly because of a resource issue. We have let staff experience it: we have a care for the carers day once a year where various staff experience different complementary therapies so that when they are providing information to patients they know what they are talking about, having experienced it. But reiki is not provided as a routine therapy.

Senator LEES—You have both talked about best practice and given us some tremendous examples of what you are able to do at Peter Mac. Are there other hospitals here in Victoria for the treatment of cancer that offer some of the alternatives, particularly the complementary alternatives, that you offer or are you fairly unique when we look at treatment options in Victoria?

Prof. Aranda—We are probably fairly unique. There are a lot of hospitals that would provide information to patients, but very few that are resourced to our level. Partly because of our philanthropic income, we are able to provide what might be considered the icing on the cake or the yeast in the bread might be the better analogy.

Prof. Zalcberg—I think that most cancer units in Melbourne would be providing support from dieticians, occupational therapists and physiotherapists. If you like, they have been considered mainstream support for patients for many years and they would be in place in all the major teaching hospitals and, indeed, in the private sector as well. When you get to things like meditation, music therapy and so on, there are a few hospitals offering music therapy, for instance. Music therapy in particular is more about communication and providing help with communication than it is about relaxation per se. The attitude of most of the hospitals around would be similar to the one that we have been discussing—that is to say, treatments which improve patient well-being, help with relaxation, help with coping with stress and help family relations, if they are not provided, are wanted to be provided, and various attempts would be made to try to provide them as best as possible. These things are, to a limited extent, available in the community as well. As regards psychology, the problem with it is that there is not enough support for psychology in the community. We have 1.5 psychologists and probably need 4.5. How does a cancer hospital not have enough psychologists? Again, it boils down to resources. Psychology and social work in the community are particularly the areas not adequately supported by current systems. Although they are not necessarily all provided, people would generally accept, I think, their role in improving patient well-being.

Senator LEES—How do patients find you? How do patients get referred to those specialists, which you mentioned earlier, that have done probably 10 operations in the last week as opposed to one in the last six months? Does it depend on which GP they end up with? Does it depend on where they live? How do patients find their way through to what we are starting to understand is best practice?

Prof. Zalcberg—I noticed Lyn Swinburne’s name was down as a witness in this inquiry; I am not sure whether Lyn is sitting behind me. People talk about the ‘cancer lottery’. Unfortunately, it is difficult here. I think it is difficult for some of the professional organisations to provide the information that is required—some have, some are trying to, some want to and some are unable to. It does depend a bit upon the GP. I am not trying to put words in Lyn’s mouth—she will tell you in due course if she believes it to be true—but I have heard that term ‘cancer lottery’. The lottery, at least in part, relates to how you find your way through the system to ensure that you are getting good-quality care. It does not matter what your intellectual capacity and your internet capacity are—they are irrelevant to knowing the answer to this question.

Prof. Aranda—That is certainly what the integrated cancer services are attempting to do in Victoria: to ask each grouping of hospitals to define those pathways of referral so that patients can access them easily and make informed decisions. It would be true to say that those of us sitting at the provider end find that the average breast cancer consumer these days is a much more informed consumer of health services. The key outcome of groups such as the Breast Cancer Network is that kind of information. If people get hooked into the network after their initial referral they can then change providers on the basis of saying, ‘This is the kind of service I expect. I am not getting it therefore I am going to look elsewhere.’ That is an incredibly empowered decision and it should not really end up like that.

Senator LEES—For some conditions you have time. You might try one and then hear from someone else who has muscular dystrophy or whatever who says, ‘No, gee, you shouldn’t be over there.’ But with cancer time is of the essence, and people often do not feel that they should even try to look around. They are very dependent. If we were to develop through the networks and through the work that the Victorian government is now funding a list of specialists or a list of services, would we not have some very grumpy people if their name was at 406, or if it did not even appear? How do we get over that issue?

Prof. Zalcberg—We might have some very grumpy people. But we also have the problem of what we do if you live in place X and there is not anyone within 1,000 kilometres. I am assuming you live in an area where there is medical care, nevertheless the persons with the expertise are not within 1,000 kilometres. So I think the framework model that has been talked about in Victoria has at least the opportunity to work, because there is a metropolitan version and there is a rural version. At least there is the hope that that might start to address this issue.

Senator LEES—So you see the government funding something that says to people living at Mallacoota or somewhere in East Gippsland, ‘You have X type of cancer. There are Y services available at ...’ And this is as a result of clinical trials. So your name might actually appear very high up on that list, because they are obviously not going to get anything at Bairnsdale.

Prof. Zalcberg—Right. In the UK, for example, in the city of London, which is a big city, there are three places at which you can get surgery for oesophageal cancer. You just cannot go to every hospital in London and be treated, because it is subspecialist. The other thing I would say to put this into a bit of perspective is that the concept that critical mass and subspecialisation is important is relatively new. It sounds crazy in a way that it should be new. It should have been something that was obvious 20 to 30 years ago, but at least the evidence that that is the way we should be practising is relatively new. There needs to be a bit of time. You just cannot throw out half the medical profession and say, ‘Guys, unless you’re going to subspecialise, you’ve got no job.’ There has to be some generational and some time effect.

Senator LEES—I was on the inquiry we did in 1994 regarding breast cancer, and that was really the theme. Was specialisation and people who were looking at mammograms all day every day better than a general radiologist, and certainly I think breast cancer has a bit of a lead on other cancers in the acceptance of that some time ago.

Prof. Aranda—What came out of the breast services enhancement programs in Victoria, particularly in the rural areas, is that it is actually possible to work with role designation, which is saying that surgeons X and Y are going to do the breast cancer surgery and they are going to be linked to this major centre. The clinicians are relatively responsive to that kind of self-regulation, as long as you are not taking away their livelihoods. I know that if you speak to the surgeon in Gippsland, David Birks, who is on the ministerial task force, he would say that they divvied up the work differently, so that those surgeons who were not doing enough breasts were compensated by getting more of the appendectomies or the gall bladders. Generally, health professionals are motivated by a desire to see the best for their patients, and if they can be given convincing arguments and their livelihoods are not taken away they will cooperate with that.

Prof. Zalcberg—The other point to add is that I would not underestimate, unfortunately, the resource rich nature of what we have just been describing. For example, I work at Peter MacCallum and I treat just gastrointestinal oncology, so I do not treat anybody with breast cancer, lung cancer or sarcoma, and I treat only the medical aspects of that. To do that in every hospital in every centre around the country—in other words, to allow people to subspecialise; I think my subspecialisation is too big already because colon cancer, gastric cancer and pancreas cancer all fit under GI—is going to be an expensive exercise. I think the outcomes will be worth it at the end of the day.

Senator LEES—I was more referring to how people find you. It may be appropriate that some specialities are still only going to be available in some places, despite what people might want out in rural areas. While it may work in some areas, somehow—maybe on the internet, maybe somewhere through the Cancer Council—there has to be some support, surely, for people who have got a diagnosis that morning from the GP but want some other alternatives. At the moment, they would not—

Prof. Aranda—I certainly think the integrated cancer services will start to advertise that fact. But at the same time the consumer organisations will start promoting—and already do promote—the kinds of questions you should ask. When the GP is setting up the referral to Dr X, you can ask questions like, ‘How many breast operations has he done this year?’ so that you can get that information early. The Cancer Council information services are very good. They will often work through with patients the set of questions you should ask at the beginning.

Senator LEES—Can you get results, though, for that particular surgeon? Can you find out that he treated 802 patients and 407 have survived?

Prof Zalcberg—It is very difficult to get that. It is important that you appreciate, as I am sure you do, the difficulties the professional societies have in dealing with this issue. If I can put in a plug, the solution to this is in the consumer group. Consumers want these answers and if we empower consumers and finance consumer groups so that they can thrive, they will provide the answers to these questions because they will demand them.

Senator HUMPHRIES—You say that one thing the government can do with respect to research into complementary treatments of cancer is to support the rigorous evaluation of less conventional treatments through specific funding to allow well-conducted studies of their effectiveness to be conducted. We heard earlier today from the Cancer Council that in their view there are no system barriers to that kind of research at the moment but the problem is an unwillingness of proponents of those alternatives to, as they put it, ‘play to the rules’ and an unwillingness or inability to use valid research methods. Do you feel that is a fair comment?

Prof Zalcberg—It is a bit hard to know whether it is unwillingness or a lack of training. Embarking on a clinical trial to demonstrate a particular theory being true requires some skill and expertise and support. I see it as multifactorial, in a way. There are people who have said to me things like, ‘This has been proven in practice in China for 5,000 years. Why do we need to prove it?’ That is one attitude. The other is the people who would like to prove it but are unable to do so because of the lack of knowledge and expertise about how to go about doing that. The third thing is the support to actually do it in the first place. Assuming that they want to show that it has a role and assuming that they have the skill base to then go ahead and set up a system that allows you to answer the question, you still have to then have support to do the trial.

Senator HUMPHRIES—What sort of support do you mean?

Prof Zalcberg—Financial support. Running clinical trials, unfortunately—and the question was asked earlier by Senator Knowles about who pays for these trials—costs money. The money has to come from either an industry sponsor, a government sponsor or an institution—an institution can be a university or a hospital. But at the end of the day there has to be some support to do the trial. These rules that you referred to are the same rules that we impose on ourselves; they are no different; they are no more or less stringent. They are basically saying that if I am going to tell a patient that drug X works, I need to be able to demonstrate that, not with my own personal experience but with a rigorous process of evaluation that shows drug X works or does not work, as the case may be, and has the following benefits and the following downsides. Those rules, we would say, should apply to everybody, ourselves included. The issue of why we do not have more trials in the alternative approaches to cancer treatment relate to those three factors that I mentioned.

Senator HUMPHRIES—Are you saying that there is a threshold that many alternative therapies cannot reach to have their approaches tested or evaluated because of the requirement for money, for example, to generate an evaluational trial?

Prof. Zalcberg—If you have somebody who wants to test something different—and we have seen examples of meditation and psychological interventions that might extend how long people live—at one time that would have been called an alternative approach. That was tested in the following way. The person who had that idea wanted to prove or disprove that it worked. He went to the NHMRC, he had the skill base and he brought around him the people that knew how to design the intervention. Half the patients got standard care and half got a course of medication—let us say for the sake of the discussion.. He then went to the NHMRC and asked for money to do the trial. All of those things were in place. The trial was done, it was completed and it will answer the question. It may not answer whether six weeks of treatment is better than 12 weeks or vice versa, but it will begin to address the issue. There is a threshold, but money is not the only solution. Putting money forward will not solve the problem if somebody says, ‘We have used this in China for 5,000 years. We do not need to prove anything, thank you’. Money will not solve the problem if the person who has the theory does not actually know how they can go about testing it. That is a solvable problem. The first problem is less solvable. The money problem is also solvable.

Prof. Aranda—In relation to the issue that you raised, Senator Humphries, about the practitioner who is not willing to undergo being tested in that system, there is a small minority of unorthodox practitioners who are charlatans and give the rest of the system a bad name, but in order to protect the public from that small proportion, everything else also needs to be rigorous. In the same way, there would be claims that there are medical practitioners who undertake unnecessary operations or treatments. They are under public purview and can be assessed and audited in the public domain. All we are arguing is that anything that is claimed to be for the public needs to be in that same kind of system. Many complementary and alternative practitioners would be willing to be tested in the right kind of system. It does require partnerships, as John said, with the people who have the skills to do that, but it also requires the same kind of access to money. Like any other fledgling discipline, accessing something like the NHMRC, just saying that those groups are open to it is the same as saying that palliative care and nursing have been equally accessing those buckets of dollars. It takes some time to build up the expertise, the credibility and the track record to access them. The way that has been approached elsewhere is to provide specific buckets of money for those groups in order to get them up to the standard that is required for national competition.

Prof. Zalcberg—But I would say, Senator Humphries, I have had companies from China approach me and ask whether I would test their herbal therapy. They would like to be able to test it in a Western country and they would like to have the imprimatur of a major organisation saying ‘this works’. I said ‘fine’. This is the way that we need to go about this. If they are prepared to test it then I am happy to help them test it. It needs to be supported and then we can go forward and do it. The important thing for people looking after patients with cancer to remember is that they are our mothers, our sisters and our wives. Like everybody else, there is nothing we do not want to give to people that we think works, but we certainly do not want people to go off and have treatments that we think are a waste of their time and their money and, in fact, sometimes denies them the actual treatment that does work. So, there is not any a priori reason why we do not want to move forward here, but the rules have to apply to everybody for the public’s sake.

CHAIR—I am afraid we are out of time. Thank you for your submission and your presentation today.

[12.12 p.m.]

SWINBURNE, Ms Lyn Mary, Chief Executive Officer, Breast Cancer Network Australia

TIMBS, Ms Susan Daphne, National Policy Manager, Breast Cancer Network Australia

LOCKWOOD, Ms Susan Margaret, Chair, Breast Cancer Action Group

MANASZEWICZ, Ms Rosetta, Steering Committee Member, Breast Cancer Action Group

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 an opening presentation, to be followed by questions from the committee.

Ms Swinburne—To start our presentation today we thought we would show you a DVD, which goes for three minutes or so. We figured you would have had a whole lot of people talking at you over the last few days and will have over the next few days. So we wanted to depict for you in a visual way an experience of one of our women.

A DVD was then shown—

Ms Swinburne—There are a couple of things that are important for you to know, to start off with. The four of us sitting here are breast cancer survivors and the views and comments that we will present to you come from our constituency. Breast Cancer Network Australia is the peak national body representing breast cancer survivors and their families. We represent 13,000 individual women and we have 125 member groups. Ms Lockwood and Ms Manaszewicz's group is the Breast Cancer Action Group, which is a state based advocacy group and one of our member groups. The reason that we can talk with confidence—we hope it is with confidence—

Ms Timbs—It is certainly with confidence.

Ms Swinburne—about what women believe and what they feel they need is that we give them regular opportunities to tell us how they are getting on, how they feel and what they need. On a big-picture level, one of the ways we did that was in 1998—when we began the network—when we held a national conference in Canberra and 300 women came to it. From what they said we listed a number of recommendations and then developed a priority plan, which was called the *Making a difference* report. Six years later, at the end of last year, we held a second conference here in Melbourne and 600 women came to that. From that conference we published a report called *Still making a difference*. We have submitted a copy of that report for you. Importantly—and this would be much easier for you to read—the executive summary lists 61 recommendations. You will note that some of those recommendations are specifically addressed to the topics that you are particularly interested in today. I would now like Sue Timbs to talk to you about some of the specific issues we would like to raise.

Ms Timbs—Already this morning mention has been made of breast cancer as one of the models of how cancer services can be delivered and the role for consumers in breast cancer treatment. The issue of best practice has been one of those areas where clinicians working with consumers through the National Breast Cancer Centre have seen the development of best practice guidelines for early breast cancer, advanced breast cancer, young women with breast cancer and psychosocial care of women with breast cancer. Those guidelines stress the importance of multidisciplinary care and psychosocial care in terms of the best outcome for women with breast cancer.

What is happening on the ground? We know the theory of what should occur, but what really is happening? Lyn has mentioned that we had a conference last year. Out of that conference, the 600 women, jointly through us, made these recommendations. The recommendations cover a wide range of areas ranging from multidisciplinary care, metastatic cancer and rural and remote issues to more specific treatment issues. We looked for the common themes coming out of those 61 recommendations. They were quite telling. I will talk about three major themes. The first is the huge service gaps in the delivery of breast cancer services across the country. That is not just in terms of services in rural and remote areas versus those in the cities; it is also in terms of services between states and between patients being treated in the public sector and the private sector.

There is also the issue of standardisation of treatment, because big differences are now developing in women's access to drugs and treatment based on their financial circumstances, as new drugs are coming out and being trialled and are not necessarily yet on the PBS for an open listing. The other important message is that the guidelines which were prepared with best practice evidence by the National Breast Cancer Centre are not being implemented on a consistent basis across the country. I sat down with the guidelines and went through the 61 recommendations. If we were able to implement the guidelines, I could tick off over half of these recommendations as having been addressed.

In the previous presentation, mention was made of how people find out about the quality of care that is being provided or the type of care that can be provided in different centres. This is something that came out of the conference. Breast cancer consumers want to know whether or not their clinician and their cancer service are practising best practice. They want to know if they follow the guidelines. They want to know if they are going to be treated in a multidisciplinary team and have access to psychosocial services. That is a real issue for women; they want that information. The National Breast Cancer Audit, which is run by the breast section of the Royal Australian College of Surgeons, is an example of a way in which best practice is being assessed across breast surgeons. We are very much in favour of that as a method of getting information through to consumers, as well as other accreditation and credential initiatives.

CHAIR—Can you explain how that works for us?

Ms Timbs—The National Breast Cancer Audit?

CHAIR—Yes.

Ms Timbs—It is an audit that is conducted of all full members of the breast section of the Royal Australasian College of Surgeons. Lyn and I actually sit on the audit committees of the audit, together with surgeons and the administrators of the audit. We have set minimum standards of care based on the guidelines. We are in the process of collecting the information to be able to look at the performance of surgeons nationally and in different group areas—state, public, private. Individual surgeons can also access their data and see their assessment.

Senator LEES—Can you make that public? Will you be able to, for example, put it up on a web site somewhere so people can look at it?

Ms Timbs—As part of the communication of the data, there is a strategy for how it is to be communicated. That is still being finalised at the moment, but certainly the intention would be that information would become available to the public. We certainly will be disseminating information on a web site and through the college. It will be across a broad range, and certainly we can give you more information about that.

CHAIR—You mentioned accreditation. Is it your intention to do your own accreditation process, or will it be done through the college?

Ms Timbs—No. I will backtrack. Last year there was prepared by a consortium, which we were part of, a national standard for the credentialling and privileging of health professions. That set out what the proper process should be before a doctor is able to perform whatever his specialty is at a hospital or a health service provider. That is working out the individual basis for the clinician. But, above that, there should be a process where cancer services, for example, or other types of services should be accredited. Part of that accreditation should be based on whether or not they actually comply with the guidelines. In breast cancer, for example, it would be that they provide multidisciplinary care, they have a breast care nurse as part of their cancer service and they have referral mechanisms to psychosocial practitioners. There is a whole range of criteria that, if you are to be an accredited cancer service, you should be able to put ticks against, and that should be reviewed.

CHAIR—What about the outcome, though?

Ms Timbs—The outcome being either plus or minus—

Ms Swinburne—Do you mean survival outcome?

CHAIR—Yes.

Ms Swinburne—It takes a very long time to get that information.

Ms Lockwood—It is very difficult to get that information for an individual practitioner. Let us say I am diagnosed today. We would not know for five years whether I had survived or not. We would not know whether we had met the basic standards, which are that around 70 per cent of women will survive for five years, and we would not really know for 10 or 20 years whether this treatment has been successful. To measure each individual practitioner against an outcome like survival which is measurable in that sort of length of time is very difficult, unfortunately.

Senator LEES—Outcomes such as adverse side effects like the impact on arms have, from my personal experience, led women to delay even going through the process because of their fears of particular surgeons. Can’t that information be more readily available?

Ms Swinburne—It is hard to direct women to certain surgeons and not to others.

Senator LEES—No, just to give them the information and let them—

Ms Swinburne—That is what we try and do. We are confident that if we can get surgeons to comply with this we are going a hell of a long way. It is also fair to say that there is quite a lot of resistance amongst some members of the College of Surgeons to make that data public. There has also been quite a lot of resistance even amongst the college about how they make sure that members are members of the breast section. It has been quite interesting for us, hasn’t it?

CHAIR—Sorry, we have probably distracted your presentation.

Ms Lockwood—That is okay. We can pursue this a little further and deal with one of the issues that we were going to talk about. There is an issue of focusing on individual clinicians and their skills, but there is also the issue of focusing on multidisciplinary teams and their outcomes. I think performance indicators for those teams is probably as important. If people work as part of a team you tend to get better outcomes, so one of questions that women can ask is: do you work as part of a multidisciplinary team? If the answer to that is yes, then you have a better chance of a better outcome. I have some information to be handed to you later on. It includes a brochure about how women can make choices and it lists a whole series of criteria. One of those is: do you work in a multidisciplinary team?

Another thing we have been doing in Victoria as consumers is working with the Department of Human Services. I am sure you heard this morning about performance indicators for hospitals. One of those is that hospitals have multidisciplinary teams, access to breast care nurses and all of those sorts of things. That is in its pilot stage at the moment. We would very much like to see those hospitals listed publicly so that you can see that a hospital meets these performance criteria. That is probably an easier way to get around some of these problems than by dealing with individual clinicians and their particular needs.

Ms Timbs—In breast cancer there have been advances made, particularly in the area of early breast cancer, but there is still a lot to do in the area of advanced disease and in the psychosocial area. In 1998 when the first conference was held the No. 1 priority from our women was for every woman to have access to a breast care nurse. We have been encouraged to see the increase in the number of breast care nurses generally across Australia, although some states are markedly better than others. But it is important to stress that access to a breast care nurse does not amount of itself to psychosocial or supportive care of people with breast cancer. The breast care nurse is certainly an important part, and women very much value the breast care role. What psychosocial care requires a way of determining the psychosocial needs of women and then having the practitioners to refer them to to address those needs. That was something that was raised earlier by the speaker from Peter MacCallum.

There is a view in some areas that breast cancer can be ticked off, that it has got there, that we have addressed things and that we should now move on to the other cancers. Of course we support that the other cancers should be funded and should be addressed, but we also think it is important that, at the moment, breast cancer is seen as a model to be emulated by the other cancers. It is important that that model continues to be able to go forth so that it provides the light to be followed, if you like, rather than breast cancer stalling while the other cancers get up to the point that breast cancer is at. We need to be able to continue to move forward. I think it is also important to reiterate the role that consumers have had in breast cancer advances. All of us here today have been part of that, but it is really critical that that role continue.

Ms Lockwood—The Breast Cancer Action Group is an advocacy group, based mainly in Victoria, for women with breast cancer. In our submission we concentrated mainly on issues for women in rural areas and women with advanced breast cancer. We emphasise these needs because we think that they have been largely ignored to date. In saying that, I would like to dedicate what we have to say today to one of our members, Anne Pennington, who lived in rural Victoria, had advanced disease and died in December of last year. It was she who encouraged us to take up these issues and move with them as a group.

Because multidisciplinary care is best practice, we support that. Because care coordination is best practice, we support that and the use of breast care nurses. I want to talk a bit about the needs of women in rural areas. Rosetta will talk about the needs of women with advanced care. Then I want to talk a wee bit more about performance indicators, though not as much because we have already touched on that. To date, much of the thinking about multidisciplinary care has been undertaken in the hospital sector. In other words, hospitals like Peter MacCallum, whom you heard from before, actually practise multidisciplinary care.

In rural and regional Victoria, because of the distances that women have to travel, it is very difficult for the hospitals to practise multidisciplinary care and for that care to then follow those women when they go back into their communities. A woman may have a breast care nurse if she is lucky and she is in hospital but, when she goes back, there is no-one to follow her up. The ideal way to follow that woman up would be within the community care sector, but at the moment there are no links between the hospital sector and the community care sector. In areas in Victoria the breast care nurse may see the woman but she does not pass her on to the community health nurse when she goes back to her rural area. It is this silo system of ‘acute care sector’ and ‘community care sector’ that is causing part of this problem. There are also resourcing issues associated with that.

I think it is time we started to think laterally across all the care needs of those women so that you can get some multidisciplinary care, care coordination and all those sorts of things when you are in hospital but you can also get a reasonable amount of care coordination when you leave hospital. The point was made by the people from Peter Mac that there is a lot more outpatient care going on now, so those links with the community need to be stronger than they have been in the past. There seem to us to be very easy things to do, like faxing a discharge plan to the community health nurse so that she knows that a woman with breast cancer is coming. It seems to be very difficult for the system to actually do these simple things. That is all I want to say at the moment.

Ms Manaszewicz—I will address some of the issues that the woman with advanced breast cancer faces and, of course, her family and children face. First of all, we do not know for sure how many people are living in Australia with advanced breast cancer. There are no population figures that can give us a clear estimate. A guesstimate is that probably one in three women will go on to develop advanced breast cancer. The figures tell us that, of 11,000 women diagnosed each year, 2,500 die. They are rough estimates. It is rather staggering that in 2005 we have major hospitals all across Australia, I imagine, and major public hospitals in Melbourne, for instance, that cannot tell you how many women that they are treating have advanced breast cancer or how many have gone through.

We feel that it is definitely incumbent upon government to fund, to resource and to provide staffing so that at least we have some accurate figures and can ascertain the true depth of this problem. How else can you evaluate the efficacy of treatment, the end results or, if you like, the outcomes, unless you know the percentage of the population that you are dealing with? Even though I am talking about breast cancer, I am not sure if my comments apply to other sorts of advanced cancer, whether it is lung cancer, melanomas or anything like that. It is absolutely essential that the resourcing and the infrastructures are there, that those figures are collected, looked at and analysed, and that improvements are then made on the basis of those figures.

The other issue which is really important for the committee to be aware of, if you are not already, is that advanced breast cancer in particular is an incredibly varied disease. People can live up to 10 or 12 years, or possibly even longer, with metastasis. Ultimately, it will kill them; but it can also be viewed, and is viewed therefore, as a chronic disease. It needs to be treated in a far different way to in the acute sector where you are rushed in as an emergency patient and undergo surgery. To live with advanced breast cancer for 10 to 12 years implies certain physical, psychological and emotional repercussions on the woman and her family and also has repercussions on the way she is managed. At the moment it would appear that women with advanced breast cancer are totally falling through the gap in terms of multidisciplinary care, whether they are living in the country or rural areas, as Sue said, or even in the acute sector in public hospitals here.

I will just sidetrack for a moment. The way that advanced or metastatic breast cancer can manifest itself impacts on the kind of treatment you might receive. For instance, if it is brain metastases, lung metastases, bone metastases or liver metastases, all of these require decision making, different treatments and different modalities. A lot of the information on the best practice for treating some of these things is simply not there. Information for women is still a priority in this particular area. From our experience, from the number of phone calls we get, that information is not always getting through. The other point is that not only is information vital for informed decision making but, as the clinical practice guidelines on advanced breast cancer, state:

> … existential issues such as concerns about death, freedom, isolation and the question of meaning may become increasingly important to people with advanced cancer. They may in fact become as important as the physical, psychological and social support domains in determining quality of life.

It is that last phrase, ‘quality of life’, which is really essential in terms of advanced breast cancer, and that is where the multidisciplinary team comes in. Often it is not an emergency intervention; it is improving the quality of life of the patient—and, as I said before, that can take years. Often the multidisciplinary team can include the neurologist, the liver specialist and the orthopaedic surgeon, if there is a complication in spinal compression. An entire range of conditions, coupled with the psychosocial and emotional aspects, need to be dealt with. Also, the women may not have an acute episode for many years. The point that I am trying to make, and that we are all trying to make, is in relation to multidisciplinary care. The inclusion of psychosocial care, the need to have actual statistical data so we can go forward and the idea, as Sue mentioned before, of a link between community and acute care centres are vital. This should all be done through multidisciplinary care.

Ms Lockwood—The other point I was going to make was about performance indicators, but I think we have already dealt with that so we would be happy to take your questions at this point.

Senator KNOWLES—Firstly, I would like to congratulate you, Ms Swinburne, on receiving your little award the other day. I saw a photo of you clutching that great big bunch of flowers.

Ms Swinburne—Wasn't that funny! Someone made some very rude remarks about my chins in that.

Senator KNOWLES—I am glad I did not notice. You have done some excellent work; congratulations to you all. It is absolutely fantastic. There are only two areas I really want to cover in the time that we have today. One is pursuing this issue of rural and regional women. To be fair, I do not think it just pertains to rural and regional women with breast cancer; it pertains to anyone with cancer living in a country area and how we best deal with that. I notice that you refer to PATS. What do you think is the effectiveness of PATS at the moment across Australia? I know that in Western Australia, for example, PATS has seen a bit of a decrease in funding over time. What is your current understanding of it throughout Australia, particularly, of course, here in Victoria?

Ms Swinburne—PATS reflects more than just the problem with the travel scheme. It reflects a bigger problem concerning the states and the Commonwealth and the relationship with them. An example is women who live near borders. A woman who lives in Byron Bay has to travel to a treatment centre in New South Wales to be able to get PATS, even though Brisbane or the Gold Coast are much closer and her family and support could be there. There are a lot of things that are not sensible as part of the scheme. There are a lot of bureaucratic difficulties and challenges for women. In Victoria, we have tried very hard to simplify the system, to reduce the number of forms women have to fill out, to try and make the system work better. I think it is probably working better than it did five years ago but there are still a lot of improvements that could be made.

Ms Lockwood—The problem is the bureaucracy. You have to travel 100 kilometres in Victoria before you can get access to what is called VIPTAS here. We have instituted some regional radiotherapy services, which are making a huge difference to people. But if you live in Horsham and you want to go to Ballarat, that is 98 kilometres, so you do not get VIPTAS, despite the fact it takes you as long to drive 98 kilometres as it does to drive 100 kilometres. There are those sorts of sillinesses.

Having said that, because we have instituted regional radiotherapy units in Victoria they have actually changed the way they organise the system to make it easier for people to use those services. It is improving but it is slow, and it is not really based on practicalities; it is based on bureaucratic rules. I think that probably sums it up for most of Australia. But the interstate problem is a major problem, particularly for people in northern Victoria who might easily go to Albury or somewhere like that. You get those sorts of problems. In our submission we mention one of the problems of women living around Echuca and Moama. It does not make sense. There has to be a better way of doing it.

Senator KNOWLES—One of your recommendations is:

Accessible and reasonable cost accommodation for patient and spouse/carer close to treatment centres should be provided.

No-one would disagree with that, but if you take the case on the DVD, that, in some respects, almost exacerbates a problem left back on the ranch, so to speak. If you take everyone away from there, particularly in a drought, then who looks after the farm? What do you see as the best balance for looking after the home interests, the children and the property while having adequate care and support while receiving treatment away from home?

Ms Swinburne—What we would like to see is more flexibility, basically, so that there is not one system that applies to everyone. There are women who live in Alice Springs, for example, and who have family that live in Brisbane. It makes much more sense for them to go to Brisbane. They could take their whole family there—the grannies can look after the grandchildren and so on—but they are told they have to go to Adelaide from Alice Springs because that is their nearest large treatment centre. That is just crazy. It does not help anybody. So I suppose the thing we would like more than anything is the flexibility to be able to somehow judge each case on its merits so that some sense prevails rather than cold hard rules.

For Kathy, the woman on the DVD, there were all sorts of systems in place. She talks about the importance of her local community and how helpful they were. It is interesting that a lot of rural women say, ‘Look, we understand that because we live in the bush we’re not going to have a treatment centre at our doorstep,’ but they are prepared to be flexible and people will step in and help them. But there also needs to be some flexibility for the woman to work out what is the best thing for her and for her family without blowing the dollars. Women, as a rule, will not be silly. They will not go and stay at the Hilton with all their friends and everyone from their town. They just want to do the right thing for themselves and everybody else.

Senator KNOWLES—Have you had discussions with health ministers about these particular anomalies that are present in the system?

Ms Swinburne—Yes. The frustration is often that everyone blames everyone else. Often when we talk to a Commonwealth department it is the states that are responsible for that; and if you talk to the states their complaint is that, if the Commonwealth gave them more money, they would be able to do that.

Senator KNOWLES—Let’s overlook that politicking, if you want to put it that way. Take your Byron Bay case: the state government provides PATS to Sydney or wherever, but they will not provide it to go to Queensland. They could easily provide it to go to Brisbane or the Gold Coast, but the state government in Queensland would say, ‘Hold on, that patient now becomes our cost, not your cost.’

Ms Swinburne—That is right, and that is the problem.

Senator KNOWLES—The patient has to be treated somewhere from the pot of money, so that is why I am asking whether there is any practical solution that you have come up with and that you have put to health ministers that would overcome that anomaly.

Ms Swinburne—We have not found a practical solution because it would be that they somehow bend each way for each other, and we have not managed to get them to agree to that as such.

Senator KNOWLES—The Queensland government’s answer to that would be: ‘It is highly unlikely that one of our patients who would be reliant on our hospital system would go to yours,’ so the quid pro quo argument does not work.

Ms Swinburne—That is right.

Senator KNOWLES—That is something to ponder, isn’t it? Another issue is the appropriate local follow-up care for telemedicine. Do you think that telemedicine is working effectively? Do you see that there are improvements that need to be made?

Ms Swinburne—I think the model from Adelaide to Alice Springs is a really good one, and that has been going for several years now. They seem to have the technology under control. I know they have been trialling it here in Victoria, particularly from Geelong across to the Western District. They have a huge area to cover and they were very frustrated earlier on with the technological challenges. They seem to have those sorted now and it seems to work relatively well. I think that there are lots of opportunities for this.

It would be great for the women to be involved in this too. A lot of the women say to us, ‘It’s wonderful that my doctor here is speaking to the experts there, but it’d be great for me to sit in and hear what they have to say too.’ So I think that is an evolutionary thing, and that would be the way that we would want to see it. It is a good model for Australia, with our huge distances to cover, and it also helps the woman. The woman does not necessarily want to be travelling five hours to see an oncologist either if she can spot him or her at the end of a TV screen.

Ms Lockwood—I do not think we effectively evaluate telemedicine. We have another example in Gippsland in Victoria where it was set up as part of the Breast Services Enhancement Program. As soon as the resources were removed because the program ceased, the telemedicine process ceased. It was basically for multidisciplinary consultations. I think that is because they saw it as a resource issue and not a cost-benefit issue. Nobody looked at the costs and nobody really looked at the benefits, including the benefits for the woman as much as for the hospital and other services that were associated with it. We still just look at these things in terms of dollars rather than trying to do some assessment of the benefit and the cost. Is that unfair?

Ms Swinburne—No.

Senator LEES—In recommendation 47 you talk about information about complementary medicines being more widely available. The evidence we have so far is that women more than chaps are out there taking advantage of a wide variety of opportunities. Have you surveyed your membership? Do you have any statistics that you could leave with us on how many women are accessing complementary therapies and what sort of therapies they are accessing?

Ms Swinburne—Perhaps I can answer by saying we also work with the National Breast Cancer Centre and we are presently working to develop a survey of women to answer exactly those sorts of questions. Anecdotally, when we had the conference, the two workshops that filled in milliseconds were the ones around advanced breast cancer and complementary treatments. The people from Brown’s Dairy ran that workshop. There is absolutely no doubt that women are very interested in following this. It is about finding out what they can individually do to maximise their chance not only of survival but of feeling good.

A frustration that is expressed by women undergoing treatment is that the hospitals say, ‘Yes, we have nutritionists and we have these people,’ but if the women say, ‘I’m thinking of going on a vegetarian diet,’ or, ‘What can I take during chemo?’ the answer is: ‘It doesn’t matter. You can do what you like. It’ll make you feel good but it’s not going to make any difference.’ There is a discard of the woman’s desire to do something for herself. She will often then go off and do it and not ever tell the doctor what she is doing.

Senator LEES—I guess this is the issue: unless we can get some pressure from consumers—and this was mentioned by the previous speakers as well—a lot of this is not going to be sorted out, because the attitude for a whole raft of different diseases is: ‘No, this is the traditional medicine and this is the route we’re pursuing. That is not properly tried and tested.’ Can I encourage you in that. I think it is going to be a bit late for our inquiry.

How do you disseminate information to your members, particularly those who are finding that breast cancer does come back, as to which doctor or surgeon they can go to? Do you get approaches from women who have just been diagnosed? Are you one of the places that they look up on the web or ring to say: ‘This is what my GP’s just told me. Now what do I do?’

Ms Lockwood—There is a whole range of answers to that question. In New South Wales they have developed a directory of breast cancer specialists—and I am sure they will be happy to talk to you about that—which will tell you who they are. They are working on doing that nationally. Another way in which we disseminate information is through our respective newsletters and things like that. We send out a lot of information. One of the things that we are particularly concerned about is that women with advanced disease do not access palliative care services early enough. So one of the themes in our newsletter this year will be what palliative care is all about. That will come partly from palliative care specialists and partly from experiences that people have had.

In Victoria we have set up a group outside the health system, but obviously with links to it, called BreCan, which provides women with support. They have set up an advanced breast cancer support group and network that allows women to exchange information amongst themselves as to who is good, who is bad and what they have found works and does not work for them. There is a whole range of mechanisms that are going on formally and informally in the system.

Ms Swinburne—The other thing that we have done is produce a resource called the ‘my journey’ kit. We provide that to all women who are diagnosed with breast cancer—hopefully as soon as possible after diagnosis. Because it comes from us and it is informed by women’s experiences, women tell us that they are more confident about it because we are not pushing any particular barrow; we are sharing with them what other women have found. We also have a kit for women with advanced disease.

Senator LEES—Do we have copies of those?

Ms Swinburne—We would be very happy to send you the ‘my journey’ kit.

Senator LEES—That would be quite helpful, thank you.

Ms Swinburne—We think it is excellent. The women tell us it is excellent.

Senator KNOWLES—It is fantastic; it is a very comprehensive kit.

Ms Manaszewicz—May I just give a plug to another resource that is being used fairly extensively at the moment. It stems from an ARC grant, with Monash University and the Breast Cancer Action Group. We have called it Breast Cancer Knowledge Online, BCKO. It is available through a Monash web site. A lot of the information there is international information. It is also information that we feel is of value to women, ranging from the evidence based to be the experiential. The primary aim is that it is tailored. So, for example, if women are interested in menopause and alternative treatments or anything like that then they can access web sites which deal specifically with that. The advantage of a web site, of course, is that it provides 24-hour access and that women can be in rural or remote areas and access the information instantaneously. So this is another thing that BCAG in particular have been plugging.

In summary, once information is disseminated through the directory, through the ‘my journey’ kit or through BCKO, women will vote with their feet. Once they learn that, say, hospital A does have a breast care nurse as opposed to the private surgeon around the corner who is not part of a multidisciplinary team and does not have a breast care nurse then I would bet that they opt for the former. Those are the sorts of publications and dissemination of results—it does not have to be statistical outcome results—that are available. Women are not stupid and they will vote with their feet.

CHAIR—I am afraid that we are nearly out of time.

Senator MOORE—I just have one follow-up question. You talked about the web site hosted through Monash. How is that updated? You had an original grant from the ARC to get it in place, but I would imagine that the key thing about that web site will be to keep it relevant. How are you going to do that?

Ms Manaszewicz—We are still looking for a final home for it. At the moment basically it is a labour of love, so we are doing it on a voluntary basis. It will hold about 1,200 resources across the entire disease trajectory, which is more than a consumer can get from any one hospital or even from the Cancer Council et cetera. So if anyone has any suggestions we would love to talk to you.

CHAIR—We are now definitely out of time. Thank you for your submission and your presentation.

Proceedings suspended from 12.58 p.m. to 1.36 p.m.

GAWLER, Dr Ian James, Founder and Therapeutic Director, Gawler Foundation

GLASER, Ms Barbara Jane, Gawler Foundation

HASSED, Dr Craig, Group Session Leader, Gawler Foundation

McGOWAN, Mr Peter Anthony, Participant in program, Gawler Foundation

SALI, Professor Avni, Board Member and Group Session Leader, Gawler Foundation

STEPHENS, Mr Scott, Patient, Gawler Foundation

CHAIR—I welcome Dr Gawler and representatives from the Gawler Foundation. Do you have any additional comments about the capacity in which you appear?

Prof. Sali—I am also the head of the Graduate School of Integrative Medicine at Swinburne University of Technology.

Ms Glaser—I am a long-term cancer survivor and former participant in the Gawler Foundation program.

Dr Hassed—I am also a senior lecturer at Monash University, in the Department of General Practice.

CHAIR—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.

Dr Gawler—As well as being the founder and therapeutic director of the Gawler Foundation, I am a long-term cancer survivor myself. It is almost 29 years today since I was given a couple of weeks to live with secondary osteogenic sarcoma, so it is a bit of a pleasure to be able to be in front of you and make this presentation. From our foundation’s point of view, we are of the view that cancer services in Australia are in what are probably the early stages of a major paradigm shift. I think this shift in the approach to treating cancer has been fuelled primarily by the interest of the public and by their interest in the better outcomes than have been achieved in recent years. It is supported by a great deal of research, which we have essentialised in our submission. It is also being driven by progressive universities providing more graduate training and postgraduate training through institutes like the one Professor Sali heads for health professionals. It is also starting to show up in progressive hospitals.

Essentially, the issue here is that cancer affects every aspect of a person’s being if they are touched by it. It affects the patient, family, friends and health professionals in their physical life, their emotional life, their mental life and their spiritual life. My sense is that medical historians are not very far away from looking back on what was in fact a rather quaint or naive time towards the end of the 20th century, where for a while the medical management of cancer actually focused primarily on the physical aspect of the person involved and gave very little regard to those other aspects.

We feel pleased to be able to make a submission, having been responsible for starting the first of the cancer self-help groups in Australia that were run along holistic and integrated lines, back in 1981, and having been very involved in the development of that more integrated approach. Today we were hoping to touch on some of the key aspects in our rather lengthy submission and, hopefully, encourage those of you who have not dipped into it to have a look at it. We also feel that, by bringing along some of the people who have used these services, we are able to put more of a human face to what is available and what is happening.

I think terminology is really important. In our submission we have suggested that there is a real need to unify definitions, and I think ‘integrated medicine’ is one of the key ones, because it is a very good umbrella term. ‘Integrated medicine’ implies that the person is considered as a whole and that attention is given to the emotional, mental and spiritual life of the person, as well as their physical wellbeing. Integrated medicine also incorporates the multidisciplinary idea that a team of health professionals work together in a cooperative venture and are driven by what is best practice and that it is available in deciding what sort of treatment possibilities are put to individual patients. When you consider that, both commonsense and research point to it as being an ideal. But when you start to consider how you put it into practice, it is very demanding to do it well. It is demanding on finances and it is very demanding on the quality of practitioners who are able to work in that sort of environment. When we consider how that might be possible, just as a broad sweep, I think it is helpful to separate what can be done medically and what can be done by the patients and their families, being perhaps very much related but somewhat different issues. When you consider the hospital environment, for a more integrated approach to occur, it needs to come from the top.

One of the things I would hope that this inquiry might do is send a very strong message to the senior people in hospitals that this is the way to go—this is the aim—because if that paradigm, that way of thinking is coming from the top then the details will be followed through quite effectively. In terms of giving more presence to the patient-orientated side in hospitals then the example of Brown’s Dairy in Perth is a good model. There is nothing like having a specific presence where these things are held to give it support.

From the patient’s side of it, we are of the view that there is a great deal that the patients can do in terms of effecting their outcomes, not only quality of life but also survival. I am sure that for some of the medical people it is still a contentious proposition. But there is a huge public interest in how much an individual can effect the outcome of their illness. I hope that hearing from some of the people who are going through our programs will help—maybe by way of personal anecdote—but the research is certainly very strong in this area and Dr Hassed will talk a little bit more about that as we go on.

Hopefully, from the patient’s point of view, it is ideal to have a situation where people can meet in a nonclinical environment. Generally, we find that groups are a much better way of dealing with all the psychosocial aspects of cancer. Not a lot of research has been done on it, but what has been done seems to indicate that, in terms of cost-effectiveness, groups are about four times more cost-effective than trying to treat people in that way on an individual basis. Many people who have researched this would say that groups are best practice and, while that could be best supported by individual counselling, groups are a very effective way of helping to deal with the complexity of the psychosocial aspects of cancer.

I would like to hand over to Barb Glaser, who is a long-term cancer survivor. She works in a fairly challenging environment, managing the Melbourne Symphony Orchestra. She is a very good example of somebody who has been through cancer and, in terms of the aspect of her life as a cancer survivor, she is a very good advocate for how, if you approach it well, your life can be enhanced through the experience.

Ms Glaser—I am the director of operations at Melbourne Symphony Orchestra and I have worked with the MSO in various capacities for the last 14 years. In the last days of December 1988, at the age of 30, I was taken to hospital with a very painful and bloated stomach and a fever that my GP could not get under control. The day after some exploratory surgery I was told by a young intern doing his ward rounds that I would need further treatment—chemotherapy or radiotherapy. That was the first information I was given post surgery. The doctor delivered the news, pulled the curtain back around my bed and disappeared on his rounds again. I was in shock. At no stage during my stay at the hospital or, indeed, afterwards was I offered any kind of counselling or given any acknowledgment that I might be upset or need help. I was diagnosed with adenocarcinoma of the peritoneal cavity, a kind of mucous cancer of the abdominal area that is extremely rare in people of my age. The cancer filled up my abdomen with mucous and, left unchecked, this mucous would have smothered and blocked all my abdominal organs. I had small tumours throughout the area. The surgeon said that it looked as though someone had spilled a packet of rice in there and that, basically, it was not operable. My surgeon and, subsequently, the initial oncologist I consulted told me that I had better do everything I wanted to do before next Christmas and that there was no treatment to be had that would help me. Wanting another opinion, I consulted another oncologist a few weeks later. This one told me that probably nothing would work but, if I liked, he could try some extremely aggressive chemotherapy that would make me very sick and that anything else I tried to do for myself—in particular, any changes I made to my diet—would be useless and a waste of time.

Between the two appointments, I had found a copy of Ian Gawler’s book, *You Can Conquer Cancer*, and had read most of it. Everything he said in there made sense to me and, besides, I obviously had nothing to lose by taking on an approach in which I took an active and positive role in the recovery I hoped to make. I did not dismiss what the doctors had to say; I used it as a starting point and did heaps of research on my cancer and the exact types of chemotherapy drug treatments that had been tried in the past. I found yet another oncologist who was prepared to try the slightly unorthodox chemo that I had uncovered in my research. This involved administering the chemo drugs through a catheter directly into my abdomen. To the best of my knowledge and that of my doctor at the time, this had not been done before in Australia. My doctor was sceptical but, with no other real options, he decided there was nothing to lose and he got on with it. Every few weeks, I turned up to the hospital, had the catheter put it, had a litre of chemotherapy fluid drained in and then waddled home to bed for four or five days until I recovered a bit. I also enrolled in the Gawler Foundation’s 10-day course at the Yarra Valley Living Centre. What I learned and how deeply I changed during those 10 days changed not only the length of my life—I am totally convinced of that—but also the quality of my life. In particular, I realised that there were things that I could do that could change not only the course of the disease but the quality of the journey along the way. I am one of the people who would loudly say that cancer is the best thing that ever happened to me.

There were several things that the foundation offered me that the medical profession at the time did not. Firstly, the approach that the Gawler Foundation had to cancer was to acknowledge that I was a person and not just a bunch of symptoms and that it was the whole of me that needed healing, not just the out-of-control, mucous-forming cells. They believed, and educated me to believe, that there were a number of things I could do for myself that would aid the healing process along the way and stop me feeling like a passive victim who had no role in her own outcome. I particularly refer to the practice of meditation, which I had never done before and which I found incredibly helpful, taking control of my diet and seeing the importance of getting my head sorted out. I realised during the 10-day course that I had a lot of anxiety about a number of personal issues and that not dealing with them was a real obstacle to my wellness. Also, in a very prescriptive way, the foundation offered a spiritual perspective on life that was enormously beneficial. I am absolutely certain that, had I not made a full physical recovery, I would have been able to have a happier, more peaceful, more resolved and much less frightening death as a direct result of the wisdom I gained from Ian, from others who led the course and, importantly, from the friends, the cancer patients and the support people I met during that time.

By the time I finished the course, I felt better than I had for years, not physically—as I was still pretty ill and had many months of chemo ahead of me—but, in every other way, I felt as though I was on a real path to wellness. On a psychological and spiritual level, a lot of the fear of death had been worked through in a very expert environment with people who really knew what they were doing, and this was extremely liberating as it often is in life when you finally have the courage and the right environment to confront the stuff that is too scary to talk about.

After the course, I had tonnes of information—and I knew how to go about finding tonnes more—about how to maximise my chances of healing through eating well. Although one of the first doctors I saw told me that fresh juices were a waste of time and that all that would happen was that my skin would turn orange from the carrots, which it did a bit, it just made total sense to me that every nutrient or toxin I put into my body would have some influence on my immune system and my outcome. I also grew to love and value my time out while meditating. Again, I am absolutely certain that it influenced my outcome.

People often asked me—and they still do—whether it was the chemo or the other things that made me get well. As far as my experience goes, that is not the right question. What helped me get my health back was a fully integrated approach, which was more than any one discipline could offer. I needed the chemo, the meditating, the diet and the psychological help. From what the doctors said at the time, they certainly did not think that just the drugs could do it. Whether I would have got well without the drugs at all, I suppose I will never know, and I do not think it matters. What did matter at the time was that the Gawler Foundation helped me to pull all the different strands together. There is a lot of expertise in a lot of fields out there but, as a cancer patient, you need them to work together. I just cannot stress that point too strongly.

This is a small vignette of how far there is still to go in this area. I was talking to a friend the other day, who is completing his final year of medical studies to become a specialist. So he has put in about eight years of full-time study. At the moment he is doing a placement in a hospital where he is dealing with terminally ill patients on a daily basis. I asked him how much time during all his studies had been dedicated to teaching him the skills of how to talk to patients in a sympathetic or empathetic way. ‘None,’ he said, ‘none at all’.

It seems cancer is becoming increasingly prevalent in our community. I am sure I have more friends who have had it than my parents did at my age but I have been fortunate to be able to suggest to some of them that they take an integrated approach to their disease and look at what the Gawler Foundation has to offer. The husband of a friend who died last year from breast cancer told me that both he and his wife strongly believe that the work that she did on her health through the Gawler Foundation added at least three years to her life. Not all of my friends who have had cancer are still alive but with no exceptions the ones who adopted a more integrated approach felt very enriched and fulfilled by the experience. They died in peace and with no fear. When medicine has done as much as it can, surely it is the experiences of the human beings and looking after the needs of the whole person that count for the most. To do this, an integrated approach incorporating knowledge, compassion and wisdom is vital. My experiences with Ian and the Gawler Foundation offered me all of this, and I cannot value it highly enough. They deserve every possible support. Thank you.

Dr Gawler—Thank you, Barbara. I would like to hand on to Dr Craig Hassed, who is a senior lecturer at Monash University in the Department of General Practice. He comes regularly to the residential programs we run for people affected by cancer at our centre out at Yarra Junction, where he lectures on mind-body medicine. Craig is going to talk a little bit more about the research that is available to support this proposition of a more integrated approach and the potential that people have to help themselves.

Dr Hassed—It is a pleasure and a privilege to be here. I just hope the medical student or the junior doctor referred to was not a Monash graduate because I hope we integrate a lot more of this into our curriculum. In fact, I have just come from three hours of lecturing this morning to our first and second year students about these very issues. I certainly encourage in our students a healthy scepticism, which is not a tendency to accept things unquestioningly without looking at evidence and considering some of the hard questions and also examining their own personal experience and clinical experience. I think there are other forms of scepticism which are not entirely healthy as well, such as a closed mindedness even in the presence of evidence and long clinical experience and also an unquestioning acceptance, sometimes of treatments that obviously have a huge amount of financial backing with that backing supporting research but not always a lot of independent research. Sometimes we are a little bit unquestioning as well about some of the things that are widely used in conventional medicine. So we try to encourage the students to have a balanced and integrated approach, if we can.

Some of the things I was speaking to the students about this morning were related very much to evidence and the holistic approach to cancer, particularly integrating the psychological, emotional, social and in fact spiritual health, and what impact that has on a person’s ability to cope and what affect that has on physiology and on outcomes and survival. From the most recent review of the literature, we can say that effective psychosocial support programs that significantly improve the mental, emotional and social health of the participants who go through them are associated with significantly longer survival and better survival. So a successful program improves mental health and quality of life.

There are also some studies which show that a program that does not significantly improve mental health and quality of life is not associated with longer survival—that is, not all cancer support groups seem to be as effective as every other. It may be related to the skill of the leaders of the program, it may be related to the particular approaches that are taught, it may be something to do with the emotional or other form of support that the participants give each other. What we can say is that effective cancer support programs do have an effect on quality of life which seems to translate into a very useful side effect of longer survival—that was from a review reported in the *New England Journal of Medicine*. In relation to specific cancers, to cite one example with malignant melanoma, there was a study by Fawzy, a psychiatrist—nearly all this research is done by psychiatrists and not oncologists, which is interesting in itself —looked at a six-week intervention for people with early stage melanoma. At the six-year follow up, he found a halving of recurrence rate and also a 70 per cent reduction in death rate. He also followed immune function and some other parameters to try to explain any observable differences and found that those who learn to deal with stress better seem to have a much better and healthier physiological defence against the cancer in terms of immune function than the other group.

So all we can say is that the only randomised control trial—for example, looking at melanoma, which is one of the cancers which we know the immune system attacks most aggressively—had an extremely positive outcome. Yet very few patients would ever be told about this. Perhaps, even if one wanted to take the most conservative approach and say, ‘There is some promising evidence but let us see whether it can be reproduced and replicated,’ one would have to say that even on the basis of current evidence, patients ought to be told something about a high quality randomised control trial reported in one of the world’s leading psych journals, but that does not seem to happen.

There seems to be a long lag between research and evidence finding its way into clinical practice and maybe this is the way doctors have been educated; maybe it is the lack of a large amount of money to promote non-patentable ‘products’ for patients, maybe it has to do with a particular way of thinking about cancer which finds it difficult sometimes to think outside the square.

I could perhaps mention another program but from a totally different dimension. I am aware of no single trials that look at a totally integrative approach looking at lifestyle, meditation, support program and so on for cancer—none that I am aware of in the whole of medical literature, which is surprising. When we look at research on heart disease in the Ornish program—stress management, group support, meditation, low-fat vegetarian diet, stopping smoking, moderate physical exercise—that associates a reversal of atherosclerosis compared to usual care. Mind you, people did not forgo their usual care either and nor in the Fawzy study did people forgo appropriate surgery. All we can say is that from that trial, looking at reversal of heart disease, there were $US58,000 per patient cost savings because they did not go on to more aggressive forms of heart disease and have to have the bypass operations of the nearly 2½ times as many cardiac events in the usual care group. So all we can say is that by any account it should be part of standard care.

For the first time, the Ornish program has been applied to a group of males with early stage prostate cancer in the watchful waiting group. That study is halfway through its progression. The preliminary findings were reported at the American Neurological Association last year, but what they found in the holistic lifestyle group was again a reversal of PSAs in the watchful waiting group for the majority, often coming back towards the normal trend, whereas for the majority of patients a progression who just had the usual watchful waiting without any lifestyle intervention. That is the first holistic or total lifestyle or integrated approach that I am aware of for any form of cancer.

If we can take a message away from some of this it is not to be unquestioning in our examination of the evidence but that at the same time we need to invest a lot more time and resources into the research which can be not only effective for quality of life, mental health and emotional health, but also potentially can save large amounts of resources for the system itself in that it supports people and helps to prevent or make more simple the management of various complications as well.

It is not just with cancer; I could cite others—for example, multiple sclerosis—where there are things that patients are not told that have an effect on the progression of their disease. This is an issue that goes well outside of cancer to lots of other conditions as well. At Monash we are trying to educate a more integrated style of doctor. My concern is that if patients do not get this sort of care—an integrated approach with the best quality oncological care that they can get—then they will tend to look outside of the conventional system, sometimes to good effect, but sometimes also perhaps looking into treatments which are not founded, getting advice which is not good, not being monitored by their oncologists or general practitioners in the way that they need to be and getting advice to forgo necessary treatments. The more that this can be a part of integrated care the better the results for cancer patients one day. So there are a few thoughts that are on the table for your consideration.

Mr McGowan—Thanks very much for the opportunity to speak to you today. I am 45 years of age. I am married. I have four dependent children ranging in age from 19 down to 12. I live in rural Victoria, about 25 kilometres south of Wodonga. I am a solicitor; I practised as a solicitor for 22 years. I sold my practice when it became clear to me I had to concentrate full time on my health. My wife, Diane Shepheard, made a written submission to this committee—submission No. 25. My evidence today is given in conjunction with her written submission. I currently have metastatic melanoma that is inoperable. It is in my chest. My medical history is that in 1997 I had a small mole removed that was mistakenly misdiagnosed. It was finally diagnosed as metastatic melanoma in 2003. Since then, I have had seven operations, six weeks of radiotherapy and a year’s treatment of Interferon, which is a type of chemotherapy. When the cancer came back after that year’s treatment, I came to the realisation that I really needed to look beyond conventional medicine if I was going to be well and disease free. At that stage—and it is still the case with me—conventional medicine offers palliative options only; it is certainly not going to cure me of the cancer that I currently have.

My current treatment, if you like, is all complementary—meditation, diet, positive thinking and exercise. With that background, and looking at the terms of reference, I feel I am able to very briefly comment on terms of reference (a)(i) to (iv) and (b)(ii). Looking first at (a)(i), ‘The efficacy of the multidisciplinary approach,’ in my experience the multidisciplinary approach within conventional medicine is excellent. I had services in Albury-Wodonga and also in Melbourne—surgery, chemo and radiotherapy. It all worked very well. It was organised by my oncologist, it was efficient and it was really good. There does not seem to be any interfacing between conventional and complementary medicine, in my instance anyway. Normally, conventional medicine is the first port of call when someone is diagnosed with cancer. In my instance, there was no referral to complementary medical services or treatment and there did not seem to be any understanding of what complementary medicine had to offer from the conventional practitioner's point of view.

Moving on to (a)(ii), dealing with case managers, when I was diagnosed with cancer I felt fear, anxiety, and confusion. My decisions regarding conventional treatment evolved quite naturally. They were taken on the basis of professional advice given with the best possible intentions. They all seemed to make sense at the time—I am talking about surgery, chemo and radiotherapy. If I had known then what I know now about other factors some of those major decisions about some of those conventional treatments would have been quite different. I was given little general information about cancer. There was no discussion or referral to credible complementary services as either a primary or adjuvant treatment. I can certainly see a role for a case manager as a source of information about cancer generally, and also as a source of information regarding referral to the whole range of services, conventional and complementary.

So it is at that initial stage that information could be provided by that case manager, but they would have to be well-informed and unbiased. In my experience, the oncologist did that for me in the conventional medicine sense, but the oncologist has a bias towards conventional medicine. GPs are too busy to provide that service. I see a possibility for that sort of case manager role being fulfilled by a clinically trained educational nurse, as seems to be the case with patients diagnosed with heart disease or diabetes.

Looking at the terms of reference (a)(iii), the psychological and social factors, in my experience of conventional medicine these factors were not addressed at all; they were nonexistent. With the complementary services and treatment there is a heavy focus on psychological and social factors. It is a huge strength of the Gawler program—the details are covered in their submission. The outcome for me and my wife was a sense of empowerment, hope, personal growth and removal of fear and anxiety after we attended the 10-day residential program at Gawler. That was in December 2003 and I have subsequently attended a number of follow-up programs at the Gawler Foundation, Yarra Valley. Interestingly, when my wife and I attended the 10-day residential program in December 2003, my feeling was that it would assist my wife in coping with my death. I went there with a positive attitude, but that was really one of the significant benefits that I was hoping to achieve out of it for us as a couple. That is just so far removed from what has happened to me since. When I look back on that and my whole attitude, it has been a complete life change for both me and my wife.

Looking at the terms of reference (a)(iv), the regional Australian services, as I have said earlier, in my experience with conventional services in regional Australia—and Albury-Wodonga is a large provincial city—they were excellent. Hospitals, oncologist, radiotherapists and chemotherapy were all available. Referrals to Melbourne hospitals and visits to Melbourne hospitals for surgery were all there and efficient. From my regional point of view that worked extremely well. Complementary services are a little bit more difficult. They are mostly sited in main cities, in my case Melbourne, and it was quite difficult to transpose what you learned in a complementary medicine sense to the rural setting. It is very difficult to get sympathetic doctors to assist you in your complementary program in the regional centres.

Looking at the terms of reference (b)(ii), the efficacy of less conventional approaches, this is an area—where as a person currently suffering cancer and going through the process—that I am quite passionate about. The efficacy of credible complementary approaches in both primary and adjuvant therapy is quite significant, and I look at the Gawler program as an example of that. You look at diet, nutrition, meditation and psychological factors. It is a holistic, informative and empowering approach. In my position these therapies are the only treatment or services that offer any hope of remission by boosting my immune system to fight the spread of cancer; it is not just treating the symptoms of the disease.

In conclusion, I am extremely grateful for the quality and efficacy of the services that I have been offered in the conventional sense—radiotherapy, surgery and chemotherapy. They have been extremely expensive services funded by the taxpayer in the main and they have been provided in good faith with my best interests in mind on the part of the service providers. But they will not and they cannot heal me of my cancer. The complementary services and treatment that I have received and continue to practice are at considerably less cost to the taxpayer. They are at considerable cost to me. They provide me with the possibility of being disease free, but in the event of my death due to cancer, they have given me the tools and knowledge to live a more enriched, satisfying and fulfilled life, despite the disease. That has been the big positive of my experience with complementary medicine, in particular the Gawler Foundation.

In my mind, the conventional approach to cancer can be described as in the common bereavement notices that you see where someone has died after ‘a long battle with cancer’. My experience with the complementary approach has been that it has offered me a long and fulfilled life with cancer. Thank you very much for your time.

Dr Gawler—Moving on, I will ask Professor Avni Sali to speak. It is probably helpful to point out that Professor Sali has been on the board of our foundation for 21 years. During that time, he was an associate professor of surgery at Melbourne university, and it was probably a fairly avant-garde situation for him to take up. He has been very much a pioneer in putting forward this idea of a more integrated approach, which is well reflected in his position now as head of integrative medicine at Swinburne University of Technology, where he runs postgraduate courses for doctors in integrative medicine.

Prof. Sali—Thank you for the opportunity to speak here today. Ian mentioned that, when I was at the University of Melbourne, a letter went to the university from the president of the Anti-Cancer Council at that time to say that it would be best if I were not involved with the Gawler Foundation and that the university should not be involved with this cancer support organisation.

My background is that I am a surgeon and I am also trained in oncology. I have worked in a university teaching hospital for about 25 years, and I have been mainly responsible for the establishment of the first postgraduate medical school of its kind, eight years ago, in integrative medicine. This medical school is primarily focused on educating doctors about complete medicine, or integrative medicine—the medicine that combines the best of both worlds, the scientific aspects of conventional medicine with the scientific aspects of complementary medicine, in order that the patient can get the best result.

Cancer is a chronic condition. In order to get the best result, you need to be able to use every possible resource. It is not a simple condition, as we well know. It has possibly the poorest prognosis of all the illnesses that exist. It is really amazing to me that in general in oncology there is so much resistance to looking at other possibilities, particularly in the area of complementary medicine. We now know, as Craig has been talking about, that when you are feeling good your body is working well. Hence when your body is working well your defences are working well, as are your hormones, your chemicals, which can either inhibit the growth of cancer if you are feeling good or stimulate the growth of cancer if you are not feeling so good. We now have scientific evidence for that. Therefore it becomes critically important to make the person feel good, at the very least.

The other thing that is important when you are dealing with a difficult condition like cancer is to at least have the patient as healthy as possible. So talk to them about their stresses and get them to get as much support as they can, perhaps from support groups and through meditation techniques, and also get them to look at their diet. We now know that there are nutrients that actually feed cancer. There are other nutrients that can inhibit cancer and can even kill cancer. In addition to that, there are other treatments, including natural treatments such as nutrients, that can enhance the immunity of the patient and help to improve their general condition. At the very least, you should be trying to make the cancer patient as healthy as possible, even if you are unable to specifically treat the condition.

Until two years ago we had hyperthermia as a treatment here in Melbourne. Hyperthermia has been shown scientifically in some cancers, such as cancer of the cervix, to double the prognosis—not double the survival but double the prognosis—when you combine it with radiotherapy. However, the centre received little support in relation to the treatment of these conditions that it eventually had to close. That was a pity because it was the only centre here in Australia to do with hyperthermia.

The general emphasis in the university teaching hospital is on diagnosing and treating the condition. There is also great emphasis on the cancer being an aggressive or non-aggressive cancer. Basically, what we really mean is not that the cancer is aggressive but that the body’s defences are not so strong and have allowed the cancer to be aggressive. Therefore, there needs to be more emphasis on the human and on what is happening to them and their overall lifestyle. It should be routine that a patient’s lifestyle is looked at—their stresses and their pressures. You do not get cancer when you are on top of the world; you tend to get cancer when you are surrounded by all sorts of difficulties that you are susceptible to.

We also need to look at the diet to see how it can be improved, and then we could look at the preventive aspects. We could go to the breast clinic or the digestive clinic, reviewing people who have had bowel cancer. All of the emphasis was on, ‘When are we going to do the next colonoscopy?’ rather than saying to the person: ‘How are things going with your lifestyle? What have you done about your diet?’ We know that all of those can influence whether or not they develop another cancer. There is very little emphasis to do with prevention. We need a change in the culture within the university teaching hospitals so that health and prevention become more mainstream. We educate doctors throughout Australia and the world, and unfortunately we do not have one oncologist who is interested enough to come along and learn about the science of integrative medicine, and we do a considerable amount of research in this area.

There is another problem too. At a general practice level, the government funds a doctor who sees a patient every 10 minutes far better than a doctor who will spend up to an hour with a patient. In fact, the doctor who spends up to an hour with a patient will earn about a third as much as the doctor who sees a patient every 10 minutes. I think 10-minute medicine is generally really very ineffective and very costly medicine.

I would like to finish off with a quote from the editor of the *Lancet* medical journal, which is one of the leading medical journals, if not the leading one. It says:

> We must act on facts and on the most accurate interpretation of them, using the best scientific information. That does not mean that we must sit back until we have 100 percent evidence about everything. When the state of the health of the people is at stake … we should be prepared to take action to diminish those risks even when the scientific knowledge is not conclusive …

This is, of course, of particular importance in the cancer patient.

Dr Gawler—Finally, here is Scott Stephens, who is fairly well in the middle of dealing with a cancer situation and can speak from very close experience.

Mr Stephens—I am 28 and a cabinet-maker by trade—I make furniture. In 2000 I had a mole taken off my leg which turned out to be a melanoma. Basically for the last five years it has been a series of battles. I have sort of beaten it several times, but each and every time it seems to come back. My approach to the disease was that when it turns up I treat it with surgery and drugs, reach remission and go back to my old life and my old job. But in September 2004 it was back again. I had a major operation on my chest this time, and follow-up scans showed that not only did the operation not go so well—they did not get it all—but it had also spread to my bowel and pelvis this time.

Coincidentally, a friend mentioned the Gawler Foundation. Until my wife and I attended one of the ten-day courses up there we had no idea of any other form of treating cancer besides mainstream medicine. Its principle of treating the whole being—mind, body and soul—made so much sense to me. Instantly I could see why all my attempts to fight the disease in the past had failed. Whilst up there, we learnt things like meditation, dealing with emotions, nutrition and diets, developing a good support network and trying to stay positive through the whole thing. It was seriously a life-changing experience.

My experience in the public medical system has also been really good. I am a patient at Peter MacCallum, and within a week of being referred there I was operated on. On Monday of the first week I had a consultation, on Tuesday and Wednesday I had scans and tests and by Friday they were operating on me. The fact that they rushed me straight through I thought was amazing. But once I had attended the Gawler program I quickly realised what mainstream medicine lacked. In the public system they never once asked me about my diet or mentioned the benefits of meditation. We did not talk about any other ways that I could try to increase the chance of my survival. They did not even recommend a support group, although I have learnt that only by attending the weekly follow-up Gawler program—which I do—you significantly increase your odds of survival. That is just by attending a support group—it is amazing.

Since December I have practised these principles strictly. I have juice several times a day and a full vegan diet, I meditate for a couple of hours a day and I quite enjoy it. It is far from a chore. My most recent scan shows good results. I have a reduction in most of the tumours. My oncologist was amazed. This integrated approach to the disease really works. I believe in it and I am sure others would if they knew it existed.

Dr Gawler—I have a final couple of comments and then I would love to get some questions. It is probably helpful to say that our organisation has been one of the main groups that have been seen to be working actively in this area of complementary therapies. We started in 1981. We have been going ever since. Currently, we have about 50 people on our staff and a budget of about $2 million. We have never received any federal government funding. We got a $15,000 grant from our state government about five or six years ago—a one-off grant.

Many people in the community have the perception that our courses are expensive but in fact we fundraise 20 per cent of our budget so all the programs that we run are 80 per cent funded by what people pay and 20 per cent funded by what we can manage to fundraise. But the fact that we put all our fundraising into offsetting the costs of the people who come to our programs means that it is very difficult to build our organisation and provide better facilities. We run our support groups in Melbourne in what I believe are very inadequate physical facilities. Although the courses are very good and people come for them, the actual amenity that we can provide with our funding is very limited.

There is a growing recognition of this integrated approach and the need for more of it. But to provide it well, particularly from the patient’s point of view in terms of running groups, it actually requires really active support. What I hope is that through this inquiry that support will come via the conclusions you are able to reach and the message that those conclusions sends out to the community generally. I hope that will give impetus to more training of health professionals in this approach so it is given more respect and weight in the overall management of cancer.

Also, there is a huge need in Australia for more research funding in this area. In the States, they have about a $US20 million budget for research funding into complementary therapies each year. In Australia, there is no designated funding in that way at all. We as an organisation first approached the Cancer Council for funding in 1984 to research what we were doing. We have always been turned back on that. With Dr Hassed’s support and the full support of the Monash University medical centre, we tried a number of times again in the late nineties and in early 2000 to get funding through the Cancer Council for research. It is extremely difficult to get that sort of funding. That is something else that could be addressed.

There is also a real need to address what to me seems like an inequity in terms of the support people affected by cancer get from funding, particularly through Medicare. Patients are well supported, in my view. I am sure you can always make arguments about this but, in the main, patients who go see their GP get Medicare support, they see a specialist, they have surgery, they go into hospital, they have chemotherapy, they have radiotherapy, and they get support for all of that through the public system. Patients can go along with those approaches and therapies in anything from a very engaged, active way to a very passive way. Somebody can smoke and drink and be treated for lung cancer and still get government support to do that. Whereas, in the current situation, if they go to a support group they actually have to pay for themselves. I would contend that, quite clearly, if they go to a support group they are going to put less of a burden on the system because they will be more independent and they will do more things at home. Evidence shows that they are likely to spend less time in hospital and they are likely to use less medication, yet they have to pay for the privilege of helping themselves. One of the terrific outcomes that may be possible and which you people could help to drive is for really serious consideration to be given to Medicare rebates going to people who are going to self-help groups particularly and self-help approaches generally.

From the foundation’s parochial point of view, we would love to get some financial assistance. We have a great list of things in our general recommendations that we could really use support with. Again, it would be lovely. Melbourne has really led the way, I think, as a city in a lot of this integrated medicine. There is the work that we do, Ainsley Meares was a pioneer in it, there is Avni’s work and there is what is going on in the hospitals, like at Peter Mac at the moment. To have some more designated space for that, like a Melbourne centre that could bring all this together, would really be a wonderful outcome as well. We have said a lot; perhaps we can answer some questions.

CHAIR—Yes, although we probably will not have enough time to deal with all the issues we would like to. Do you get many referrals from what we might describe as the orthodox cancer specialists or centres?

Dr Gawler—We get a few referrals from oncologists but not very many. More and more when patients talk with their specialists about coming to a place like ours they get support rather than discouragement, but there is still quite a range in that, actually. A lot of patients do feel that their mainstream medical people are not very supportive of this approach. As a consequence, I think too many patients are quite shy about telling their doctors about what they are doing for fear of having what they value devalued.

CHAIR—How many people are in your program at any one time?

Dr Gawler—We run a 10-day residential program where people come as a group. The groups usually average around 36 people. At our residential centre at Yarra Junction those programs are running most months. With our groups in Melbourne we tend to have about 25 people in the group and those groups are ongoing. We are limited in what we can do in Melbourne by our financial situation, actually. If we had more resources, we would be running more groups.

CHAIR—So there is a larger demand for your services than you are able to provide for?

Dr Gawler—Yes, and I am sure that around Australia there is a great interest in this. We get people coming from all states of Australia, and we get a lot of people coming to our residential program from New Zealand and, increasingly, from Asia. In New Zealand there is very little at all like what we can provide in Australia in this way.

CHAIR—I do not want to take up much more time, and there is a lot I would like to ask you, but there is one question which I think you need to address for us. It goes to the terminology that is being used. You have talked about complementary therapy. We heard representatives from Peter Mac talk about complementary therapy—I think these were their words—as not really changing the natural history of the disease but basically just enhancing the patient’s wellbeing. From what I understand, you have been saying you would not agree with that definition of complementary medicine. I just want to get your view of complementary medicine and your therapies clearly on the record.

Dr Gawler—In our submission we have a section on the definition of key terms. Perhaps I can refer senators to that section. We used the definitions that are currently in vogue and have been defined by the National Center for Complementary and Alternative Medicine in America, which is a large body that is probably the authority in this field in America. They have definitions which I think are quite workable. They do define complementary medicine as that which works in conjunction with orthodox medicine and they define orthodox medicine as that which is taught in medical schools and practised in major hospitals. In that definition, they do not address the issue of whether complementary medicine is therapeutic or passive support. I think your question is suggesting that the definition you might have had from elsewhere is that complementary medicine provides what is effectively passive support but does not have a therapeutic role.

CHAIR—Yes.

Dr Gawler—I think there is both commonsense and a lot of research that says complementary therapies are actually therapeutic and can actually affect the outcome. I think all the studies indicate that is highly likely, and commonsense tells us that how you respond to any situation in life is likely to affect the outcome. I was just talking with Barb and I know we both feel that if we had not done these complementary therapies we would not be here today. I feel no doubt about that. As I say, there is quite a body of research and we have got about 160 references in our submission which we can summarise. But, if we are trying to get a figure on this, I think the best estimate that is reasonable—and this is a conservative estimate—is that when people do these complementary therapies in medicine they are likely to double their survival time. That seems to match with the best research that is available at the moment. As well as that, you consistently get people who become long-term survivors—like Barb and I have—which would be quite outside the expectations of mainstream medicine.

Dr Hassed—I am just going to add a footnote. I think that would be more of a common perception than a definition that is generally applied in medical discussion and debate, so that would be more of a common perception of complementary therapies. Lumping in ‘all complementary therapies work’ or ‘all don’t work’ and trying to sort the wheat from the chaff is a very important issue in relation to complementary or integrative supportive therapies. That would be like saying ‘all medical therapies work’ or ‘all don’t work’. But I think the definition you gave about them being ‘only supportive but not therapeutic in any way’ is more of a common perception.

Senator HUMPHRIES—Can I come back to this point about the distinction between therapeutic things and interventions designed to assist the mental state of a cancer victim. In what you and Professor Sali have said today, for example, you have picked up this tension between conventional medicine and alternative medicine, and this is going to be the key problem not just in us recommending that there should be a different view about complementary medicine but in governments taking up those recommendations if we were to make them. There is this resistance on the part of conventional medicine to many of the things that are being done in fields like yours. The troubling thing about the area of the therapeutic effects of complementary medicine is the lack of apparent hard data about how well it does affect the natural history of a disease, particularly cancer. I am still not sure why that evidence is not available. Dr Gawler, you were here this morning and you might have heard the Cancer Council of Victoria talk about the unwillingness of proponents of complementary treatments to play by the rules, an unwillingness to use valid research methods. Have you encountered those sorts of attitudes or reluctance or the sense of an ‘I don’t want to be part of that system’ approach on the part of some proponents of alternative or complementary medicines?

Dr Gawler—If you do not mind my saying, in your question you have highlighted a couple of the issues. I will start with the terminology. With respect, I would say that a lot of people with cancer would find it uncomfortable to be described as ‘victims’, particularly given the way we would talk to people. A victim is somebody who is powerless. We would rather talk about ‘cancer patients’. Even that is probably better terminology. Even ‘people affected by cancer’ is probably more politically correct these days.

CHAIR—They were actually described as ‘consumers’ by some people today, which I found a little bit bizarre.

Dr Gawler—I myself think ‘patients’ is the best word. I feel comfortable with that. ‘Victims’ reflects what I think is an old view that when you got cancer, you were a victim and there was nothing you could do about it. The approach that we take, as represented by integrated medicine, is that there is a lot you can do about it and that, even if the medical options are rather limited, people still have their own potential to influence their situation.

The next point is that you used the word ‘alternative’. In the field of cancer medicine, ‘alternative’ is a word that has very much been used pejoratively. Particularly in mainstream medicine, alternative medicine implies medicine where people are going to go and do something other than mainstream medicine. In the definitions that we have set out, the actual definition of alternative has two aspects to it. One is where there is a genuine alternative, like a proven alternative. If you, say, had appendicitis and you were in China then there would be genuine alternatives: Western medicine—surgery—or traditional Chinese medicine, which treats appendicitis quite well. They would be reasonable alternatives to consider in choosing which one to go to.

There is also what in mainstream medicine is very much regarded as the bogy in this field, which are the unproven alternative remedies, like the ‘wing of bat’ idea—that is, take that and it is going to cure your cancer. My own feeling about this is that when you look at people who are involved in complementary therapies, there are those who are very keen to work in conjunction in the true complementary sense, like I would suggest our organisation does. We have medical people who present our programs and who we work very closely with. We are always trying to build bridges. But then there are other people who do take a much more adversarial approach to this and are much more cavalier in how they progress.

One of the services we provide to a lot of people with cancer is to help to sort out some of these issues. We probably help quite a few people who have turned their back on conventional medicine to go back to it. We tend to attract people who are nervous for whatever reason or have a mind-set against, say, surgery or chemotherapy. Very often they can come to us and see us as being very patient focused and interested in their welfare. We can talk them through their concerns and help them to do what is actually in their best interests. Likewise, we probably help some people realise that there may not be much point in taking chemotherapy if it is only going to give them side effects and not have much real benefit for them.

Senator HUMPHRIES—You have talked about good and bad complementary medicines—there is some good stuff and some stuff that is not worth approaching and using. How does a funding body—for example, the Commonwealth government in considering who to allocate Medicare rebates to—distinguish between those two sorts of medicine when there is not really much empirical evidence about what actually is therapeutically effective or beneficial or not?

Dr Gawler—Again, with respect, one of the problems in this field is that the perception of the lack of evidence for complementary therapies is more of a myth than a reality. There is a huge body of research. Perhaps Craig might be best to speak some more to this. I keep up to date with it as best I can but it is a huge field and the amount of research that is available is really extensive. I think we put about 160 relevant references into our submission. They are really just key ones—it seemed like a lot, all the same—and they were probably more than we thought we would do at the start. They are key references that support this. So in answer to your question, I think it is a matter of recognising that there are groups that are well trained and well qualified that are doing a very good job in this field and there are other people who are not so good. There needs to be a way of assessing those values, I think. But it is the same in any field. You get a spectrum of competence and expertise.

Senator HUMPHRIES—Would there be value in there being more dialogue between these two sides of medicine? We heard this morning that there were only ad hoc opportunities at conferences and things for these two views to come together and engage each other. Is there some alternative approach you would suggest towards the communing of these two sides of the system?

Dr Gawler—This hearing provides a sort of an opportunity for that to happen. I guess it will be interesting to see what comes out of this. At a state level it is disappointing that we do not have direct input into the task force into cancer services here in Victoria. I feel that we are peak body representing patients’ interests and this more integrated approach, but there is a lot going on in that field that we are not consulted on. When there is an opportunity, we try to make presentations. We run a conference each year but it is very rare to get oncologists turning up to that. Quite a lot of nurses come to it. Craig, can you think of other opportunities?

Dr Hassed—I think the issue you raise is a really important one. The way we approach teaching our medical students at Monash is to leave aside an adversarial attitude and try and look as objectively as we can, from various points of view, at what works, what helps, what might be symptomatic treatment, what might have some sort of circumstantial evidence for better outcomes in terms of survival or other progression measures, or what might have a curative effect and is waiting to be studied. In relation to knowing how to accredit or how to fund, when standards are being set up for general practitioners, for example, there is a clause that if you have been in practice for a certain period of time then that period of experience is recognised. Perhaps there could be some recognition of the most established, tried and true courses already—some sort of accreditation body to look at standards, to look at approaches and to try to give some sort of guidance or stamp of approval to practitioners who might want to refer to some sort of service or to patients wanting to explore services.

Maybe there could be some sort of broad based body that could look accreditation, look at standards and give guidance. In relation to research, that body could also allocate research funds to groups and consortia who, again, have a broad base of experience. When research is done just by one person in their own area and their knowledge does not go outside of that, and you do not have oncologists speaking to psychologists or to immunologists or to sociologists and so on, you tend to get a very narrow band of research initiatives and evaluation. So I think broadening that and funding consortia with reliable track records would be very valuable. It is really important, and I speak as a practitioner, to try to help patients make the best decisions for themselves and to try to educate medical students to have as balanced and as open a view as is reasonable. It is not easy.

Prof. Sali—There is a major difficulty in this business of getting together with oncologists. Last year through Monash—and with our postgraduate medical school, the Gawler Foundation and the Australasian Integrative Medicine Association—we actually organised a wellness conference for general practitioners and other medical practitioners. The dean of medicine at Monash—where Craig is, mind you, who is doing all of this good work of trying to introduce this area of medicine at that university; and it is, I must say, predominately through his energies—got over 30 letters of objection about that wellness conference being held, especially with such suspicious organisations. So it really is a major cultural problem—a very important one.

Senator LEES—Who sent the letters?

Prof. Sali—Staff members within the faculty of medicine. They did not want to be involved with such a dangerous activity.

Dr Hassed—They were predominantly from the oncology sector. The way we tried to set up the conference was to have keynote speakers and workshops looking at evidence and science and other ones looking at practice. We tried to invite people with experience and track records in all of those areas in the various disciplines we were looking at. I must say that, although there was a vocal small group of resistance, the support and encouragement I have had from the great majority of people at Monash has been tremendous. I could not have hoped for better. So the collegial support I have had, particularly in the Department of General Practice, has been tremendous in terms of open-mindedness. We were talking about this balanced approach before. I could not have asked for more from the great majority of my colleagues, but certainly trying to organise a more collegial, open debate is important. We had 150 general practitioners there wanting to know about the science, so we are certainly very encouraged. Conferences and education are an important way of spreading information.

Senator LEES—Looking specifically at medical training, how do we break down the barriers? We have Monash, but I take it that in no other medical schools around Australia do doctors have the opportunity to hear about alternatives and to look at the patient in a more holistic way?

Dr Hassed—There would probably be more now than previously. A holistic view of the importance of communication is much more recognised now than previously, probably in terms of integration into the curriculum and there being a bit more on content, science, the ethical and clinical aspects, the mind-body interaction and so on. Monash probably has more integrated into the curriculum than anywhere else, but I would certainly be happy to be corrected if there was evidence elsewhere.

Senator LEES—Should it be set as a standard? One way of setting various goals for universities is through the funding strings. Is that something this committee should be looking at?

Dr Hassed—I think the Australian Medical Council have nibbled at issue without completely taking it on. It is a difficult issue. We are probably in the middle of a generational change. Schopenhauer said that the realisation of any truth goes through three stages—in the first stage it is ridiculed, in the second stage it is resisted and in the third stage it is taken as self-evident. I think we are somewhere in the middle. I think there do need to be standards. At a minimum, a modern, trained doctor needs to know about complementary approaches, holistic approaches and integrated approaches. There is a bare minimum, because the number of people who are using these things and not telling their doctors is a significant concern.

Senator LEES—Perhaps we need to get Treasury on side and convince it that it is going to save money, and then it might become—

Prof. Sali—Almost every medical faculty in the US has an integrative medicine component, and I think it is a disgrace that here in Australia more than two-thirds of the Australian public are using some form of complementary medicine and most doctors would not have a clue what their patients are doing. There really needs to be some stimulus in trying to change that culture.

Dr Hassed—That issue of the potential health care savings of a more holistic and integrated approach is vital, because I do not think the health care system as it currently is, with an industry that supports more intervention and more expensive intervention, is sustainable. That is not an argument against good quality research and care, but if we do not take a more integrated approach I do not think we can afford it for another decade or two.

Senator LEES—This is a personal comment, but if we do not get patients involved in their own health we are not going to be able to have a sustainable health system.

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

[2.50 p.m.]

ENG, Dr Peter, Full Member, Fellow and Board Member, Australasian College of Nutritional and Environmental Medicine Inc.

SPIJER, Mr Daan, Chief Executive Officer, Australasian College of Nutritional and Environmental Medicine Inc.

CHAIR—I now welcome our next witnesses, from the Australasian College of Nutritional and Environmental Medicine. 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 Spijer—I start off by letting you know that I am not a doctor, so I cannot answer any questions on the medical side, but I can certainly answer questions to do with administrative and political issues. I also want to say that Professor Brighthope, who put in the written submission to you, is not able to be here today as he is interstate. He has spoken to Lyn Beverley and she has said it is fine for him to be listening in on this mobile so that, if there is something we say that he feels needs an extra comment from him, he can speak out.

The college—or ACNEM, as I refer to it—is a non-profit postgraduate medical college. It receives no funding from any other body or from government. Its only income comes from its membership and from its training, with little bits coming from other enterprises. Its funding is all from its own activities. It has a history of over 25 years and is considered in this country to be the peak body in nutritional medicine and environmental medicine. It is both a membership organisation, so it is a professional organisation, and a training body. It has trained around 12 per cent of Australia's GPs and just a handful of specialists, including a few oncologists. Those oncologists who have trained with the college are finding huge success in applying what they have learnt with us.

Nutritional medicine is a preventative as well as a curative approach. It has to do with lifestyle factors. It is supportive of chemotherapy and radiotherapy, so we are not talking about a replacement for those but something that can actually work in with those and make the outcomes more effective. Dr Eng will probably say more about that. It can also make the experience for the patients a lot more pleasant, because both chemotherapy and radiotherapy can be very unpleasant, and it can, in fact, allow higher doses of those therapies without killing the patient. Nutritional medicine is also about increased wellbeing. It is about better quality of life and it can reverse some cancers. Environmental medicine, which is another side of the college, has to do with environmental influences on health, both external and internal—the gut, for instance, would be seen as an internal environment. Again, they are preventative and lifestyle factors.

The college runs a fellowship program, and I would like to comment on something that one of our fellows, Dr William Barnes, mentioned at the hearing in Perth—that is, that a number of doctors were grandfathered. I looked at the *Hansard* and, in fact, everybody—even those who were grandfathered—had to sit exams. We are very clear about that. Nobody was given a free hand in just because they had been around for a long time. It is very important, because we value that fellowship. At the moment we have about 175 fellows and about 57 candidates. Our membership is about 650 to 700 doctors, but we have about 3,000 doctors on our database who have indicated that they are interested in what this college teaches and what is represents but who, for various reasons, have not gone beyond putting their toe in the water.

One of the things I want to stress is that we are not about an either-or choice. It is not: 'Do what we're doing instead of what is happening out there and you'll be better off.' It is a matter of integrating. You have heard from the Gawler Foundation, who talked very much about an integrative approach. That is very much what we are about. Nutritional medicine allows orthodox medicine to do what it does best, which really is acute care, and in some cases it is very good at dealing with ongoing conditions. But where orthodox medicine has something to offer in those chronic conditions, integrating nutritional medicine with it actually gives much better results.

The main services that the college offers are postgraduate training and seminars, both professional and for the public—something was said earlier today by the professor from the Peter Mac about needing to educate the public more because that is where the drive is coming from—and an active referral service. That is again something that came up in questions in relation to the breast cancer support groups. We run a very active referral service so that people can actually find doctors who are trained this way.

One of the important things in our training and our seminars is that the material that is put out there is backed by hundreds, if not thousands, of references and by years and years of clinical experience. Most of the lecturers are doctors actually practising in this area as well as academics. Professor Sali, for instance, has been on the faculty of the college on and off. In fact, ACNEM was one of the active parties in setting up the Graduate School of Integrative Medicine at Swinburne University of Technology.

Another issue which is very important is the cost benefit. This is something that was brought up by you, I think, Senator Moore, or by Senator Lees. There are certainly cost benefits and there are actually cost savings. The question of whether this country can afford its health care system is a very vexed one at the moment. Our answer would be: 'No, it can't, in the way it's going at the moment.' But the figures are out there and it can be shown that even minor changes—dropping the government support for pharmaceuticals that are not performing and replacing them with nonpharmaceuticals which are at least harmless and are possibly useful, so they would do no more harm and probably less harm than the pharmaceuticals they would replace—would knock billions of dollars off the PBS over the next couple of decades. Those figures are readily demonstrable. In this way of approaching it there are huge savings to be made and it may actually be one of the answers to any government's problem about how it is going to afford to continue to support health care in this country.

Some years ago ACNEM sponsored a number of international cancer congresses with internationally renowned speakers. Unfortunately those congresses were spurned by the establishment and by the media so a lot of what was offered in those congresses has been lost to this country because those people who needed to hear about it were not there to hear it and turned their backs on it. There needs to be a change in culture, again as several of the speakers from the Gawler Foundation indicated.

Nutritional medicine offers a cheap alternative to a lot of orthodox medicine. It is effective. It leads to an overall increase in wellbeing which in itself leads to better health. On the question of evidence, some years ago we were asked by the RACGP to show that what we were doing was in fact evidence based. We presented them with references that came out in just one year supporting this sort of medicine. They asked us again some months later and we said, ‘We have sent you the references.’ They said, ‘We’re sorry, there are so many we have not had time to look at them.’ So there is so much evidence that it is actually hard to keep up with it. Dr Eng will say something now about the medical side of the college’s work.

Dr Eng—The problems we have with mainstream doctors being against nutritional medicine date back to 1910 when the American congress commissioned Professor Abraham Flexner to recommend a curriculum for medical education in American universities, because each medical school had different standards. In 1913 the Flexner report on medical education in the United States and Canada was adopted by congress which allocated years and years of studies to anatomy and pathology and zero hours to nutrition. The Commonwealth and British medical schools have adopted the same curriculum. So, as I have found in my experience practising medicine, even in Australia when you mention nutrition medicine the mainstream doctors just get their backs up and say it is rubbish.

I wish to tender a letter written about a patient of mine to Dr Greg Wheeler, who is the radiation oncologist at the Peter MacCallum Cancer Centre. He saw a patient of mine—I have deleted her name; we will call her June—who had lung cancer. She came to me for adjuvant treatment for cancer using nutritional supplements. I wrote to him:

> You said in respect of my “alternative health preparations” that I have advised her to take, you “must admit that some of them I have no idea what they do. Reviewing ones that I did know however, she was on a significant level of vitamin C and zinc together, I think to an almost dangerous point so I have suggested that she cease taking some of these and takes the multivitamin, which seem to give the RDI for this”.

The patient was too frightened to tell him that she was taking them, but she has taken them. I will tender to you a letter from specialists who have been treating her saying that she is completely free of metastasis. Three years down the line, she is completely well. But she told me she is still too frightened to tell Dr Wheeler, whom she goes to for follow-up, that she is on antioxidants.

For two terms I have been a member of Swinburne University of Technology council. When Professor Sali and Professor Brighthope said they would like to establish a graduate school of integrative medicine, at one council meeting members of council brought letters from the Royal College of Physicians, the Royal College of Surgeons and the Royal College of Obstetricians and Gynaecologists all saying that nutritional medicine is rubbish. I stood up and said to my chancellor, Richard Pratt, ‘If we say that nutritional supplements are quackery we should use the umbrella of a tertiary institution like Swinburne to do double blind studies to show that nutrients are rubbish. Do not say they are rubbish when overseas studies have shown they are evidence based.’ To which Richard stood up and said, ‘Peter, you are the only one who is saying this and I support you and we should have more vigorous debates like that.’ That is on the record in the minutes of Swinburne university council meetings.

I believe this inquiry has come about because of Peter Cook. It is public knowledge that he has got cancer from a mole that spread to his lungs. He was referred to me for advice on nutritional medicine. I sent him some studies and said that he should be using nutritional medicine, including melatonin. He saw his oncologist who said it was rubbish. I said to Peter, ‘Show him the studies and get him to read them and report back to you.’ He read them and said to Peter: ‘I am sorry, you are right. The studies show melatonin is effective in killing cancer cells.’ Peter Cook said, ‘Fortuitously I have been going from Perth to Canberra and been taking melatonin every night.’ It just shows that oncologists in general do not read beyond what the drug institutions want them to read in terms of cancer treatment. When they go home from their work either they are too tired or they do not read, in mainstream medicine journals, proper studies done in tertiary institutions to show that nutrients are effective in cancer prevention or cancer treatment or as an adjunct to cancer treatment. Ian Brighthope has given you a one-page letter, I believe, and I welcome any questions you may wish to ask because some of them could be quite technical.

Senator HUMPHRIES—Thank you for that submission. Before I start, right at the end of your submission there is a sentence that does not seem to be finished. I am intrigued about how the sentence was meant to be completed. It begins: ‘Again, there is good evidence that at all levels of the health system’, but does not seem to end. Was a comment going to go there?

Mr Spijer—I think that is just a problem with the copy you have. It reads:

> Again, there is good evidence that at all levels of the health system—from the researchers to the doctors, the pharmaceutical industry and within government and the various regulatory bodies—State and Federal.

Senator HUMPHRIES—That is what I have, but it does not seem to make any sense.

Mr Spijer—I agree.

Senator HUMPHRIES—You can take that on notice and put a supplementary submission in. The question about the effectiveness of nutritional medicine or environmental medicine is an issue that you have very strong views about, and today we have heard a lot of evidence and read other submissions regarding not just the particular field in which you practise but others as well that might be described as complementary alternative medicines. I come back to a question I have asked other witnesses: what do we do to assess the validity of these sorts of medicines when we do not have mechanisms that distinguish between effective alternatives and ones that might be described as quackery? We have had evidence that there are those sorts of things out there—things that are called ‘wing of bat’ type medicines. We do not seem to have a basis for distinguishing between those two. What do you suggest we should recommend to deal with that?

Dr Eng—I always tell patients that, if you want to use complementary medicine, go to a member of a college or go to a doctor who has been trained in nutritional medicine at a place like Avni Sali’s Graduate School of Integrative Medicine.

Senator HUMPHRIES—The problem there is that you say that members of your college are reliable and they practise good medicine—and I have no reason to doubt what you say—but funding bodies such as the Commonwealth government, which might be deciding where to allocate Medicare rebates, will need something more than that. What you have said today suggests that there is antipathy by more conventional medical practitioners towards some of the things that members of your college do. If we recommend that members of your college should be taken more seriously, I am sure alternative submissions will be made to the Commonwealth government that will say, ‘We don’t yet know whether these sorts of medicines do improve anything, and we haven’t seen the evidence,’ and so on. How do we overcome that problem?

Dr Eng—I take any patient that comes to me with cancer through, for example, the use of indo-3-carbinols from broccoli and brussel sprouts. I say: ‘Here are the studies. You go home and read them. Come back and we will discuss it and, if you feel it makes sense to you, go and get them.’

Mr Spijer—Dr Eng makes a very important point there that the studies have been done to a large extent. A lot of what doctors trained by this college and other doctors who practise nutritional medicine rely on are the studies that have been done overseas. I suppose it is a shame that, because of our small population here, there is less money available to do these studies. A lot of studies have been done in America and Europe. Many of these have been published in the mainstream literature such as the *New England Journal of Medicine*, the *Lancet*, the *British Medical Journal* and the *Medical Journal of Australia*. So many of the studies have been done. When the authorities here would like studies to be done in Australia, the basis for those studies would be the overseas studies. It is interesting, for instance, that the medical literature shows that glucosamine is the best treatment for osteoarthritis. It does not have the side effects that non-steroidal anti-inflammatories have. However, the non-steroidal anti-inflammatories are supported by Medicare while glucosamine is not, yet it is the preferred treatment when you look at the literature. But mainstream medicine does not look at the literature in an unbiased way, and that is one of the points that Dr Eng made in relation to Senator Cook’s oncologist—that when it was pointed out: ‘Here is the evidence for melatonin,’ he went and had a look and said, ‘Oh yes, it’s there in the literature.’ So in many cases the research is there.

Dr Eng—When I recommend that patients use nutrients in the treatment of cancer, I always say: ‘You have to take the studies home, read them and go through them slowly, nutrient by nutrient, until you understand why you are taking them. If you read the studies, they do not make sense to you and you think it is quackery, I will accept it, but read the studies first.’ My feedback from patients has been that, in general, 90 per cent accept it and 10 per cent do not because they cannot afford them. So I look after the gentry in Melbourne, including big company chiefs, who are very intelligent. QCs and judges also use them, and they are very analytical.

Senator HUMPHRIES—You said that the Royal College of General Practitioners asked you twice for evidence on the effectiveness of your therapies. Did they come back to you with an evaluation of what you gave them?

Mr Spijer—We pointed out that we had given them just one year’s worth of references and suggested that they scan through them to see what value or what level of evidence they were, and we have since had a very happy relationship with them. They are now satisfied that the evidence is there. In fact, we are going through the final stages of our accreditation as a provider of education for the RCGP.

Senator MOORE—I have a lot of questions, and I know I will not be able to ask all of them. I will ask about two different areas. In the fourth paragraph of your submission you say that there is a ‘difficulty obtaining some of the substances due to regulatory restrictions and hurdles’. We have not had that evidence before, and I know people have mentioned that in other places. Would you mention something on record about that particular issue and about the role of the TGA and whether you have had any relationship with them? The other question is: has your organisation been approached by the state government to have any involvement in their various working groups and processes around the cancer priority that they are using at the moment?

Dr Eng—I wrote to the local Minister for Health about nutrition supplementation, and she did not read my letter. I am sure she gave it to a bureaucrat from the department of health, who told me that they have no reason to look beyond what is in practice in Victoria at the moment. I am happy to tender the letter to you. Could you repeat the first question?

Senator MOORE—It was about the difficulty of obtaining some of the substances due to regulatory restrictions and hurdles.

Dr Eng—I will give an example regarding DHEA—dehydroepiandrosterone. A double blind study done at Osaka University medical school shows that if there is a deficiency in that hormone, production of which peaks at age 25 and then starts to drop, one risk factor is chronic fatigue. I had an American patient here who was trying to save money and said: ‘I don’t want to pay for it to be made locally by a compounding chemist. I want to bring it from the United States.’ I measured his DHEA level, his prostate enzyme levels and his testosterone level. The TGA wrote to me and said, ‘Give us the studies on why you are going to use DHEA.’ There are a large number of studies on DHEA from the New York Academy of Sciences, which I have read. I do not have the time to teach the doctor the biochemistry of DHEA and the studies done on it.

At one time I also tried to bring in coenzyme Q10, and a doctor from TGA said, ‘Show us the double blind studies that show they can be used in Australia.’ This was about eight years. I always have resistance from the TGA. They are mainly dominated by mainstream doctors, some linked to the pharmaceutical industry, and the minute you try to bring in something they ask for reams of studies. One way of circumventing this is to tell the patient to apply overseas and import it for their own use, and that is what I have been doing, but it costs them a lot of money to bring it in.

Mr Spijer—And there is a problem with patients importing for their own use. We are lucky in Australia that we have a very solid manufacturing industry under pharmaceutical standards, so we can be sure that what is manufactured here is manufactured properly. We have very little control over what comes from overseas. For instance, from a discussion I had with Professor Brighthope, I know that he inspected a manufacturer in the USA and found that the raw ingredients were coming from Mexico, where there was no proper control. So it is very hard to know that what patients bring in is not contaminated, is of the dosage that is says and so on. There is a problem there. Some supplements—for instance, selenium—are ridiculously low in the limits that are allowed in tablet form. I think it is something like 50 micrograms for selenium—I may be corrected; it may even be lower—but it is safe up to about 800 micrograms.

So it is nowhere near what is known in the literature as even approaching any toxicity. Selenium has been shown in many studies to be a preventative for cancer and other conditions.

In terms of the state government, it brings in the whole political side of things. This college is represented on a number of government bodies. I think we still have somebody on the complementary medical advisory council which advises the TGA. At the moment one of our board members is on a working party, together with the RACGP and the Australasian Integrative Medicine Association, looking at what recommendations should be made to the Victorian Medical Board on the training of doctors who practise nutritional medicine. As a result of the government’s response to the Bollen committee report, *Complementary medicines in the Australian health system*, it is likely that medical boards around Australia will require doctors to be trained in non-orthodox areas in which they purport to be practising.

CHAIR—Thank you for your submission and your presentation today.

[3.22 p.m.]

BLOCH, Professor Sidney, (Private capacity)

LINDNER, Dr Helen Dawn, Member of National Executive of College of Health Psychologists and Chair, Victorian State Committee, Australian Psychological Society

STOIGES, Mr David Lewis, Manager, Professional Issues, Australian Psychological Society

FAZANDE, Ms Martine, Senior Administrator, Professional Issues, Australian Psychological Society

CHAIR—I welcome the next witnesses, from the Australian Psychological Society, and Professor Sidney Bloch. Information on parliamentary privilege and the protection of witnesses and their 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 and I now invite you to make an opening presentation, to be followed by questions from the committee.

Mr Stoiges—As well as being the manager of professional issues at the Australian Psychological Society, I have a background in health psychology and I am a clinical neuropsychologist. We are very aware that many of the members of the Australian Psychological Society work in health settings, many of them in general medicine areas where the treatment of cancer patients is part of their work. We are also very conscious that the society has a philosophical commitment to multidisciplinary care and we would like to think that we speak on the allied health end of that whole spectrum of service provision, as well as for psychology.

Where we began in our thinking about this was that cancer is a multifaceted disorder, and psychosocial factors, which are so easily forgotten, have a major influence on the incidence, progress and outcome of cancer. The major established issues of mood, attitude and particularly behaviour management are one of the focuses of our presentation.

I want to say one other thing and then I will hand over to Helen, who is one of our experts in this area. We see ourselves as providing an adjunctive therapy, an adjunct to the mainstream approach to the treatment of cancer. We would not adopt the notion of it being an alternative therapy; we do not see it in that light. We see it, rather, as supportive, both in terms of its contribution to other services as well as in terms of outcome. We see the fact that we are involved in the psychosocial end of the process as having a significant impact on outcome.

Dr Lindner—I wanted to emphasise that a vital component to the psychosocial health of patients and the economic good practice for their management really comes down to effective self-management strategies from cancer patients, not just in the acute phase when they are going through immediate treatment and surgery but during the long-term treatment that they quite often need to have. They are not always in a hospital setting for the whole period. They are often out in their homes and their workplaces trying to maintain changes. That self management could involve dietary changes and, for a lot of them, it could involve changes in smoking behaviours, medications that they are required to be on and physical activity to increase even just wellbeing for any upcoming surgery.

As with many other chronic illnesses, we may know what best practice is, but it is not always easy to implement. The resistance of patients, the tendency for dependence rather than self-reliance and the impact of mood disorders and psychological defence mechanisms on resilience and constructive behaviours is problematic at times. In many areas of chronic illness, such as obesity, it is possible to establish a good resume for the patient but its implementation is something else. We might know what we need to do but we cannot actually do it. This very much applies to cancer patients, as it does to many other patients. The area of interest of psychologists is self management. It has been shown that managing distress and anxiety around the illness and increasing adherence to the treatment resume have a significant impact on outcomes.

We see our role, as David was saying, as allied and concurrent with recommended treatments for the medical area. We believe we have an important role in getting those to be working effectively. Adherence to recommended treatment involving the assessment of a patient's readiness to change is an important factor which psychologists have the skills to manage. They might not have to change one or two behaviours or follow one recommendation. It is quite complex with many of these cancer patients. They are not always ready to assess that. Dealing with the ambivalence to change that they might have, looking at their motivation and moving that on is core training that psychologists have. They are able to tap into that motivation.

Quite often adherence and motivation to change is not directly related to the health issue in itself. It could quite often be related to family or work issues. I had one client who was recommended changes and treatment and was not adhering well. She was fairly isolated and had some other issues. The motivation turned out to be caring for her dogs. She decided to start looking after herself, making the changes, preparing for surgery that was needed and also preparing for effective recovery from that surgery. Her motivation was not directly related to her but to other things that were important in her life. I think tapping in and finding out what is going to move the patients is very important.

It has also been shown that psychosocial support and psychological interventions, individually or in groups, improve the person's quality of life and capacity to interact better with their social environment, in their family, in their workplace and in the health-care system. So it is not just in one particular area but in quite a range of areas. The adapting to a whole range of requirements, such as the monitoring of their state of disease or turning up for blood tests, treatment, doctor's appointments and so on, is an area we can impact upon.

The other area that the psychologists are particularly well trained in is that of dealing with mood disorders associated with cancer. The comorbidity that is quite often found in chronic illness and in cancer patients as well is depression and anxiety. It might not be a causal relationship in terms of the onset of cancer, but it has very much been found to be there in terms of people managing their cancer—their psychological well-being generally and their physical health issues after a diagnosis, throughout treatment and following treatment. There is well-established evidence that psychosocial intervention, such as cognitive behavioural therapy, interpersonal therapy and subgroups of that—motivation interfering or readiness to change frameworks—can be just as effective and can have more lasting impact than drug therapy for depression or anxiety. So in the comorbidity aspects of cancer we could play an important role.

The added benefit of these approaches is that they are less invasive, in a physical sense, if a patient has a comorbidity of negative mood. They can be working with those issues that impact on their cancer and that also impact on their quality of life. If they can have psychological treatment with a minimal amount of extra pharmacological intervention related to, say, depression or anti-anxiety medication, and remove those well-known side effects associated with those medications, we believe there would be a better outcome for the patient.

Mr Stoiges—Can I just say—in conclusion to our oral presentation at least—that the implications of this for the patient are significant from our point of view because we feel that there is a range and extensive area of activity within the patient’s condition and illness that can be assisted significantly by psychological interventions. That leads us to say that there is a work force of trained psychologists out there that can assist in the improvement and enhancement of the treatment program that is currently part of the protocol for treatment in cancer centres, and which we are looking to have available—I guess that having those psychologists ‘available’ is the way in which we would view it from our members’ point of view, but it is essentially about making a contribution to the patients’ wellbeing. We would like to recommend that those sorts of processes be looked at and we have made a few suggestions in our submission as to how they might be implemented.

Prof. Bloch—Thank you very much for giving me this opportunity to appear before the committee. I think that sometimes when we use the expression ‘psychosocial factors’ it is rather a vague entity and people do not quite know what we mean; Dr Lindner has, obviously, given us some illustrations of that. But I always start with my own personal experience: when I was a first-year medical student I did not know what psychosocial meant; but I did know that when my brother had brain cancer—he was a bit younger than I—it caused havoc with me, him and the family. We did not know whether we were coming or going; we did not whether he was going to live or die. I am happy to say that he is still alive at age 60, so it all turned out well. But, for the time that his brain cancer was, if you like, overwhelming our family and me it was just awful.

I have seen this so many times in personal life and, of course, in professional life. When a person has cancer, the impact in the emotional sense—I am purposely going to avoid psychosocial; I think it is too fuzzy an entity—of that journey is sometimes just overwhelming, as in my own case. Last night I was phoned by a friend to say that her mother had died last Thursday after a brief illness with bone cancer in the leg. Her leg was amputated because they thought that might cure her. But, just a few weeks later, they found evidence of secondary spread throughout the rest of her body and she died, again, in very painful circumstances. Emotionally, for the family, as my friend told me, it was a harrowing thing. It reminded me of my own experience decades ago.

Given that one in four adults will suffer cancer—some of us in this very room may get it—I think we have to be mindful of this dimension and recognise that we cannot afford not to get involved in the comprehensive care. I am afraid I do not go for the word ‘adjunctive’—again, I do not know what it means. I regard decent care as comprehensive, which includes the biological, the psychological and social. All three are equally important. As we have heard, you can give as much biological treatment as you like but, if the patient is so thoroughly depressed and suicidal, it will not make much difference to their biological welfare.

The reason I personally wanted to come here is that, since working in Australia since 1989 in this field, mainly as a researcher, I have been heartened that we are able to confirm what I have been saying anecdotally. I could spend the next several hours giving you illustrations, but then you could probably give me illustrations too from your own lives where, emotionally, things have been very tough for people. I think what we are now ready to do is apply some of the research findings that people in Australia and elsewhere have managed to achieve. What I submitted was a list of references—I hope it was not, in any way, self-serving; it was not meant to be. It was to give an idea about what we do know and what we do not know.

To illustrate very briefly, through my own experience, one in nine women in Australia will get breast cancer. If you take the women who detect the lump and then go to the GP and oncologist and so on, from our own figures of 303 women, roughly 42 per cent of those women will show a depressive reaction. It is not just grief or sadness. It is actually quite a marked picture. In other words, it reaches clinical proportions. I can go into the detail of that a bit later if you want. That is a very big percentage. Comparable figures emanate from other studies both in Australia and elsewhere.

The journey is obviously immense from the very first feel of the lump, when a woman has her breast tumour, to the other end when she dies because treatment has not proved adequate. At the other end, we have also done studies of family therapy for families that we can identify. Half of the families where a parent has cancer do very poorly in their adaptation to that situation. The other half do well. This is a point we need to stress. In my talking about these matters, we are not saying that every single cancer patient gets depressed or every single family falls apart, but a big number do. I have given the figures for breast cancer in women. From studies done at St Vincent’s and related clinics in Melbourne, the figure for the families that do not do well is roughly half. We published a book recently called *Family Focused Grief Therapy*, which demonstrates that pretty well.

That brings me to my second last point. There is no real purpose in finding out all this data—42 per cent, 50 per cent—and doing nothing about it. To me, that is a ridiculous state of affairs. What I would really love to see in this country is the application of these findings. For example, we conducted a study of these 300 women and gave half of them group therapy for six months and the other half three sessions of relaxation therapy. We found over follow-up that the women who had, if you like, the sizeable therapy benefited reasonably well—I will not say hugely well, but reasonably well—in terms of quality of life from that work. The support they gave each other was just fantastic. To be part of that study was actually very uplifting spiritually, I would have to say. So we have to apply the findings to how to help.

In our program at St Vincent’s and the University of Melbourne, we first tried to detect the need and the pattern—what is the psychological and emotional need, and what pattern does it take—and then what sort of therapy would be best applicable. For example, in the case of newly diagnosed women with breast cancer, all those women are potential beneficiaries of a group therapy process going for six months. In the family focus grief therapy, only half the families—and we can identify these families with simple screening questionnaires—need our attention. The other half can teach us how to cope with the death of a parent. So ultimately the data is there or will be there. Of course, we have not filled all the gaps. We have turned to prostate cancer in the last three years and again are trying, with 400 men with prostate cancer and a couple of hundred men without cancer as controls, to find out what the needs are and what are the patterns of disturbance and distress. Out of that will hopefully come what we think might be a helpful therapy. We think couple therapy in their case.

I could go on with the detail—I will not, obviously—but the bottom line is getting the staffing. That includes psychologists, social workers, psychiatrists and nurses—those four groups, probably, in the main—to apply the findings that we have from our research into the regular day-to-day clinical arena. If you look at the staffing of institutions, Peter Mac is one of the biggest cancer centres in the country and one of the biggest in the world. If I had to give you the staffing—they may have done so already—it is deplorable. Compare that to a place I am going for sabbatical in February—the Memorial Sloan-Kettering hospital in New York—were there are no fewer than 10 psychiatrists, 10 psychologists, six training posts and 11 doctoral and postdoctoral fellowships. That hospital is big too, the biggest cancer centre in the US, but by comparison we are minuscule. That seems to me to be a reflection of how much we still have to catch up. I will leave it there.

CHAIR—Thank you. I think Peter Mac indicated they had 1.5 psychologists on staff. Is the society aware that the Department of Health and Ageing's Cancer Strategies Group recommended the use of psychologists in providing psychosocial care for cancer patients in its recommendations for cancer control back in 2001? If you are aware of that, have you pursued that with the department?

Mr Stoiges—Yes, we are aware of it. I am glad you know about it. So do we. Our difficulty is not that we have not pursued it but that it is difficult to get it prioritised in budgets because it really comes down to local hospitals and local centres who wish to take on those propositions. Like many Commonwealth department recommendations, they stop at the state. They are the sorts of problems that we have encountered with that particular proposal, but thank you for highlighting that issue. It is something we are conscious of.

Senator MOORE—Professor, are your groups and faculty involved with the state government process that is now prioritising cancer and an integrated approach at the Victorian state level over the next three to four years?

Prof. Bloch—We are aware of these developments. In the case of the University of Melbourne, we are just getting going with a proposal for a centre for psychoncology. I know the term is a bit unwieldy.

Senator MOORE—How far away is that? I read about that.

Prof. Bloch—It is probably either in the distant clouds so you cannot see it or, if we are lucky, it might be close by. I have no idea. In other words, some senior professors will be meeting shortly. We want to put up a bid. We want to go to the university. The university, no doubt, will go to the health department. On a state level, we want to see what they have at Sloan-Kettering in New York. Without that, we will not be able to further this area. The idea of getting another 0.5 psychologist at Peter Mac to amplify the 1.5 is just a drop in the ocean. We really need centres of excellence. We need models to demonstrate things. Although I am a St Vincent's person I think it is probably best placed at Peter Mac, because that is obviously the big cancer centre. I would love to see that sort of model in all states and territories.

Senator MOORE—Can I hear from the Psychological Society about the integrated plan across the eight centres in Victoria?

Mr Stoiges—I am aware of it but as far as I know none of our psychologists have commented on developments within their own areas. We have branch committees in each state that can feed that activity back to us. I have had contact with a couple of the major centres—one at the Austin and at the Peter Mac—and as far as I am aware there has been no movement from that perspective. I would be interested to follow that through but we have had no interaction with the state government over it or any request for us to be involved.

Senator MOORE—It is just that they are looking at the integrated model on which you commented. I am wondering where your profession fitted in. In terms of work force issues, what is the current state of training and the numbers of psychologists and psychiatrists—I think you mentioned them—who are trained in this specialist area of oncological support?

Mr Stoiges—From a structural point of view, the society has specialist colleges. There are nine specialist colleges and one of those is the health college. They carry, if you like, that responsibility, although there are occasions when clinical psychology also overlaps in this area. Helen is on the national committee for the health college, so perhaps I can ask her to comment on that.

Dr Lindner—We coordinate at La Trobe University the first program in Australia to offer master's degrees and doctorates in health psychology. We are also on the accreditation committee for programs around Australia. It is growing. There is definitely a demand. We have seven programs in Victoria and two other ones, one in New South Wales and one in Queensland. The University of Canberra is looking at starting a program for master's degrees and doctorates in health psychology within the next 12 months or so as well. Programs are training people in areas of health. They are not only about oncology, but that is a specified area that the college requires the course to cover, along with basic medical science, pharmacology and the psychological factors related to the appropriate interventions and the evidence based practice for that as well as other areas such as diabetes, heart disease, asthma and a number of others.

Senator MOORE—Is that postgraduate training?

Dr Lindner—It is postgraduate training: a master's or doctorate in health psychology. Part of the training of a health psychologist is not only in the clinical health end, which is working with the patient or with the families or even with staff. We have done some work at St Vincent's in supporting staff through their placements and looking at that particularly in terms of dealing with end-of-life issues with their patients. Training in health psychology is also in health promotion, which is about getting people to respond and to have tests and to take up self breast examination, for example. So there is a preventive end, along with treatment, rehabilitation and end-of-life issues. There is some training.

Prof. Bloch—In the psychiatric realm, the College of Psychiatrists requires six months of training in what we call consultation liaison psychiatry. This is the interphase between our work and the medicine, surgery, gynaecology and so on. During that training, trainees invariably get some exposure to the cancer side of things, to psychoncology. Formal courses in psychoncology are very rare in this country. We have one at the University of Melbourne—which includes a module on psychoncology and palliative care, symptom management and the like—and it has been quite popular. We have also managed to get one training position—which is a one-year post at Peter Mac—as part of our St Vincent's training. This is an ad hoc arrangement, so it is by chance that we managed to establish that. As I said a bit earlier, once you have a centre for psychoncology, everything can spring forth more luxuriously—more fruitfully, if you like—because then you can get training positions and so on, but at the moment it is a bit ad hoc.

Senator MOORE—Hopefully, that will change.

Prof. Bloch—I hope it is in my lifetime.

Senator KNOWLES—I am a little bit ill at ease, I suppose, after the second day of hearings to think that we are still talking so much about the need for emotional support—and I like that term much better than the psychosocial stuff that you referred to. Let's face it, if a busload of tourists see a bunny knocked over on the highway, the first thing that is offered to them is counselling. I would have thought that, following the diagnosis of cancer, the first support would be counselling for the patient and for the family. What do you think the incidence of non-referral is in Australia today?

Mr Stoiges—Do you mean for those services?

Senator KNOWLES—For those services.

Mr Stoiges—Rather negatively, I have to say, it is fairly high. I will respond to the emotional versus psychosocial issue. Emotional factors are only one aspect of psychosocial, to dignify the term a little. One of the major components of the psychosocial is behavioural. Although emotional and behavioural issues often overlap, you can encourage people into positive behaviours, apart from their emotional state, and you can often induce changes emotionally, purely by utilising behavioural change.

Senator KNOWLES—As a layman, I see that all as one.

Mr Stoiges—Absolutely. They are integrated, but I am pointing out that there are different aspects to it. We know from well established psychological research that you can induce emotional and attitudinal change purely by behavioural change. Although they are integrated—and I would not argue against that for a moment—they are nonetheless important aspects and need to be identified as separate, because they all provide us with tools to assist patients to move, to change, to adapt and to utilise those sorts of strategies. I strengthen the notion that psychosocial, even though it is psycho babble—and I accept all that—does have more components than just emotional and it is important to identify the cognitive, the behavioural and the affective components, which are all open to adjustment and utilisation in this process.

Senator KNOWLES—Let us come back to the more important aspect of my question—that is, the incidence of referral.

Mr Stoiges—I think it is very low and I think it is to do largely with a system that is very much focused on the medical angle. That is a very important aspect and do not take away from that. But I do think that we have not been successful in persuading people of the importance of the psychosocial and emotional part of this whole process. So we do need to do a lot more work in reinforcing that process and encouraging our medical colleagues to utilise those opportunities, skills and processes. There is no question about that.

Prof. Bloch—From my point of view, you can only refer to a service when it exists. There is no use referring to cyberspace and so on. For example, when we did our family study we trained 16 family therapists, mainly psychologists, social workers and a couple of nurses. They did a great job over the five to six years that we conducted the study. The research money came to an end, the study came to an end, we got our results and we have the book and other papers. Guess what has happened to the family therapy program. It does not exist because we cannot get any funds for those 16 therapists who were so well trained. They have gone in all directions—some are doing private work and some are doing completely different jobs. That really saddens me. In fact, it is very frustrating and it happens repeatedly. If you have a service, the referrals will come in. We know that. In fact, you get overburdened sometimes if you provide a good service.

CHAIR—Regardless of all the reasons why people may not be getting psychological support, Senator Knowles and I specifically want to know how many people presently are getting adequate psychological support after they have been diagnosed with cancer. I know you may not have the exact figures, but is it one in 10, one in 100 or one in 1,000? What numbers are we looking at?

Dr Lindner—I can give you an example from the Alfred. They have one psychologist who spends some of her time in oncology. I have a regular internship of a doctor in health psychology appointed to the Alfred to help her with that work. They are absolutely snowed under and I cannot give her any more because I have more placements than I have students. It is not just oncology; there are other areas where there is really a demand for that expertise. The funding is not there. They cover some of the demand, which is only a small amount, just at the Alfred, from those two individuals.

CHAIR—But we are still not getting even a ballpark indication, which is what we are looking for.

Mr Stoiges—Let us say that in a unit that has a psychologist or a liaison psychiatrist available—

Senator KNOWLES—And not necessarily an oncological psychologist.

Mr Stoiges—Granted, accepted. We may just have either a clinical or a health psychologist whose specialty is not oncology, who might see at the best—as a passing acquaintance—half the patients in the ward. I worked in an oncology ward. At best you met perhaps half of those patients at the bedside. You did serious work with no more than 10 per cent. That is just the public hospital sector. We have not even talked about the private hospital sector, where in many instances you would not find a psychologist anywhere in the centre. So in some sections of our service we are not getting any intervention. There might be a social worker called in for emergency cases, where somebody really is in serious distress. Once again, it is a sort of emergency medicine model, whereby you might call in someone when somebody is seriously distressed. But, routinely, probably 10 per cent would be the best guess I have.

Senator KNOWLES—Why are people not being referred to psychologists in private practice?

Mr Stoiges—You are asking the wrong person. I can only say that our experience is that it is not seen as a routinely necessary or vital exercise. You have two problems: one is the awareness of and familiarisation with the protocols by the people who can refer and the other is that there is no public access to the resources that you are talking about. Whereas you can send them off to a psychiatrist or a GP and expect Medicare cover, that does not happen for psychologists in private practice. So it is an access issue to some extent; it is an ignorance issue in the other context.

Prof. Bloch—One additional way of answering the question is that we have 3,000 outpatients a year in oncology at St Vincent's. There is one social worker who is only part-time. There are no psychologists. There is referral to psychiatrists if there is a major problem—as David is suggesting it would need to be a major suicidal depression or that sort of thing. But more routine care—I do not think it is routine; it is comprehensive care—does not exist. So if you take a percentage of 3,000 it is probably a few dozen at most. So we are probably talking about one per cent, four per cent or three per cent. In other words, the unmet need is considerable. That is the only way you can answer that at the moment, because the figures are just not quite there in scientific terms. But it is undoubtedly considerable.

Senator HUMPHRIES—I have one quick question. On the second last page of the Psychological Society's submission you refer to a study which shows that there were savings to be made by dealing with the psychological elements of cancer. When was that study done?

Mr Stoiges—I would have to take that on notice and give you a reference. I would be happy to do that because we would not have said that without there being the relevant data. We just have not put the reference in and I apologise for that.

CHAIR—Thank you all for your submissions and your presentations today.

[4.04 p.m.]

HOCHBERG, Mr Ivan, Convenor, Oncology Social Work Australia

HOLLAND, Ms Cynthia, Legal Representative, Oncology Social Work Australia

TODD, Ms Karen Lee, Coordinator, Special Projects Group, Oncology Social Work Australia

TOKATLIAN, Ms Nicole, Member, Oncology Social Work Australia

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

Mr Hochberg—I work at the Alfred Hospital in Melbourne.

Ms Holland—I have been in oncology social work for 20 or so years. I work at the Royal Women’s Hospital but I am here as a representative of Oncology Social Work Australia. I am also a barrister.

Ms Todd—I work at Geelong Hospital.

Ms Tokatlian—I am a senior social worker at the Royal Children’s Hospital in Melbourne.

Ms Holland—I have been in oncology social work for 20 or so years. I work at the Royal Women’s Hospital but I am here as a representative of Oncology Social Work Australia. I am also a barrister.

CHAIR—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 Hochberg—What I have chosen to do is to write something which I will read to you, because it is easier for me to read, and then we are happy to enter into a dialogue with the committee. I have provided copies of what I have written. J was 54 years of age when he was admitted to hospital with acute back pain. He was a successful accountant, married with adult children. Within a period of two weeks he learned he had an advanced bone cancer and his life expectancy was measured in months. When the treating team met with him and his family to discuss returning home for what time was available to him, with tears in his eyes he asked his wife: ‘Is it all right that I come home?’ What reduced him to a state where he felt he was no longer of value to his family?

M, a 57-year-old woman, had just had surgery for a newly diagnosed bowel cancer. She and her partner were very frightened. They only had each other, having come to Australia some five years ago. She was the main breadwinner in the family. She was scared that through having this illness she would lose her job, yet she is a valued employee. They did not know how they would be able to afford to live while she was undergoing treatment. How would they survive this diagnosis? What suddenly turned this person’s world around, to the extent she lost all sense of confidence in her position as a valued employee?

E was diagnosed with a brain tumour at the age of six. E is the middle child of three children. The tumour was resected and he received chemotherapy and radiotherapy. Since his diagnosis four year ago, E has missed a substantial amount of school and repeatedly asks his mother: ‘Why did this have to happen to me?’ He feels different from his peers and has had trouble making friends since his diagnosis. E’s mother, J, states that she has continuous feelings of dread, anxiety and guilt: ‘Will the tumour come back? How will we manage if it does? Did I somehow cause this tumour?’ With the demands of treatment and hospitalisation, J has not been able to return to part-time work. This has lead to significant financial strain and personal stress for both J and her husband. They both feel that they have failed as parents and are isolated within their friendship group. They have limited family support and both struggle to maintain the financial viability of the family while still taking an active role in their children’s care. These are all real life examples.

We would like to thank and applaud the Senate for this inquiry, and we very much appreciate this opportunity to present to you today about the psychosocial impact of a cancer diagnosis. Each day oncology social workers confront similar situations as just described. We are here today to talk about this from a professional perspective, not with research evidence, statistics and access to specialised language—that is in our written submission—but in a manner that tells the story, through our clients’ eyes, of their experience of a cancer diagnosis. It is an experience of change and challenge.

Cancer is a chronic condition. It also has the potential to be life-threatening. Most chronic conditions significantly compromise quality of life through activity limitations and impairments. Most chronic diseases are long term and persistent, leading to a deterioration in health. Most chronic diseases are not immediately life-threatening but are common and a leading cause of premature death. The social implications of a chronic condition are that it affects quality of life, requires lifestyle changes and impacts on relationships; it involves substantial commitment by carers; it requires a wide range of community supports; it fluctuates, being episodic and progressive; it contains elements of uncertainty; it is expensive; it can be unresolved and potentially life-threatening; it affects employment and potentially leads to poverty; it is associated with social isolation; and it impacts on the whole of life.

Oncology social work has been in existence for over 30 years and is a subspecialty of health social work. The manner in which we work acknowledges that a cancer diagnosis places normal people in an abnormal situation that can be frightening, unfamiliar, challenging and uncertain. We offer a range of counselling modalities suitable to an individual’s or family’s needs, assistance in decision making, crisis intervention when appropriate, assistance with difficult to solve practical problems, information about the psychosocial impact of cancer, the teaching of cognitive reframing and problem solving skills to assist in adjusting, information and education about the health care system, assistance in identifying appropriate resources and linkages within the community, the development and coordination of discharge plans for in-patient hospital stays that are appropriate to an individual’s need, grief counselling and assistance with recovery and return to normal activity post treatment.

A cancer diagnosis changes normal existence and threatens an individual’s sense of being socially connected. Subsequently it impacts on the individual and the family in maintaining a sense of equilibrium. Our written submission’s main premise is that social connectedness is central to maintaining physical, emotional, psychological, social and spiritual health. Cancer as an illness and by its sheer magnitude can and does disrupt social connectedness and thereby challenges the patient’s, family’s and/or carer’s belief in their quintessential value.

The central emphasis of the social work role is on enhancing the reciprocal relationship of the person within their environment. We are concerned with how physical, psychological and social difficulties and differences affect a client’s sense of identity and feelings of competence, self-esteem and wellbeing. As a profession we are committed to a holistic approach to care. Within Australia oncology social workers are the largest single group of professionals solely dedicated to the provision of psychosocial services to those living with a cancer. We estimate there are 200 workers within Australia who identify as practising under our subspecialty. That is not to say that other treating disciplines do not offer a component of psychosocial care in their overall service delivery model.

Central to our written submission is the critical shortage of specialist oncology social workers to meet the demand for psychosocial services. Currently we largely operate on a crisis driven model of service. The requests in our written submission for investment in upgrading psychosocial services may seem exaggerated but they are not, and our client groups’ experiences are a testament to this. They are a commitment and affirmation of the value of each person who has a cancer diagnosis and the challenges they face along the cancer journey.

Rather than continue with a formal presentation looking at psychosocial services to those with a cancer, we have four of us present today: Karen Todd, Cynthia Holland, Nicole Tokatlian and me. This is an opportunity to explore the psychosocial experience of living with a cancer from a client perspective with professionals who have over 55 years of direct accumulated clinical experience. Thank you.

Senator HUMPHRIES—We have heard of a number of areas where there are shortages of appropriately skilled staff, not just the area of oncology. All over medicine in Australia there are shortages of nurses, doctors and so on. Given that there are shortages of staff in your profession as well, is it appropriate to recommend significant increases in funding immediately? There will presumably be a long lead time to recruit the numbers required to make the sorts of on-the-ground differences which extra funding could make.

Mr Hochberg—Yes. I acknowledge the fact that there are training needs. At the moment oncology social workers do not have any specific training. Most of us have trained on the job, although Oncology Social Work Australia has made an approach to one of the major schools of social work to establish a postgraduate training course. There are undergraduate social workers coming through the system now who could fill the positions. When we talk about making an immediate financial contribution towards the significant staffing shortages, I believe that if you do not start somewhere then inevitably you are never going to be able to start meeting the need. Maybe some of that contribution will be for education. Certainly our submission talks about education specifically—that is, educating some of our professionals towards having a career in oncology social work.

Senator HUMPHRIES—We have seen some evidence of specialisation in other fields that deal with cancer causing problems in itself and there being a need to coordinate the provision of care to people with cancer, so you are talking about case managers or case coordinators to help bring together the various occupations. I assume you would suggest that oncology social workers should be within that umbrella. Is there a case for saying that the creating of silos within the field of social work might not be a good thing, that it is better to have generalist social workers who can range across a range of medical problems rather than concentrating resources in one particular field of social work, namely oncology social work?

Ms Tokatlian—The University of Melbourne has started a master's in health social work which is looking at the generic field of health social work and there can be some subspecialties within that. When we advertise a paediatric oncology position we get a number of very good applications—it is a field that lots of people want to work in. Certainly we would be looking at a very sound proficient generic medical social worker who can then have some on-the-top training around oncology. There are concerns within professions around getting to a position where you become too specialised, but in social work, just as in many professions, there are layers of specialty and there are skills that cut across all the different fields. A generic social worker who has worked in a medical field we would look at as someone very appropriate to work in oncology.

Ms Holland—I have been specialising in gynaeoncology for 17 to 18 years. Having had students for about 16 of those years and having had a bias towards training them in particular oncology, rather than having a generalist approach, I do not agree with the generalist approach. I do not think it develops the worker. I do not think the worker meets the needs, but they do not know that they are not meeting people's very specific needs. It is like my training in law, working in a specialist area—it actually makes me very clear on what I am doing in reducing things to three Melways points. I do not think people who are not skilled or trained in something can comment on what they do not know and that is a sad thing in social work, as it is in other fields.

Mr Hochberg—We have been lumped in the hospitals with social work and generic social workers and in the last 10 years there have been substantial cuts to social work services. Inevitably, what happens is that they look to see wherever they can make cuts. There are many examples of where they have just cut oncology social work services completely, looking at it as being a generic service, and then you just do not get a service to patients in that particular area.

Ms Todd—The demand on social work in aged care, for example, is so high that often the resources are drawn into that area, and us being involved in cancer services is sometimes seen more as the icing on the cake rather than doing really essential stuff such as moving someone out of the acute hospital bed and getting them into a nursing home, for example.

Ms Holland—I think you need to look at an international comparison—Ivan is the Australian representative; Ivan, you need to speak about that—for oncology social work, because of the specialty of it: what is an oncology social worker, what is an oncology related psychologist, what is the similarity or difference? I feel very clear on those areas.

Senator HUMPHRIES—Do you see the cuts that have occurred in oncology social work in recent years, not just in Victoria presumably but across Australia, not as a comment on the value that administrators see in oncology social work but simply a product of other pressures on hospital budgets?

Mr Hochberg—That is correct.

Senator HUMPHRIES—What jurisdiction or country provides best practice as far as you are concerned for integrating oncology social work into cancer treatment and therapy?

Mr Hochberg—I think we would all agree it would be the United States, who have pretty well developed their psychosocial services and oncology social work. They have a leading role in doing that. There is the Association of Oncology Social Work, which I am involved with. They have their own journal, the *Journal of Psychosocial Oncology*. They are involved in a number of programs and initiatives, acknowledging that you are never going to have enough social workers to meet the demand. So they actually have looked at developing a whole range of different programs that enable them to get to larger groups of populations so that they can have the benefit of some psychosocial input. Some of those programs are run jointly. For instance, the Living with Cancer program, which in the States is called I Can Cope, has recently been taken over by the Association of Oncology Social Work and the American Cancer Society—they are both jointly running and maintaining this program. They have done a lot to look at the fact that even they have shortages, and therefore how they can address those shortages. They have developed some quite unique, innovative programs.

Ms Holland—In 1976 Washington poured quite significant funding into a study heralded and led by William Worden and Avery Weisman, a psychologist and a psychiatrist. They opened up the field of psychosocial oncology in terms of naming what areas fitted in with what. Then people like Jimmy Holland at Sloane-Kettering, referred to by the last speakers, provided quite a skilful multidisciplinary approach. For the research that I have done in the medical faculty at Melbourne university there is no funding. I have done a PhD while I was working full time et cetera. There was none of that sort of definition and funding. In the last eight years maybe there has been some sort of attempt. General hospitals probably do not understand the deep-sea diving that is required with the word ‘psychosocial’. An example is care of children with the majority of my patients who are single mothers and who do not have any support. Ivan’s second example, the lady with bowel cancer, is probably a scratch on the surface of 90 per cent of my population.

Senator LEES—A number of states are reviewing their treatment of cancer, how they deal with it, how they support and arrange services. Has your organisation been involved with the Victorian review and the setting up of the frameworks and the new services that have come in?

Ms Todd—In Victoria there are regional integrated cancer services. I know most of us would be involved with the ones that cover our region. I am involved with the one in my region.

Senator LEES—Is that going on to recognise the shortages and to recognise that this area—

Ms Todd—We hope so. They have only recently commenced in Victoria. I met with my people only in the last couple of months, so it is all very new. We are keeping our fingers and toes crossed.

Senator LEES—As far as your involvement is concerned, is one of your aims to look at the availability of your social work services as well as training aspects? You have commented on preferring to have people trained. How do you go about that? At what stage in a social worker's training—post-qualification or during the training—do you become an oncology social worker?

Mr Hochberg—Oncology Social Work Australia started up, only 14 months ago, because we realised that our profession and what we had to offer was at real risk. One of the main things that we recognised was the need for ongoing training. That usually would be after you have been in the field for a couple of years, I think. You would probably get a position, as Nicole just mentioned, and you would have broad skills in provision of social work services within a hospital setting and knowing what is required—generic skills. But then after a year or two years working in the specialist area you would really benefit from training. Everything that we have initiated has been off our own bat, with no support or involvement of any government agency or voluntary agency. We are really just doing all of this.

Senator LEES—So it is on-the-job training; it is training within the hospital setting; you are not sending people out to a university.

Mr Hochberg—No.

Ms Holland—We have been trying, as Ivan indicated before, to get a postgraduate course running, which would be voluntarily started by us as advocates for that area, the thing being that training needs to start at an undergraduate level. As I indicated earlier, for 16 years I have had undergraduate students. But it needs to continue because the evolution of working with dying women, in my instance, or dying families basically on a daily basis requires some personal coping strategies and survival skills which one cannot come up with individually. That requires maturity and some sort of ongoing evolution. Going to a general social work department with people who are not trained in providing that sort of aid—I would like to allude back to that—is a big demand.

Ms Tokatlian—We in paediatrics are a much smaller group, obviously, given that the rate of diagnosis is smaller than for adults. We have been very heavily involved in the Paediatric Integrated Cancer Services initiative. Certainly with training, paediatric social work is a specialty of social work, and on top of that you have health social work and then on top of that you have oncology paediatric social work. I think that at the Royal Children's Hospital our general social work department is very good at supporting the social workers, whether they work in oncology, diabetes or wherever they might be. So there are some differences depending on the health network that the social workers are employed in.

Senator MOORE—Do you have association with the Cancer Council of Victoria or with their working groups or board? Is there a social worker from your specialty involved in the board?

Ms Todd—I am not on their board directly, but I am on their Victorian oncology clinical group executive, representing social work.

Senator MOORE—One of my own experiences with social work in hospitals relates to the amount of work you have to do to demystify what is out there in the community for a family or a person, as your experience and case studies have shown. Do you find that people are aware of what is out there when they are in that process? Do most clients have any knowledge or awareness at all about what is available for them?

Ms Todd—My experience would be they mostly do not. People tend to have been living their life and then they get their cancer diagnosis and it is a different life they move into. They have been working full-time and then all of a sudden they have to negotiate systems like Centrelink, the ministry of housing or palliative care services out in the community—a whole array of services. They have never had any contact with those agencies before, so I find that a large part of what I do is to try to introduce people to the services in a way that I recognise as being at their own time and pace. Often they are still thinking: ‘Hang on, I’ve got cancer, have I? What does that mean?’—let alone trying to put food on the table and making sure that they have an income. There is so much for the person to try to integrate at one time.

I would say most people are pretty unaware of what is available out in the community until they have the need to find it. And then they often need to find it very quickly. A great example: last week I was referred to a young man in my cancer centre who had come down from Queensland. He said to me, ‘I’ve come to Victoria because I’ve heard cancer services are better in Victoria than Queensland.’

Senator MOORE—That is the rumour.

Ms Todd—He had advanced metastatic melanoma. He was a very sick young man with three young children and was unemployed and homeless. He came down in a car and had nowhere to live. He was living in a Salvation Army motel. I needed to find him housing, I needed to get him hooked up to Centrelink, I needed to get him linked into palliative care for his pain management, I needed to look at schooling for these children and I needed to talk to his partner. All of this stuff he needed a long time ago, but it all had to happen then and there because he had already been in the emergency accommodation at the Salvation Army for a week longer than he was meant to. There are a lot of systems to negotiate and these people are often very ill and do need help to do that.

Ms Holland—Largely, people need the money today. Negotiating the caravan park is tricky. There was a period of five years where we ran voluntary fundraising and probably raised about $500,000 over that time. We paid for people’s concrete cemetery stones, for example, when mum had five children and could not even buy school shoes. The welfare grants of the Anti-Cancer Council of Victoria were invaluable to my services and I had some fabulous people in the Melbourne community who, by craft work, raised about $50,000 or $60,000 a year. That was very helpful but as social workers we are dealing with the people who are desperate here and now because they cannot go to Safeway supermarket or buy any clothes. This has just tipped them over the cliff. I think a distinctive feature of social work is that we are working on the ground. Somehow I cannot let that woman go out of my office with no Christmas dinner when the grandma who has cancer is looking after the four kids while the daughter is drug dependent. I cannot say no to her, but in the end I have to because there is just nothing there.

Senator MOORE—I have one last question. One of the things we find is that people who have cancer are no different to anybody else so that the same social problems continue to happen.

Ms Holland—That is right.

Senator MOORE—You have seen the terms of reference for this inquiry. The second part of the terms of reference are to do with complementary and alternative treatments. In your experience as social workers, do clients talk with you about their confusion about what they can and cannot do, the issue about information sharing and those sorts of things? I would like to draw that out from your professional stream about what the clients tell you.

Mr Hochberg—I would like to respond to part of your first question when you said something about cancer affecting normal people who are then confronted by abnormal situations.

Senator MOORE—Yes, I was saying that kind of thing.

Mr Hochberg—That is very true and that is why a lot of our workers are looking at developing programs that can reach a larger group of people than just the one worker or the half worker that is allocated to deal with cancer. In response to your question about alternative treatments: often people speak to us in confidence. They do not want the doctors to know because they are fearful of the reaction. My tendency as a practitioner is to encourage them to discuss with their doctors the implications and also to acknowledge that their reason for being in hospital is that they have a belief in the medical system and what it has to offer them. That is an implicit acceptance of what is available. And the other options they look at should fit in with their belief structures and what works for them. That will be of benefit to them, as well. I am not encouraging them, but if they are going to choose something they should not just look at what is the latest thing around. They need to look at whether it fits in with their understanding of their illness, their body and their belief structures. I certainly encourage them to discuss it with their medical practitioner because it is so important that there is a sharing of that.

Ms Holland—I would like to add something. Who pays for the sharks teeth herbal lotion? Who pays for the psychologist? Certainly the hospital cannot and the psychologist has a minimal charge fee. I know $60 is not a possibility for 90 per cent of my patients and they cannot go to a psychologist so they might look initially for the evolutional hope of complementary therapies or whatever. But usually they cannot afford it and it is terribly frustrating to feel that they are letting themselves down or taking a self-blaming approach. So where complementary therapies can be paid for—including therapeutic services, meditation and all sorts of things—that is fabulous, but the majority of people who walk through a door such as mine, as a public social worker, are not able at all to pay for those types of luxury items.

Ms Tokatlian—We have found at the Royal Children’s Hospital that we have been able to institute some group programs to address this issue. We have had lectures and education sessions by our doctors talking about alternative or complementary therapies and looking at why parents might choose them, the pitfalls and the benefits. We have had situations where parents have felt guilty if they were not able to afford alternative or complementary therapy when the family next door are doing that. They ask themselves whether they really care enough for their child. These are some of the dynamics that we work through with families on an individual level and also on a group-work level.

Like my colleagues with adult clients, we have to struggle with our resources and sometimes we feel that a group-work approach is beneficial for families in supporting each other—that there is a benefit from that that they do not necessarily get just from the one-to-one work they do with a professional social worker or psychologist.

Senator KNOWLES—How do you deal with that competition between next-door neighbours? I mean that is life, isn't it? One kid might have a PlayStation 2 and the next-door neighbour's kid only has a skateboard or whatever. How do you deal with that?

Ms Holland—Absolutely. I think it is very difficult. People may know that there is a family in the media at the moment who are overseas and have raised an enormous amount of money to get some treatment in New York. There are families in Victoria who have not been able to achieve that for their child. So that is something that is an issue at the moment. How do we deal with it? A lot of it is about having a good working relationship with families and being able to address issues of guilt that sometimes surround that particular issue—the child next door has a PlayStation but my child does not. Often there is a broader issue of guilt around, 'Have I done enough for my child? or, 'Am I a good enough parent? Some of it is around working with what is the reality and what are some of those feelings that are invoked by having your child or someone very close to you diagnosed with a life-threatening illness. So it is a complicated matter, but I guess that we are aware of it. Some of it we deal with in a group situation—and parents are often very good at talking to each other. They may say, 'Okay, I might not be able to afford the PlayStation but I'm doing this and that.' So they normalise the experience amongst themselves. That happens informally on a ward situation, in outpatients and in a group-work setting. It is also something that we pick up individually with our clients, with the patients and with the parents.

Ms Tokatlian—We are in a different situation where we actually see all families of children who are diagnosed with cancer. We do a routine screening and then we really have to prioritise our involvement. So we will not necessarily be able to work intensively with patients and families from the diagnosis. But, as I say, we prioritise our involvement and we try to make ourselves available to families and set up a relationship so that they know they can come back to us. I think that is very different to the adult patients.

Ms Todd—We would probably have a similar answer to that given by the psychologists in response to your questions at the end of their presentation. There might be one of us for several thousand patients.

Senator KNOWLES—Given that, Ms Holland, I come back to your earlier statement when you said that 90 per cent of your clients are single mothers. Is that what you said?

Ms Holland—I would say that 90 per cent of my population would be struggling for money, and a significant percentage of those would be women on their own with or without children.

Senator KNOWLES—So what happens to the others who might need help as well when your resources are fully expended on those particular groups?

Ms Holland—Could you clarify what you mean when you say 'others'?

Senator KNOWLES—I am talking about others who are in a family situation or whatever. You say that a large percentage are financially deprived or single parents, but there are obviously a lot of other women who are confronted with the same problems. Your time is devoted to the other group, so what happens to them?

Ms Holland—With the crisis model, being fairly experienced I prioritise them on the basis of urgency—for example, there is the 79-year-old grandmother on her own with no support and nothing down through to what we have just described. I do it by emergency-urgency, and I see people fairly quickly given that I have been in the job for a long time. I get people working with me on moving forward, because it is important to become calm again after having had a huge death threat destabilise them. They come in and then I quickly refer them or provide them with resources et cetera. For about five years we prioritise the children of the mother.

Getting back to your question, no-one who has a need is missed, because the nursing staff act as a siphon for that. We work as a team on the unit. So there is always a nursing conversation at the bedside which would help. It is more the late treatments rather than the fourth-line chemotherapies plus the palliative care that I have to prioritise. Early treatments have a lot more of a 'hope' phase whereas with diagnosis there is the shock, which usually needs someone holding the person's hand. Advanced treatment requires a therapist and palliative care requires someone to pretty well pick up the pieces and keep the person breathing.

Senator KNOWLES—So you are put in a very difficult position, aren't you, because you are basically asked to pick winners and losers? When I say 'winners and losers' I mean those who can access you and those who basically cannot because of your demand.

Ms Holland—I do not ever miss people in the sense that, I suppose, I have put in a lot of after-hours work over the years—weekends et cetera—until the protocols changed. I think we are in very difficult position, definitely. I think the whole of Australia is, and not just me or those of us sitting along this table. It is all of our families who miss out. Again, we do not know what we are missing out on—some sort of family resolution before mum dies or whatever situation. I do not speak about that anymore; I just do what I can. I feel privileged to work in oncology social work—it is a fabulous position. We have tried to make it a science rather than a generalist sort of situation. We just do what we can and it is a real privilege.

CHAIR—I am slightly confused, so I will ask you to clarify something: I thought I heard you say that everybody with a need has that need attended to. That is not the picture that is being painted in your submission or by anyone else.

Ms Holland—In my unit I try to do that personally, but it means that I do not work within the office hours.

Mr Hochberg—Cynthia is a unique individual and is prepared to do that. If you look at most contexts in which we are practising, you will see it is very much hit and miss. The way we often receive referrals is when it severely impacts on the other staff members to the extent that they hear that something is wrong, they cannot ignore it any longer and they then say, 'We will get social work.' Most services that I am aware of in Victoria do not provide anything for outpatients—it is all inpatient focused. So, if you are an outpatient, you have to be in crisis to get social work. Maybe Karen can inform you better about that.

Ms Todd—I would agree that that applies across Australia, not just in Victoria. Most social workers are funded as inpatient social workers. When I was employed in my job I was told my emphasis was to be on the inpatients because of the demand on getting people into the oncology wards and the demand on the beds. I get asked by the outpatient staff to come and see someone when there is a patient, like the young man I mentioned to you earlier, who is homeless in a motel, or there is someone breaking down in the doctor's room and the doctor does not know what to do—the absolute crises. Ideally, these people should be picked up way earlier; they should not be allowed to get to these absolute crises. It would be wonderful in adult cancer services if we could do what they do in paediatrics, where every person is screened. When a person gets a diagnosis of cancer their family situation, income, and housing are all assessed and their needs identified. We can say, 'This person needs this; this person needs that.' But, unfortunately, most of us are very much working on a crisis basis only. It is often, unfortunately, the person that cries or yells the loudest that gets the help.

Ms Tokatlian—Can I just add that in paediatrics, which is relatively better resourced, we are still being very reactive to patient need rather than being preventative. We have tried to look at some group-work programs; we are working for the Cancer Council around a peer-support model. So we are certainly trying to be more and more preventative, but, in terms of the optimal psychosocial care provided by social workers, and in conjunction with our psychologists, psychiatrists and other colleagues, I would say that we certainly fall short of that. Partly, this has been identified by the Integrated Cancer Services review; psychosocial care is one of their priorities. In terms of need, certainly, we do a lot of after-hours work as well; but the need is great.

Ms Holland—I do not want to confuse you by saying that the world that I work in is thoroughly resourced and fabulous. I work with various levels of need and I am saying that the majority of needs are urgent and desperate et cetera. I would like to think that the job was well done on that sheet of paper, but I am not extending that to a huge tick and saying everything is solved. It is just working with the resources; what we offered at the hospital 10 years ago is not what we offer now, and I see no private patients under any circumstances. As Karen said, one is given a protocol for what one does in one's job, and one blocks the rest of the needs out. For example, I used to do a lot of research, and it is a gaping hole in social work, which is often accused of having an artistic lack of definition. I did do research, but it was an all-night lifestyle to get that PhD out of the way. That does not help the general worker who has got children at home and who has to go home at six o'clock. I do not want to deceive you with anything I said. It is just said with the enthusiasm of trying to do a job well, having had 17 years at the hospital I work at and almost 30 years as a social worker. It is why I have another profession.

CHAIR—I just wanted to clarify it, because it was in response to a question from Senator Knowles asking about the others.

Ms Holland—Of course.

CHAIR—We are not quite getting the description consistently across the board, but I am quite clear now.

Ms Holland—I am sorry if I am deceptive in my words.

CHAIR—No, deceptive is not the right word. Thank you very much for a very important contribution to our inquiry.

Committee adjourned at 4.46 p.m.