COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Services and treatment options for persons with cancer

THURSDAY, 31 MARCH 2005

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Thursday, 31 March 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 Cook, Knowles, Lees, Marshall and Moore

Terms of reference for the inquiry:

To inquire into and report on:

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

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

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

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

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

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

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

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

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

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

WITNESSES

Committee met at 9.31 a.m.

BURTON, Mr Kingsley John, Project Director, Health Reform Implementation Task Force, Department of Health Western Australia

FONG, Dr Neale, Acting Director-General, Department of Health Western Australia

HOUGHTON, Ms Liza, Senior Project Officer, Health Reform Implementation Task Force, Department of Health Western Australia

SAUNDERS, Professor Christobel, Chair, Western Australia Cancer Services Task Force, Department of Health Western Australia

THRELFALL, Dr Timothy John, Manager and Principal Medical Officer, Western Australia Cancer Registry, Department of Health Western Australia

CHAIR—I declare open this hearing of the Senate Community Affairs References Committee. The committee is commencing its inquiry into services and treatment options for persons with cancer, and I welcome the witnesses.

Dr Threlfall—My brief submission principally concerns information systems rather than clinical matters. I have a summary report with a couple of illustrations which I would hope to pass out to the committee and talk to if time permits.

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

Dr Fong—Thank you very much, Senators, for holding this inquiry into something that we think is extremely important. You have received our submission. The Western Australian health system is undergoing some radical reforms and will be the centre of a lot of activity in reforming both health service delivery and health planning over the coming few years. I was appointed in August last year to implement what was a fairly groundbreaking report by Professor Michael Reid, former director-general of the New South Wales Department of Health, into our system here. That is in train. It has been in slight recess for our state election but now that we know who the government is we will be working fairly full-on to implement the reforms that were highlighted in that report and to take the system forward.

Cancer services were a fairly major component of the deliberations of that committee. Professor Reid outsourced a review of cancer services in 2003-04 to Professor James Bishop from New South Wales, whom I am sure you will come across in your deliberations. He did the cancer component of that report. Our job now in the Department of Health here is to implement the reforms overall, which, as I said, are quite substantial. We are pleased that today this has provided some focus at the national level on the planning and provision of cancer services.

We have appointed what we have called the Western Australia Cancer Services Taskforce, which Professor Christobel Saunders—who is a breast surgeon here and a researcher of renown—is chairing for us. The task force comprises a number of clinicians, which is outlined in our report, trying to bring serious energy and expertise to the table to better plan and deploy cancer services in Western Australia.

That is by way of introduction. There are going to be lots of things happening over the coming months and years here in Western Australia. We are excited about that. The state government here now has a mandate to implement its reforms. There are some serious dollars required. A capital works program of $1.7 billion over the next 13 years will be rolled out. There is a whole heap of things that will require a lot of collaboration both at the state level and with the Commonwealth in terms of primary health care reform. I will now invite Professor Saunders to address the issue of cancer and outline some of the highlights from our submission.

Prof. Saunders—Once again, thank you for giving us—and I speak on behalf of clinicians and patients with cancer in this state—the opportunity to look at what we think are some very important issues in cancer. Fairly briefly, over 20 minutes or so, I will outline a bit of the background of the Western Australia Cancer Services Taskforce. But, first, I will take the opportunity—as this is your first visit to people who have put in submissions—to outline cancer in Australia. You have probably all been well briefed on the subject, but I will mention a few things as a clinician. I will then concentrate on some of the points that the Senate inquiry has said it wanted addressed and some of the key recommendations that we as a cancer task force would like to see.

A PowerPoint presentation was then given—

Prof. Saunders—The 2002 figures on the slide were put together by Tim Threlfall from the Cancer Registry. These are Western Australian figures, but obviously if you times them by 10 that is about what you would have in Australia. We had nearly 8,500 new cases of cancer in Western Australia in 2002 and, sadly, 3,266 people lost their lives to cancer. As you know, cancer is the commonest cause of death in people in Australia and will affect one in three men and one in four women in this country. So it is a huge public health problem.

We know that the incidence of the common cancers is increasing, probably largely because we are an ageing population but also possibly because of improvements in screening—so we are picking things up at a higher rate. But the pattern of those tumours is not changing. Still the big ones that we see are breast cancer in women and prostate cancer in men, and melanoma and colorectal in both men and women come a close second. We also know that survival is improving. Australia now has one of the best survival rates for cancer in the world. I believe that quality of life for cancer survivors is improving as well. We as doctors have been treating patients in a different way. We are thinking about survivorship issues, and we think that quality of life is actually improving.

For those of you who I do not believe are doctors, I will briefly go through the management pathways. We largely define cancer as early cancer and advanced cancer. Most of our patients will present with early cancer. What I have tried to show in the presentation is that there is a whole spectrum of what happens with cancer patients. It is not just the doctors treating them. There is a whole spectrum from diagnosis, which may involve many different branches of medicine as well as other people such as radiologists and general practitioners, through to the actual treatment, with surgery and adjuvant therapy—by that we mean things such as chemotherapy or radiotherapy.

Then, very importantly, there is the long-term follow-up. Seeing that most of these patients will be cured nowadays, there are all of the survivorship issues. However, some patients will obviously go on to develop advanced cancer and a few will present with it. Again, there is a whole spectrum of disease management from the diagnosis and staging of that advanced cancer right through to palliation. It is important to remember that, when you are treating a patient, the patient comes at the centre but there is a whole series of people who will input into the treatment of that patient, including a lot of different medical specialities, nurses, social workers, physiotherapists and, indeed, the patients' families and friends. So it is very much a multidisciplinary thing.

But there appear to be holes for patients along the journey, otherwise the committee would not be here having this inquiry. That is probably what the guts of your inquiry is about. We therefore need to look at ways that we can plug those holes by improving the system. I think that is what we are here for. Those holes can occur anywhere along this continuum of care. It could be that patients are not referred quickly enough. It could be that there are problems with screening programs—in diagnosing them. There could be problems with therapy or follow-up. Quite often there may be holes in this multidisciplinary approach to care. Perhaps people are not getting together in a multidisciplinary approach. Perhaps we do not have all of those things in place. Perhaps we do not have enough information for the patient. I think it is about looking for those holes and trying to plug them. To give you an example, things work fairly well in something like breast cancer, where patients have good screening programs and come through well-organised models of care with a multidisciplinary approach. That is in a large teaching hospital for a patient with a common cancer, but I think a lot of our gaps lie with patients with rarer cancers, who perhaps are largely treated in the private sector, where these things do not mesh together.

Neil has already explained quite a lot about what is happening in health reform in this state. By way of background, the task force has come out of some recommendations from Jim Bishop's review of cancer services. It has also built on quite a lot of earlier reviews of health. I think there was a bit of a review overload in this town, but there is now a lot of excitement because we feel that we are beginning to do things and there is an end in sight. To that end, we have put this task force together for a very specific period of time. We convened in January and we are hoping to report by June. By that stage, we want to have developed a framework for cancer services in this state and a plan of how it could be implemented. That plan will include the appointment of a director of cancer services, who will develop the plan further and then implement it. That is the background. We thought it important, therefore, to show to you what we are doing in this state so it can be meshed in with what is happening at a national level.

We think this inquiry addresses quite a few of the areas we in the task force think are important, and I hope to show you over the next few minutes how it meshes in, but primarily we will cover part A of your inquiry: the conventional delivery of cancer care. The task force does not have so much expertise in part B: the delivery of less conventional and complementary therapies. Although we do firmly believe that they are an important part of cancer care, they need to be approached in an evidence based way. Therefore, at this point in time I will beg your indulgence to go over a few things. I am not only an academic but also a keen teacher. As this is your first public hearing, I thought I would use this opportunity to give you a little tutorial. I give this to medical students, so please excuse me if I am belittling your intelligence. I think it is important when assessing the evidence in cancer treatments to think about how, as doctors, we do this. Interpreting data and assessing the evidence is remarkably difficult. We must look at not only the volume of evidence—about 10,000 journals are published on cancer alone—but the weight of evidence: for example, how scientific were the studies of different treatments, were they done well, how reproducible are they. There is also a lot of individual interpretation of that evidence as well as political pressure—which I mean with a small ‘p’, not a big ‘P’—for example, how we as a community and as a society think we should use or not use the treatments that we have. Also, most importantly probably, is the art of medicine—treating the patient as an individual and not as a statistic.

I will give you a little scenario that I give to some of my medical students. Let us pretend it is a few years ago and you have been asked to purchase a breast screening program. You have been given however tens of millions of dollars that would be and you have put it out to tender. Five tenders have come back. These are the kinds of figures that we see quoted all the time. Screening program 1 reduced the risk of death from breast cancer by 34 per cent, which is pretty impressive and you often see it in the newspapers. Screening program 2 produced an absolute risk reduction of breast cancer death of 0.06 per cent per annum. Screening program 3 increased the risk of patients surviving breast cancer from 99.82 per cent to 99.88 per cent. In screening program 4, 1,592 women have to be screened to prevent one breast cancer death. In the fifth program, they said they can reduce the risk of breast cancer death but other cancers will increase by about 3.9 for every 10,000 women screened. Which of those would you choose? Of course, the answer is that they are all exactly the same. It is just different ways of presenting the data, and I think that we have to be very aware of that when presenting the evidence.

I would also like to add one more scenario to that. We do have breast-screening programs and they have been hugely successful. They have revolutionised the way that we manage breast cancer, both screen detected and symptomatic. They have done that because they have improved audit, data collection and multidisciplinary care. The way breast cancer is treated is almost a model for many other cancers. That cannot be factored into that equation, and one of the difficult things that you are going to have to look at is how those kinds of system changes cannot be factored into a very scientific or mathematical model but are important.

Back to what I was supposed to be talking about after that little diversion: what are some of the key areas that we as a task force are wanting to address? Really, it is the whole gamut of cancer care right from prevention and early detection through diagnosis and referral systems. Can we improve the way that GPs refer patients and whom they refer to—there are a lot of issues and treatments particularly in some cancers that need to be looked into—and how research and education and training mesh into that treatment? Work force development and work force issues are a huge problem, which I will come back to in a little while. Provision of patient information, I think, is extremely important as, of course, is palliative care. The last two are really embedded in the ones above. Those are the problems with rural and remote care and the private hospital, private service interface, I think we find difficult to deal with particularly in

Australia. Having come from the UK five years ago, I find this a hard one to deal with here in Australia. So how are we going to cope with that?

In terms of your terms of reference, the first thing we had a look at was the efficacy of a multidisciplinary approach to cancer treatment, which, as I have already mentioned, is a critical part of best practice care that does not always happen. How can we make it happen? We have decided on the model of developing tumour networks to try to make this happen. For most of the major large volume tumours, if there is a network approach which would cover the whole state both rural and metropolitan and bring all the disciplines together, that would improve the management for patients. But to facilitate that we really need guidelines, clinical indicators. We need a widespread audit. If we do not know what we are doing, how can we possibly improve it? Largely, we do not know the outcomes well at the moment. We need to accredit those services and credential people delivering those services, and I think those things are going to need a national as well as a local approach.

The second thing within the terms of reference was the role and desirability of a case manager or care coordinator or, as it is termed in Canada, a ‘navigator’, which I think is a very good term. It is something to help people get through that really difficult time when they are faced with cancer with all of these different people trying to help them. The model of care coordinating will be very different depending on where that person is based, whether from rural areas or metropolitan areas, and what sort of group of patients they are looking after. It is not the one thing fits all but we need to do a scoping exercise to see how that can be done.

As you heard from Neale, the state government are supporting that and we are able to appoint 20 of these positions. But, if you think about it, 20 people for over two million people are not actually very many and is not going to go very far. We do think that the Commonwealth need to support the development of this kind of role and perhaps even take it one step further and develop the idea of nurse practitioners—nurses who can actually deliver some of the treatment. That is a fairly controversial area but one that would be worth exploring, and it needs to be done at the national level.

Senator COOK—Without trying to interrupt your flow, standing in the shoes of a patient diagnosed with cancer, can you pick up in your presentation at some point—maybe now or later on—and walk us through how that nurse coordinator and the network interact with the patient.

Prof. Saunders—Let us think of an example of where care is worst, and that is a patient diagnosed with lung cancer out in the countryside somewhere—in Meekatharra, perhaps, a long way towards the north. It would be an elderly patient possibly with not a particularly good education who is quite unwell with other things, who presents to his GP with a problem with, perhaps, coughing up blood. His GP does some X-rays and whatever they do up there—it may be done in the private sector—and then refers him to a doctor in the nearest town, which may be many hundreds of kilometres away. This elderly patient without very many resources has to try to get to that doctor. The doctor tries to work out what is wrong. The patient is then referred down to another doctor here in Perth. The patient sees lots of different doctors in that clinic and is asked to come back two weeks later because there has to be some treatment and he will have to stay in Perth for while for the radiotherapy. There might be a need for chemotherapy. The patient is asked whether he wants to have it or not and he is not sure. There are all of those problems.

We envisage a case manager or care coordinator being the point of contact. One of those people would be appointed for that region and the GP would perhaps put the patient in touch with that care coordinator, who would come and meet them, go through their diagnosis with them, give them some information about their diagnosis—what it means, whether it means they are going to die next week or not, what kind of treatments are on offer, whether there are any clinical trials on offer and who the best person to go to is—and talk about questions like: 'Am I sure that this person I have been referred to down in Perth is the chap who knows about lung cancer? Maybe I should be going to somebody else.'

So the coordinator will provide them with a lot of information, will help to organise some of the PATS—the travel scheme—problems for them and will perhaps organise a social worker because they cannot look after their farm anymore, they have run out of money or they or their wife need to have some psychological counselling. They are really somebody who helps navigate the patient through the system but who has very set and specific times of contacting the patient. While they are acutely unwell the coordinator will have set times for contacting them and will help them a lot but will also be there afterwards—not all the time but for specific contact times. So at six months, she—and it probably will be a she, because most of these nurses are—will get in touch with the patient again to ask: 'How are you going? What problems are you having? Are you back at work at the moment?' They would check those kind of things. Also, as I said before, the service is going to vary depending on whether the patient is in a rural or metropolitan area and what their tumour group is. A patient diagnosed with breast cancer in Perth will have very different needs from an elderly patient with lung cancer in Meekatharra. So they are going to have to be a very special person with a lot of resources and a good ability to pull those in. Does that help?

Senator COOK—That helps. I do not want to distract you or take up the time of the committee unnecessarily, but one of the themes that I want to explore during the course of these hearings is: what can cancer patients do to help themselves, to take responsibility or charge of getting better? You have talked about services delivered to the patient. What access to the services available can the patient call up when they want it?

Prof. Saunders—I think without information the patient cannot, and that is the problem. Most of us have never had cancer before, so we have absolutely no idea what is there. Why would you? But information is power, so giving the patient the information to do that is very important. Once they have that information, they know what they can do and then they can access that a lot better.

Senator COOK—When people wake up at 3 a.m. and start wondering about the advice that their specialist gave them in the very short, cryptic time that they had with them, can they ring up this person—not necessarily at 3 a.m., but at the next reasonable hour—and talk them through their anxieties and fears?

Prof. Saunders—They can, or if the person they call cannot do it then they will know who can. They may suggest that they ring the Cancer Helpline, for example, which is provided by the Cancer Council, a non-government organisation. As I said, I do not think they will be able to do everything, but they will have the resources to be able to point the patient in the right direction.

Dr Fong—One of the critical issues in terms of the health system in Australia is that it is absolutely fragmented—the left hand does not know what the right hand is doing, and there is the Commonwealth-state issue on primary health care. Quite frankly, GPs do a great job, but they are not the answer for chronic and complex disease, and you want to put cancer into that category. Chronic and complex disease is our great health burden for the next 10 to 30 years, and we need to coordinate care and encourage self-management from patients because we just do not have the work force, nor is it sustainable cost-wise, to provide a work person to do everything for people. It has to be an empowering strategy, driven largely by information technology. There has to be that available information to be able to call up and be directed to the person they should speak to. GPs could do that role, and I have challenged them to do it here, but I do not think that they will pick up the role. If they do not pick it up, someone else has to pick it up. Then comes the funding issue—the access to the CMBS—because currently the states would have to pick up that funding.

Senator LEES—For a lot of people it seems—and fortunately I do not have personal experience of this—that they get on the net at 3 o'clock in the morning and start wandering through sites. I have personal experience of someone with another chronic illness, and who knows which site you are on and whether it has any information that is of any value? Is that something that you are looking at as well, in that you can help people find their way through—

Prof. Saunders—Exactly. It is providing good information. It already exists. For example, if a patient did phone the Cancer Helpline or one of the many other cancer support organisations, they may well be pointed in the direction of good, well researched, evidence based web sites that will give them accurate information, such as the National Institutes of Health web site in the United States, which is a fantastic source of information, or the National Breast Cancer Centre site in Australia. But they do need to know where to go. I do not think we should leave everything down to a nurse, and it is important that the education of doctors is also improved—such as their communication skills and how to get some of those decisions over to patients.

Mr Burton—Christobel, I suggest that you also talk about the network of cancer services and how that will interact.

Prof. Saunders—The tumour network?

Mr Burton—Yes.

Prof. Saunders—You did mention that. Patients at the moment are not sure if they are accessing the right care. You do not know if you have gone to the right person or not. We do feel very strongly that there is good care here. There is undoubtedly excellent care in Australia but, as I said, there are gaps—not everybody can access it. If you have that in a networked way so that patients have a referral system, they can make sure that GPs are referring them to the right person. Having a tumour network—and the nurse looking after lung cancer wherever will be fed into that tumour network—means that patients know that they have access to the right kind of care and the right kind of information about what is available, including all the alternatives and the clinical research, which they do not have access to at the moment. That needs to be not just for the public sector but also for patients being treated in the private sector. Personally, I find that quite difficult sometimes. Sometimes they are not sure if they are seeing the right person.

That does fit in neatly to your third term of reference, which is about models and best practice of addressing psychosocial factors, because a lot of that does come down to patient psychosocial concerns. We certainly need to facilitate implementation of the very good national standards and guidelines that are available now for psychosocial care of adults with cancer, and we need to build on the work of the NGOs. But the main problem is equitable access. There is often not enough psychosocial support for patients, particularly, again, in the country, so we need to look at how that can be improved.

The fourth term of reference is about delivering services and treatments to regional Australia and Indigenous Australians. Quite frankly, this is a national disgrace. The fact is that if you are diagnosed in country Australia you are twice as likely to die of many cancers and if you are an Indigenous Australian you may be many hundreds of times more likely to die. It is something that is unacceptable for a First World country. I find it an embarrassment, I really do, that we can continue this way. We have to do something about it, and it is not something that we can do at just a state or local level. We need to look at how we are delivering services to the country. The big problems, according to people in the country, are work force issues, including nurses and doctors. We need to look at some way of improving that, because we cannot just go on the way we are.

What are the barriers that we as a group, as the task force for cancer, saw to the implementation of best practice? As Neale has already mentioned, there has been a lack of coordinated networked services, and we are trying to overcome that by developing a plan and developing things such as the tumour boards. There has certainly been a lack of clinical and managerial leadership in cancer. Hopefully, having a Director of Cancer Services will help address that to a certain extent. As I have already mentioned, the shortage of a cancer related work force—and not only the doctor work force but important positions like radiation therapists, nurses and nurse care coordinators—is something that I am sure will come up over the course of your travels around Australia. There is a lack of resources in some areas such as radiotherapy, and there are the constraints of geography, which we cannot really expect you to do too much about, but we need to think about that.

Some of the solutions to these barriers that we have thought about would include a national approach to radiotherapy, which undoubtedly there has been a lack of access to, and this state is unfortunately one of the worst in the country, or has been up until now. The education and recruitment of a cancer work force, as I have already mentioned, is something that we need to urgently address. There have been some studies on what is needed in the cancer work force, and we need to address those. The issue of credentialling and accreditation is something that has been looked at from a national level previously under the Cancer Strategies Group, and perhaps it will soon be looked at under this new body, Cancer Australia. It needs to be done at a national level as well as at a local level. That is how patients are going to know if they are getting the best possible care—if they go into accredited services to credentialled practitioners.

We need to think of ways that we are going to encourage this apparently ideal system of care, with a multidisciplinary approach to care and with good psychosocial support. For that we are going to have to look at Medicare item numbers for those things for all practitioners. Lastly, we have been twiddling our thumbs for a number of years over colorectal cancer screening—1,000 Australians die every year because we do not have a screening program. I would like you urgently to think about that. That is all I have to say for the moment, so I would welcome some questions.

CHAIR—I invite Dr Threlfall to make some comments.

Prof. Saunders—I purposely left data out, Tim, so you can talk about it!

Dr Threlfall—You have already covered a lot of ground to which my small submission is very relevant. I wonder if I might distribute to committee members a couple of pages which I have not yet presented because the information is more to refer to later on. Thank you very much for the invitation to come along for such an important opportunity to get a few issues across. What I have very rarely had is a chance to present anything about data issues at such a high level. I hope to demonstrate by a couple of simple examples, if you have not already heard, that what is underlying all these things that Professor Saunders and Dr Fong have mentioned is a need for good information.

In particular, the topic of staging information comes to mind because it is one of the few things that sets us apart from some of the other countries. It is what sets the population based cancer registries apart from the hospital based cancer registries—the clinical or departmental cancer registries. We just do not have a population based collection system for cancer staging information, except in New South Wales, where, strictly speaking, it is not staging information so much as a cut-down version of measuring what we call the extent of disease.

What I basically hope that the committee will take note of is something which bears on all the terms of reference rather than any particular one: I hope you could place some sort of high priority on federal funding for a population wide collection of cancer staging data. The need for this is clear. Clinicians want it. I referred in my original submission to the fact that our cancer survival report from several years ago was widely praised by clinicians but its relevance was questioned in the absence of staging information. I am very much in favour of population based registries as opposed to clinical, departmental or clinician based registries because they are unbiased and they can include the full spectrum of the disease process in the whole community without any opt-out sort of provision. In the current climate, in which privacy is given more and more emphasis—and rightly so—I still believe there is a place for a no-opt-out provision population registry if we are really to have good data on which to base decisions about spending public funds.

We in the WA Cancer Registry conducted an NCCI—national cancer control initiative—funded project a couple of years ago to pilot and cost the collection of staging information. That is now out there. It has been published and people have been going around knocking on doors to see if various state governments or federal bodies might take this up and encourage it by way of federal funding. I emphasise the federal funding because we have a multiplicity of data collection systems in the different states. We all have different software and different legal frameworks within which cancer notifications are made, and yet, with the cooperative spirit which has developed over the last 10 years I have been in this area, coordinated in the AIHW's National Cancer Statistics Clearing House, we at least have a situation where all states are reporting within a reasonable time a similar set of data items which can be meshed together and used to produce reasonably good national reports. Ten years ago that was not the case. It has taken that long and it has all been done with carrots rather than sticks: it is done without any legally-binding national minimum data set framework. The same sort of thing could be done again if only the money were available.

There are a couple of examples in the information I gave you. I refer to the graph with four lines descending from left to right showing, basically, that the further you go after a diagnosis of cancer the less likely you are to survive. However, the lower line refers to the earliest calendar period of the registry's well-documented history from 1983 to 1987. The five-year survival was 70 per cent for diagnoses made in that period. Twenty years later we have moved up to 91 per cent. The problem is that, if we knew this was a graph for lung cancer, for which there is no screening program and for which late presentation is routine, then we might think that the figures are due to improvements in treatment. However, if we thought it was for breast cancer or colorectal cancer—if we had a screening program for that—or, as we have unofficial screening programs, melanoma, then we would not have a clue from a graph such as this, without knowing if the stage distribution had shifted, whether we were dealing with better treatment of the same spectrum of disease or whether we were just detecting cancers earlier in their life cycle and the rate of cure at a given stage has not changed one bit.

I am a population health physician with a keen interest in making decisions as to where the money would be better spent to encourage the continuing improvement and coverage of screening programs, particularly in rural areas. It may be that screening is already picking up everything at an early stage but we are not using the right chemicals or radiotherapy. It is my view that staging is one of the key things that will produce a quantum leap in our ability to interpret such basic information, which we can do quite easily. It is easy to plot a survival curve, but to know what it means over 20 years of history—or even over two or three years, where things are changing rapidly and new treatments are coming on line all the time—we really need more information, and ideally we need it at a population base level. We need to know about everyone, rather than just those who turn up at a particular cancer centre at a particular hospital.

As an example of what we can do, I have attached a page of graphs and the first page of a report that landed on my desk just yesterday. It is based on data from the Northern Territory by Dr John Condon, who runs a registry there. It is a good report which has produced stage based cancer survival figures in the whole of the NT, and it has 10 years of information. It had to be specially funded, and the staging data had to be pulled from files retrospectively. I think the figure quoted was that it was only 88 per cent complete. So straightaway, because you do not have the information being collected in real time, you have to go back to the archives—people have passed away, doctors have moved, surgeries have gone under, sometimes records get passed on and sometimes they just moulder away. If you do not do this in real time then the information is nowhere near as complete.

I can only guess at the great reception we would have got in this state or elsewhere if we had been able to produce this sort of graph for WA a few years ago when we did our first public survival report. This sort of information makes it so much more useful. So I present this report, for your interest, as an example of what can be done. If it were done in a more current and timely fashion, it could be done better and without the extra work required to go back and dig out things from archives. We could move to this at a national level, given a little bit of funding.

I feel wary about saying that we could stick with our estimate of one and a bit full-time persons to collect staging information for WA on the top 10 or 15 types of cancer because, of course, two years later on, HR issues move on and some hospital’s medical records departments become harder to access, so we might find that we need 1½ or two people for WA. But if that is sufficient for 10 per cent of the population then maybe we need two dozen people in the whole country—and that is not an awful lot to spend, in my view, for what can be of immense benefit.

Senator COOK—Dr Fong, let me go to what, for me at least, is the nub of the presentations that have been made. There are two elements. Firstly, I am overwhelmingly struck by how fragmented the service delivery is. People are working in different areas doing different things that are all aimed at the same laudable objectives but without much coordination or cooperation. First of all, it strikes me that a lot of money would be saved if we had better coordination up front and, through those savings, a lot of money would be available to fund some of the work you were talking about. What is the problem here? Is there no overarching authority that can bring some coordination to this field? Do you, the health department, talk to all of these people? What is the nature of the federal-state dialogue on this question?

Dr Fong—That is the nub of the problem, I believe. In terms of the state based services—and I do not think this is different from any other state—we have for many years had very hospital based care delivery. The empires of the hospitals grow up, and the clinicians who belong to that hospital own the patients. Their interest is the patient, of course, but it is also the hospital and health service they belong to. They do not necessarily have a state-wide interest in the coordination of the health system. They are really interested in their career at that hospital. We are breaking that down with a move to an area health service model with a much more collaborative approach to the planning and delivery of services. We are saying that you can no longer start up a high-level tertiary service just because it is your particular interest. It has to be in the interest of the state in terms of a sustainable system. We are putting in place a state-wide cancer program. The framework we will put in place is a collaborative one across all of our area health services and all of our clinical disciplines. We are moving towards that. We hope that there will be a consensus approach to the plan and to the provision of care. That is the first step.

It is different for the primary care sector and all of the other associated support staff in primary health care. We do not have the ability to tell divisions of general practice, ‘This is what you will do’. They are completely autonomous. They are funded through the CMBS and through people that pay. We try and collaborate as much as possible, of course, and that is starting to happen, but it is a long journey. But you are right—provision of information is the key thing that will break down a lot of those barriers. We hear a lot about the electronic health record. It is the gold standard; it is the pot at the end of the rainbow. But we have not got the information that is in a GP’s surgery when we turn up at an emergency department at a tertiary hospital, the information is not there. The patient care outcome will be improved if the information is available. It is not made available because the system does not allow it. We are investing a lot in some fairly basic technology. It might not be an electronic health record in the first instance; it might be a call centre. We have got call centres and telephones and we are the most progressive state in the Commonwealth with respect to health call centre technology and the use of it in terms of information and consultation by phone. We will be doing a lot of that stuff, which is not just the big end stuff.

Senator COOK—I understand that answer from a state health department point of view, but let me invite you to do an adventurous thing, Dr Fong, and sit in our seats for a moment. If you were looking at the problem from our perspective, do you have any observations to make about what we might recommend that would bring great coherence to this? If you want to take that on notice, please do.

Dr Fong—The state-federal divide is the big issue with respect to the provision of health care. Funnily enough, a lot of people are driven by the financial incentive. If there is no financial incentive to cooperate with the state for a privately funded GP or a GP who is funded through the CMBS, they will not necessarily do it. We are working proactively, but if there were financial incentives for them to cooperate with the state to provide care then that would be very useful. If we were able to access some of the federal funds—we are disadvantaged from the CMBS in Western Australia; we spend hundreds of dollars per capita less than other states do because they do not access CMBS. There are no GPs in a lot of our regional areas, so people go to the state based service. If I was in your seat I would not be pushing the argument about whether the feds take over health or vice versa; I would be pushing for cooperation and making it possible to financially align the incentives for primary care and secondary and tertiary care.

Senator COOK—Okay, hopefully we will talk to the feds about their view on that as well.

Dr Fong—You have got questions, but there are two other things I wanted to make sure you noted before I leave.

Senator COOK—You laid out this morning your plan and where you are heading. It looks to me, without having digested every element of it, like a well thought through, comprehensive approach that embodies some of the things that are prominent in our terms of reference. But it seems to me that it comes down to an argument that you have got the plan but the Commonwealth have got the money and if they would only make more money available then you would be free to implement the plan and things would move forward. That is putting it crudely, but that is how it looks structurally to me. What can you say to the Commonwealth about why they should do this, because they have budget constraints as well. All of us sitting up here, other than Senator Lees, expect to be in government at one time or another and administering it from a Commonwealth point of view, so the states' perspective is quite important to the Commonwealth. If the plan you outlined today, which I think is impressive, were implemented, are you able to say to the Commonwealth that savings are available because of the preventive nature of the plan—that fewer beds are required to be occupied for shorter periods, that sort of thing—and the overall pressure on the health system would be eased? Can it be authoritatively asserted here that there are savings by doing this—quite apart from the health dividend which is, of course, fundamental?

Dr Fong—That has to be the driving issue at the end of the day: that it provides a better patient outcome. I believe there are savings. Can I quantify those savings right now? Not at the moment; I cannot. But there have to be savings. I do not think it is completely substitutive. The cost of home-based care or community-based care is still going to be fairly significant. But all of our work so far has shown that it is certainly still cheaper than bed days in tertiary hospitals. Have we quantified that? We are in the process of doing that. So there should be more money to go around. We are not here today to just say, 'We want more money from the Commonwealth'. The money that is provided needs to be better allocated and better coordinated. I am not sure whether the quantum of money is the issue; it is about how it might be allocated.

Senator COOK—What is the Commonwealth's response to these overtures?

Dr Fong—We have not gone to the Commonwealth yet in terms of laying out our plan. Our plan is in process. I want to move away from pilots—I am sick of pilots and demonstrations. My catchcry here in Western Australia in this reform program is: if we have got evidence that it works we are going to implement it and we are going to implement it systemically and not just pilot it again. Quite frankly, we are sick of that. We need to leapfrog in terms of reforming what we do and how we do it. So hopefully when we do knock on the door on specific projects with the Commonwealth we will have a good business case that will show that there are savings and, though the project may not be completely substitutive, there will be a better outcome at the end of the day.

I want to push the self-management issue very strongly in our reform program—managing your own health, wellbeing and illness. We are not going to be able to sustain the costs of having a health care worker to coordinate every piece of someone’s illness; it is just not going to happen. Here in WA we have been working on some groundbreaking stuff with Edith Cowan University—and you should come across it—at the Virtual Medical Centre. It is a private commercial organisation working on software and applications to assist people to manage their own health, whether it be cardiology or cancer and so on. That has been a collaborative effort between the Silver Chain Nursing Association, which is a home-based nursing group, and Edith Cowan University and the private IT developer.

I think later on this morning you are seeing Dr David Joske from the Sir Charles Gairdner Hospital and the Browne centre—yet another good innovative way of assisting patients in symptom management, taking a self-management approach and knowing what is going on so that they are then, in a sense, controlling it. We would certainly advocate that approach to care and think that needs to be rolled out not just in cancer but in lots of other areas.

Prof. Saunders—Further to that, David Joske, the professor of general practice here and I have a project running, looking at a patient-held record, so that patients with cancer have their own records. It is very empowering. It means that you can avoid lots of admissions for side-effects and things like that. In the UK all obstetric patients hold their own records—they have a little red book. It is such a good idea. But there is resistance to it, so we have an NHMRC grant to prove that it works. If it does, that might be a nice way forward in the future.

Senator KNOWLES—That is quite innovative, isn’t it? What has been written about you has always been so mysterious and you never know.

Prof. Saunders—You even have to write in this record what the aim of treatment is, that is, whether it is curative or palliative, and that is a very confronting thing to do.

Senator KNOWLES—Very confronting. Professor Saunders. I will come to some of the issues you raised in your presentation. You talked about improving diagnosis and referral systems. That rang a bit of an alarm bell with me. Someone on the outside would think that if someone presented to a general practitioner the referral system would be fairly straightforward. Clearly it is not, from your presentation. Could you run us through what the difficulties are and what needs to change to improve the system?

Prof. Saunders—I will have to give you a fairly personal view, perhaps not one that is representative of everybody in the state—I do not think there are any other cancer commissions coming to talk to you today—and bear in mind that I was trained in a very different system from this, within the NHS. There is some good evidence that referring patients to doctors who have good experience in treating that kind of disease improves survival. For example, in breast cancer, which is my area, if you are treated by a surgeon who treats large volumes of cancer—and a paper was published in a journal only last month by a group in Western Australia; you will hear some more about that this afternoon, I think—then you will have up to 50 per cent more chance of surviving the disease, and that kind of makes sense. Nevertheless, for a lot of diseases, and particularly the less common ones, GPs do not necessarily know who to refer to, or they refer to people through historical patterns—perhaps to people they have known for a long time and to whom they have referral patterns.

Our plan is to develop preferred referral guidelines, and that will go through tumour networks. The patients will be referred to a group of people who are accredited—so we know what their outcomes are; they collect their data and they can look at their data to see what their side effects, recurrence rates and all those kinds of things are—and to physicians who have credentials, physicians who should be treating large volume cancers. That is not to say that a surgeon in the country could not do a mastectomy—he or she may well be able to do one—but that person would have to be linked in to a network, linked into multidisciplinary care and all of these others things so that we can collect data, audit what they do and know that they have good outcomes. I feel extremely concerned that patients' outcomes are often not optimal because they are not referred to the right person.

Dr Fong—And that information would be publicly available. That is our intention.

Prof. Saunders—Absolutely.

Dr Fong—As a patient, you would know whether the doctor was part of the tumour network and you would make your own decision at that point as to whether you wanted to see that particular specialist.

Prof. Saunders—When you get to New South Wales, I am sure Cancer Voices NSW will come and see you. They have produced a directory of breast cancer services in New South Wales. It is almost like an Egon Ronay guide. People put their own things in but it has a kind of star rating such as whether you have a breast nurse in your practice and whether you take part in clinical trials. You create your own clinical standards or benchmarks of care and then see whether they come to them. It is trying to do that on a bit more of a—

Dr Fong—Objective.

Prof. Saunders—Yes—a national level and perhaps a non-voluntary level.

Senator KNOWLES—I can imagine that there would be many specialists who would clap their hands with glee at the prospect of that and, equally, there would be a number who would be horrified at the prospect. How do we bring on board those who are less inclined or more reluctant to have such an accreditation system?

Prof. Saunders—A very interesting document was published last week which you may want to read. It is about accreditation of cancer services, and it was put together by Tom Reeve and

Bruce Barraclough of the Cancer Strategies Group. I would commend it to you to read. The MBCC wrote it and it was commissioned by the Cancer Strategies Group, which is part of the National Cancer Control Initiative. They have looked around the world at different ways of setting up accreditation of services. It is not so much about the credentialing of people, although that is coming next—that has been commissioned. We now have to formulate a way of doing that here in Australia without stepping on too many toes. Ultimately, the patient is what matters.

Senator KNOWLES—Coming back to the general practice stage, I know of a circumstance through a friend who had gallstones not so long ago. The general practitioner said, ‘We need a general surgeon who specialises in gall bladders.’ So he went right through the whole thing and said, ‘Yes, I reckon this guy would be the best one in Perth because he basically homes in on gall bladders.’ I would have thought that was pretty routine. What you are saying to me is that that type of detail is not necessarily routine.

Prof. Saunders—No. Within the public sector it is changing. For example, if I put on my operating list next Tuesday that I was going to do a lower bowel resection, theatres would say, ‘Christobel, forget it; it is not going to be you.’ Sadly, outside the public system that is not done. And outside the public teaching hospital system that is not done. So that is all part of—

Senator KNOWLES—But this was in the private system.

Prof. Saunders—Then that was a good GP. But it is not necessarily the case. We know that patients are not always referred. It is not done maliciously, necessarily, by any means. I think often it is just that people think it is simple: a patient has breast cancer; she needs a mastectomy—anybody can do that. So it is not just the surgery, it is then the whole package of care that comes after it. That is what we are suggesting, that if there is a tumour network with a whole package of care, you could have a preferred referral pathway to that network.

Dr Threlfall—I will make a comment on that, if permitted.

Senator KNOWLES—Certainly.

Dr Threlfall—I think the whole basis of problem or quality with that sort of approach, looking down the list until you find what you want, depends on whether it is in the yellow pages and on either personal memory of a name or the size and the colour and the boldness of the ad, such as a cosmetic surgeon’s ad—they are bigger and brighter.

Senator KNOWLES—This is not the yellow pages.

Prof. Saunders—No, but it depends on how they advertise themselves.

Dr Threlfall—It needs to be an objectively judged sort of thing, so that colour and brightness and size of the print do not influence the decisions. Objective things like qualifications, experience, whether they have a breast nurse and that sort of thing—

Prof. Saunders—Having benchmarks, and if they meet those—

Senator KNOWLES—This was some register that the general practitioner had of the various surgeons.

Dr Threlfall—Unfortunately, they are usually things one either has to pay to be in or has to be in a particular specialty college to be in. If people also pay for display ads in the same publication, all these things can lead to bias based not on quality but on perception. Doctors are just as much, I think, prey to that sort of misleading influence as the public.

Dr Fong—The public will demand it soon. It is coming. It is already in the US. It is driven in the US by the managed care organisations that only contract with certain providers if they actually present their results and their credentials. The fund is there, the payers will say, ‘We are not going to send this person here because they are not accredited.’ Our accreditation here is the RACS, the Royal Australian College of Surgeons. If you have that after your name, you are in, you can do what you like, basically, in our sector. It is starting to change and it is changing because of data.

Prof. Saunders—And public pressure.

Dr Fong—And public pressure. But doctors in particular love data. They will respond to data. If surgeon A has a length of stay for a hip replacement that is 12 days and everyone else in Perth has 10 days, you can guarantee that that surgeon over a period of time will start to come down. They do not want to be keeping someone in hospital for longer than someone else. They do not want to have an error rate or a failure rate or whatever it is. That is where we need to go for public pressure. But it is driven by information. You have got to actually have the information.

Senator KNOWLES—So how do we, from a federal perspective, bring that accreditation around?

Prof. Saunders—I think that is going to be a job of Cancer Australia, so that needs to be supported and pushed through quite quickly. Things like the data systems that Tim was talking about are vitally important in that as well. Without the data, as Neale said, you can’t—

Dr Fong—In the public sector we can regulate it. At Royal Perth Hospital just over the road here we can say, ‘You’re not doing this particular operation because we don’t think you’re up to it and the data shows it.’ Hopefully people will come on board voluntarily—surgeons and others—and that is where these tumour networks we are putting together come in. Collaboratively they will see the data and say, ‘I shouldn’t be doing this,’ or, ‘I can do this.’

Prof. Saunders—The two places where I personally find it difficult are in the smaller peripheral public hospitals where there are visiting medical officers and they seem to be able to do more or less what they want without audit in lots of different fields. Gynaecology is a good example. A huge number of women get laparoscopies for no apparent good reason. And of course that happens in the public sector. But we would hope that the public sector will come along behind the private sector when they see what a good thing accreditation is. I am sure they will.

Senator KNOWLES—I want to move on to the issue of rural and remote problems. I do not think anyone would disagree that the facilities in far-flung parts of Australia are obviously not as good as they are in the metropolitan areas. Equally, we would be whistling Dixie in a west wind if we thought we were going to replicate everything that is in the metropolitan area into every single solitary town or region within Australia. Therefore, I come to the comments that you made, Professor Saunders: you consider it to be a national disgrace. How do you resolve what you consider to be a national disgrace without taking it to the replication stage which is just simply impossible for a whole range of reasons, not the least personnel and cost?

Prof. Saunders—There are two ways. We need a good plan in place with the idea of cancer units. They could be run by a general practitioner, an interested surgeon or even a nurse in the larger towns, and in the smaller remote places there would need to be a lead clinician. Again that clinician does not necessarily have to be a doctor with an interest in cancer but they must be very protocol driven to ensure that patients are plugged in to the right services. If that means patients have to come to Perth then they come to Perth or a major metropolitan centre. It is important that patients have access to and information about those services.

The second thing is the work force. I think it is all very well to say that if we improve the systems, we can improve care—which we can. But, from talking to people within our cancer task force here, the work force in the country appears to be an extremely difficult issue. The turnover of general practitioners is very high; the turnover of nurses is very high. There are not very many trained nurses out there, so we are actually going to have to go out and train people and encourage people to go to regional Australia. I do not know the best way of doing that necessarily but I think it is a challenge that we have to meet.

Senator KNOWLES—Therein lies a difficulty. If you look at, say, someone who has cancer in Fitzroy Crossing as opposed to someone in Leonora, Norseman or Kojonup, one would hope that, as an Australian citizen, they would have equal rights to someone who lives in Wembley Downs. But that is not the case and we are a long way from it being the case. That is where I would love to be able to get some answer as to how we do it. Do we do it on a regional basis? Do we look at the Kimberley, so if you are in Fitzroy Crossing then you have to go to the regional hospital, Derby moving to Broome? Is it in the Pilbara or is it in the Great Southern region?

Prof. Saunders—I think we do it partly on a regional basis, yes, but we have links with the metropolitan services. That will be the nice thing about a tumour network. That network would obviously be based in the metropolitan region but it would reach out. You would know that if you were diagnosed with a sarcoma—a very unusual tumour—in Leonora, you would get referred to the correct group of people here in Perth. But perhaps if you were diagnosed with something fairly straightforward in Geraldton then you could be managed in Geraldton but those doctors in Geraldton would have the ability to link in, perhaps by teleconferencing, with multidisciplinary meetings with the doctors in Perth so that they knew that if the patient needed chemotherapy afterwards that would be appropriate or whatever. So it is regional but linking into these tumour networks.

Senator KNOWLES—Because the provision of diagnostic tools is equally difficult.

Prof. Saunders—It is equally difficult.

Senator KNOWLES—The other thing that is equally difficult is the communication and the maintenance of contact with family and friends from country areas because sometimes it is more difficult to go to a regional centre than it is to go to Perth.

Prof. Saunders—It is not going to be one thing fixes all.

Senator KNOWLES—That is right. That is why when you say it is a national disgrace I am very interested to explore how you consider it can be resolved.

Prof. Saunders—Those would be the ways which I would suggest and which we are looking at now.

Senator KNOWLES—Thank you. I have millions of questions but not enough time.

Senator LEES—Again, I have lots of questions and not much time. I go back to what you have mentioned a number of times, Professor, regarding the resistance to some of the things that you are recommending and some of the changes that you want to see. In my time in the Senate particularly—about 12 years now—we have heard about nurse practitioners and there have been a number of measures put in place to encourage that, but there is also a lot of resistance still sometimes from individual doctors and sometimes from divisions of general practice. Sometimes it is at the specialist end, sometimes it is in the private sector and sometimes it is in the public sector. How can we get through—I hate to call it empire building—people liking to do what they have always done in their own particular way and seeing it as a threat when other methods are suggested?

Prof. Saunders—It is something I have thought about a lot since coming to Australia because it wasn’t so much of a problem in the UK, I think largely because we simply did not have the funding. So it is better to have a nurse doing something than nobody doing it. But it is different here; there are more doctors here. The professional sensibilities, as you say, are therefore much stronger. So it is partly a cultural thing, but I think it is also important that we look at outcomes. If the outcomes for the patients, in terms of whatever benchmarks you show for a particular cancer, are as good by another practitioner then that would be reasonable. But there are lots of other complex things such as indemnity cover and insurance. So there is not an easy answer. Anyway, I do not honestly know whether I am the best person to answer. I am quite an enthusiast for the idea, but I cannot echo that for all my colleagues. Neale, can you add anything? You have been around in the system longer than I.

Dr Fong—It was a great question. We need new types of health care workers.

Senator LEES—To me, some of it involves payment, some of it involves insurance and a lot of it involves training. At the moment, we do not seem to have the cooperation that is needed between the medical training in universities and the training of nurses so that there can be some blending there. Some of the schools are now in the doctor-medical area, and nurses should be involved in that type of training.

Dr Fong—Absolutely.

Senator LEES—Indeed, GPs, particularly if they are going to go into rural areas, should be able to get specialist training far more easily. Are you looking at that specifically in the cancer area?

Dr Fong—We believe that getting the work force right is the No. 1 issue driving reform in this state. We need to get enough of the right people. But it is not just about getting more medical students or more nurses. It is about having different types of health care workers for the future. It is not just about nurses and doctors.

Senator KNOWLES—We need quality accommodation for nurses in country areas.

Dr Fong—It is about that too. It is about having different types of people. For example—and I will go out on a limb here, but it is not too much of a limb; the UK has been doing it for years—we do not need to have a three-year trained registered nurse handing instruments to a doctor in an operating theatre as a surgical scrub nurse. You could have a one-year trained person, a technician, doing that type of thing. We have consultant specialists doing things that junior medical staff should be doing, and we have medical staff doing things that nurses should be doing. There are all sorts of issues like that. Unless we get our head around that and bite the bullet, the people are just not going to be there to train.

Senator LEES—We have just been through this in our aged care inquiry. We were told that three- and four-year trained nurses should not be the ones handing the medication to patients, because they are desperately needed elsewhere. But I will not digress. As you look at a star system and at giving patients greater power to make some of their own decisions, will you be looking at the area of complementary services or other alternatives, whether in allied health, dieticians or whatever? How do you see that fitting into your star system—so that people can log onto the net at three o’clock in the morning and, say, find a dietician who specialises in people with a certain sort of cancer?

Prof. Saunders—With my other hat on, I am Vice President of the Cancer Council of WA, and later you are going to hear from Susan Rooney, the CEO of the Cancer Council of WA. We produce quite a lot of literature for patients. We have a cancer helpline, a 1300 number, that patients can ring and get a lot of information about complementary care. But, as I said at the beginning, we need good evidence bases for a lot of the complementary treatments. I think that a lot of the complementary treatments will not do the patient any harm, but some of them may. I think we need to know the efficacy and side effects of some of the treatments on offer before we can recommend them. Unless they go through those strict scientific processes of assessment then all you are looking at is faith.

Senator LEES—Someone recently put it to me that they were on a new diet and they went back to their specialist and were told: ‘There is no evidence for that. I can’t recommend that you do it but, as it has reduced your daily migraines to almost zero, increased your energy levels and enabled you to get back to work, I suppose there is no harm in it.’

Prof. Saunders—The UK have approached that by appointing a professor of complementary cancer medicine, in Exeter, I believe, to try to assess some of these treatments in a scientific manner. Maybe that is something we should think about here, as part of one of the existing cancer institutes, such as in New South Wales, or even as part of something else.

Dr Fong—I would like to comment on that. Just last year I had the privilege of going to the Memorial Sloan-Kettering Institute in New York, the so-called No. 1 cancer hospital in the world. It is a huge place. In a previous role in the private sector, we were developing a comprehensive cancer centre which we were going to establish in Western Australia. Now that I have moved to the private sector I am, maybe more so than Christobel, a bit more pro the idea of what the US calls 'integrative medicine'. It is a huge field. I think it is hugely untapped in terms of the effect it could have on our health system. I am going to be pushing very strongly that we get into this, not just for cancer but for other chronic and complex diseases. I am not sure what it means, but I think there is a lot happening in the US.

The Memorial Sloan-Kettering Institute, which is the No. 1 traditional cancer medical model hospital, has a division that looks at the centre for integrative medicine in cancer. It is not just all the herbs and that stuff; it is aromatherapy and massage—all the stuff that I think has to have some effect. I do not think we give enough credence to that. We are not disagreeing here. I am just saying that we want to push that margin a bit, so I am pleased that you are looking at that in part B.

Senator KNOWLES—It cannot all be voodoo.

Dr Fong—No, exactly. If Memorial does it, there has to something in it.

Senator MOORE—Dr Threlfall, I want to concentrate my question on your work—on the staging stuff. I was fascinated by the paper and by the comments from Mr Elwood that there is a difference of opinion. Some people think we already have it. I am interested in what is next, because the documentation you have provided for us seems to have overwhelmingly clear evidence that this can and should be done and will not cost very much money. That is how I read all those pages. Where does it go now?

Dr Threlfall—There is a precedent of a kind in that in 1966 the National Breast Cancer Centre funded the countrywide collection of tumour size and lymph node status by dishing out money to cancer registries on a population basis. It was based on our population in the states and it carried on for a year. Some of us felt so good about it that we have struggled on ever since with that funding no longer being present. We kept doing it because it is so useful, so interesting and people want to know about it. Others have given up because they are even more strapped for cash and staff than the WA Cancer Registry is.

We are in a privileged position in that being in the state government we are integrated fully with various other data systems in terms of linkage and deduplication and that would not happen anywhere else. Other cancer registries in the cancer councils in the various states—in the main, five out of the seven of them—maybe do not have some of those benefits and they have had to scale back their operations. Whether the same thing could be done for staging information, I do not know, but it is not a bad way to start. My suggestion would be that, if federal funding were found to launch an initiative based upon producing extra staff dedicated solely to the collection of staging information for a year or two, then you would get enough information based on a couple of years of data, I am sure, to allow a more rational objective assessment of the national data, which would enable the powers that be, whether it is you or someone else even higher up, to decide whether to continue this in the form of either tied grants to the state health systems or increased general funding and trust the state health departments to distribute it wisely. I do not know.

I suppose that I would like to see it start, at least, somewhere. We know how to do it and we have an agreed staging system that we would use. It is the American Joint Committee on Cancer—the AJCC—the sixth edition. I think we would all agree in all the states that that is the national standard to use. So we would have consistent collection systems straightaway, and we would be able to get it up and running very quickly. If it were only for a year, I do not know whether, given the human resources constraints and the processes of getting staff on board in the health departments, particularly, that could kill such an initiative if not enough lead time were given. So a grant for a year or two, with warning enough to get staff arranged, would be the way to go.

I do not know that we can say that this information is actually going to see the reduction in the amount of money spent on health. Increasingly, the Cancer Registry not only collects statistics but also supports research projects dealing not so much with the surgical facets as with the psychosocial and the rest of the life type facets of cancer care and how the patients are affected by their disease. Because we are curing heart disease and diabetes, people are living longer to get cancer. Because we are curing cancer, people are living long enough to get a second and third melanoma, breast cancer or an old-age type of cancer when they have survived their testicular cancer, and children with leukaemia almost routinely survive if diagnosed early and treated properly. So I do not know that we are going to see the actual number of dollars spent on the health care system reduced by funding cancer staging collection, but we will be basically improving people’s quality of life. As a public health physician, I think that is more important, because if we do not spend it on health we are going to spend on something else.

Senator MOORE—Are there objections in the discussions you have had? You have said that 10 years down the track there is a lot more agreement than there would have been—and the kind of data that is collected. Are there any objections to this process beyond the budget?

Dr Threlfall—I do not think there are likely to be, other than in some areas of legislation. In our case, the example is that the Health (Notification of Cancer) Regulations are part of our Health Act. We are lucky we have it, and we can change it by taking it to parliament. It takes months, but you can do it. We could add staging information to those regulations as one of the things that has to be supplied. There may be states in which the private sector particularly may be reluctant to provide the information without legislative protection. So there would be another use for a good lead time or warning period so that states could get their act together in terms of revising their regulations so that they could be assured that there would not be any legal quibbles by their sources of data.

It is a big issue: national, consistent privacy legislation should either allow the states to do their own thing that overrides it in a good cause or specifically allows this sort of thing without patient consent because of the benefits of a population based registry. That is another thing that this committee could give some weight to in its report. The privacy legislation has a big influence on the potential flow of information to support this whole system that Professor Saunders and Dr Fong have been talking about.

CHAIR—Regrettably we are out of time, so thank you for your submissions and presentations today.

Proceedings suspended from 10.47 a.m. to 11.05 a.m.

BOOTH, Ms Patricia Joy, Consumer, Cancer Council of Western Australia

LEIGH, Mrs Amanda, Director, Cancer Services Division, Cancer Council of Western Australia

REVELL, Ms Ann, Consumer, Cancer Council of Western Australia

ROONEY, Ms Susan Hannah, Chief Executive Officer, Cancer Council of Western Australia

KATRIS, Mr Paul, Executive Officer, Western Australian Clinical Oncology Group

CHAIR—Welcome. Does anyone have any comment to make on the capacity in which they appear?

Ms Booth—I have a Bachelor of Social Work and have worked extensively in cancer care in the UK and here.

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

Ms Rooney—I will talk fairly briefly, assuming that you have read our submission. One thing that is important for us about having the consumers here is to present their point of view as well. We will put a lot of emphasis on the consumers’ point of view because I think, even though we are a consumer organisation, once we make those statements they are inevitably filtered throughout our views.

One of the important things in the multidisciplinary approach to cancer treatment is that it has been accepted, and there is evidence, that it is actually the best practice in cancer treatment. It also enables consumers to have a more holistic approach to their care; it takes in the whole aspect of being a person with cancer. Given that cancer is a chronic disease, it is not just about them having one element seen of them as a person. The important thing around the multidisciplinary approach is that, whilst it is accepted and used in a lot of areas—for example, in breast cancer—there are a number of areas in which it is not utilised. Certainly, it would seem that there is clinician resistance to some of those things happening. There are issues around funding as well, but more often in the private sector than in the public sector there is less of a multidisciplinary approach. That will be borne out by some of what our consumers will tell you. Rather than going through all of the evidence around it, it certainly is something that is standard practice in places like the US. The clinicians who have worked in other places and then come back and attempted to use a multidisciplinary approach here have often been stifled by the response from their peers. I will now hand over to Pat or Ann to add to what I have said on multidisciplinary care.

Ms Booth—I worked in the UK in a medical model team, and I think that I could safely say that the treatment team that I was working with in the UK was very effective in providing support to patients from when they first came into the hospital system to when they left and either went home or died from the cancer that they were diagnosed with. When I had cancer myself, I was a patient in a private hospital. The care I had in the hospital was absolutely phenomenal, but one of the major problems for me right from the day I was diagnosed was the fact that I had a handicapped daughter. I was a parent on my own, and the difficulty for me was trying to work out what I was going to do with this handicapped daughter—who was going to support her and who was going to look after her. That was just a nightmare for me. I cried and cried, not because I had cancer but because I was so worried about what I was going to do with this girl and who was going to help her cope with that journey that I was going to be undertaking. I had been her mother, her support, her nurse, her doctor and her best friend, and that was a massive task for me.

If there had been a multidisciplinary approach to that problem, I would not have had anywhere near the trauma that I had prior to the surgery. I think a lot of people had the trauma prior to the surgery because of coming to terms with the disease with which they had been diagnosed and the outcomes of that. But for me personally the biggest trauma was the fact that I did not know, and there seemed to be nobody out there to assist or to help with this girl.

Ms Revell—By way of a brief background, I feel that I was very lucky in my cancer journey because six months before I was diagnosed with cancer I had another illness and through that I met a terrific surgeon who I really trusted. On the day I was diagnosed I rang the surgeon and he called me in the next day and I had my surgery two days later. It was all very quick. I had complete faith in him. I knew nothing about cancer. I never knew anyone who had it or any experience of it whatsoever. He was able to refer me to a good medical oncologist and a good radiation oncologist. I took his word. I was very lucky that he steered me well.

When I woke up four days after being diagnosed, after having a lumpectomy for breast cancer, a nurse came in and she was talking about oncology and tamoxifen et cetera. I did not know what on earth she was talking about. She left some booklets with me from the Cancer Council. From that, that was my one-stop shop. I went to the Cancer Council after I was released from hospital and there I found out a lot of information that helped me in situations that might arise with treatments, and that gave me some terrific information. But in many ways going to the Cancer Council was a bit late because by that time I had already agreed on a treatment. I had already started my journey, so I did not have the benefit of having different information, different people coming in. I had to seek out a lot of the information myself from the Cancer Council, which was luckily a bit of a one-stop shop. There was no one place I could go to get information.

At the beginning when I started my treatment I did not have the benefit of having that knowledge that a multidisciplinary team would give me to start off so that I could make an informed decision. It was more or less the case that you are quoted statistics, and you are just one statistic—‘80 per cent out of 100’ sounds pretty good. So you say, ‘Use whatever regime will work.’ Eighty per cent or more is better than nothing. You are given a lot of statistics, a lot of information when you first go to the doctor. You really need someone—other people in the team—to explain that to you and to say, ‘This is the reality of it, not just the stats.’ I was very lucky in that I had someone I could trust and he steered me well. I know that other people are not so lucky.

Ms Rooney—To categorise that, I have also had a consumer say to me that when she first saw her clinician he said to her, ‘You’re the baton, now I’m going to hand you on in the relay.’ The difference between a multidisciplinary approach, when somebody such as Ann says, ‘Sit down,’ who has talked to you about all of those things and also has had someone who is involved with the psychosocial side and brings the whole person into it, as opposed to being handed on down the chain, is huge in terms of the impact on somebody in their journey with cancer.

That brings us nicely to the care coordinator role and also, from our perspective, the different roles that can happen in terms of the health model and how NGOs can work within that. At the moment, as you have heard, I think that providing information is really important. But we would see that it should be an adjunct to what happens around the edge of that, rather than to say we should actually necessarily be the primary source of information. Information should come at the first point for people when they are dealing with their clinician.

Mrs Leigh—To pick up on the issues around the complexity associated with the cancer journey from diagnosis right through to support after treatment and surgery, ongoing care and support in the community, you have probably heard from some of our colleagues—and it is certainly in our own submission—that it is of great value to have somebody within the multidisciplinary team to be the supporter of the patient and their family, because cancer obviously affects more than, as we have heard, just the patient themselves, and there is evidence to support that. You have probably heard the term ‘cancer care coordinators’ and about the manifestation of nursing positions and possibly even administrative positions to assist the multidisciplinary team with, if you like, the seamless coordination of the ‘baton’s care’, just to use Susan’s phrase, and to humanise that in a very often dehumanising health care setting.

As an organisation, we are extremely supportive of the concept of a coordinator who not only is both patient support and advocate but is integrated with the multidisciplinary team and the teams that the patient has to traverse. We are also quite supportive of the fact that that individual can access information and interpret that information for our diverse community. Many patients—Pat and I have spoken about it—do not have the language skills often to even read the literature that we produce. If you have somebody to read that through with you and then to chat about it, it is of great value.

For some years now the Cancer Council in this state has had in the localities a small number of nurses who have acted in the role of, if you like, psychosocial support coordinator. They bridge the link between the health system and the home and help home patients adjust to the massive change from being sort of at the centre of the universe when you are having your treatment and surgery to being—when all of a sudden ‘the baton’ has been discharged—at home. Our cancer support nurses are in the localities, and they mobilise services and resources and empower the patient.

One of the things that is not necessarily rigorously looked at is the ongoing living with cancer issues that people face—changes in body image, changes in mental state. The support of a coordinator throughout the journey, and after the intense component too, can help patients and their families adjust to some of those issues. We are going to leave with the Senate inquiry panel an additional submission which gives an overview of the kinds of services that are available in Western Australia that we would like to strengthen further based on what we have learnt and heard from consumers in terms of their own journey and the need for them and their families to have that support. It can come from the most qualified professional counsellor, but it can also come from a volunteer who has had cancer or who has been exposed to cancer. We have male volunteers who have volunteered their time to support the husbands of women with cancer, so they get a buddy system and a chance to talk bloke to bloke, which, in many ways, is a far more acceptable way for them to get support than having professional counselling.

It is important that the inquiry considers a range of support strategies that are available or could be available across the community. The concept of rehabilitation is not necessarily bedded down in cancer treatments. It is very much a cut-off point for patients and their families, and they often feel very lost after the initial intensity has subsided.

Ms Revell—My surgeon was in the private hospital. He said that if I went public it would be at least a month before I could have my operation, so I decided to go private. I was not in any private health fund, but I thought I needed to have the operation as soon as possible. He referred me to a radiation oncologist at a public hospital, so my medical team was over a couple of sites. There was not much continuity. I have no problems at all with the treatment in either system—it was terrific; it was great—but there was no continuity of treatment or care. It was the Cancer Council that provided that. They stepped in where, in my case, the health service was not adequate.

I live in the hills, so I could not really come down to Perth easily, and they have got a cancer nurse in the hills who is absolutely terrific. She was really my main caregiver or the coordinator for my treatments. I would have treatments, I would come back and she would ring me up and ask how I had gone or whether there were any problems. She always remembered when I would have my treatments and was always there with the phone call and with handy, practical and helpful hints and reassurance that just was not there in the health system.

There was also the phone buddy. I know that that was just mentioned. All of a sudden, out of the blue, I got a phone call from someone who introduced herself as my Cancer Council phone buddy. I never met her, but she used to ring me regularly. She was someone who had had cancer and I could sort of bounce things off her—things that you think are silly, that you did not want to bother people with, that you think are so insignificant or that I suppose you are just embarrassed to ask different people about. But with someone who has had cancer, you can bounce things off them and say, ‘I know this sounds a bit silly, but...’ So my main coordinator for my wellbeing was actually the Cancer Council.

Ms Rooney—One of the reasons that the Cancer Council uses this model is that there are gaps that exist in the health system. The best way would be for Ann to have had a coordinator at the beginning, because by the nature of how we provide the services we are not part of that team. So there is a disconnect there. If you have a care coordinator who is part of that team, there is a better approach to that coordination of care. Then, as a non-government organisation, our role can be very much to deal with that external support and the rehabilitation side of things, which is not dealt with so much in the health system.

Ms Booth—As I said, my journey started in a private hospital in Western Australia. I was diagnosed with bowel cancer. After the surgery I discovered I had a colostomy bag and that I had secondaries, which meant at that stage that I had a 50 per cent chance of being alive five years later. That was in 1989. They can’t get rid of me! It was an interesting journey, because two surgeons and my local GP were in the operating theatre.

After the surgery, I had what they call a stoma sister, who teaches you how to live with your colostomy bag—how to manage it, how to change it, how to understand what is going on, what to eat, what you cannot eat and how you actually function. While I was in the hospital, she was quite remarkable. She was basically spending 15 hours a day nursing only me, one on one. When I was advised that the cancer had spread into another part of my body, I asked the doctor, ‘Well, what does that mean?’ He said, ‘We’ll talk about that later.’ So I said to Sue, ‘What does that mean?’ and she said, ‘I’ll go to the library and I’ll get you the information about what the diagnosis is, where the cancer has spread and what your prognosis could or couldn’t be with or without treatment.’

I eventually left hospital. This lass took me up to what they call the Ostomy Association, where you get your bags for recycled lunches. She took me up there, introduced me and said, ‘This is what you’ve got; we’ve filled out all the red tape et cetera.’ She was quite remarkable in the journey, and the stoma nurses do that in any of the government hospitals or the private hospitals. They are employed only to work with people who have bowel cancer surgery.

I then went home. I was discharged home and they had arranged for Silver Chain nurses to follow up, and they have a stoma nurse who comes to the home to check whether you are managing, whether you have got any difficulties or problems. So the follow-up service that had been provided by the Silver Chain Nursing Association was quite remarkable.

I was then referred by someone—and I do not know who; I think I just got a letter—to see an oncologist. I went to the oncologist with a friend of mine. I said to the doctor that we were both social workers; she had written down the questions that I had formulated in my head and she was going to write down the answers as we asked the questions. The doctor was kind of thinking, ‘I don’t like this.’ Anyway, at the end of it the doctor said, ‘Okay, we’ll book you in for such and such.’ They made an appointment and then he said, ‘We’ll see you on such and such a date.’ I rang up and cancelled the appointment because I had not made a decision about whether I was actually going to go on with the chemo treatment. I wanted to do some more research myself and find out what I wanted to know about the particular disorder I had.

Eventually I had five days of chemotherapy treatment and I ended up in St John of God Hospital. I was later transferred to Royal Perth Hospital on life support for about six weeks. It was interesting that during that time there never appeared to be any coordinator. There appeared to be nobody who was the master of ceremonies. If I needed my colostomy bag changed nobody came in and said, ‘Mrs Booth, come on, we’ll help you with changing it.’ I would have to ring the buzzer and say, ‘Excuse me, can somebody help me fix up my colostomy bag?’ I found that absolutely mind-boggling. It was good because I had to take responsibility for that, but when you are that sick and you are very badly affected by the chemotherapy it is a pretty traumatic journey to go on.

Six weeks later I walked out of the Royal Perth Hospital. I had no hair. I had dropped to 32 kilograms in weight but I was 42 kilograms when I was discharged. I went home and I had one lot of doctors in the hospital saying to me, ‘You have to ask yourself why you are going to have any more chemo.’ The other lot of doctors were saying to me, ‘You have to ask what it can do for you if you go back. It may kill you next time.’ I was in the middle of that and suddenly I had no-one. The only person I saw who was from a discipline other than doctors or nurses was an occupational therapist who came in and said, ‘This is a voucher. Get somebody from your family to go and get you a wig.’ A wig was the least of my worries.

I think there should have been a coordinator to pull all those loose strings together. All of the time that this was happening my daughter’s accommodation, which friends had been able to arrange, had broken down on two occasions and at 9 o’clock or 10 o’clock at night she would arrive at Royal Perth Hospital in tears. They would bring her up to my room. I would be very agitated trying to calm and settle her. All of that had a very adverse effect. If there had been a coordinator who could have pulled the team together and asked, ‘How are we going to resolve this particular problem?’ I think it would have been a much easier journey. I know that there are many women—and they are women—out there, who are carers of disabled people, and who have been patients with cancer. Some have made it and some have not.

Senator KNOWLES—What happened to your daughter during your recuperation?

Ms Booth—She went into a Salvation Army hostel. Her regression was quite chronic: she was bed-wetting and soiling. She was not taking her medication and was not eating. She kept running away. She had gone to the bank and taken out about $4,000 and it was just gone. The bank rang me and I said, ‘I’m sorry but I’m in hospital and there’s nothing I can do about it. I can’t do a thing.’ I guess I could just concentrate on getting as well as I could as quickly as I could, never knowing at that stage—that was at the surgery stage—what the journey would mean.

Eventually the Salvation Army said that they were going to discharge my daughter to her father’s care. Unfortunately he took her to my home, opened up the house and left her there on her own. Friends then told me that she was running the streets so I caught a taxi back to my house—because I could not drive—and proceeded to look after her. My brother then bought into it and said to the local doctor, ‘Pat just cannot look after her. There is no way she is capable of looking after her daughter. She is not physically strong enough to look after herself, let alone look after the girl.’ So the local doctor then got her into a hostel but while she was in that hostel she got raped because there was not the necessary supervision and support. So that in turn created more problems and more stress.

Having worked on a team, I know that as social workers we did psychosocial counselling but we also looked at the practical matters. We looked at the financial problems that people had, how they could get financial assistance and how they could get all sorts of assistance for children. We made arrangements about who would take the children and care for them at a particular stage. But it was a pretty rough journey with my daughter. I have since been able to put all sorts of things in place so that if Mr Cancer comes back—he will get a fight—the reality is it would be much easier. The journey was not a nice journey.

Ms Rooney—It illustrates that cancer is not just about the person who has cancer. It is about their family and a care coordinator and a multidisciplinary team—those approaches treat the person holistically in their environment along with the family. If you do not have that, those things fall through the cracks, as both Pat and Ann have been able to testify.

Ms Booth—Although my doctors—the oncologist and the surgeon—were aware of those issues, there was nothing that they could actually do and there were no services for her to be referred to.

Mr Katris—One of the items for discussion with the inquiry relates to psychosocial aspects of cancer care. It is well held, and there is very good evidence, that people who have a consideration regarding their psychosocial situation in terms of distress and anxiety definitely can improve their lot. One of the problems that we face is that we do not have a lot of dedicated funding in this area. You take the charities out of the equation and every major teaching hospital of 400 beds and above around the country just does not have the resources within its clinical psychology service units to be dedicated to a chronic disease such as cancer. We are not arguing that every person needs to see a clinical psychologist, but everyone deserves a psychosocial assessment, just as they get blood counts and other clinical aspects assessed.

We have got fantastic documents that have come out of the NHMRC endorsement process through the Australian Cancer Network, as well as COSA—the Clinical Oncology Society of Australia—in lung cancer and epithelial ovarian cancer and colorectal cancer. If there is one common theme that goes all the way through, it is the adherence to a multidisciplinary model and also psychosocial assessment as part of the cancer journey. It is very well held that Australia has world-class standards of survival outcomes and treatment guideline adherence in the area of breast cancer. There is no doubt about it: our survival figures are as impressive as those of anywhere in the world. But they are not in other areas.

In some of the high-volume cancers such as lung and colorectal cancers, which are equal with breast cancer in life years lost, we just do not have the evidence that they are managed anywhere near as well. Again, from the charities' perspective, a lot of our services are provided to women with breast cancer because they have a louder voice and they are a more coordinated consumer movement. Our two consumers here have shown you examples of the distress they have had to go through. But these are examples of two people who are very articulate and who have managed to navigate their own way through it. With the minorities and with some of the less popular or less high-profile cancers in terms of media understanding, we just do not have the same level of coherence in the service delivery.

We often talk about care coordinators. We are very concerned that we would need to have coordinated care to occur first before we actually had a coordinator as part of the team. Our state government has committed $1.2 million for the next four years towards dedicated funding for care coordinators. But if we do not have coordinated care in service provision and if we do not have the disciplines talking to each other, it will be quite token. We feel that unless they are part of the team and unless they are an accepted part of the management and hierarchical structure of the cancer service, they will have an uphill battle.

Ms Revell—It is a real roller-coaster ride; there is no doubt about it. Also, you do feel isolation when you are finally cut loose after having your treatments and you wonder what to do and where to go. There is a lot surrounding being a survivor. That is hard to come to terms with. People around you do not survive; you wonder why you did. You wonder about recurrence.

Recurrence is always a huge issue. I found that going to see a clinical psychologist was absolutely necessary for me. I went for almost two years. Sometimes you feel that perhaps you do not really need to go, but you actually do because even the smallest things really affect you and really have a huge impact on how you are going to live the rest of your life. You feel, ‘I do not want to go back to the life I had; I want to learn from this thing that has happened to me and make something positive out of something negative.’ The clinical psychologist really helps you to do that, really helps you to come to terms with it and decide how to live the rest of your life. It is critical.

Ms Booth—I suppose my own personal journey in cancer was assisted by the fact that I had actually worked and studied at university in the area of cancer and, having worked in a hospice, I really had my head around the issues of cancer and of dying. I think that is very important. So, when I actually faced my own nonbeing, it was easier for me to come to terms with that and I had a whole truckload of skills that I could take with me.

I now do some work at the haematology unit in the Brownes Dairy Support Centre for Cancer and Leukaemia at Sir Charles Gairdner Hospital. I do some counselling there with haematology patients. The head of the department refers specific people. He is a brilliant person in the sense that he has wonderful listening skills and he listens and hears and he is able to detect when his patients are in trouble. He refers them to me and I work with them. Sometimes I see them two or three times; sometimes I see them 15 or 16 times. I can certainly say from my perspective that, when I have finished seeing these people, it has been a pretty incredible journey that I have travelled with them. I find it most intriguing that they say to me, ‘Well, of course, you know, people who have never been there and have never had cancer would not know how it is.’ I say, ‘Yes, I think you’re right.’ I cannot say to them, ‘Yes, I do know that you’re right—I have been there and done that’. I cannot do that. But it is a very interesting thing that they say.

I was recently asked to appear at a state cancer nurses research conference on a panel with four other people. I was there as a consumer, but the social worker in me always listens. Three of those people on that panel were in a lot of trouble from psychosocial issues. My heart bled for them and there was nothing I could do, because I was there as a consumer. So I am kind of caught: you are pulled this way where you know this is what is going on and this is what they are feeling, but you are on this side of the fence. I can say that the need for psychosocial care and counselling for people is vital, particularly for people with cancer. I am not certain why it should be cancer more than people with heart problems or diabetes. People still have that feeling in their heads: cancer means a death sentence.

Ms Rooney—Again, I guess the issues around it are that the psychosocial care is very fragmented—it comes from various different areas. We provide some counselling. As Paul has identified, there is not very much dedicated counselling within the system. So it really becomes an ad hoc hit-and-miss issue for patients or consumers in terms of accessing psychosocial care.

On the issue of models for rural and remote areas: you multiply the difficulties many times—there are access difficulties et cetera. The key thing in addressing the issues in rural areas is basically ensuring that you have a model. We have identified a step-down model of care. It identifies where people, where they can, can have treatment and access to services close to home, and, where they cannot, that they can then go to a centre such as a cancer centre where they can have access to very specialised treatment and then come back home and have those things joined in. For example, we have people from the country who come for six weeks of radiotherapy and stay at our lodge. But, again, they do not necessarily have a multidisciplinary approach. They are also not necessarily linked into care back home. So where you do have to come to a city centre to be treated—for example, it will be radiotherapy in this state—it is about there being linkages back to where you are from so you can stay home for longer, because there are certainly a whole lot of social and economic issues about being dislocated. Perhaps we could move on very briefly to the less conventional—complementary—side of things. Amanda will provide a brief overview.

Mrs Leigh—It was quite interesting to also listen to Dr Neale Fong's support for the concept of complementary medicine and an integrated approach. The Cancer Council have been banging this drum, certainly for the last couple of years that Susan and I have been around. We have also managed to work in partnership with colleagues at the Brownes cancer support centre, where they have a tertiary based cancer support centre that provides a range of complementary therapy at a very low cost—the first six sessions are free. People can go there as part of their program to receive their treatment but also be part of a complementary therapy program. Dr David Joske, who is the haematologist that Pat referred to, has pioneered that more integrated approach, certainly within this state. There is great potential and opportunity for that to be strengthened further with some of the other tertiary centres and some of the more regional general hospitals around this state as well. We would very much advocate that kind of model.

From our relationship with colleagues in the medical profession, we would certainly support the need for research and accurate information for consumers of complementary therapy. Many independent private practitioners are very good at marketing themselves and advocating cure as opposed to alleviation of symptoms and enhancement of wellbeing. The Cancer Council does have a position on these approaches inasmuch as we support them as complementary treatments as opposed to alternatives to mainstream clinically trialled treatments. Through our Cancer Helpline we provide information as best we can about what is known about all of those interventions—whether they are substances, touch based or talking therapies. We research the literature, but we are finding that there is no central body that we can go to for up-to-the-minute information on complementary therapy. We would present that as a particular barrier to achieving best practice.

I note also from our consumers' paper that they strongly advocate access to information on complementary therapy and its benefit, its value, its cost, how long people have to do it for, where people can access it and the qualifications of the practitioner and how they have been credentialled. We have an extensive credentialling recruitment process for our own complementary therapists, but we can only vouch for them; we cannot vouch for others in the field. We provide our therapies free to our consumers, within our own premises, but there are lots of other practitioners that we are very concerned about. What happens is that it potentially discredits the work of the Brownes centre and the cancer councils across the country—particularly in this state, because we have gone into it with some determination to provide this service and support the provision of this service for consumers.

Ms Rooney—The key for us, again, is access to information for consumers in one place. There is a bit of a Mexican stand-off happening in that one clinician might say, 'All of that's rubbish,' and someone on the other side is saying, 'This will cure you.' So we want a place that is easy for consumers to go to and be able to balance that and which is not necessarily someone who has a vested interest either way.

Ms Revell—Complementary therapies are really so important. They help you with the side effects, your mental state, your immune system—they just make you feel better. Also, lymphoedema is a huge problem for breast cancer survivors. All these therapies really assist. When you are not feeling well, it is hard to seek them out if they are all in different places. It is hard to know whether they are a good practitioner, just a mediocre practitioner or a terrible practitioner. You need that good information from a credible source and to know that you are getting the best complementary treatment that you can.

Ms Booth—I had so many people phone me up to tell me about different alternative treatments that were available, which I have shared. Sometimes I think that, had I followed through with everything, I would be dead from exhaustion. I know that people were doing that because they cared, but you are there and it is happening to you, not to them. I used to say, ‘Thanks very much for the information.’ I will share one story. At one stage, when I was in Royal Perth Hospital I woke up in the morning and my feet and legs were swelled up like this, and I am not a very big person. I spoke to the nurses and they were not at all perturbed.

I knew that I was in big trouble when my feet and my legs had got to that stage. All day, every time somebody came near me I would speak about my feet and my legs. Nobody listened and nobody heard. A friend of mine came in after work that night—another social worker—and I said, ‘Beth, look at my feet; they are just awful and I am so frightened.’ She said, ‘I did a weekend workshop on reflexology. Stick your feet out of the bed. I will massage them.’ She went and got some cream and stayed there for three hours and massaged my feet and my legs. They went down and I never had any more problems. My brother insisted that I go to an Ayurvedic doctor—I thought, ‘Hello!’. Then I was taken to someone else for acupuncture and I was thinking, ‘This is worse than the cancer.’ So after that I decided that it was finished and that I was going to do it my way and do it with traditional medicine. I have to say that the reflexology sure worked. I have not had puffy feet or legs since.

Ms Rooney—Again, I think it is about people’s ability to make choices and get information and access. That is the key point to make.

Senator COOK—I want to go to one statistic that Professor Saunders put down this morning. The question is to you, Ms Rooney. She said that one in three men and one in four women are affected by cancer in their lifetime. Is that the statistic you have?

Ms Rooney—Yes, it is.

Senator COOK—So we can run off that as a basic indicator?

Ms Rooney—Yes.

Senator COOK—Secondly, is the Cancer Council a registered charity? How do you obtain your operating funds?

Ms Rooney—We are a registered charity. The majority of our funds come from the community.

Senator COOK—You have a big community event coming up—that is the commercial end of it.

Ms Rooney—Yes. We have Relay for Life on the weekend.

Senator COOK—There are a number of questions from the evidence that I, out of deference to my colleagues, will not have time to go through. Maybe some of those will be followed up by some of the other senators. I just want to mention that you, Mr Katris, said that everyone deserves a psychosocial assessment and access to a clinical psychologist at the time of their diagnosis.

Mr Katris—Yes.

Senator COOK—That is an area that I hope we can explore in more detail in the course of this inquiry. What I want to come to is what was evolving interestingly when the Department of Health was here this morning as a discussion between Professor Saunders and Dr Fong about holistic or integrated care. It seemed to me, without wanting to typecast anyone and certainly without wanting to criticise anyone, that Professor Saunders was flying the flag of the medical profession, arguing that a lot of this holistic care or integrated care is not to be highly regarded or in fact is to be dismissed. I am putting words into her mouth which she may not have used. Dr Fong was saying, 'This field deserves greater investigation.' I am wondering if you, Ms Rooney, or anyone else on your panel who you would care to nominate, might comment on this area from a patient's point of view. It seems to me that you are caught in the dilemma involving doctors wanting to administer treatments that are proven on a scientific basis—that is, by being sceptical about conclusions and testing them until they are well established. There is the dilemma between what is proven and what is promising—what is not yet proven but may eventually become proven and which patients without many options want to look at in terms of giving themselves a better chance. Can you offer any views to guide us about how we might approach this division—which I think is typical and not related to Saunders or Fong—about the evidence based approach, or what is proven, versus what is promising?

Ms Rooney—Again, some of it comes down to information and some of it comes down to structure. The first thing that we hear from people if there is promising evidence around something but not evidence so that it can be part of a conventional treatment is that consumers will often ask us, 'Will it hurt me? Will it interfere with my existing treatment? If it doesn't, then I am going to try it anyway.' So it is those kinds of questions that people want answered.

How much it will cost is another issue. That is one of the things that we think is important too, because people are quite vulnerable at that stage to people who make all sorts of claims. It is that process of being able to say to somebody, 'It may not reach this level of evidence, but it is promising.' You could have, for example, a web site that people could look at that said: 'What is this? Okay, it's promising. No, it doesn't interfere with this kind of treatment,' et cetera. People could look it up and ask, 'Are there any harms? Are there people or particular groups who should not be taking it?' That would help people make their decisions and be more informed when they are talking to their clinician, particularly if their clinician is very anti that kind of thing.

The other thing that is important is that integrated model with complementary therapy sitting in the grounds, like the Brownes centre does, for example, within Sir Charles Gairdner Hospital. It becomes somewhere that patients can access easily and can make those decisions for themselves when they are on that site. If you looked at the integrated model that is used in some of the places in the states that I heard Dr Fong talking about, it is then about the acceptance that these areas can work side by side and that they are not enemies of each other. Information for patients and access to accredited people practising complementary therapies will help that process and you can actually link that into an accreditation system across the country in terms of cancer centres, which is also an important aspect of this—so if you are an accredited cancer centre you must have this information and access to these complementary therapies.

Senator COOK—Do you think there are professional jealousies, to put it fairly directly and crudely, about looking at the orthodox versus the less orthodox?

Ms Rooney—Some of it is about risk, certainly, and also it is about some extreme claims from other sides as well. I often hear doctors talk about complementary and alternative therapies in the same breath rather than actually understanding that there is a separation of those types of things. Risk is a very large aspect of that for clinicians and the evidence based side of things. As an organisation, even when people ask us about complementary and alternative therapies, we can only say to them, ‘There is no evidence that the alternative side will actually cure the cancer, but we can certainly give you evidence on how it can complement things.’ We do not have the resources to keep up to date on everything that comes in—and there is certainly a lot of money spent in the United States on that—so if you had a central unit you could actually access that information. There are certainly completely different views on how the world works, and that has an impact on it.

Senator COOK—I am going to ask you two questions. This is the first one: accepting the argument that there are some charlatans out there purveying snake oil, but not letting that cloud the view that there are a lot of people with very worthwhile things to contribute, from a patient’s point of view what does the Cancer Council think should be done about that, if anything? My second question is about what is proven. In my mind it comes down to the question: proven to whom? There are, at least in my review of the literature—which I do not propose to be authoritative or necessarily comprehensive—a lot of things that are proven where there is considerable evidence which would justify a clinically based conclusion and which are still not yet accepted by the conventional medical field.

Ms Rooney—Even when you look at the difficulty of putting elements of known research into practice, we know that there are things that can be done on the conventional side of things that are not put into practice yet. That relates to how guidelines are followed, resources et cetera. Even from the conventional side I have often heard statistics bandied around that if we put into practice that which we already know on the conventional side, there would be a 25 per cent improvement. I think there is that problem. There is also the issue of levels of evidence. Paul can talk more authoritatively on this than I can, but there are identified levels where you can say, ‘The gold standard is clinical trials.’ Paul, there are a levels of evidence from level 5 down to—

Mr Katris—Expert opinion at level 5 all the way through to systematic reviews and meta-analyses at level 1. But that would increase the enthusiasm of some of the doctors to look at developing unproven or newer therapies if they were in a safe environment such as a clinical trial. I know that is frustrating for patients, because they need to be randomised and they might not actually get the treatment that is promising, depending on which arm of the study they are getting added onto, though it will increase clinician enthusiasm in the domain we are discussing.

Ms Rooney—It will also enable consumers to know, if you were able to provide that information about these different levels of evidence, that they could say, ‘There is some evidence, but this is what level it is.’ Again, that is an informed choice. I do not want to talk on behalf of consumers, Ann, but you would be given some level at which that evidence was.

Ms Revell—I think you get to the stage where you realise that everyone has their own agenda. If you have done years of study as an oncologist, then you want to give people chemotherapy. Even the experts do not agree, so it does get very confusing as to what your choices are.

CHAIR—We need to leave that there and move on, I am afraid.

Senator KNOWLES—I want to come to one point, which carries on from where you just left off. I find it a bit amazing that there have not been sufficient double-blind clinical trials done with some of the alternatives. Some of these companies that have some of the alternative therapies are very wealthy. I cannot for the life of me, as a supporter of some of the alternative therapies, understand why that is so. Do you know why that is so?

Mr Katris—Unfortunately, we are not familiar with a lot of great level 1 evidence for alternatives that can actually cure cancer. I would not think there would be too many doctors who, if there were genuine cure potential for a substance or methodology, would not be beginning to experiment and utilise it. What we get frustrated with, as Susan refers to, is the lumping of treatments—the massage of one’s feet or legs is thrown into the same basket as a snake oil that could be dangerous or just does not have the safety aspects. That is a concern.

Ms Rooney—The other thing is the limited resources, particularly if you look at the resource being placed into things that are translating, again on the conventional side, into practice. So that is where the money will go to first with clinical trials, because there is a whole list of those that are not funded yet either. There is a lot more funding, for example, in clinical trials around drugs and oncology because you can make money out of that, but there is not so much around surgery. It is about where the priorities come down if you are giving out the money. In places like the US there is certainly more money placed in that kind of research because, again, there is a bigger bucket, so you can get to that. I really think it is a question of resource and money. We already cannot get to the ones that are on the conventional side; you are not going to get to the alternative.

Senator KNOWLES—You touched on my next question: how do you weed out the reputable versus the disreputable practitioner?

Ms Rooney—I think there is a possibility there to look at credentialing, so again a process by which people have to go through training and then be identified by some sort of professional body. Certainly some of the complementary therapies are beginning to do that a lot more, but it is not obligatory. You do not have to do that as a complementary therapist; you do not have to belong to some particular group, for example.

Senator KNOWLES—The massage therapists have done it themselves, haven’t they.

Ms Rooney—They have, but I could still hang out a shingle tomorrow and say I was a massage therapist. There is nothing to stop me doing that.

Mrs Leigh—It is not regulated.

Ms Rooney—It is not regulated. So regulation is part of that, and again comes cost—they come hand in hand. Regulation is expensive.

Senator KNOWLES—So it comes down to consumer beware, say in terms of massage therapy, because you have some who have gone into self-regulation and others who, as you say, could hang out a shingle tomorrow.

Ms Rooney—That is right, and that is where the integration is important. If under the auspices of, say, the Cancer Council—we have people that we accredit and make sure they go through their processes with their association; the Brownes centre has a process a well—you integrate and have something on site, then the consumer knows those people have gone through that process. They do not have to try and look it up in the *Yellow Pages* and say, ‘Who’s checked this person?’

Senator KNOWLES—I want to put a question on notice to Ms Booth, or to any of you on the panel at the moment. It revolves around the care of other family members in the absence of the primary care giver. In your experience, where is that today compared to 15 or 16 years ago? What needs to be done from here on? Most of us are involved in another inquiry at the moment that is talking about young disabled people being placed inappropriately in nursing homes. It would be very useful for the committee to know where that has gone and where it should go, in your opinion. You can take that on notice if you like.

Senator LEES—If only we had a bit more time; I will try and be quick. Firstly, you heard the earlier evidence from the department and the real interest and, it seems, commitment to a multidisciplinary approach. To me, it seems that you are in the ideal position to expand and build on what you are already doing to fit into that. What are the barriers that you see that are really limiting your ability to fit into the model that is now being developed?

Mrs Leigh—To pick up on some of the issues around the concept of professional jealousies and the issue around trust with regard to referral to the allied health supporting services and/or NGOs such as ourselves, we have had very highly credentialed counsellors for two years plus in this organisation and we are only just getting referrals from some of the clinicians in this town.

Senator LEES—They now have the ability under the new Medicare agreement to do that under the enhanced primary care packages, which are for anyone who has a chronic illness, which is defined as an illness you will still have in six months time—or longer. But it seems that we are meeting an enormous resistance on the part of doctors to refer someone who they have just diagnosed with cancer to, say, a psychologist or a specific specialist nurse or someone who can do some of that.

Ms Rooney—I think it is an issue of control: ‘It’s my patient.’ That is where the difference with a multidiscipline team comes in, in that that person is part of that team and so there tends to be a broader view. There is a very strong sense of ownership of a patient, of them being ‘mine’.

Senator LEES—How do we break this down? Obviously there are a lot of people trying to. Some of it seems now to be coming from patients, because as patients find out that their GP can refer them to, for example, a chiropractor or an acupuncturist under this program you are getting the push from that end. But is further resourcing of the Cancer Council needed? Should there be requirement that, wherever someone is diagnosed in Australia, there must be an information brochure from the Cancer Council physically handed to that patient at that time?

Ms Revell—A lot of it could be to do with education. A lot of times the doctors do not even think about the other aspects or whichever medium you happen to be in—I do not think they even think about the other things you might need or want. It just does not enter their mind that that is what they deal with. So I think education has a lot to do with it.

Senator LEES—I can leave this next question on notice. Do you have any figures or any information on the percentage of GPs that would automatically let their patients know as the diagnosis comes through that the Cancer Council is there and that is where they should go? If you have any research or information—

Ms Rooney—We do not have that information.

Mr Katris—We have a GP cancer education project that we think is quite unique in the nation. It is located at the Cancer Council. It is funded by the department of health. There is one project officer who purely and simply every day of the week is responsible for providing up-to-date education in the area of cancer control. Referring back to these fantastic documents that we have that were produced and endorsed by the NHMRC, each one of these documents has a chapter on GP roles and on psychosocial assessments. The education opportunity is there. But we wonder, because they are developed for the cancer treatment specialties—surgery, medical oncology, radiation oncology and haematology—whether people actually read the psychosocial chapter. But every one of them has this; it is routine now. The NHMRC and the nation are to be commended for actually doing that, though the service delivery has not matched. The GP bit is very intriguing as well. The treatment teams that are medical speciality driven—those in the teaching hospitals particularly—do not have GP liaison. To access them, from what little I know about the enhanced chronic disease model, the GPs need to have undertaken some training; but, also, our medical specialists could probably do with a little bit of an education about the availability of and access to them. That is another role for us, I am assuming.

CHAIR—We are going to have to leave it there, unfortunately. Thank you very much for your submission and your presentation today.

[12.06 p.m.]

BULLEN, Dr Ivy, Chairperson and Honorary Chief Executive Officer, Balya Cancer Self Help and Wellness Inc.

HAN, Dr Jason, Honorary Chief Executive Officer, Balya Cancer Self Help and Wellness Inc.

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

Dr Bullen—This is just a brief history of Balya. We are a charitable organisation, incorporated. We began in 1989, when Balya was founded by me because I really believed that there was a great need to treat the patient as a whole person—not just to treat the disease, not just to look at cancer, but to be aware that this is a person we are dealing with, that they have a life, they have a family, they have feelings and, most likely, they have children. It is important to recognise all those things when you are dealing with cancer. Balya was founded for those reasons. The idea was to take people, on a time-out basis, away from the everyday traffic, from televisions, telephones and people, and the stresses of everyday living when they had been diagnosed with cancer, so that they could have that time out and be able to assess their lives and to have support. It was our aim to teach them about lifestyle changes that they could make and tools that they could use to make life better for themselves.

We support the family as well as the patient. We like it when we can get people to attend as patient and partner or even with family members—some of the children have often come to retreats as well. A large percentage of the work we do is on communication—Dr Han is going to talk largely about his side of that—and nutrition and the value of getting a person as healthy and as fit as you possibly can, which is going to help them deal with all the big issues of cancer. We also help them to psychologically deal with those issues.

We talk about anecdotal evidence, and I know there is much debate on whether anecdotal evidence is as good as double-blind placebo studies. I think it is important that we recognise that anecdotal evidence is evidence from people. Too often specialists get very concerned that if there is no black-and-white study showing that something is so then it does not work. We have to remember that studies are not related to individual patients. Many studies might address an aspect of a treatment; they might address a drug and whether it works or not. But nobody is going to know how an individual patient is going to respond because every person has their own potential for responding, their own motivation, their own level of support and their own level of hope. There are many factors involved in whether a patient is going to do well or not.

If this is all right, I will give you one of the reasons that I became involved in Balya. It dates back to my time as a resident in the hospital when it became very obvious to me that patients with cancer needed somebody to talk to. They did not just need to have drugs prescribed. This goes back to the seventies; I realise things have changed. They did not just need a team to stand around and address the drug situation, tell them what the prognosis was and then send them home. My case involving anecdotal evidence was an 80-year-old man who was supposedly dying, who was on a morphine drip and lying in bed with the blinds pulled. I asked him if there was anything that he had wanted to do before he died. His reply was that he had wanted to go to England to see his family but he never had the chance. Because of his cancer he was there to die and he knew that he only had days or weeks to live. So I was determined to find something that he could try.

Many thought that I was quite crazy but I got some travel brochures for him because he had wanted to go back and meet his family in England. I picked up every travel brochure that I could that related to where he had come from, put them on his bed and said: ‘Why don’t you just read these? Why don’t we just get you fit enough to see if you can’t travel and do the things that you wanted to do before you die?’ To cut a long story short, he became extremely motivated. He read the brochures, and I think that planted pictures in his mind of something that he wanted to achieve.

We booked the trip. I found doctors in England that would look after him and I talked his family. I was only a first-year resident at that stage, but it became obvious to me that this man was getting more motivated every day and he was looking better. I got him off the morphine drip and onto what they used in those days, which was Brompton’s mixture, which he could drink orally, and I got him eating mushy food. Eventually the physios walked him up and down the corridors. I put him on vitamins, which I believe made a big impact on him being able to get the strength to do this. As it turned out, he left the hospital, caught the plane, travelled around England for 18 months and came back to die in his own home in the country with his family. This was a death at home with family around him. He was able to enjoy those last days and he certainly enjoyed the previous 18 months.

That is called anecdotal evidence. If that is not evidence, I do not know what evidence is. That was in my mind throughout my years of general practice and it really pushed me to believe that we have to do more for people who have cancer. We should be able to motivate them to make their own lives better, to make life better for their families and perhaps to achieve some goals and take some pressure off the health system. I think that keeping people well, with a healthy immune system, good food and a good healthy determination to be better, is beneficial to everybody.

Dr Han—I will just deal with a couple of the issues that we brought up in our submission. The first issue relates to rebates for cancer retreats. In our submission I summarised the reasons for asking for the rebates. But I want to add that, as we know, most health services are rebatable either through HBF or Medicare. Balya’s services are all health related and yet are not rebatable.

The second point in my submission relates to rebates for Balya psychological counselling. I want to add to that point that all clinical psychologists have provider numbers from HBF, Medicare and Medibank Private. As a Balya psychologist, I have a different degree but at a doctoral level. All my services are health related, yet they are not rebatable.

Senator COOK—I have attended a Balya retreat and found it immensely beneficial. I felt I should make that declaration. Since Balya was established, how many people have attended your retreats?

Dr Han—Balya was established in 1989. In the initial few years we were running three retreats a year with 60 participants each time. In January 2004 we got the new building at Gidgegannup and started running nine retreats there with 25 to 30 participants each time. In other words, all the retreats were very well attended. The demand for services such as Balya is offering keeps increasing rather than decreasing.

Senator COOK—Dr Han, have you heard the statement: ‘You are what you think’? As a psychologist can you tell me what that means and what evidence there might be to justify it.

Dr Han—‘You are what you think’ stems from the basic principle that your emotions have a direct impact on your health. Negative emotions bring about a suppression of the immune system. In other words, negative emotions affect your health adversely. Positive emotions enhance the immune system and therefore bring about a favourable effect on your health. My premise as a therapist is to bring about a shift from negative to positive emotions, thereby bringing about a change in the health of the individual. My system works on three levels—the behavioural level, the speech level and the thought level—to bring about a change in the emotional content of a patient. The effects of negative emotions such as stress, anger and guilt on health are very well documented in the book *Psychoneuroimmunology*. I have a photocopy of the cover of this book, which I will pass on, and I suggest that anyone who is interested should read this book. There is another book, one of many about cancer and stress, which talks about how stress can have an adverse effect on health. All these are very well documented. There are articles written by MDs and PhDs.

Senator COOK—We have heard a bit during this inquiry about what is proven and therefore medically known as fact and what is not proven but may be regarded as promising. You have just outlined a view of a psychological approach, if I can put it in those terms, and you have provided references to those books, but to what extent is that researched and backed up? Is that what those articles and volumes are about?

Dr Han—I have, in addition, a list of articles which have been written—it dates back to 1987—on all the positive effects of psychological intervention in cancer. I will also leave that with Beverly.

Senator COOK—Do you get patients referred to you by oncologists or by other medical specialists?

Dr Han—I would find it very hard to recall anyone that was referred by an oncologist.

Senator COOK—What I am coming to is that there does not seem to be much reference from oncologists or other medical specialists to psychological support and counselling, in your case, yet there is a huge body of evidence that you have referred to that justifies the view that it makes a big difference in cancer cases. Is that a fair comment?

Dr Han—That is correct, yes.

Senator COOK—Dr Bullen, at least in my reading, in Germany and France it is rebatable to go to a health farm or spa, because the purpose of the national health schemes in those countries is to treat the whole individual in their environment and deal with the disease in that context. Is that the sort of example you are trying to put in practice in Australia, and is that one of the reasons you think your scheme should be rebatable?

Dr Bullen—I believe so. I do not know whether it is on a par with what they are doing in Germany but I certainly believe that, as we are teaching people skills that can keep them healthier and that can hopefully reduce hospital admissions and make their lives much more worthwhile, it would be very beneficial to patients to have some reduction in fees. We keep our Balya fees to a basic minimum, as I am sure people who have seen our brochures know, but we obviously need to cover expenses. We also have a sponsorship system where we invite members of the public to sponsor a patient to a retreat, because there are those who cannot afford it at all. That system tends to work very well. It means nobody is excluded from going. But, if someone dealing with cancer is in a situation where perhaps their partner or carer is not able to work as often, because they are home giving a lot more support, and therefore their finances are a little bit stretched, on the whole I believe that something like a rebate for a retreat, where it is going to help them get healthier and live life better, might be very beneficial to them.

Senator MOORE—I was asking about how you survive. I work with a group on the Sunshine Coast that relies on community sponsorship. Is that the model that you were talking about, Dr Bullen—you have community fundraisers and that kind of thing to help you out as well?

Dr Bullen—The way we get our funds is by doing mail-outs, which we do ourselves through the office, to people who have maybe donated little bits and pieces to us in the past. We will perhaps send them a letter from someone who has thanked a previous sponsor and say, ‘This is how beneficial it is to the patient to be able to go, and they would never have been able to experience this if they had not had the financial help.’ We do get a reasonably good response there, but it is not enough to be able to say we can help everybody to come to the retreat at a cheaper rate.

Senator MOORE—Do you work with the Cancer Council? Are you part of their services?

Dr Bullen—We hope that they refer patients to us. We regularly send them brochures and we regularly put brochures in the hospital in the Brownes Dairy area, in the oncology wards. Whether they are in a prominent place, as they should be, I do not know but people do tend to find them and come to retreats.

Senator MOORE—Do you keep a record of where people come from and how they find out about your services?

Dr Bullen—When people make an inquiry we ask them where they found out about us. I guess most people have found out about us from a pamphlet at a doctor’s surgery—they go to general practitioners as well—or their general practitioner may have recommended us to them. General practitioners definitely do refer patients to the retreats. A couple of oncologists refer patients to retreats, but not all of them do. We have a radiotherapist or two who refer people to retreats as well. But it is not done widely enough. I wish all the specialists would say to patients: ‘Please do this. Go and learn about how you can help your own life to be better.’

Senator LEES—My understanding is that under Medicare GPs can now refer, certainly to psychologists, three or four sessions a year. Perhaps that is something the committee need to ask the health department and others about. I want to go back to the question of practical evidence versus scientific evidence. I do not quite understand the process but, looking at all the submissions, I can see that there is a lot of practical evidence of people benefiting enormously when they have peace of mind—when they can be got to a state where they are relaxed and calm and the stresses upon them are reduced. Once scientists start looking at trials, is part of the trouble that there are so many variables? If you are changing a person’s mental wellbeing, if you are interfering, as some might say, by prescribing them vitamins or if you then start saying to them that they need some physiotherapy, isn’t that a whole world of just too many variables for the scientific community to cope with? Should we simply go back and redefine what evidence is and start talking more practically?

Dr Bullen—That is exactly what we believe is happening. I think Dr Han would prefer to answer that question.

Dr Han—If you are a researcher, the most important thing to you is to find out which modality has affected the results and the outcome. If you are a patient, the most important thing to you is that you recover. I think in our culture we have underrated anecdotal evidence. We place too much value on statistical studies and big studies. When I was researching three decades of research in education, I found out that one thing was missed—subjective response.

Most of the researchers had assumed that everyone would react in the same way to the same situation. The fact is that they do not. We are all different. In the area of stress research, you will hear doctors say, ‘There is no relationship between stress and illness or cancer.’ These doctors have read only some of the studies, and these studies have omitted subjective response. I have looked through the studies on subjective response. If you look through every study which has explored the subjective response, you will find a link between cancer and stress, cancer and depression and all the negative emotions.

Senator LEES—Would it be too far for this committee to go to say that we need to think again about what is evidence and evidence based medicine and that we need to focus on what works rather than on what has had a double blind placebo trial three times?

Dr Han—Absolutely.

Dr Bullen—You brought up the subject of a patient taking vitamins. There are so many things that are not recorded in studies and one of them is sleep. How much sleep does a person get? How much exercise does a person do? How motivated is that person? What is their individual potential? What sorts of spiritual beliefs and support do they have? That is all going to make a difference to how a person is going to respond—this is the subjective response that Dr Han is talking about. Do they take some vitamins? Have they had some advice on nutrition and supplementation?

Senator LEES—Even in current trials those items are put to one side and not even looked at. We are talking about pharmaceutical companies doing trials on the latest medication. A lot of those questions are not asked of the patients at all, no matter whether they are on the blue tablet or the white one. Who is taking vitamins? Who is seeing a psychologist? Who is having exercise? All of that is ignored over there, so why are we having so much trouble over here?

Dr Han—In other words, a lot of the relevant variables have been left out.

Dr Bullen—There is one big issue. A study done at the Mayo Clinic with Linus Pauling had patients looking at the benefits of vitamin C. That eventually did not prove that vitamin C made any difference to the group supposedly taking vitamin C. However, it turned out—and this was not published—that everybody went home and took vitamin C. That was because they were all cancer patients. If such people know that you are doing a study on vitamin C and that it might do them some good, they do not care about your statistics; they are going to go home and take it. That is what they need. Eventually—I think a couple of years later—somebody took it up and published the true evidence, but the first story published was that it did not make any difference, and most orthodox doctors took that on board.

CHAIR—Thank you for your submission and presentation today.

[12.32 p.m.]

DAALE, Dr Peter Leonard, Chief Executive Officer, Cancer Support Association of Western Australia Inc.

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

Dr Daale—From the outset I would like to make it clear that I am a doctor of business administration and not a medical practitioner. I say this to avoid confusion and to highlight the fact that I am not beholden to any particular cancer treatment paradigm from an academic training point of view. I have 25 years of experience in health care across the areas of financial underwriting of hospital and medical insurance, management, planning and delivery of surgical hospital and medical clinic services, and support services access and delivery in the non-profit sector. Within this context of service delivery, my primary interest is to reduce the existing asymmetry of information on cancer and treatment options between patient and practitioner in favour of the individual diagnosed with cancer, allowing for better informed dialogue and participation, with the aim of improved outcomes. The method we use at the Cancer Support Association is neither directive nor prescriptive but rather one of creating quality information-based access platforms.

If I can just digress for a moment on this information issue, we heard Dr Fong talking about fragmentation and empires, and we heard Professor Christobel Saunders talking about power as information. The representative of the Cancer Registry was talking about the importance of staging in order to validate the survival outcomes, which currently is not widely available. If you cannot assess the information in terms of end outcomes, then how you are going to research all your services to deliver better outcomes—from both a health outcome point of view and a cost efficiency point of view—becomes somewhat meaningless.

In terms of the question ‘What is evidence?’ the gold standard, so to speak, in medical services delivery is peer reviewed trials that are quantitative in their design. A researcher or a statistician can look at a cancer study—and let us assume it is well designed—that is used to test a particular chemotherapeutic drug. If it demonstrates its efficiency within a certain significance level, then the drug is subsequently approved. For the patients, that significance outcome may be quite meaningless because it may extend survival from 12 months to 14 months. The two months is valuable, but in terms of ordinary lifetimes and the ordinary understanding of survival and recovery, they are two completely different things. The evidence that is often discounted more often than not relates to qualitative studies. They may still be subject to the same rigorous research design—that is just an aside.

Coming back to my presentation, the mission statement of the Cancer Support Association of Western Australia is to empower individuals and the community towards wellness, healing and sustainable health. That mission statement is supported by four key objectives: to help people recognise the importance of the environment and their personal contribution to living well and dying well, to promote a holistic and inclusive evidence based approach to self-care and healing, to provide information resources, support services and learning opportunities for healing and for the prevention of lifestyle diseases and, finally, to enable individuals to make informed decisions about wellness and health and to gain a greater sense of control over their life.

CHAIR—Dr Daale, we have your presentation in front of us. Given the amount of time we have, would you summarise it for us, which would then give us an opportunity to ask you questions.

Dr Daale—That is fine. I will go directly to the delivery of services and options for treatment on page 3—and keep in mind the information you have in front of you which I have just given to you. The comments that I make here are based on five years of experience with a membership base that varies between 500 and 600 members, most of whom are diagnosed with cancer. Within that membership base we lose about 100 individuals a year to the disease itself. Of the numbers who are non-diagnosed, there are those who care for those who are diagnosed and a smaller component of individuals who are well and who are interested in prevention. All of them, when they have gone through an induction course, tend to express to a greater or lesser degree the comment, ‘Why were we not told about these services before?’—not so much because our services are so unique, better or different, but simply because they focus on empowerment through the information access platforms that we provide.

I have stated here quite openly that their regret as to ‘Why have we not been told?’ is based on the lack of information on treatment impact, side-effects, outcome and quality issues, potential causes of cancer and future measures to reduce probability or recurrence, including significant lifestyle factors, environmental factors, and the psychosocial and multidisciplinary support available in oncology clinics and hospitals at the time of diagnosis, which could have reduced their fear and anxiety and their ability to make better informed choices.

The medical model to which the multidisciplinary teams referred this morning really only referred to surgeons, oncologists for chemotherapy, radiation oncology, physiotherapy—all the clinically based services. They are seen as the treatment model, the one that is based on valid research, the one that is based on proven outcomes. We teach people when they come, hopefully at the beginning of their diagnosis, that they should look at all the evidence, not just in terms of whether it is called promising or not but in terms of outcomes compared to no treatment at all. The other thing we teach individuals is that they should measure everything through a filter which says: whatever you do, it must do no harm.

Many of you have had friends or family who have been exposed to serious surgery and chemotherapy, and you will know that with chemotherapy there is an enormous impact on the immune system and, whilst it may, from a clinical perspective, reduce the size of the cancer, the drugs are highly toxic in their own right and a whole number of measures are taken through the treatment process to ensure that the treatment can be stopped before it kills the patient. If you then look from an end result point of view or from an epidemiological perspective at whether cancer with treatment is better than cancer without treatment, from a medical model perspective, then if you are the consumer you are not entirely filled with confidence in terms of outcomes. If you then also look at the treatment and you say, ‘Does it do harm?’ you cannot in all sincerity say that it is harmless, because it affects quality-of-life issues.

I have picked up comments throughout today from individuals who have gone through a cancer diagnosis themselves and there has been a lack of information. One lady referred to a cancer treatment drug called Tamoxifen. Tamoxifen is well known for application to women who are at high risk of breast cancer and it has a roughly five-year protective umbrella. After that, the umbrella diminishes and the drug itself raises a person’s risk of a gynaecological cancer. So, if the treatment is highly focused on a particular segment of the disease and only on suppression and possible eradication and yet one does not look at the greater picture, then one has to bring into question the validity of the treatment.

Having said all of these things, we do not pass judgment on whether the treatment is good or bad. All that we do is provide individuals with access to information platforms that are interactive and informative and based on evidence and peer review. If you go to our organisation’s services online, for example, you will see cancer profilers and you will see access to the Swiss Institute of Bioinformatics, which is a medical search engine. You will also get a direct link to the National Centre for Complementary and Alternative Medicine. That is part of the National Institutes of Health, which is a US federally funded institution but is based on mainstream science for alternative treatments—not complementary treatments, so I am not talking about massage or meditation, which quite well support the mainstream: these are alternatives. So people do have an information platform they can go to in order to access the evidence.

Again, in terms of the first point, numbers of people regret that they were not given access to this information right from the start. I think it is relevant for me to say this: I launched the cancer profiler in Western Australia—or in Australia; it was the first instance—in 2001. I then extended an invitation to the WA Minister for Health to launch the profiler. That was handed to the Department of Health, who contacted me and asked me two questions. The first question was whether it had been validated in Western Australia. I said no, but that it had been validated over a number of years in the United States and is now fully endorsed by the American Cancer Society.

The second question was whether I was not concerned about giving the general public access to too much information. My answer to that was that if the information is quality and evidence based and is provided in a surrounding where support is offered if it raises further questions then the public has a right to know. They are the sorts of issues we deal with in terms of information access.

The second thing is that we heard in the presentation this morning about a multidisciplinary approach. Certainly, there are multidisciplinary teams within hospitals but they only consist of individuals trained within the medical model paradigm. To assume that only the medical model holds scientists, researchers or academics of note is somewhat presumptuous, if not outright arrogant. If you take a wider view and look around the world you can come up with a number of leading researchers and institutes that offer alternative medicine type publications. I have already referred to one of them, the National Centre for Complementary and Alternative Medicine, which is quite a giant in its own right. Professor Saunders already referred to that institute. However, her opinion of alternative opportunities was not all that convincing. For something to be truly multidisciplinary it needs to be multidisciplinary across different paradigms.

There is always an issue of how much money can be made available and, if it is made available, whether we get better outcomes. My view would be that you do not necessarily need to put more money into it but you do need to make the network work better and make it more inclusive. That will start to go across professional patches, if you like, that are being protected in hospitals or oncology units or what have you. That is a challenge.

My fourth point is that, based on the feedback we obtained from members of the Cancer Support Association—assuming we consider them representative—in their support group meetings and counselling sessions, one would have to conclude that prevailing mainstream medical model practitioners and alternative treatment practitioners are tolerant of one another at best and adversarial at worst—a situation which can only be overcome with genuine mutual respect and cooperation in patient management and research, with active cross referral and follow-up complementation.

The second issue is how complementary and alternative treatments can be assessed and judged. Firstly, it is obvious, to me at least, that equal amounts for research should be made available to both mainstream and alternative paradigms. If that does not happen then, even with the best intentions, you will not always be able to dismiss things that cannot be easily peer reviewed, published and studied over a number of years.

The other thing is that equal value should be given to well designed, from a research point of view, qualitative as well as quantitative studies. We have heard the Cancer Council refer this morning to psychosocial assessments. But the assessment is one thing, the follow-up and implementation is another, and if you want to decide what works and what does not then you also need to put some resources in there. Taking a somewhat idealistic and perhaps old-fashioned point of view and thinking about the pretechnology days of medicine where observation and the patient-doctor relationship was much more generalist, rather than one of a quick prescription and out the door, then evidence based research for alternative cancer paradigms and treatments may initially require some extra money being spent, but in the longer term it may very well deliver a model that is a lot cheaper to run because by and large it is not based on technology.

The third point is to acknowledge—I think Dr Bullen made a comment about that—individual patients. I probably would go even further and say that, if we look at the history of medicine, the major breakthroughs have not come from large clinical trials—they have improved things at the margin at best. The major breakthroughs have come from very eminent and able clinicians with keen observations as to what happened in individual patients. It does not matter whether we refer to people like Coley and his work in cancer or Pasteur and his medical work: these were all based on observations initially. So a breakthrough with individual patient outcomes and then a study as to why these individuals are so unique—what made the difference for them—may very well pay off a lot better than saying, ‘Okay, here’s another chemical combination, let’s test it and see if it brings a statistically significant improvement in the outcomes for whatever cancer it might be,’ and keeping in mind that most therapeutic or chemotherapeutic cancer drugs are on the toxic list in any case. So if you go back to your principle of no-harm outcomes and you look at end results—as they do in the States, for example, at the National Cancer Institute where they have a database called SEER, based on surveillance, epidemiology and end results—then you are starting to get a bit closer to what the gentleman from the Cancer Registry was talking about.

I would put my focus on information access for cancer patients that is genuinely inclusive, not just based on one singular model. I would build referral networks that go across the different paradigms. I would go to government involvement in terms of the accreditation process and the minimum required documentation in terms of what you normally would do in a medical or non-medical but health care consultation. I would look at ethics and a whole range of things where you can make a low-cost intervention rather than let the industry regulate itself, because there are many business interests involved and there are many empires to be maintained.

I could wrap it up by saying something about the grand plan we listened to for the restructuring of the health care delivery here in Western Australia. It may be that we are a totally insignificant organisation that does not contribute terribly much, but I have to say that I certainly have not been approached in any shape or form. When I listen to the presentation on the model and I look at the diagram that Professor Saunders put up, I find nothing in there about alternative medicine practitioners. Even the patient, I think, was an afterthought, and not included within the circles themselves.

Senator KNOWLES—We have heard today from the Cancer Council, Balya and now you. I am interested to know how you all work together and whether there is any cross-fertilisation of information or services and where the patient fits in with those three groups, and I would probably include the Brownes Cancer Support Centre as well. There seems to me to be a little bit of overlapping and duplication here.

Dr Daale—Absolutely. Dr Fong was very correct in saying there was fragmentation. That applies not only to the medical model but to any alternative care models as well. I stated in my submission to you that we do refer individuals to the Cancer Council. We refer individuals to the Cancer Information and Support Society in Sydney. We refer to the Gawler Foundation in Victoria. We refer to the Kingsborough Cancer Support Group in Tasmania. We refer to the Balya self-help centre here in Western Australia and we also refer to a whole range of general and specialist medical practitioners and other health care practitioners who we feel take a more genuine, inclusive, holistic approach to the treatments.

By the very nature of looking at alternatives as well as the mainstream, many of the specialists, practitioners or organisations we cross-refer to tend to be in what I call the non-invasive category. They look at causes of cancer, lifestyle factors such as diet, chemical trace elements that people may be exposed to et cetera. So we do cross-refer. If you asked me how many referrals we get, I would say that, within that circle of practitioners, we get referrals from the Gawler Foundation in Victoria, from practitioners such as Dr Serge Toussaint, Dr Igor Tabrizian, Dr William Barnes, Dr Hira Singh and probably about a dozen more—I cannot remember them off the top of my head.

The same is true for alternative care practitioners who may be more focussed on the homeopathic model. That is very prevalent and common in Europe. References were made to Germany, but that approach is just as common in many ways in my country of origin, which is Holland, and in Switzerland, where we refer to the Paracelsus Clinic, which is a homeopathic medical mainstream facility. Unfortunately, there is very little point in us referring people here to mainstream oncologists because they get that information already from their own practitioner. We probably get zero referrals from mainstream oncologists. The only one that I can readily recall occasionally referring is Dr Arlene Chan at Royal Perth Hospital.

Whilst I find that a pity, we try to address the problem. I have quantified the size of our organisation for you in our paper. We work as six full-time equivalent individuals and that is it. Our budget is around $800,000 a year, which we have to raise ourselves. Most of that goes into services delivery. We have three PhDs, two masters degree graduates, one bachelor degree graduate and three support staff, not all full-timers. We then create the information platform and provide support groups, counselling and other support services like meditation, remedial massage and lymphoedema massage. But the main focus is on information sharing. We have an excellent library. We have been fortunate enough to receive a $50,000 grant from the Lotteries Commission to update the publications in the library, but, other than that, our entire funding is raised individually. On average we get $20 and $30 donations from the general public.

Senator COOK—I have a declaration of interest—I am a member of the association. I think that one of the biggest challenges we are facing here is to try and get a greater degree of cooperation between the so-called orthodox medical field and the less orthodox medical field—that is, complementary and alternative areas—and to get more cross-communication going so that we treat the individual and their environment with the disease rather than simply focusing on treating just the disease. On page 4 of your submission at point 4 you talk about encouraging practitioners from both paradigms in joint research and peer review of research. Are you aware of where that has occurred at all?

Dr Daale—There certainly are incidences. In my submission I made reference to a person I often refer individuals to, and that is Dr Ralph Moss. He is based in Pennsylvania, publishes widely, does a lot of research, presents at mainstream conferences and is involved in joint research. In Western Australia it is not all that prevalent. If you go to Royal Perth Hospital, they have psychologists; if you go to Sir Charles Gairdner Hospital, they have the Brownes Cancer Support Centre. The Brownes unit has just published a research paper which reflects the number of services they deliver. At a stretch, one could say that involves people with a medical background and people with no medical background, but that is not really the sort of the research I am talking about.

If you want a concrete example, I get inquiries every day about a substance called B17, which is also known as laetrile or amygdalin. It is an extract of the apricot kernel. If patients ask that question of their oncologists, they basically get laughed out of the room, and that is pretty much a standard answer. However, if you go to the information network of the National Centre for Complementary and Alternative Medicine you will see the evidence published and presented on laboratory trials, animal trials and human trials, and then the classification of the outcomes and the impacts. Provided it is administered by someone who knows what they are doing—and in this case it is more than likely to be a medical practitioner—you would have to make a judgment that this is a worthwhile thing to consider. It is not terribly expensive. That is just an example.

To go back to the health department, that has not been validated here in Western Australia. Things like that could be validated, whether here in WA or across Australia, with scientists or people from across the spectrum who are trained in mainstream science, in research, theses, development and testing, et cetera. That would not be all that difficult. At present I am advertising for a registered psychologist with a strong research background because I want to try and tap into some sort of joint research, where we can make a start. I know it is going to be pitifully small, but it is a small start somewhere, I guess.

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

Proceedings suspended from 1.02 p.m. to 1.40 p.m.

BUSH, Ms Dorothy Mary Elizabeth (Betsy), Private capacity

OLIVER, Mr David James, Coordinator/Manager, Brownes Cancer Support Centre, Sir Charles Gairdner Hospital

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

Ms Bush—I am here as a consumer; I have consumed my cancer.

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.

Mr Oliver—I have for you a letter from Dr Joske, who is the founder of our centre. He is head of haematology at Sir Charles Gairdner Hospital. Would you like me to read through that, or can I leave you to read that at your leisure?

CHAIR—You can leave us to read that and just take us through your presentation, thanks.

Mr Oliver—I would like to show you a presentation which is a fairly standard talk that I give. It will explain to you about the centre and how it works. I would like to be able to show you today that we have a working model that is successfully operating in a mainstream public teaching hospital, and we have actually helped three regional centres open similar models. We believe our model can be adapted to any situation quite easily; it is very flexible. We by no means believe this to be the final say in models. The centre is completely self-funded and run by volunteers.

A PowerPoint presentation was then given—

Mr Oliver—This slide shows the history. It began in 1996 with Dr Joske approaching the hospital and making links with people in England at Macmillan Cancer Relief and the Mount Vernon Hospital in London. Brownes Dairy, a big milk company here in WA, chipped in $208,000 to fund the centre, to refurbish the building where we are, which used to be Westpac bank. Unfortunately they do not give ongoing funding, so that needs to be clear. The Leukaemia Foundation funded us for our first 12 months; they funded half my wage. We have received recognition from different organisations. We opened to the public in September 2001. I will move you through this fairly quickly because I know time is limited. The main thing I would like to point out is that we have a research committee, formed with Professor Linda Kristjanson. Some of you may know her from Edith Cowan University. She is a very highly respected researcher in Australia.

We now have an advisory board of businesspeople who, within the next month, are to start fundraising for us in the business community. Dr Joske and I have done talks all over Australia, mostly in Melbourne and Sydney. Dr Joske spoke to the haematological scientific conference in

Melbourne last year. I spoke to the Integrative Medicine Conference in Sydney. Dr Joske also spoke to the Integrative Medicine Conference in Brisbane. Appealathon have sponsored us this year, which has been a big financial help. We now have our latest research data, which I have made available to the committee. We continue to have a lot of interest from all over Australia and from other hospitals.

That slide is just to show you the embracing philosophy. We look at different philosophies; we do not judge or say that one is better than another but just allow people to come in and maintain their own belief structures. This slide shows computer access—the creative visualisation group. The aims of our centre are: to improve quality of life by alleviating distress, improving understanding of disease, developing patient empowerment, improving access to other support networks, fostering psychosocial research and the integration of complementary therapies into the mainstream system.

The last one is probably regarded as the most controversial thing we are doing. But really, we are not doing things that are any different from what is really happening in mainstream hospitals. In other words, we are supporting patients while they are going through their treatments. We are linking them up with mainstream organisations such as the Cancer Council, the Leukaemia Foundation and the Cancer Support Association. We are just doing it in a slightly different way through the use of complementary therapies. We would also like to become self-supportive.

The definition of complementary therapy is those treatments, interventions and supports that are given alongside mainstream medical care. They aim to support and enhance a person’s quality of life. A lot of people misunderstand complementary therapies. They tend to lump them into ‘alternative’ straightaway. You start talking about aromatherapy and people think ‘alternative’ and the shutters tend to come down. I would like to emphasise to the committee that the touch based complementary therapies that we offer at the centre—we have steered away from herbs and vitamins and controversial treatments—do not conflict with mainstream treatment. They can be given alongside any mainstream treatment quite safely. So we are using touch based therapies.

Our policy is nil by mouth—which is not food but herbs and vitamins, and we have steered away from that deliberately. We are a drop-in centre so we provide a safe nurturing environment. Already we have done and have been part of good quality research programs. Our policy is that as long as the therapies do no harm then why not let the patients do them. We cannot necessarily prove that they do good in that scientific model sense but, equally, we cannot prove that they do any harm, using a scientific model. So we are saying: let the patient be the judge. Some people come in and try reiki and say, ‘That is a load of nonsense; let me try something else.’ Other people come in and try reiki and they think that it is the best thing that ever happened to them. They come back three days later and say that they have had the best three nights sleep they have ever had. So for us that is a success. All the treatments are free and are also available to all the family members. We support mainstream treatment at all times and we have got quite strong guidelines on that.

I guess the selection of therapists is a controversial area. We have said that we will follow public sector guidelines. They have an interview with me and they have a police clearance, which the hospital does, and they have to have proof of qualifications and be a member of a governing body. We also have an orientation and training program for our therapists. We always tell them never to massage over a treatment site or a disease site and always allow for private therapy. In other words, we are so inundated with patients that we cannot service them all. There is the two-week waiting list for aromatherapy. We actually encourage the patients to visit to see our therapists privately. Since they are volunteers we say, ‘If we can help you guys in business, that is fine.’ That is the only way we can keep up with demand at this stage.

We tell the therapists not to practise outside their area of expertise. If they are in the centre or the hospital to do reiki they are not to do counselling. They do not give advice and are told to stay within their modality. They are told not to influence patients against mainstream treatment and not to claim accreditation with the hospital. They must not claim that they can cure a patient and must not take bookings on-site. They cannot approach a patient. Our policy is that we only take referrals—but anyone can refer. We find that the ward clerks are our biggest referrers because the nurses are in touch with the ward clerks and they know what is happening on the wards and they just refer down to us all the time.

So we have a system that is working very well. These are the therapies on offer—you may be familiar with some of them. I would not really call acupuncture a touch based therapy. We have done research on that on xerostomia, which is a dry mouth, a side-effect of radiotherapy, and we found that it improved the dry mouth. We now have the radiotherapy department referring patients to us all the time for dry mouth. So that has been very successful.

We have counselling. It is not so much psychology based counselling as listening-ear based counselling. It is not about just offering these therapies on the ward or to the outpatients. It is about having a centre where they can sit on the couch, have a cup of tea, talk to the volunteers, choose whether or not to receive treatment and also have access to information. So we offer a package. That is the secret to our success so far.

I do not really have time to talk about these individually, but that slide shows aromatherapy on the ward, pranic healing, hands-off massage—if such a thing is possible—and reflexology. Our research data shows that 150 visitors per week come into the centre. The latest research has shown that we are doing 340 treatments a month. It is growing. I am having trouble getting qualified and experienced therapists at present. They are all volunteers. Our model is not sustainable unless we start to pay some of these people. Our study was of 564 participants. Their average age is 55. Almost 85 per cent are female, which is culturally normal. That is what you would expect. Men tend to lock themselves in the shed, in the garage or in their room and not seek treatment. I have a funding proposal to put a shed and a bar in the hospital, but I do not think I am going to get it!

We also found that 24 per cent of people had told their doctor that they were getting complementary therapy treatment from us. That is statistically normal as well. In other words, they are not telling their doctor that they are coming to see us. We suspect that is because they are afraid of the doctor’s reaction. However, they were quite happy for us to tell their doctor—91 per cent said that.

Senator LEES—As long as they were not there at the time!

Mr Oliver—Yes. That is an interesting statistic which ties in with research that has been done at the Peter Mac Hospital in Melbourne.

This slide shows a breakdown of the types of patients we are seeing. You can see that the orange is mostly outpatients. The blue is carers. The yellow is inpatients. That is probably closer to 20 to 25 per cent now, because we are doing a lot more inpatient work. We treat any patient on the wards, not just cancer patients. We will treat any patient on the wards that the nurses refer. The six per cent is the staff—the green one. We do quite a lot of PR. We invite staff to come in and try the therapies, and we find that they refer a lot more patients to us once they have tried them themselves. It is pretty interesting.

The next slide gives a breakdown of the types of patients. You can see that it is mostly breast cancer patients. We do not know why there is such a large percentage of breast cancer patients. It could simply be because the breast clinic is referring all their patients to us, and I suspect that is probably what is happening. You can see that a very wide spread of cancers are presenting to us in the centre. One thing in particular was brought home to me last year. The nurses brought to us a gentleman in his mid-50s who had advanced prostate cancer. He was very upset and very tearful. They thought he was in pain and was upset about his prognosis and his treatment. We sat him down for half an hour, had a chat with him and discovered that he was upset because his relationship with his daughter had broken down and they were no longer speaking. That was what he was upset about. That is what we are here for; that is what this centre is all about—making an emotional connection with people.

There is an interesting point about the research which I particularly want to make. We asked people to fill in the forms on the first, third and sixth visit. The yellow column on that slide is from their first visit. That is when they are feeling the worst. Then, as the columns go down, they show an improvement. So you can see that, for all those quality of life assessments, there is an improvement over six treatments. They receive six treatments over anything from a six-week to three-month timeframe.

The blue and grey columns, the second and third columns on the slide, are interesting. The second column shows how patients are feeling before their third treatment and the grey one shows how they are feeling immediately after their third treatment. There is a significant short-term improvement. In a palliative sense, there is an immediate improvement. It is pretty obvious—you have a massage and you feel good. But there is also a long-term improvement from their first visit to their sixth visit. That is pretty consistent throughout the research. We are quite excited about that. We believe that from a quality of life point of view there is certainly a very strong case for using these therapies. I do not know if any of you are into statistics; I am certainly not. But the research people tell me that the research is very good quality and very tight, and there is definitely something happening at the centre that needs further research.

The next slide shows the symptoms. The research on these is not quite as clear, but the interesting ones are pain, fatigue and nausea. You can see, going from the blue to the light blue column and from the purple to the violet column, a huge, immediate improvement in pain. The slide shows that there is a significant, immediate improvement. It is the same with fatigue, which is a big issue in modern medicine for cancer patients, and also with nausea. So we believe that a palliative application can be made.

We often get the nurses ringing from the wards saying, ‘We’ve got a patient with a tumour. He’s in pain and we don’t want to give him any more medication. Can you do something?’ We come up and give the patient reiki for 10 minutes and their pain is completely removed. They are then able to get to sleep. They wake up three of four hours later and the pain is back again, but it is less, so they are able to control it more with drugs. We see that a good synergy could happen and we believe that there is a good case for that.

In summary, we believe that we provide safe, supervised access to complementary therapies in a teaching hospital setting. We represent a unique fusion of mainstream and complementary medical approaches. As far as we know, what we are doing is not happening anywhere else in Australia in a mainstream teaching hospital. Our research shows that it is possible to assess the impact of the therapies and also show marked improvements. On the left side we have mainstream medicine and on the right side we have complementary medicine. We believe that it is now time to bring these two together. There has perhaps been a split in the past, but we believe that it is time to bring the heart and the head, as some people might refer to them, together to look at the best of what each has to offer. We see the centre as bridging the gap between these two ways of thinking.

Our people, our volunteers, are the real heroes. I am very humbled to be able to work with the volunteers. There are some pretty high-powered names on our research committee, on the steering committee from the hospital and also on the management advisory group, who are businesspeople who passionately believe in what we are doing.

The last slide shows a statement from Dr Joske that we think that, given more funding, we can certainly do more research. Sir Charles Gairdner Hospital has a very good research reputation. We believe that one of the issues with research is that funding has simply not been available to do it. Professor Don Iverson from Wollongong University recently gave a talk and he mentioned some statistics from England. Their medical research budget is £170 million. Their complementary therapy research budget is £300,000. He is saying, ‘That’s the reason that there is no research happening on complementary therapies. We need to fund it.’ I realise that is not your role, but I think I need to make that point. Thank you for your time.

Ms Bush—Firstly, I would like to thank you for coming over to Perth to hear us all. I feel as though it is a great privilege to have the opportunity to have my say on an issue that I feel so strongly about. I have not actually prepared anything but I guess I wanted to give a bit of the flavour from the perspective of my story as a patient. Thirteen months ago I was the same as everyone else out on the street, just trotting along. I found a small lump in my neck. The next thing I knew, there was a diagnosis of cancer. That has turned my whole life completely upside down—in a fairly positive way in the long run but there have been some hurdles to go over along the path. I had a bit of preparation, I guess, for the diagnosis in that my cousin died from cancer about seven or eight years ago, so I had read Ian Gawler’s book. In the back of my mind, I knew there was something out there. Also, five years ago they found out of the blue that my daughter had a massive hole in her heart. That experience made me realise that every day is very important and that today really matters because you do not know what will happen tomorrow. So in a way I was semi-prepared for a diagnosis of cancer.

When it came, I suppose the first thing that hit me was the fear of telling my children and my parents. When you think of cancer, you generally associate it with a death sentence. That is how I perceived it until about 12 months ago. So there was a bit mental leap to make. In part, I feel very lucky in that the specialist I was immediately referred to do was David Joske, so I started off quite a bit ahead of a lot of other cancer patients that I have met since then. I have had quite a few visits to the centre here. The centre made a huge difference to my perception of going to the hospital. I would go not only to receive chemotherapy and other nasty things but to lie down and have a massage for an hour. At a time close after diagnosis, when I had a veneer of control but where everything underneath was turbulence, it was such an oasis. It was a wonderful place to visit.

Through the support centre I also got to know about the Cancer Support Association in Cottesloe. I started going to their support groups. That mixing with other cancer patients opened my mind to other approaches. I heard how they were addressing similar problems to those that I was coming up against. That had a huge impact on my life. Also while I was here I picked up a leaflet for a visit Ian Gawler was making to Perth. That was last May. That was a real turning point. I went to his weekend workshop in Fremantle. I knew that there was something I intended to do myself about the cancer in addition to the treatment that I was currently undergoing, but that gave me the direction, basically. It gave me information on nutrition, meditation et cetera—things that I started to put into place in my life that made such a difference. I became so much more positive about it all.

I then went over to the Gawler Foundation in Victoria for a ten-day retreat. That was the most profound experience—I really cannot describe it. It showed me so many areas in my life where I could make a difference. There were so many things I could do free of charge that would help me to get better. It also gave me the hope that I could actually beat the cancer myself. I have non-Hodgkin’s lymphoma. The type I have is deemed to be incurable by Western medicine. But going over there and listening to all of the different things that affect your immune system and the things you can do to help yourself made me realise that I can do it myself. I will accept the conventional therapy that is available but there are myriad other things that are out there. It gave me confidence that I can turn my disease around myself.

Basically that is all I want to say. I will leave time for questions. The main things that have made such a difference to my life with cancer have been the support groups: the support centre, the support from the Gawler Foundation—all of these things run on a shoestring that are here, there and everywhere. My children went to workshops for children who had parents with lymphoma and leukaemia at the Leukaemia Foundation. These all made such an impact on my life.

Senator COOK—I am going to declare an interest. I have visited the Brownes centre at Sir Charles Gairdner as an outpatient. You introduced me to reiki there, which, I might say, I have followed up at the Cancer Support Association. I am interested in that part of your submission dealing with multidisciplinary approaches. To what extent is the Brownes centre involved in the multidisciplinary approach at Sir Charles Gairdner? Are you part of the team or are you an add-on to the team?

Mr Oliver—We are officially part of Sir Charles Gairdner Hospital. We have spent the last three years proving ourselves and establishing a name for ourselves. We find that, increasingly, we are being referred to, but, in terms of what you mean by as a part of a multidisciplinary team, I would say that we are probably a bit on the outer in that sense. Nevertheless, we actually bypass most of the referral mechanisms within the hospital and go directly to the patient. We have our brochures in all of the waiting rooms and wards. We find that the nurses are our biggest point of referral. I think that officially, in terms of multidisciplinary care, there is a lot of scope for us to be included more widely in the different facets—social work, OT, physio, radiotherapy, diagnosis, surgery et cetera. We get lots of referrals from those areas but I do not think that we are officially part of a referral process. I hope that answers your question.

Senator COOK—Yes, it does. What you seem to be presenting here in terms of the statistical evidence—I think statistical evidence quantifying outcomes has a considerable amount of value, since this is a field in which the medical professional itself discusses outcomes—is a very positive tick for the work that you do at the Brownes centre. Anyone looking at those statistics could not fail to be impressed by it. It corresponds with the personal evidence Ms Bush has just given about her own experience in coming into contact with what I would describe as less orthodox methods of treatment, spreading your wings in that area of the alternative or complementary treatment field. I know you could define these terms more closely. Are you satisfied that the medical professional itself takes account of those sorts of outcomes when it thinks about treating patients?

Mr Oliver—That is a very difficult question to answer, but I think I can answer it. In my experience—and that is all I can talk from—at the hospital, when we first opened, I am not sure whether they really thought we would survive more than six months. I think they really thought they would have all these mung bean hippies wandering around the hospital telling everyone to stop their mainstream treatment. Now, after three years, we are finding medical students wanting to do work experience with us during their holidays. We are finding increasingly younger doctors referring their patients to us. Many what I would call ‘enlightened’ older doctors are doing the same. But there are factions within the medical professional who I do not think will ever accept these types of therapies, no matter what evidence we put before them, because they have a certain mind-set, perhaps from the seventies, when complementary therapies were alternative and I believe there was a lot of damage done. And I must say that I am guilty of being one of those people. I think both sides have matured since then, but there is a lot of room for improvement. From my personal experience I do not think that enough credit is given within the medical profession for what can be done with complementary therapies in terms of psychosocial support.

Senator COOK—The state government is working on a plan, which I am sure you are aware of. They outlined it to us this morning. Were you able to have input into that?

Mr Oliver—I sent a submission to my codirector. I am not sure whether it made it into the presentation that was given to the government.

Senator COOK—Do you know if there is any intention to address some of your financial needs through that state plan, given the results you have got—that you actually help in this field?

Mr Oliver—I do not believe there is any provision at any level in government that I am aware of to provide funding for us. To be fair, we have only publicised our research results in the last six weeks, two months.

Senator COOK—If they did not know, they could not do it.

Mr Oliver—That is right. We have approached government at a state level through Mr McGinty, but we have not made any official approaches through the health department. We are really a work in progress. That is how we see ourselves. I think we are at the point now where we need funding to progress.

Senator COOK—Can you quickly address the question of this work you were doing to try to bridge the cultural divide, if you like, between your field and the more conventional field?

Mr Oliver—Yes. We believe that our very existence is doing that. But we also have educational programs for nurses. We talk to doctors whenever we have the opportunity. I gave a talk to 40 midwives at King Edward Memorial Hospital yesterday. I am doing a talk for the Leukaemia Foundation tonight. So we do it through dissemination of information. That is about all we have done, really. I think we need more recognition from higher levels within the health department and within government.

Senator COOK—I will be quick, Ms Bush, Congratulations on getting better at this stage and long may it reign. You seem to be a person motivated to go and find out all this material and adapt your life to the needs of treating your disease. Is that a fair comment?

Ms Bush—Yes. At the beginning, I got onto the internet and searched all over the place, but I suppose I have never gone near anything complementary before. I had always used just mainstream medicine—not that I had needed much, anyway. But it was more the fact that it was there and easily accessible that got me going there. What if it had been out in the suburbs and if I had not already had the introduction when I went for my diagnosis? When I saw Dr Joske he brought me into the support centre and showed me what was available there. That to me was a crucial step. It took me through the wall; it took me through the barrier. It took me three months to get to the Cancer Support Association. At the time I thought, ‘I don’t think I need to go to a support group.’ I had not been, but once I had gone—

Senator COOK—My question then is about if had you not met Dr Joske—if you had met someone else and you were not referred on. Speaking as a patient, what do you think we should do about trying to alert people to this field? Is there anything that you think that, if you were in our shoes, you would recommend should be done?

Ms Bush—There is closing the gap with the doctor who has given you the news of diagnosis or the GP who is dealing with you. I said to my GP, ‘The best advice I can give you is that, if you have a new patient with cancer, give them the leaflet for the support centre and the Cancer Support Association and say, “Just ring them up or go down and see what they’ve got.”‘ It is somehow breaking the wall. I have friends who have been diagnosed with cancer and they have not come through Charlie’s, and they still think, ‘I don’t need support; I can cope with this on my own,’ whereas I know that they would benefit so much. I think there should be some sort of a referral—having some means of contacting or getting patients to these places that can do so much good right at the very start. I realise I was lucky.

Senator COOK—An introductory thing?

Ms Bush—Yes.

Senator KNOWLES—First of all, congratulations on what you do. I think it is absolutely fantastic. I suppose, as a consequence of that, I find it somewhat difficult to understand why patients are so reluctant to tell their doctors that they are participating in the activities of the centre. As you say, it can do no harm; it can only do good. Why is it that patients are so reluctant to tell their practitioners that they are involved in getting massage, reiki, reflexology or whatever it might be?

Mr Oliver—Can I answer that question to start with. I think it is because of the mind-set of the seventies and eighties, when there was a lot of enmity between alternative and mainstream treatments. To be realistic, with complementary therapies—I do not really like using the word ‘alternative’, because I do not think that is necessary anymore—regulation is an issue. Standards do vary. But it is like any treatment: there is good and bad within any profession. Traditionally, doctors have pooh-poohed complementary therapies. Patients have gone to doctors in the past and said, ‘I’m having reiki,’ or ‘I’m having aromatherapy,’ or whatever, and the doctor has said, ‘That’s a load of nonsense.’

Senator KNOWLES—But what I am getting at is: so what? Fortunately, my doctor—who has just retired—was very much into complementary therapies. The one that I now go to is certainly very much in favour of them as well. But, if I went to a doctor who was not in favour of them and who pooh-poohed and said, ‘Why are you doing that?’ I would say, ‘Because I want to.’ It would not matter a toss to me whether or not they thought that was good. If I thought it was doing me good, then ‘Que sera.’

Mr Oliver—Absolutely.

Senator KNOWLES—Is there a fear that they might be crossing or antagonising the doctor?

Mr Oliver—I think that is a major part of it.

Senator KNOWLES—So ‘the doctor on the pedestal’ thing is still very much alive and well in the minds of a lot of people?

Mr Oliver—I think it is a lot less so. My experience at the hospital is that I have patients coming to me all the time talking about their experiences with certain groups of doctors. Basically, they are fearful of the doctors’ responses. I have staff coming to me for treatment and they say, ‘Don’t tell my boss.’

Senator KNOWLES—That is Dark Ages stuff, isn’t it?

Mr Oliver—It is absolutely Dark Ages stuff. I faltered in my answer to Senator Peter Cook because there is such strong feeling in certain areas. We think that if we had a referral mechanism in place to refer patients to the centre we would not be able to cope. When I went to see one of the radiotherapists at Sir Charles Gairdner Hospital—where his department is treating 400 outpatients per week—he said, ‘You don’t want me to refer all my patients to you because you would not be able to cope. I will only refer the ones who really, really need support.’ So it is a huge issue.

Senator KNOWLES—Okay, you would collapse under the weight of constant referral. Today you have gone through the issues in relation to making appointments and making private appointments. Do you keep any records of the level of uptake of people who want to privately access some of these facilities?

Mr Oliver—We do not have any record of that.

Senator KNOWLES—You do not have any of them coming back to you. I noticed, Ms Bush, that you are in a good situation because you live in Shenton Park and you are around the corner from Sir Charles Gairdner Hospital and therefore your access was fine. Mr Oliver, do people from Joondalup or Kalamunda or wherever come to you while they are inpatients and ask, ‘How do I access this outside?’

Mr Oliver—That is exactly what happens. While they are receiving treatment at the hospital as outpatients they come and see us. After their treatment finishes we do not see them again. We only see them when they come back for a check-up. So we have wondered whether having a treatment centre or a drop-in centre offsite would be beneficial for those patients who do not want to come back. Generally they do not like coming back into the hospital so we do not see them. That is something that is very common. One of the things we want to do is track how many patients are seeing our therapists privately. We do not do that at present but we have recognised that issue.

Senator KNOWLES—For the *Hansard* record, would you briefly explain craniosacral therapy?

Mr Oliver—I will do my best. Craniosacral therapy is a very gentle therapy that involves stretching the spinal column and probably using a bit of kinesiology. It is balancing the energy flow up and down the spinal column. They use very gentle—imperceptible—movement to balance the energy within the person receiving it.

Senator KNOWLES—You mentioned kinesiology.

Mr Oliver—Yes. Kinesiology is like touch for health. It uses a technique of balancing the left and right energy flow within the body. We are getting into the field of holistic therapy and energy fields. The theory is that we all have an energy field within us and that it can flow. The energy field flows around our bodies and we experience pain when there is a blockage in the energy field. So by the using kinesiology or any of the other therapies we can restore the energy flow. It is based on the same system as acupuncture. You restore the energy flow and the pain goes.

Senator KNOWLES—What is Bowen therapy?

Mr Oliver—Bowen therapy is a bit more like acupressure. They are a using a bit more pressure but it is very gentle. It uses acupressure to move the fascia over the bony structure of the body, which causes it to relax, which then releases energy flow. It restores energy. It is very good for fatigue.

Senator KNOWLES—What is pranic therapy?

Mr Oliver—I have a list that I can email you. Pranic therapy is similar to reiki—although they would all disagree—and healing touch, in the sense that it uses a hands-on healing technique that channels a cosmic or universal energy through the healer into the patient. The theory is that it goes to wherever it is needed within the patient, so the therapist does not actually need to know what is wrong with the patient or diagnose them in any way, which is a good thing from our point of view. It is a bit like the laying on of hands in the Christian tradition, only these therapies have come from Asia or India.

There is a lot of controversy around these therapies, especially reiki. People who have a strong religious background have some trouble with these concepts. What I always emphasise to people is that they are not a religion or a belief. You do not need to even agree with them. You do not need to believe in them. They are not a spiritual practice; it is just something that is happening. It is an exchange of energy, which apparently they can measure these days. I always say to doctors and nurses when I am talking with them that you do not have to agree with your patient trying these therapies; all you have to do is keep the dialogue and communication open with the patient so that you at least know what the patient is doing. It is not about believing in these treatments.

Senator MOORE—Mr Oliver and Ms Bush, you began by saying you had found a model that works. I support what you are doing, but it seems to me that the model has now reached a stage where you are based on volunteer labour, you do not have enough resources to treat all the people who need you and you are not fully involved in the team that is developing the process. So the model has a way to go.

Mr Oliver—It definitely has a way to go; we do not deny that. We believe that it is growing and evolving. When we started, there was nothing in place—there is no precedent for what we are doing. We have had to learn and grow by our mistakes. We believe we have a basic model in place that works and that can be transplanted to any hospital. The next stage is to then integrate it more into the team, as you were saying, because it is going to grow.

Senator MOORE—And fund it.

Mr Oliver—Yes. It is not sustainable to have volunteers forever. We will always need volunteers. We worked out that, if we paid our volunteers, it would be costing $360,000 a year. That is really a donation in kind that they are making to see this happen. They are very much supportive of the vision. These people believe in this: 95 per cent of our therapists are making a living from their therapy, so for them to lose a day out of their income is pretty significant.

Senator MOORE—So it is the intent of the process, based on the paper that you have given us today, to integrate further into the practising process.

Mr Oliver—Yes. We would like to see other centres open in other hospitals, especially Royal Perth Hospital, where there is interest. St John of God in Subiaco have been talking with us, and we have given them a lot of advice for when they build their new cancer centre. That will be another two years away, but they have plans to open a centre like ours.

Senator MOORE—I think that is the step forward: when someone is building a cancer centre, you are inbuilt.

Mr Oliver—Yes. We are planning to conduct a mini-conference in the next three months in Perth and invite interested parties from other hospitals in Perth to have a look at our model and discuss it.

Senator MOORE—Have you had interest from other teaching hospitals across the country?

Mr Oliver—Only from a nursing level. I should not really say ‘only’, but you know what I mean: not from an executive level. I have approached the CEO at Peter MacCallum. Craig Bennett was the CEO at Sir Charles Gairdner Hospital. He opened the door for this to happen at Charlie’s. He had a support centre there that was five times bigger than ours, which was empty when I went to see him. I said I could guarantee to fill that centre within four weeks. He looked at me and knew exactly what I meant. He said it is still probably a few years away, given the cultural way of thinking—it needs to be accepted much more by the medical profession that these therapies are not competing with the medical profession.

Senator MOORE—A true sense of complement.

Mr Oliver—It is a true sense of complement.

Senator KNOWLES—Do you have other non-professional volunteers working in the centre?

Mr Oliver—Yes. Half of our volunteers are reception volunteers—what we call ‘meet and greet’. They are the first point of contact. It is amazing; all of this is generated by volunteers. They collect the data, see the patients and make bookings. It is all done with volunteers. I have an assistant for four days a week now. Our data is actually 12 months out of date. We have a year’s data that we have not entered into the computer because we have not got the staff or the time to do it.

Senator KNOWLES—What is your catchment area?

Mr Oliver—We are open to any patient in WA.

Senator KNOWLES—But what do your statistics show as your main catchment area. Can you put a radius out from Charlie’s?

Mr Oliver—I would say the Perth metropolitan area is where we receive most of our patients from.

Senator KNOWLES—Is it up to the foothills?

Mr Oliver—I do not have that data at my fingertips. We do all the demographic data, so we do have that there. Twenty-five per cent of our patients are coming from other hospitals. We have a lot of country patients who come and visit us, especially from up north or from Esperance and Albany. We have assisted a centre to open in Albany, in Bunbury and in Narrogin.

Senator MOORE—Are they similar centres to yours?

Mr Oliver—We have assisted them. They have approached us for assistance and we have helped them get going with our guidelines.

Senator MOORE—Are their centres linked to the hospitals?

Mr Oliver—Their centres are linked to the hospitals in those areas.

Senator MOORE—Co-location of hospitals seems to be a critical point.

Mr Oliver—It is a key ingredient. It needs to be linked to the hospitals.

Senator MOORE—Ms Bush, have your kids come to the centre with you when you have gone there?

Ms Bush—They have not. They are aged 11 and 13 now. I nearly brought one once when I was going to have a bone marrow biopsy, I think it was; I think she went to a friend instead. Otherwise I would have been quite happy to pop them down with a book.

Senator MOORE—I am interested in children coming through the centre as well.

Mr Oliver—Certainly there is a huge scope for children.

CHAIR—Thank you for your submissions and presentation.

[2.37 p.m.]

DEVERALL, Mr Clive, Private capacity

CHAIR—I welcome Mr Clive Deverall. For the purpose of the *Hansard* record, could you state the capacity in which you appear today?

Mr Deverall—I am here as a cancer patient and as someone who has worked in the cancer industry—if you can call it that—since 1977.

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, and I now invite you to make an opening presentation, to be followed by questions from the committee.

Mr Deverall—Thank you very much indeed for the opportunity. I mentioned being a cancer patient because I think it changes one's perspective of the problems that are faced by individuals once they have received that diagnosis. My situation was similar to Betsy's: the lump on the neck syndrome, which you try to ignore for a period of time until somebody ends up putting a needle in it and you end up with a diagnosis of non-Hodgkin's lymphoma—a fairly rare one but you then find out it was the same one that caused the early demise of Paul Eddington of *Yes, Minister* fame.

The rarity of the tumour was interesting, because three a year, if that, are diagnosed in this part of the country and you could not find a clinician who would agree on who should treat it. It is a cancer of the bone marrow which symptomises in the skin. Haematologists think it is theirs but the dermatologists say, 'No, it's ours,' and you end up with a poorly managed rare tumour. Fortunately—crossing my fingers—mine is behaving itself at the moment, even though it is an incurable cancer.

My commentary will focus on the problems and the logjams in the things that should be happening, particularly in relation to multidisciplinary care. This is from the experience that I gained as Director of the Cancer Foundation of Western Australia until 2000, when I was diagnosed and decided to give away full-time work. I have since continued as a consumer representative on the National Cancer Strategy Group, which is part of the Department of Health and Ageing, and as a consumer representative on the research committee of the NHMRC. I also chair the Palliative Care Association in Western Australia and am a member of Cancer Voices, a consumer group for cancer patients, which we have just set up in Western Australia and which replicates Cancer Voices in New South Wales.

Overhead transparencies were then shown—

Mr Deverall—You have heard of Silicon Valley. This is acronym canyon! This list illustrates what is going wrong. A significant number of these organisations receive a lot of federal government money. Some get state government money but the majority are individually tumour focused, which results in the proliferation of the different organisations and their community organisations, either companies limited by guarantee or incorporated associations. I have noticed already that I have left two out. The list does not include the AMA, which has an interest in cancer on behalf of its members, and it does not include the various colleges, who are one of the biggest problems facing the reorganisation of cancer services in Australia.

All these are in the context of what I have written in my submission, and I put patient ownership here. This morning Christobel Saunders made a brief reference to this, particularly in the private sector. What happens is this: a GP refers, usually to a surgeon, and a surgeon may then take a decision on clinical grounds to refer that patient directly to a medical oncologist or a radiotherapist. More often than not surgery is the first intervention, but at some stage, if the patient is admitted to a hospital, public or private, they become the property of the consultant who has referred them, particularly in the private hospitals where there is no medical infrastructure. All you have is a collection of consultants who refer patients, and God help anybody who attempts to do anything else to that patient. With respect to patient ownership, nurses observe it, all allied health professionals observe it, and hospital administrators observe it, particularly in the private sector, because they rely on their income from those patients that are referred by consultants.

The difference, even in teaching hospitals, is significant. At Sir Charles Gairdner Hospital or Royal Perth Hospital, again, there is a consultant. The hierarchy used to be on the little plate at the bottom of the bed. You would look at it and see the consultant’s name and the resident’s name, and the pecking order was illustrated. Little has changed; we still live in hierarchies in the medical system, particularly as far as the treatment of cancer in Australia is concerned. This is adversely affecting the situation. It cuts rights across multidisciplinary care. Even in teaching hospitals, patients with bowel cancer are looked after by one consultant. Adjuvant chemotherapy is essential these days. It is part of the guidelines for the treatment of bowel cancer, but more often than not the guidelines, which are beautifully produced by the Australian Cancer Network, are not necessarily followed, even in a teaching hospital.

As we heard this morning, there is no clinical audit—certainly no clinical audit in any private hospital in Western Australia, and there are only two that I know of in the whole of Australia where the clinical outcomes are audited. In teaching hospitals, again, hospital based cancer registries are all over the place. They cannot talk to each other. It is bad development of information technology. In one teaching hospital here they were asked to provide a figure of how many cancer patients they had treated in the previous calendar year. They could not answer the question. They just did not know. Again, it is bad information technology, which Tim Threlfall referred to earlier this morning.

Regarding multidisciplinary care, which I referred to in my submission, you had this tsunami of consultants who had been to the Sloan-Kettering Cancer Center in New York, the MD Anderson Cancer Center in Houston, the Mayo Clinic and the Royal Marsden Hospital coming back here in the eighties and nineties full of great ideas for tumour meetings, tumour boards, multidisciplinary care and comprehensive cancer centres. They did their best, but, again, they were the new kids on the block coming back to Perth or Melbourne or wherever with all the good ideas in terms of efficient management of people with cancer but nothing ever happened. Multidisciplinary care was acknowledged, talked about at meetings and developed into comprehensive cancer centre concepts, but, again, nothing ever happened. This goes back, as I say, to the early 1980s. It is not a new thing. Everybody knows the benefits of it, but they have retreated, particularly the colleges and individual practitioners, behind the words—and beware these words—‘levels of evidence’, which are used as a shield, like ‘demonstrated benefit’. They are all an excuse not to do anything.

I remember one meeting where we had senior consultants from around the country, but they would not accept what multidisciplinary care was. They already thought they were doing it. What they were doing, in fact, often in private settings, was indulging in a collegiate atmosphere: perhaps picking up the phone, perhaps seeing somebody in the coffee room or passing them in the corridor and talking about Mrs So-and-so or Mr So-and-so. That is not multidisciplinary care. With multidisciplinary care at the Royal Marsden, the Royal Edinburgh Hospital or Sloane-Kettering there is a tight protocol. It involves clinical trials. Very few patients who are treated are not involved in some form of clinical trial. There are tumour meetings at least twice a week. No patient is owned by a single consultant—I emphasise that. That is so important. They have cancer registries; they have clinical audits. At clinical meetings they identify poor outcomes because of infection following a surgical procedure or because of a bad bleed in the theatre. All these things, which involve information that is available, are discussed as to why these outcomes have happened. It is vitally important.

David Oliver was very polite on psychosocial support, but the recalcitrants in his hospital are of a certain age and nothing will cure them. They will never refer anybody to anything to do with psychosocial support. They described David Joske as the ‘mung bean man’ when he first brought this concept to Perth. We then had the visit of the person who first set it up in England at the Mount Vernon Hospital, Dr Jane Maher, who is now the medical director of Macmillan Cancer Relief. That organisation, which was the most conservative of cancer organisations in Europe, now has a director of complementary therapies—a qualified doctor who gets all the information from the United States, where most of it lies, and provides people with on-the-spot advice at any level of inquiry. There is not a teaching hospital in this country where there is a line item in the budget for psychosocial support for cancer patients. When I say that, the Peter MacCallum Cancer Centre calls it something else. But as you have heard from David Oliver, the former CEO of Sir Charles Gairdner has gone to Peter MacCallum as the CEO of that famous institution, where they have a large empty area that was for their psychosocial centre not being used.

The National Cancer Strategy Group produced a report in 2000 identifying 13 priorities to improve outcomes for cancer patients to control cancer. One of those was providing access to counselling for cancer patients—recognising that not every cancer patient will need it but that there are many who do and that it should be provided by either psychologists or other suitably trained health professionals. That recommendation survived rigorous scientific analysis. It went through the unit in Melbourne that does all these measurements of quality-adjusted life years saved and disability-adjusted life years saved. All of us were totally gobsmacked when it came out, having got through all that lot, as having sufficient levels of evidence to qualify as one of the 13 recommendations. That was 2000; this is 2005 and nothing has happened.

There is poor palliative care. Palliative care is the cinderella of medical services in Australia. It is the last medical speciality on the block. But of course it is delivered by nurses, so it has never been that highly regarded—it is a nursing model of care. In teaching hospitals around the country you can get it—not necessarily in dedicated beds or in a dedicated area—but come 5.30

on a Friday evening, there is no palliative care until Monday morning when the palliative care consultant comes back.

There are enormous things that need to be done just in organisation and methods, and it would save money. Applying proper palliative care in a teaching hospital, taking those patients that consultants have refused to refer to palliative care and making sure they do refer them would save a lot of money. We have this DRG system—diagnostic related groups—where you find how health care is costed by the Department of Health and Ageing. When you look at palliative care, DRGs are 60 per cent less expensive than DRGs that are applied to patients in the curative stream. Whatever you may say or want as a patient, if you are in a teaching hospital, you are in a curative stream system. That is where palliative care struggles, particularly in teaching hospitals in the public sector.

The most important thing is patient ownership. There are beautiful new private sector centres opening up. There is one at St John of God—$25 million worth down the road here. Big signs go up saying ‘comprehensive cancer centre’, ‘cancer clinic’ and all the rest of it. But, as I mentioned earlier, there is nobody actually there in charge of coordinating services. There are no tumour meetings, there is no hospital base cancer registry and no clinical audit. It is just a loose collection of consultants who rent rooms and put people into beds in that hospital. There is no coordinated comprehensive multidisciplinary care. There is often no psychosocial support or, if there is, you are getting it as a private patient because you might be able to get a rebate from your private health fund from a psychiatrist or, if you are lucky, from a psychologist. Patient ownership is worse in the private sector than it is in the public sector.

Experimental treatment is rife in the private sector. With my own cancer, I got all these word of mouth recommendations. I was told about a treatment at the Prince of Wales Hospital in Sydney called extracorporeal bypass treatment of the blood, where the blood is bypassed, taken through a machine, irradiated with ultraviolet A radiation and then introduced back into the body. There it was, in a kosher hospital, with no levels of evidence—which is what they all use—saying, ‘Yes, you can treat people with those sorts of protocols.’ When I eventually found out who was doing it they were most surprised that I had tracked them down.

In another teaching hospital, in this town, there was hot towel treatment, where you are embalmed from head to toe in hormone ointments—steroids—wrapped in hot towels and then aluminium foil. You are put in a bed for 24 hours and cooked, just like a chicken. Again, there are no levels of evidence and nothing published, but there you are. Complementary, alternative or unproven treatments may have their struggles, but somehow there is experimental therapy going on in some odd places. But again, in the private sector there is no overview of how patients are treated. Palliative care is referred to in the glossy leaflets, but it is very much a token.

Nursing homes have tried really hard since the standards were upgraded and since palliative care standards were pushed hard into that sector. But there is just no margin in terms of looking after people in that age group—disregarding the young ones, who shouldn’t be there; rather, the older ones—to provide proper palliative care. If anything happens, more often than not they are just getting referred straight to hospital. There are obviously always the issues of comorbidity—often they are suffering from something else as well. Psychosocial support is virtually nonexistent. Patient ownership is the key factor there.

There is good news on clinical trials. We have had a few negative comments about clinical trials, but basically without clinical trials with a multifactorial disease like cancer nothing really moves forward, particularly with people who have advanced cancers. We have profited tremendously from clinical trials in America and Europe because they have got the numbers. We struggle here in Australia because of our small population. We have linkages with countries throughout the world to run clinical trials so that we get the statistical effect by having large numbers of people being entered into clinical trials.

The best example of all is with children’s leukaemia and other paediatric malignancies. Back in the terrible eighties, children in Western Australia in particular had 60 per cent mortality from children’s leukaemia. They appointed a new haematologist who locked the Children’s Hospital here into the American clinical trials group, which now has 22 hospitals, and now around 90 per cent of children achieve lasting remission from leukaemia and certainly from some of the other more common paediatric tumours. Now there is more good news. The NHMRC have at long last—they have been a bit like Ben Hur—set up a national clinical trials centre, which is good news not just for cancer; cancer is part of it. We hope of course that it is going to continue to be funded, because these things are only as good as the length of time that they are sustained.

The bad news is that there is still fragmentation, so that centre has got to try to gather in all the information from the trials that are going on. When the Western Australian Clinical Oncology Group started five years ago, it focused on clinical trials and even after three years it was still discovering funny little clinical trials going on here, there and everywhere. Most of these were funded by pharmaceutical companies. The pharmaceutical companies are getting up to some of the tricks that the tobacco industry used to get up to way back in the seventies and eighties and perhaps the nineties: significant inducements—the $600 that clinicians get every time they accrue a patient into a trial, harnessing patients for PR stories and setting up consumer fronts. There is one that was set up in the week before last—the coalition of cancer advocates, which is funded by Roche and is going to massage the media by putting these people in there with shroud-waving stories. There is a lack of transparency: where do the results go? Recently the editors of international medical journals agreed that they would not publish the results of clinical trials unless they met set criteria. That is going to catch a lot of the results of these trials. But the main thing for Australia is to have a national clinical trials centre, and in that clinical trials centre there is no reason why we should not see some psychosocial trials and complementary medicine trials; they are made for it.

Referring briefly to my recommendations: multidisciplinary care is absolutely critical, and hospital based cancer registries are critical, and they must be able to speak to each other. I have recommendations on sustained psychosocial support, and also on GPs. At the moment it is unusual if GPs see 30 to 35 cases of cancer in their professional lifetime. Most would probably see 20. A lot of people think GPs see cancer all the time—it is just another disease. They get barraged by cancer societies and every other organisation dealing with every other disease. It is very tricky. Being a GP is a terribly difficult job.

Look at the methods of referral at the moment. There is a lack of any multidisciplinary care or published data on the volume of patients that surgeons who treat breast cancer or bowel cancer are seeing—and that is what you want to know. It is essential to know what is the pedigree of the consultant that you are being referred to. How many recalls have they had from the operating theatre? How many patients have they seen? Do they participate in clinical trials? There is a whole host of things. Through Cancer Voices, when it becomes a national organisation, we hope to really lobby hard for that. At the moment it is more often the case than not that a GP is going to refer you to somebody they went to medical school with or play golf with. Non-government organisations can be very helpful in developing this proposal. They have got lots of volunteers, lots of people and power to lobby. The state cancer councils, the Cancer Support Association and Balya—all these organisations should be involved in multidisciplinary care. Consumers must have a voice in how these things are planned and run. Outcomes and results must be published. That is vitally important. There is accreditation and credentialing, which I have mentioned in my submission.

The Australian Cancer Network, which operates out of the same office of Cancer Council Australia, is a fantastic little organisation. It runs on an oily rag. The person who started it was Professor Tom Reeve. He is a former president of the College of Surgeons, so it was like gamekeeper turning poacher. He knew exactly who to get hold of, who to get together to get these guidelines put together on how particular cancers should be treated. They have now produced guidelines, a very solid document, on how to accredit places where cancer is treated, public and private. It is recommended reading.

On credentialling: whereas you accredit a centre or a clinic, credentialling is for the individual. The colleges do not like this. Their members do not like it. They do not want to have their names in a guidebook, like Cancer Voices in New South Wales did for breast cancer. They prefer the status quo. Credentialling is vitally important because the GP needs to know who they are referring to, and the patient, above all, should feel some degree of comfort as to where they are being sent. That can best be overseen by the Australian Institute of Health and Welfare, for example. They could easily oversee that, or the NHMRC or the Department of Health and Ageing. It has got to have a solid base to it.

Complementary therapies are so easy, and there is so much information on them, but we do not have it here in Australia. The National Institute of Health and the National Cancer Institute in America have got divisions that do nothing else. In the United Kingdom there is Macmillan Cancer Relief. It is all there. All we need to do is pull it in—it would not take much money—and tailor the information to be provided as a public information facility. That would be a starter for people, GPs and even cancer specialists, because all too often they are treating with disdain inquiries their patients are making of them.

The other day in a private hospital I saw a patient suffering from lung cancer. The oncologist came in, saw this thing on the side of the bed, picked it up and said, ‘What’s this?’ Then she just threw it down on the bed and said: ‘That’s just coloured water. They get hairdressers to do it.’ It was totally dismissive, and the patient just did not know what to do. That is what one has to overcome. We need more information, more transparency. It is not a difficult thing to do. It could be handled very easily through the NHMRC, who have recently sanitised some money for research into complementary therapies. But you will not get orthodox researchers applying for it, because they do not see it as a good thing on their CV. They want something else that is going to get them a good job or another research position.

As David Oliver has presented, we have got a model. Mount Vernon Hospital in London, Sloan-Kettering, the Dana-Farber cancer institute in Seattle and MD Anderson Cancer Centre at Houston have all got them. We just need to run with them some more, break down some of these resistances that exist within the medical profession and get these therapies interacting with orthodox treatment. But it will not happen unless you have got the background of multidisciplinary care.

Senator COOK—I have just one question. That was a very comprehensive and well put together presentation. The international evidence that you have pointed to—Sloan-Kettering and all of that—is pretty impressive. This afternoon Brownes gave fairly impressive evidence as well. Are we just looking at the hardening of the arteries here? Are people doing what they know and nothing more—they have tunnel vision—and so it needs to be changed? I still do not quite understand why the barriers are so firm and cannot be shifted. Based on logic, the case seems to me to be fairly compelling. Is it just a matter of running some demonstration projects?

Mr Deverall—Yes. The demonstration projects will be okay because, when you have a demonstration project, you try very hard, but they have to be against a background of the introduction of multidisciplinary care, so that the demonstration project ends and in they go. You are right, it is tunnel vision.

Senator COOK—I used to sit on the razor gang in the cabinet dissecting budgets and cutting back expenditure and all that sort of stuff. The first question you ask is: if we do this, will it create savings and, if it does, can that money then be used to develop a more comprehensive, progressive line of treatment? Where are the savings in adopting this type of approach?

Mr Deverall—Jason Han from Balya was talking this morning about stress. That is a research question that the NHMRC could easily look at. When you get a cancer diagnosis, there is a psychological impact. Some people find their own way—they have treatment and they have a successful outcome and that is it—but the majority of people have to cope with it one way or another. Providing support in a variety of different settings is going to save a lot of co-morbidity. It is an easy question for public health professionals to research. I sit on an NHMRC research subcommittee which deals with applications called enabling grants, which are worth $5 million over five years—it is serious money. I have said, ‘Look, there are all these complementary therapies and psychosocial types of support, so why don’t we encourage people to apply for that money?’ And the response has been, ‘Whoa—that is a good idea, but that is not what we normally look at.’ So you can lead a horse to water, but you cannot make it drink. It is a generational thing as well.

Senator COOK—Sit in our shoes for a moment, Mr Deverall. What would you recommend we do? You have made your recommendations here, but is there anything you want to add?

Mr Deverall—Multidisciplinary care is an essential priority. In order to achieve it, one has to look at Medicare funding to provide a financial incentive, because the quickest way of getting the consultants to participate with great enthusiasm is to let them know that they are going to get a bit more money. And the AMA will back that. So that is a mechanical thing that could be done. It has been talked about ad infinitum at meetings but no-one has ever put it up as a proposal to the Department of Health and Ageing. As Jason Han mentioned, private health funds will not provide any rebate for psychological counselling—although you can claim for running shoes from your health fund. I mean, really! So there is a lot more to be gained through some of these simple mechanical things. I could write out a list of a lot of simple, little things that relate to that. So multidisciplinary care is one, and another is getting the NHMRC or some other agency to start immediately gathering the information on complementary or alternative treatments, so you have it all there and then decide how it is going to be put together for public access.

I presume that you never get everything out of these things, so I think that those would be two simple things to do. You have the national service improvement frameworks, which the Department of Health and Ageing in Canberra will talk to you about. They have lifted that from the National Health Service in Britain. It is a great idea. It is not just for cancer; it is for all the chronic diseases, but it is not going to work unless you have incentives or force. I think historically force from the Commonwealth to the states never seems to work. There has to be a financial inducement within the framework of Medicare.

Senator MOORE—Thank you for that presentation; I found it very useful. You say that you have two representative positions now and you have explained a little bit about the response you have had when you have raised issues at the NHMRC. Have you raised the kinds of issues that you have raised today for us as the consumer rep on the Cancer Strategies Group?

Mr Deverall—Yes.

Senator MOORE—What was the response?

Mr Deverall—The Cancer Strategies Group does not have any money. It has money to run the meetings, but it has never had money to actually do anything.

Senator MOORE—It can make recommendations, though.

Mr Deverall—Yes. But of course Cancer Australia, this new organisation, has some money. I think it has come in with $3 million or $4 million.

Senator MOORE—Are the kinds of things you are talking about popular and supported in the Cancer Strategies meetings?

Mr Deverall—They are not exactly popular, no.

Senator LEES—Thank you for the presentation. I think most of my questions have been answered. I just want to ask you about another strategy that the federal government can adopt—to directly fund a group such as the Brownes centre here, given that it seems that they are virtually totally voluntary, and then either request or somehow require the NHMRC and others to come in and assist them with the evaluation of what is happening, what is going on.

Mr Deverall—The person who led the research evaluation of the Brownes centre, Professor Linda Kristjanson, is on the council of the NHMRC.

Senator LEES—So it is all there. It is just a matter of formalising it.

Mr Deverall—Yes. But, again, it would be better if it was within the system and embraced by the hospitals. It is still not embraced by the hospitals. They have this area but its existence is teetering on the edge every month. Where is the money coming from?

CHAIR—Thank you for your submission and your presentation.

Proceedings suspended from 3.18 p.m. to 3.33 p.m.

HALL, Ms Sonja Elizabeth, Private capacity

ROSENWAX, Dr Lorna Kaye, Sub-Dean, Health Science, University of Western Australia

CHAIR—Welcome. Do you have anything to say about the capacity in which you appear?

Ms Hall—I am from the School of Population Health at the University of Western Australia. I have been researching cancer care for about the last three-and-a-half to four years. The views I present today are my own and not necessarily those of the university.

Dr Rosenwax—I am from the Faculty of Medicine and Dentistry at the University of Western Australia. I am a member of a research team that over the last couple of years has been doing research on palliative care. The research is funded by an NHMRC grant.

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 submissions. I now invite you to make an opening presentation, to be followed by questions from the committee.

A PowerPoint presentation was then given—

Ms Hall—Thank you for the opportunity to present here this afternoon. I hope you have received the seven publications that I have produced already and that you have had the opportunity to read them. First of all, I thought I would go over the results in summary form and then talk about some of the policy issues emanating from those results. I thought it was really important that I state up front my philosophy towards cancer care. I believe that it should be equitable. That was one of the reasons for my research. I was concerned that there were inequalities in cancer care across Western Australia. However, I also work partly as a health economist, and I am very conscious of the fact that we need to work within our limited resources. This means that we need to use the money wisely. One of the things that we have not been very good at in the past is evaluating our policies to see whether they have had the impact that we want them to have. These are the three philosophies I am coming from today.

As you have probably noticed from the papers I sent you, we have been looking at four of the major cancers in Western Australia. We have selected those cancers because they carry the largest burden of disease and, also, to a large extent, they are preventable. We have looked at the effects over the last 20 years of disadvantage on who gets surgery and who does not get surgery and the influence of that on survival. There are six major areas of disadvantage that we have looked at. The first is socioeconomic status. Then we have looked at the effect of rurality. We have looked at not just rural residence but also admission to a rural hospital, to try and pick up the separate influence of the health care system as opposed to just residential status. We have also looked, to some extent, at the private health care system. We have looked at who has private health insurance and access to private hospitals. But I am not going to make those last two issues important today. If you want to ask questions at the end about those two issues, I will answer them. Lastly, I have looked at Indigenous status. I have looked at that separately because I am very much of the belief that the Indigenous issues are unique and should not be considered as part of the general cancer strategies that we put into place.

This next diagram looks very convoluted. It is not half as bad as it looks on the surface. Basically, this is how we get the data for the research we do. It is called the Western Australian Data Linkage System and is held here at the health department. For the studies we have done, we have taken the hospital, cancer and death data and linked it together, de-identified it and then used that for our analysis. This is a great way of being able to use the administrative data that we routinely collect to evaluate policies that we have in place quickly and cheaply to see if we are having the influence we want.

Using that data, I have summarised the findings of the seven papers you were given previously. Looking at the four cancers down the side, we have looked at who received surgery and their survival rates. For breast cancer, we looked at who got breast-conserving surgery as opposed to mastectomy, allowing for the fact that almost every woman does get treatment for breast cancer. For lung cancer and colorectal cancer, for which a lot of people do not get any surgery, we just put any surgery versus no surgery. For prostate cancer, we put radical prostatectomy versus any other form of care whatsoever.

As you will see if you look across this, in the lowest socioeconomic groups we see reduced surgery rates in almost all the cancers—and reduced survival. When we look at the effect of being in a rural area, we see that residence does not make much difference. Those are the arrows going straight across, indicating mixed or no effect. However, if patients had their first admission at a rural hospital with one of the cancers of interest they were much less likely to get any surgery whatsoever. Even if they went in for diagnostic testing, the chances of them going forward with further surgery were significantly reduced. The last two columns report very briefly on the effects of the private sector. We noticed that we tended to have increased surgery rates in the private sector, but this is not necessarily leading to improved survival, which is a fairly important point. Colorectal surgery is different to the other surgeries in that we did not actually find a huge difference, except that again rural hospital patients were less likely to get surgery. That is quite an indictment of a universal health care system when it comes to a very basic disease such as cancer.

Some people have argued that our results are all related to the stages of the cancers at the time they were diagnosed. That is one of the issues which we have taken up and tried to address. We have been able to do it to a certain degree within these results. It is hidden. But overall most of the literature from Australia and overseas does not actually indicate that the stage of the cancer is a major reason why we are getting this difference in cancer care. We are not particularly finding that people who are in lower socioeconomic groups or in rural areas are diagnosed with cancers that are at too late a stage for surgery. We think there are other issues going on here. A good example of that is the breast reconstructive surgery line. Breast reconstructive surgery is not stage related. It is normally done for women who have had a breast mastectomy rather than breast-conserving surgery. Again, we can see the same pattern of decreased surgery in lower socioeconomic groups and higher levels of surgery in the private sector.

You could argue that this could be stage related, but it is probably not completely stage related. More importantly, though, if this is stage related, it indicates to me that we need to be doing something about when we are diagnosing cancers in patients in disadvantaged groups and what we can do at that point to bring them quickly through the system to get their testing and diagnosis done faster, so they are actually still at the treatment stage at the end of that. I would very much argue that this indicates that, if this is stage related, we need to do something about finding what the problem is for those vulnerable groups.

Senator COOK—Does that indicate that in the private sector where doctors will be paid for their operation there is a higher incidence of operation?

Ms Hall—Absolutely.

Senator COOK—And therefore there are perhaps some unnecessary operations?

Ms Hall—That is what the results seem to be indicating.

Senator KNOWLES—Doctors get paid in the public sector, too.

Senator LEES—It is not as much.

Senator COOK—In the socioeconomic disadvantaged group there may not be much money in it. But that does raise the argument as to whether surgery or invasive surgery is the benchmark, because the survival rates seem to be better in the lower areas.

Ms Hall—I am having trouble hearing over the jackhammers.

Senator COOK—If I understand that diagram, the survival rates seem to be better in the socioeconomic disadvantaged area.

Ms Hall—No, it is reduced survival in those groups. Where there is less surgery, there is less survival.

Senator COOK—That is what I thought, first of all.

Ms Hall—As I said before, I have put the Indigenous results quite separate to the other results because I believe it is a unique case. One of the problems we have with the Indigenous results is that the data linkage systems do not pick up every Indigenous person who comes through the system. Within Perth, it is about a 75 per cent pick-up rate. When you go out into rural and remote areas, it is more like 90 or 95 per cent, which indicates that the results I am presenting here are an underestimate of what is actually happening out there in the community, so it is probably worse than this. We found that Indigenous people were less likely to have lung cancer surgery and less likely to have colorectal cancer surgery. I think this is a particularly important finding when you think about the very high smoking rates that we have in the Indigenous population—it is about 50 per cent, which is 2½ times that in the non-Indigenous population. I believe that is an issue.

For breast cancer, we did not find any real difference between the Indigenous and the non-Indigenous population on receiving mastectomy or breast-conserving surgery, but the prostate cancer results were a lot more difficult to analyse. We looked at radical prostatectomy, but we also looked at non-radical surgery, which is more the palliative procedure to try and relieve the urinary systems in men. For that, we did not find any difference between the Indigenous and the non-Indigenous population, but in the whole database, covering 20 years, we could find only one Indigenous man who had had a radical prostatectomy. We cannot do any analysis of that one person at all, but I think the fact that we found only one is an indication that something is going on there. Allowing for the fact that we know that this is an underestimate of the Indigenous people in our data linkage systems, I think these are actually quite frightening results.

Most of my work has looked at variations in cancer care. I know that the major remit of this inquiry is to look at cancer care per se, but I think the variations in treatment patterns and the subsequent effects on survival are really important issues as well as the overall issue. We do not know the reasons for these variations. It could be the stage, but, as Senator Cook has already pointed out, it could be supply factors. People may be more likely to receive surgery if the surgeons are easily accessible; it could be that certain hospitals are supplying surgery more readily than other hospitals; or it could be patient demand characteristics, where patients could be demanding more care if they are in higher socioeconomic groups, more educated or more metropolitan. Certainly, people with private health insurance might say, 'I'm paying out all this money here. I'm going to get something for my money.' We do not know the answers to that and we do not know the barriers to access from the approach we have taken. So at the moment we are in the process of doing a small lung cancer study to look at these issues in much more detail, but the results of that study will not be ready until June, which is too late for the inquiry.

Senator MOORE—Someone this afternoon gave evidence that the way they were referred dictated their choice. They went to the GP, got diagnosed and then that person referred them to someone. Is the referral process the kind of thing you can pick up in your study?

Ms Hall—No, we do not look at referral patterns. It will be possible, when we link in Medicare data in the future, to start to look at those issues, but for now, with the data that I have, no, you cannot. If you repeated the studies now, you certainly could start to get an indication of that. With our small lung cancer study, because it looks at just 60 individuals in really close detail—which is about a four-month supply, if you like, of lung cancer patients—we will be able to pick up on some of those issues.

CHAIR—Can I also ask a clarification question on those figures that you had up before. I do not want to get into a debate amongst the committee about private health insurance, but there will be people in the lower socioeconomic group who actually do have private health insurance—

Ms Hall—Absolutely.

CHAIR—so have they been taken out of that group altogether?

Ms Hall—No. The way we did our analysis was that we modelled and allowed for all these other variables. What I have shown you today is the independent effect of each one, allowing for the effects of the other variables. Because I am a public health person, my primary focus is always on prevention. When we miss out on prevention, it is on the early detection of cancer. So I believe that primary care is absolutely fundamental to where we have to go with cancer care. Health promotion and health education have got to be primary. All the evidence that we have shows that they are cost effective. They are good ways of picking up early-stage cancers, where the treatment is cheaper, but, more importantly, it is not so difficult for the patients and their families and the survival rate is much better. So, for me, primary care is the most fundamental area that we need to look at.

One of the things that we have to do is to really think about our general practitioners out there in the community and how we can encourage them positively, particularly with the vulnerable groups, to look at ways in which they can identify patients earlier, encourage screening, encourage early diagnostic testing and—coming back to Senator Moore’s comment about referral patterns—refer on quicker through simpler referral pathways. I think these issues are absolutely fundamental. Even if we put in these ideas—and the whole underlying factor of my studies was that stage was the issue—doing these things is only going to help the whole population. They are cheap, quick, easy things to put into place; whereas, when we think about hospital care, we are thinking about much more difficult treatment patterns. We are thinking about a much more difficult area of care.

I really believe that the cancer care philosophy we have in this state at the moment—and I can only speak for this state—is fundamentally flawed. We have a large number of good programs, but they are ad hoc, they seem not to be networked, and I strongly believe that we need to have a coherent approach to cancer care that patients and their families can access easily. So I am really forwarding the idea that we have cancer centres of excellence. I know it is something that was brought up once before in the Bishop report a couple of years ago, but we do not have any economic analyses of whether this is a cost-effective thing to do. Internationally, there is very little done on the cost effectiveness of providing cancer care and the different ways of providing it. However, if we start to look at patients’ utility or quality of life, I believe that managing them in a cohesive environment with access to multidisciplinary teams, where they have psychosocial care as well as physical care, is a fundamentally good way of going.

Cancer care is also getting increasingly costly as time goes by. One of my concerns is that, at the moment, we are spreading our services too widely. We are missing out on capturing good, high-quality cancer care—particularly when that uses a lot of high technology and resources—for people in the outer metropolitan areas and the rural areas. In fact, the remote areas are not such a problem, because those people tend to come to the teaching hospitals in Perth. It is those outer area people who are, I think, the most vulnerable groups, particularly when you look at the lower socioeconomic areas within that category.

I personally think the centres were a good idea, partly because of the provision of the multidisciplinary team but partly because I think they serve as something that the public can be proud of. They can identify with them. Within this type of environment you get highly specialised surgeons, clinicians and a care environment with ease of patients within that rather than this ad hoc approach where patients may or may not hear about the Browne centre, the Cancer Council or Crawford Lodge et cetera. I think we need to bring some coherency to this whole debate.

I also think that the establishment of these sorts of centres will help to reduce the variability in cancer care for vulnerable groups at the moment by making easy pathways of referral from GPs through to these centres in whatever format it takes—whether it is IT, paper or telephone format—and where GPs can get quick and easy access for their patients, whatever their socioeconomic status and wherever they are, to these sorts of centres. I believe that will offer a really good way of ensuring that we do not get the variability in care that we are seeing at the moment.

More importantly, I think there is a lot of evidence out there that centres that see large numbers of cancer patients have better outcomes for their patients. If you are only seeing one breast cancer case a fortnight or one a month, it is not a major skill area and your knowledge may not be as good in that particular area. We know that clinicians who treat, sadly, 10 or 20 breast cancer patients a week get the best outcomes. They have the best networks with the oncologists and psychosocial support et cetera. I think this is a really important facet.

I almost see these as one-stop shops, if you like, where patients can go for all areas of their care from diagnosis through. That would include palliative care. That care would be managed by a case manager so that the patient could have a continuity and contact point. They could be made aware of all of the different facilities that are available that at the moment they just do not get to see. I think that bringing in these centres will be very difficult, although we already do it for a number of different diseases. We do it for cardiovascular surgery and some of the rarer cancers like leukaemia and lymphoma. I would argue strongly that, if we can do it for those sorts of more rare cancers, we should be doing it for the cancers that are the biggest burden in our communities.

I can really understand that patients would not want to necessarily come up to the city for care, but that is the optimum care. They can then go back closer to their home areas and pick up on chemotherapy or any other type of cancer care they need locally. With outreach services from the centres to the rural and outer metropolitan areas, I think we can really improve our care and follow-up care with patients.

Again, I have put Indigenous care separately. I very much took what I call a top-down approach to looking at the Indigenous population, which is just literally looking at the figures. I do not believe that is the best way of identifying what the needs are within the Indigenous population. I think we need a bottom-up, community approach where we go out into the communities, find out what is really happening and together work out strategies. There has been some really good work done in the Northern Territory and Queensland by people like John Condon et cetera. I would very much hope that they have given evidence to this committee.

Senator KNOWLES—Can I ask whether or not you have taken into account the attitude in many Aboriginal communities that that treatment is white man’s medicine and unacceptable to their culture?

Ms Hall—I strongly agree with what you have just said. As I said, I have used a top-down approach. I number-crunched and that is all I have done. I do not have the skills to go in and work with them. That is why I think we need people to go into their communities, work with them and identify ways of getting through those sorts of barriers if that is what they want. It might be an Indigenous choice that that is what they do not want. But I do not think it is for me or anybody else to make those decisions without going in and talking to them.

Senator KNOWLES—But without taking that into consideration, that can skew the results that you got on Indigenous health generally.

Ms Hall—It can—which is why I think it is interesting that, for breast cancer, there was the same breakdown percentage wise of women having both types of surgery and yet for the other cancers there was not that same pattern. When you consider cancers like colorectal cancer, where people will often present as emergency admissions which require surgery because they have an acute obstruction to their bowel and they are in a great deal of pain and at death's door without surgery, the fact that even in that situation we see reduced surgery rates is probably an indication of what you are saying. I think we really need to address those issues quite independently of the non-Indigenous issues. I would see that we should have separate strategic plans for the Indigenous community in this area. They could be held in the same document, but I think the Indigenous area should be separately identified. I know from some of the Indigenous co-workers I had on my work that one of the things they said quite strongly was that previous cancer plans have not been implemented well in the Indigenous communities; they have been on paper but they have not actually been implemented.

Senator MOORE—Do you make a distinction between Indigenous people within the urban environment and those within the remote and rural environment?

Ms Hall—I have not. It is one of the things I did not look at with my data because the numbers are just too small.

Senator MOORE—It is just that I think there is a difference in terms of people's understanding and access. I know the numbers that you used in the paper were quite small, but it is just one more thing to look at in the next round.

Ms Hall—I think one of the misnomers we have is that Indigenous people in rural areas have the worse health when in actual fact it is often those in the outer metropolitan areas.

Senator MOORE—There are so many variables.

Ms Hall—Absolutely—and certainly beyond what I can talk about today. To conclude, I really cannot emphasise enough that we must monitor any policies that we put into place here. I believe that one of the best ways of doing that is to use these data linkage systems which we have available here and which are becoming more available in the other states. But those systems—and I know Dr Tim Threlfall spoke about this this morning—must have cancer staging data on them; they must be resourced for that.

Dr Rosenwax—Thank you very much for inviting me to speak to you today. I had not intended to speak. Sonja told me about this inquiry, so I sent along a copy of a technical report and that was my effort. Then I received an invitation to speak. What that did was to ruin the last week of my life because I have had to go back and crunch numbers for cancer specifically. So you owe me an Easter break!

The reason I got interested in specialist palliative care services was because a very close friend of mine died of cancer. On reflecting on her death, I believe that she had a very good death. She had access to specialist palliative care services; she was able to die where she wanted to die, which was at home; her family had come to grips with what was happening; and it was a good death. That made me think that there are probably lots of people in Western Australia who actually do not have such a good death and who are they. I am quite a social animal, and I was at a cocktail party where I came across a medical anthropologist who had just done her PhD in palliative care. I thought: ‘I know how to crunch numbers, you know about palliative care. Let’s get together, get an NHMRC grant’—which we did—‘and let’s find out who is missing out on palliative care services in Western Australia.’ That medical anthropologist is Bev McNamara and I am Lorna. We also have Professor D’Arcy Holman, an epidemiologist who is very well known in Australia, and we involved Ellen Nightingale, who was president of the Cancer Foundation of Western Australia at the time.

As co-investigators we had a representative from the Silver Chain Nursing Association. Silver Chain, in Western Australia, provides the majority of home based nursing—about 90 per cent of all nursing care—to Western Australians. Jill was involved, Dimitris was involved, and he is an expert in aged care. Janine Culver did the initial crunching of numbers. She was our project officer and research fellow. I will provide a much simpler view of the WA record-linked database. It is the most amazing system, and this is a number-crunching piece of research that I am about to talk about. Our next research—which is going on at the moment—is where we actually get our hands dirty and we talk to people who are dying. But you will have to hang out for two years for that bit of research.

For this research, looking at palliative care services, we had the system link-up for a 2½-year period. We linked up everyone who had died within that 2½-year period in Western Australia, with the times they had been in hospital and their use of Silver Chain facilities. Then we had it all de-identified because we did not need their names. We had a database of some 27,000 people over the 2½ years, which is a good number to work with. I like numbers. Then we had to make some decisions about how we were going to use the Western Australia linked database in order to conduct our study.

We had to decide how we were going to look at the delivery of palliative care. Palliative care seems to be delivered in two ways in Western Australia. There is a generalist approach where it might be delivered by a GP in isolation, and there is also a specialist approach where there is a specialised team of people looking after the person and their family. They might have someone who is specialised in pain management, they might have a psychologist, a nursing team, an occupational therapist—whoever—within that specialist palliative team. We decided that, until we link up into that record-linked system of Medicare information, we cannot look at a generalist approach towards the delivery of palliative care services because we do not know what the situation is. There is a coding for whether a person receives specialist palliative care services within the record-linked database, so we could track who receives specialist palliative care services. By looking at specialist palliative care services we were able to see whether they received specialised palliative care at home, within a hospital, a hospice or as an inpatient.

We had to decide what constitutes the end stage. Is the end stage the last day of a person’s life, six weeks, three months or whatever? We arbitrarily chose to look at the last 12 months of a person’s life. We were looking at the services they used in hospital or the specialist palliative care services they received in the last 12 months of their life. Then we had to decide who should be eligible to receive specialist palliative care services. Ideally, it would be based on who actually needs the service. But the ideal world does not exist. So the only way we could use the record linkage database was to have it based on conditions: what diagnosis does a person have?

When we did our initial analysis, we looked at everybody who died within a 2½-year period. We looked at the last 12 months of their life, and we looked at certain conditions that they had. We looked at cancers—which is what interests you—but we also looked at a whole lot of non-cancers. We ran a series of focus groups and we read the literature. We were told that these people who are dying of these conditions should also be eligible for and be getting specialist palliative care services. So over the last week I had to separate information about neoplasms from the rest so that I could present you with some information. The nine conditions that we felt should also be eligible for specialised palliative care services are heart failure, renal failure, liver failure, COPD, Alzheimer's, Parkinson's, motor neurone disease, Huntington's disease and HIV-AIDS.

What did we find? We found that over the 2½ year period about 30 per cent of the deaths were from cancer, about 10 per cent from heart failure, five per cent from renal failure, about five per cent from chronic obstructive pulmonary disease, two per cent from Alzheimer's, liver failure, all the way down to less than 0.1 per cent for Huntington's disease. Nine per cent of people who had died in that 2½ year period had died of more than one condition—not only did they have cancer but they may have also had renal failure, or not only did they have Alzheimer's but they might also have had liver failure. Nine per cent had more than one condition.

We then looked at their use of specialist palliative care services. Were these services provided to these people just at home—the Silver Chain Nursing Association is just for people at home—or just in hospital or in a combination of home and hospital, or did they not receive any palliative care services? First of all, I separated out the neoplasms—those with cancer—and we found that, of those people with cancer, about 24 per cent received specialist palliative care services only at home, about another 19 per cent just in hospital in specialised units and a quarter of the people received specialist palliative care services both at home and in hospital. But about a third of those people who died of a cancer related illness did not receive any specialist palliative care services in Western Australia.

Those people who were unlucky enough to have a neoplasm and a non-neoplasm—that is, cancer with something else—did not fare as well. We found that they were still receiving both home based and hospital based services or both, but in fact only half of those people received specialist palliative care services.

Senator KNOWLES—How do you know whether those people receiving no services were doing so voluntarily?

Dr Rosenwax—We do not know, and that is why we are getting our hands dirty at the moment. We are following up with the carers of every person who died within a year's period to find out if they knew specialist palliative care services existed. It could be that they are not accessing those services because they do not know that they exist.

Senator KNOWLES—Or they are not accessing them because they do not want to.

Dr Rosenwax—They do not want to, they do not read the literature, which is in English, or they live so far away that they cannot get access to it and they choose to die up in wherever. So that is why we need to do the next part, which we are doing at the moment, to find out. It is a good question.

Senator MOORE—The category of both home and hospital—that is, when you definitely go into hospital for some palliative care as opposed to for acute moments.

Dr Rosenwax—Yes, it is a specialist unit within the hospital.

Senator MOORE—People go in and out.

Dr Rosenwax—Yes, in and out, in and out. That is exactly right. For those people who died of a non-neoplasm—one of those nine conditions that I just talked to you about—there were awful results. Only three per cent of those people got home based palliative care services, four per cent got hospital based specialist palliative care services and one per cent got the ‘in and out’ home and hospital care, and about 92 per cent did not get any specialised palliative care services in Western Australia.

I then drilled down to look at those people who died of non-neoplasms. Was it equally distributed across all those nine conditions? Did they all fare as badly as each other? In fact, no they did not. The proportion who did not receive specialist palliative care services varied. Of the people who had Alzheimer’s, 96.6 per cent did not receive those services. You can see all the way down the page to those people with HIV-AIDS. Half of those people received specialist palliative care services and the other half did not, but the numbers for some of those conditions are very, very low. Between those nine conditions there were differences in what proportion of people received specialist palliative care services.

I can say so far that a significant proportion of West Australians did not receive specialist palliative care services. The people with cancer were the most well serviced. However, one-third did not receive specialist palliative care services, and those people exclusively with non-neoplasms were the least well serviced in that less than one in 10 actually received specialist palliative care services.

What I did then was look just at the people who died of cancer—you will probably like this bit. I wanted to find out the likelihood of them receiving specialist palliative care services in the year before they died and whether being richer or poorer or older or younger made a difference I looked at how many people died of cancer in that 2½ year period and what proportion received specialist palliative care services. I looked at whether males or females fared better, and I adjusted for that. I fed into the system all the variables: whether you are male or female, whether you are socioeconomically advantaged or disadvantaged, and whether you come from a rural area or the city. The variables adjust for each other. The system negates everything and comes up with the true likelihood of receiving specialist palliative care services. I hope that makes sense.

Senator MOORE—What is ‘OR’?

Dr Rosenwax—Odds ratios—the likelihood. I will run through that. In Western Australia, more males than females died of cancer in that 2½ year period. Sixty-eight per cent of males and 67 per cent of females received specialist palliative care services. The figure 0.98 tells us that females were two per cent less likely to receive specialist palliative care services. But when we adjusted for how old the females were, whether they lived in the country or city, or whether or not they were Aboriginal, they were seven per cent more likely to have access to specialist palliative care services. If we look at marital status, unless they were widowed, there was not a great variation in the proportion who received specialist palliative care services—fewer widowed people received access to specialist palliative care services. This data indicates that if you are single or widowed—or if we are not sure of your marital status—you are less likely to have access to specialist palliative care services. If you are single you are 32 per cent less likely to have access to specialist palliative care services.

Senator LEES—And now you are in the process of finding out why?

Dr Rosenwax—Yes, that is right.

Senator LEES—So you probably have no-one there, at that critical time, to support you or help you into specialist palliative care services.

Dr Rosenwax—That is exactly right—and that is the stuff we need to find out.

Senator KNOWLES—Or to be the driver.

Dr Rosenwax—Yes.

Senator MOORE—If they were married, you would ask their families. How are you going to find that out for people who are single or widowed?

Dr Rosenwax—In the next study?

Senator MOORE—Yes.

Dr Rosenwax—We have access to all of their records, but we will ask the carer.

Senator MOORE—So there would be a carer for those people?

Dr Rosenwax—Yes. It might be their spouse, it might be a child, it might be a friend or it might be a nursing home. In that 2½ year period, 30 children died of cancer in Western Australia, 63 per cent of them received specialist palliative care services and they were twice as likely to get access to specialist palliative care services as those aged 85 and over. We are now comparing it to those aged 85 and over. Everyone gets better access to specialist palliative care services than the aged do. The most well serviced are those aged 25 to 34.

Senator LEES—Do you mean by ‘the aged’ people specifically getting the care, or do you include nursing home care generally? You do not include general nursing home care as ‘palliative’?

Dr Rosenwax—No.

Senator LEES—It has to be specifically palliative within the nursing home?

Dr Rosenwax—Yes, that is exactly right. Aboriginal and Torres Strait Islanders who die of cancer are 50 per cent more likely to have access to specialist palliative care services. There is very little difference for socioeconomic advantage or disadvantage. Those who live in rural areas are less likely to have access to specialist palliative care services. The least likely to have access to specialist palliative care services are those who live in remote areas. What we can say so far is that those people who are dying of cancer are significantly less likely to receive specialist palliative care services if they are single or widowed, aged over 85 years and live in a region other than a major city.

I compared the services received by someone dying of cancer to the specialist palliative care services received by someone who dies of a non-neoplasm—one of the other nine conditions that I spoke about before. The neoplasms are shown on the slide in white, and that is the information I have just presented to you. The people dying of non-neoplasms, those other nine conditions, are presented in green. You can see that only nine per cent of males and eight per cent of females who die of one of those nine conditions receive specialist palliative care services. Once again, when we do all the adjustments we see that a greater proportion of married people receive specialist palliative care services, compared to anyone who is divorced, single or widowed. You are more likely to get care if you are married than if you are single.

With age, once again the proportions are much lower. Let us look at the odds ratios. None of the odds ratios for non-neoplasms is significant, but you can see that if you are aged 15 to 24 you are ten times more likely to have access. If you are lucky enough to get specialist palliative care, you are ten times more likely to get it than someone who is aged 85 or more. Indigenous people with non-neoplasms are 30 per cent less likely to receive specialist palliative care services. So in fact there is a big difference in access to specialist palliative care services, depending on what your condition is, if you are Aboriginal. If you are dying of cancer you are more likely to get care. If you do not have cancer you are 30 per cent less likely to get care. There is very little difference in socioeconomic disadvantage and where you live. Once again, being in a remote area you are less likely to receive specialist palliative care services. However, if you are in an inner regional area and dying of a non-neoplasm you are more likely to get them.

In summary, the rate of use of specialist palliative care services by people dying of cancer is much higher than the rate for people dying of non-neoplasms. Yet one-third of people dying of cancers do not access specialist palliative care services. Once people are in the system, they are well serviced by specialist palliative care services, both at home and in the hospital system. They are also more likely to die at home. There is heaps more information on that in the report. But once you are in the system you tend to stay in the system. The likelihood of receiving specialist palliative care services is not equally distributed across conditions or across a number of demographic factors like being old or all the other factors I have talked about—in particular, age, Aboriginality and geographic remoteness.

Senator COOK—Ms Hall, your work is for the National Health and Medical Research Council. Have you in any way fed into the state government’s preparation for a plan on cancer in this state?

Ms Hall—Yes, I have. One of the authors of most of my papers, you might have noticed, was Dr Harry Sheiner, who used to head up the WA Clinical Oncology Group at the Cancer Foundation. Through that conduit we put our work forward and it was used by the Cancer Council in arguing for certain strategies to be put forward into the state plan, particularly for rural areas.

Senator COOK—So your information is available to the state plan, and one expects it to have been taken on board in that context.

Ms Hall—If the Cancer Council has been successful in its endeavours, yes; one would hope.

Senator COOK—At least we have heard you. That is the point.

Ms Hall—I think so.

Senator COOK—In the work that you did, did you just consider what we would call conventional treatments? Did you look at integrated or holistic treatments?

Ms Hall—No, we did not. At the moment our WA data linkage system is not able to pick up on that and I am not sure how in the future it could, because it would be given through such a diversity of organisations and professional bodies. I am not convinced. I would also be very reticent, without having any knowledge of the cost effectiveness of non-traditional ways of treating cancer, to bring those thoughts into the system, where I am very conscious that our resources are very limited. I think we need to make sure that we have good, effective care available to all. For me, that variability in care is one of the major issues. We do know that it is the higher socioeconomic groups who tend to want the less traditional type of cancer care. That is not to null and void it. For me, it is not the foremost issue that we face at the moment with cancer care.

Senator COOK—Did I hear you correctly—or was it someone else who said it—indicate that if we got more coherence in this field there would be cost savings to the health bill?

Ms Hall—I believe so.

Senator COOK—Are you in any position at all to give us an idea of the dimensions of what those savings might be?

Ms Hall—As I say, my other hat is that of a health economist. We really have not done any major works that I am aware of in that area. One of the important points I made was the fact that, if we can catch cancers early, treatment is cheaper—we know that—and the outcomes are much better and survival is better. That indicates that we will have a higher prevalence of people who have or have had cancer walking around in our communities, and there will be ongoing costs associated with them and with their follow-up. Fundamentally, at the moment, the problem we have is that cancer care is so expensive, and the more aggressive it is the more expensive it is to treat and that is exponential. I do not have the figures available to answer that question, but my gut feeling, from the data I have seen, is that having non-coherent care is very expensive. We push some of the costs back onto the patients who can afford it, and the others go without.

Senator COOK—Can I just ask you this question, which may be taking it too far but you will tell me if I am: is there any sort of rough order—a wet finger held to the wind—estimate you could give us?

Ms Hall—No.

Senator COOK—In your submission you mentioned that rural and non-specialist centre surgeons will not approve the notion of case managers to facilitate treatment. What is the reason for that?

Ms Hall—The underlying premise of what I am saying is that I do not believe that surgeons who have small caseloads should be operating on cancer patients. They should be operated on in major facilities by specialist surgeons who see a large number of people, have the best networks of patient care and have the best outcomes. When we looked at people with prostate cancer—and I did not give you this information, so I will give it verbally—who were treated in metro and rural teaching and non-teaching hospitals, we found that non-teaching hospitals and rural hospitals have much worse rates of surgery and much worse survival rates than teaching hospitals. For me, that is a prime indictment and it is why we need major specialist centres.

Senator KNOWLES—Your Easter was well spent. It was a very good, comprehensive presentation; thank you. Ms Hall, could I ask you about your main recommendation of primary care, health promotion, education and screening and how that links with the lower socioeconomic output, because the thing that worries me is that you say we should get more education and promotion but, invariably, it is the lower socioeconomic group that is less aware of that.

Ms Hall—I am glad you picked up on that. Getting to those hard-to-reach groups has been incredibly difficult from a health promotion and education point of view. However, we do have good examples around the state of where we have managed to get to those groups reasonably successfully. For example, BreastScreen WA has managed to get higher screening rates among rural women than it has among metropolitan women. If you look at Quit, the smoking campaign in WA, by going into areas like the trotting races, the greyhounds and the footy, they have been able to make quite good inroads with the Quit campaigns for the groups of people that attend those events. It is possible to get to those groups, but we need to approach them in a different way.

There is also some work that has been done using things like RSL clubs and using very widely read women’s literature—like *Woman’s Day* and *Woman’s Own*, just to name a couple—which has been really good at getting health messages out there to some of the lower socioeconomic groups. I think that is one way of going. That is why I also premised that with the fact that I think we should be doing something with GPs, because those groups of people are really tough. Maybe it could be a financial incentive. That has a cost attached to it, but I think that getting GPs to home in on those vulnerable groups and talk to them on an individual level—which we know works with smoking—about cancer care and cancer prevention and identifying people at risk and testing those people earlier would be invaluable.

Senator KNOWLES—It is also a case of educating people to detect a problem themselves, to know that they have a problem, so that they actually present to a general practitioner earlier rather than later.

Ms Hall—That is what I am saying. I mentioned women’s magazines. There is some evidence that women tend to be better at accessing health care and making their male partners access health care. I think that going to some of these alternative ways of encouraging health education for those groups can be a really positive way to go.

Dr Rosenwax—Also, you can go through the school systems as well, starting at kindergarten level and bringing into the curriculum the health promotion message from a very young age. It is being built into the secondary school curriculum at the moment.

Ms Hall—The blue-collar work force is another way. Getting into the factories has been quite positive for a number of different areas.

Senator KNOWLES—This was put to me some time ago about the lower socioeconomic or less-educated group of society. The example used was colorectal cancer. It was the belief of the person concerned that they just had constipation, so it could go on for months and months, seemingly rectifying itself periodically. It is not an uncommon symptom. That person ends up presenting far later than they would otherwise have done. That part of education is difficult as well, because it is still an area where we say, ‘We do not talk about that!’ We have to break out of that mould and educate at the same time.

Ms Hall—For me that raises two questions. How are we are going to get to these difficult groups? We know there is more cancer in some of these lower socioeconomic groups, so we really need to use our health promotion experts—I am definitely not one—to get into these groups of people. The other issue that raises is the fact that what you are alluding to there is that these people are found at a later stage, because they have lived with it longer. In fact, the evidence does not always support that that is the case. I think we are also at risk of taking the victim-blaming approach rather than actually trying to home in on what we can do in a more positive way.

Senator KNOWLES—That is right; that is what I am trying to do: look at the front end instead of trying to solve it at the back end and try to find how we get to those people earlier rather than later.

Senator LEES—I have one question on the issue of privacy. We heard from an earlier witness that this is an issue when it comes to trying to work out what is happening, what is working and what is not working. You both referred to the Western Australian database. Is it an issue for either of you in your research?

Dr Rosenwax—No, it is not an issue because we get de-identified data with no names.

Senator LEES—In terms of actually tracking who, for example, is using what we know as complementary as opposed to those that are just having traditional cancer treatment, are you able to get hold of those records as well?

Dr Rosenwax—No.

Senator LEES—So it is basically that records are not kept in that area—it is not a privacy issue; it is record keeping—

Dr Rosenwax—That is exactly right.

Ms Hall—I would like to add to that that a lot of patients are very reticent about telling their doctors that they are having alternative care. So even the medical records are not going to be particularly helpful in that area. That is where my small lung cancer study—and, I am assuming, maybe your study, Dr Rosenwax—may be able to offer some answers.

Senator LEES—So is that one of the questions you are asking the carers and the families—whether or not the person who had cancer or whatever was accessing other treatments?

Dr Rosenwax—Exactly: what services they used in their last year of life.

Senator LEES—So you would pick up acupuncture, aromatherapy or all of that.

Ms Hall—Yes, all of those services.

Senator LEES—Thank you.

Dr Rosenwax—Assuming that the carer is a good surrogate for the person who died, and that is where we are at at the moment: we are testing that out.

CHAIR—We were just having a bit of discussion about this de-identifiable data that you have got. How do you do the next part of your study if you cannot identify these people?

Dr Rosenwax—The next part of the study is not de-identified. We have ethics permission from the university, from the health department and from all the relevant bodies. It is identified.

Senator MOORE—And the same with your small lung cancer study?

Ms Hall—Yes. We are using identified data and we are looking at permeation issues, holistic issues—every issue we can think of—referral patterns, diagnostic testing patterns, the works.

Dr Rosenwax—One of our plans once the Medicare data is linked to the record linkage system is to reanalyse that data set that I just talked about. Our team can then talk about generalist palliative care services, not just specialist palliative care services.

Senator MOORE—In Brisbane we have a hospital that specialises in palliative care. It is widely known that that is a palliative care centre. Is there a similar place in Perth where the major focus of one hospital is that service?

Dr Rosenwax—No. There are units within private and government tertiary hospitals and there are some cottage hospices, but there is not one hospital—

Senator MOORE—We have those as well, but there is just this one centre that has been there for ever.

Dr Rosenwax—There is work being done by Kathy Eagar, who is from the University of Wollongong. She has done an excellent report recently on palliative care services in Tasmania. She and a group of people are setting up a database Australia wide that will link into morbidity data across the states and will build in this palliation aspect of it as well so that we can have a bit more of an Australia-wide view of things. One of the questions you may have wanted to ask us is: is Western Australia representative of the rest of Australia?

Senator MOORE—We would never be game to ask that question.

Senator KNOWLES—Is Australia representative of the world?

Dr Rosenwax—We cannot answer that. We are one of the very few places in the world that has all these records linked together. It is an extremely powerful tool. We are the envy of the rest of Australia, if not the rest of the world, because we have so many systems linked together and we can track people for 20 years—every hospital service they have used across whatever hospital they went to and whether they are on all sorts of different registries. So it is an amazing tool.

Senator MOORE—And that is a creature of history, the system; it has just happened?

Dr Rosenwax—No. It was linked about six years ago. It has been talked about for many, many years. Other states are trying to do it, but they just cannot. It really is quite amazing.

CHAIR—Thank you both very much for your work, your submissions and your presentations today.

Dr Rosenwax—Our pleasure; thank you.

[4.41 p.m.]

BARNES, Dr William Henry, Private capacity

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

Dr Barnes—I am here as an individual nutritional physician. I will make mention of ACNEM and my role in that, but I am not representing it at this hearing.

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. I now invite you to make an opening presentation to be followed by questions from the committee.

Dr Barnes—My role here is as an individual who probably stumbled into the area of nutritional medicine some 15 to 20 years ago. I worked in psychiatry before I became interested in nutritional medicine. I was prompted by a lot of my patients and people who came to me—books were thrust in my face to be read and information was put to me to find out my view on this. Because of my counselling background and because of my interest in people’s attempts at self-healing and promotion of their own healing, I saw that nutritional medicine fulfilled a good role for me within medicine. I am generally classified as a general practitioner, although probably about 60 to 70 per cent of my work now is in the area of what I call nutritional oncology. I am now a fellow of the Australasian College of Nutritional and Environmental Medicine. I am on the faculty board of that college and I lecture and train GPs and other doctors in the area of nutritional medicine.

I am here principally today, as a working nutritional doctor in the area of oncology, principally, to discuss the issues and to discuss some of the relevance of my particular skills and what I bring to the area of oncology and general cancer management. I also want to open up this concept of a team that I have heard discussed in the previous presentations. Doctors trained in the area of nutritional and environmental medicine have a great role within this whole team approach, not only as general practitioners—and there are many general practitioners who have training in nutritional medicine—but also as people who may well specialise more in nutritional treatments and nutritional approaches to oncological practice. As we heard in the previous presentation, the people who do the most do the best, in the sense that, the more you do and the more you are involved in that area and the more you are actually working within that area, the greater knowledge base you have and the greater referral system you can offer.

In the area of nutritional medicine, we have a role in prevention by correcting underlying nutritional biochemical problems. I want to quote from an article, which is in the information I have given the committee. It is an old article but it is from what I consider to be a very thorough review published in 1996 in *Scientific American.* When I was reading the article through, I was thinking: things have changed in the last 10 years, but in other ways things have not changed in the last 10 years. I have given you a couple of articles, but I would just like to read a small section from this one, ‘A plea for prevention’:

> Michael B. Sporn, professor of pharmacology and medicine at Dartmouth Medical School, has argued repeatedly, in print and at the podium, that an “obsession” with curing advanced disease has blinded cancer researchers to the promise of prevention.
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> … … …
>
> “The concept that people with cancer were healthy until a doctor told them that they’ve got an invasive lesion makes no sense at all,” Sporn says. “And nobody in the oncology community is doing anything to change that viewpoint—except for a few believers in chemoprevention.”

I guess that brings us back to the issue of probably 50 to 60 per cent of cancers being related to diet and to dietary factors, yet very little is being done there. There may well be small amounts being done with dieticians, but there is certainly a very small amount of credibility and credit being given to the doctors who have training in nutritional medicine in terms of both prevention and possible management of oncological conditions.

The second issue is the area of treatment. As we move into this century, more and more people are wanting to be a do-it-yourself, or DIY, patient. Unfortunately, in many medical practices the DIY patient is to a large degree a nuisance because they ask difficult questions. They are often researching their own information. They may well have the wrong end of the stick in terms of their information. But, from my point of view, these are the people who potentially could have the best outcomes in anything that they do.

The availability of the skill, the time and the inclination to deal with these patients is often outside the standard oncological practice. Within the area of nutritional medicine, we often provide a framework and an opportunity to spend time in considering people’s particular viewpoints. My view is that, if you treat somebody with a treatment that they actually believe in, you have already won half the battle. I believe if you provide a treatment that people are not informed about, that they have poor information about or that for various reasons they have adverse feelings about then the treatment will not be nearly as successful as it could be.

The concept in general oncological practice that the stand-alone chemotherapy, radiotherapy and surgery are all that is needed within the framework is not correct from the viewpoint of most patients. They actually want to do things for themselves, they want to seek out information and they want to know what they can combine. From my perspective, it is very difficult to discuss my particular interventions and ideas with my oncological colleagues, because to some degree they do not recognise the role that I may well fulfil with their patient or they may see my role as an interference within that process. I would like to see patients given the opportunity to have more access to, and be encouraged to see, people such as me to discuss these issues.

Another issue that I can see is that a lot of people are accessing the alternative health community. I think we had statistics recently that over 50 per cent of patient care was being done by non-medical practitioners. One of the roles that I fulfil within that community is that I am able to—and I will often go to—their training seminars. I know what they are taught. I know what the information is. Often I am the port of call for these natural practitioners to refer back to within the medical system.

Often the practitioners do not feel that they have any access to the medical system, unless they can talk to somebody who may be sympathetic to their particular case. In a situation where they believe a patient is at risk, they do not feel that they can refer that patient back into a system to somebody who has the expertise and also the facilities to deal with that patient and who can get them back within the general hospital or the general medical community environment. I am often used in that capacity, to bring patients back within the general medical world. I act as a liaison between those two worlds.

I also provide nutritional approaches and support to patients who are going through conventional therapy. Again, this is an area which raises a lot of conjecture as to how it should be used, whether it interferes with the oncological practice that has been prescribed and whether it is of advantage to the patient to do this. However, patients are voting with their feet and are requiring and requesting these kinds of approaches. My viewpoint has been to offer it and make it available. Often, patients in that situation say to me that they do not want to discuss this with their oncologist because of the negative attitude that the oncologist will have to the fact that they are seeing me and working with me. Often, what I say in that situation is that it is their choice, that they have the opportunity to declare it and discuss it with their oncologist or not, and that it is their prerogative in that matter.

With regard to the area of palliation, which is the third area that I have become involved in, often the things that we do, even with active treatment, can also be used as palliative therapy. As I say, there are three things that can happen to you when you get cancer: you can get better, stay the same or get worse. The rate at which a person deteriorates may well be dictated in terms of the options and treatments that they have. People say, ‘Natural therapy did not work,’ but what was the basis of that discovery? Did it help them? Did it alleviate some of their stress? Did it relieve some of their symptoms? Did it slow the progress of the disease? Did it improve their wellbeing whilst they were dying? These factors have not been looked at with regard to that. I always go back to the issue of: above all, do no harm. If you can provide a treatment which is relatively safe, has few side effects and may well have some impact—not the greatest impact but some impact—on the demise of the patient and the progress of their disease, then at that level you are providing a palliative service, which I think is extremely valuable.

The questions that come up include: does nutritional medicine work; is it of value; how do we know; and is there research that is actually validating what we are doing? These are the thorny issues that always get thrown at us with regard to our role as nutritional physicians. A lot of primary research is being done within university environments, and a lot of research is going into nutrition and its effect on cancer. However, to translate that into large trials that can then be quoted and used within the medical community to prove that it does or does not work involves a lot of money. Patent law, patent medicine and the whole area of protection of medicines by the concept of patency are issues that we always see in nutritional medicine because we are not using patented products. We are using foods, food related products and products that have been made from foods, herbs and what have you that do not attract the kind of patent law that would then attract the money and finance to research them. Does that invalidate them? I would say no. At some level people want that, and as a society we may not necessarily have to use just the patentability of a product to look at its efficacy and usefulness within a patient’s condition.

The second issue is the patient’s right to choose. People have a right to choose. More and more people are looking on the internet and looking at all the options that are available, and they find it difficult to go and discuss these things because, as you are probably aware, when you start looking at the internet how do you sort out the wheat from the chaff? Who do you go to? Who do you talk to? Who has done that sort of research—not so much in the mainstream area but in the lateral areas—and can advise you on whether you should be taking soya genistein because you have an oestrogen positive tumour? That is an issue that I, as a physician who has actually examined that, can start to explain—who could and could not use soya in their diet. These are the kinds of issues that we would be dealing with. Then of course you have the concept of people feeling much more comfortable when they have a sense that they are using both natural and conventional therapies. Often people will do a conventional therapy if they know they can run a natural therapy in parallel to that, and they feel more comfortable with that approach.

In the area that I work with, if I were going to start to work with nutritional medicines, I would look at both social factors for people and their nutrition—their dietary sources and things like the potential for heavy-metal poisoning and other deficiencies of minerals. I would look at diet and I would counsel around that. When I am working with nutritional supplements, I can use them as just replacement supplementation or I can work with supplements at what I would call physiological or pharmacological doses. This is often where we get into the situation—and I know that this is an issue that is coming up with Codex and other things that are coming—where we can use some nutritional supplements, such as vitamin C, for instance, at extremely high doses. The evidence is coming out now that, if you do use it in extremely high doses with certain other supplements, this is not just wasteful pee but in fact it has a direct oncological effect against cancer cells. So here we are not just replacing something that might be deficient; we are also using something that is considered a natural substance in small amounts, but we are using very large pharmacological amounts to achieve a certain outcome associated with a certain effect on the body. We would find the same with certain mushrooms. We would find that with soya. We would find it with a number of different things. We can use substances pharmacologically or just as replacement supplements.

What are the problems that occur? One of the problems I see is that there are too many laypeople in the cancer business without any proper training or any guidelines about how they can practise or any regulation about the level of service that they can provide. Again, I think this is where nutritional medicine comes in. Because we are often seen as being more on the fringe and we will often be listening and working within the naturopathic world as much as within the medical world, we can often provide that level of support to those people, and we provide an alternative to some of these laypeople who may well be in the business of cancer treatment where they should not be.

I personally think that there needs to be more regulation in regard to this. I think that any doctors who get involved in this should be proficient—and I know that these things are happening at a government level and that doctors who are moving into the areas of nutritional and environmental medicine are being required to do courses in these areas so they have proficiency in them. For that, I am promoting ACNEM—which is a college—and its affiliations in the area of herbal medicine and what have you, because this college has provided training for doctors for over 20 years. It has the track record. It is becoming more credible. It is providing a level of training which starts at the beginning and takes GPs into first, second and tertiary levels of training—such as the level I have got to myself, where I am now a fellow of the college and I can actually feel proficient at dealing with some of the more difficult medical problems that people approach me with. That is really all I have to say, and I would really like to answer any questions in regard to this.

I have given you some articles out of *Scientific American*, because they do start to talk a little bit about the concept of chemoprevention and some of the other areas that I am working with, such as the blocking of blood vessels by lowering copper, which is called antiangiogenesis. So, in nutritional medicine we have ideas and areas where we are working, and also the concept of working in a number of different ways—not just working to kill cancer but also supporting the immune system, providing the nutritional support that may well be required and using parallel treatments associated with oncological treatments at the same time.

Senator COOK—I have to declare an interest. Dr Barnes is my doctor as far as nutritional health is concerned. It sounds like a bit of a parade today, but I might say that I am very pleased to have him. I am not quite sure where to start asking you questions, Dr Barnes, but perhaps this would be the best place: when you receive a new patient, my understanding is that you ask them to go and have a blood test, take a hair sample and get that analysed. Can you just tell me what is the purpose of all of that, and how does it set up your treatment approach?

Dr Barnes—The first thing I would do is take a history. The second thing I would do is examine all the information and discuss with the patient the information they have brought so I can be sure that what they are presenting with is actually the condition that they actually have. If I am not satisfied that there has been sufficient medical work on a patient of a conventional type then I will undertake to do that in the first instance.

The second aspect is that I will start to look at them. I guess I wear a conventional hat in the first instance, and the second hat that I put on is that of a nutritional physician. I will start to explore using other methods which may not be as well accepted or as mainstream in terms of trying to understand the nutritional basis of the patient. Part of that may well be to do specific blood tests or things like hair tissue analysis, detoxification tests on the liver, analysis of heavy metals and those kinds of things.

Senator COOK—Is there some sort of tendency among Western Australians when it comes to heavy metals to show a higher copper content?

Dr Barnes—Copper is one of the issues that I see. Copper is not a heavy metal. I am not the main protagonist in this town about copper levels in patients. What we do know is that copper is an important part of the growth of a cancer. There are a number of stages within the growth of a cancer. In the main I see patients whose cancer is accelerating—they have failed conventional therapies or what have you. In those patients you want to try to control the cancer. The first thing I want to do is get some control, because most people are in a situation where they have a cancer that is growing out of control and they are very concerned. If you create stability in a patient and they do not get any worse, you have actually done a great thing, because you then give them time and can actually develop further strategies.

We know that copper is involved in the formation of blood vessels that the cancer will attract. The cancer requires copper to attract the new blood vessel and to improve its supply of blood. Like any army on the march, it requires supply—the supply of nutrients and what have you. By limiting the copper in the patient, without causing a frank deficiency, we can limit the ability of the cancer to gain new blood supply and in the process slow the growth in that cancer and possibly mediate and help that patient with other treatments. That is one of things that I have been doing and working with within my own practice.

Senator COOK—I want to very quickly explore the argument that comes up all the time about proven therapies, which, if I could put it in these terms, we hear from the conventional treatment side and the so-called unproven therapies. You have just described a process of dealing with copper in order to try to limit the growth of cancer cells. Can you tell us what scholarly backing there might be for that point of view?

Dr Barnes—I do not have the paper in front of me. You have to look at the genesis of therapies—where they come from. This is one of the things that I alluded to with regard to the internet. I am not avoiding your question; I just want to elaborate a little bit. A lot of the information that you will get on the internet is information that will quote a piece of information that will quote a piece of information that will quote a piece of information. You will find that it will go all the way around. Often these are unreferenced, unrecorded pieces of information. You need to have scientific training to understand that we should not use that; we should be looking for the referenced information that has been developed.

The question of how far that has been researched is the issue that you are actually raising. Say, for instance, in the area of the anticopper therapy and angiogenesis, who should we be using it on and how much research has been done? The answer to that question is that the research is relatively new. You could say, ‘How come you can justify the use of that particular therapy in patients?’ You have to make a line call on that. You have to (a) inform the patient about it, (b) tell them about the potential side-effects, and (c) tell them that in fact it is not a registered therapy at this stage of development and that it is under the Special Access Scheme, which exists for category A patients. Are you familiar with the Special Access Scheme?

Senator COOK—No.

Dr Barnes—The Special Access Scheme is run through the TGA—the Therapeutic Goods Administration—and outlines that, if a patient has a terminal illness, they are considered a category A patient. On that basis they can go to a doctor and request an unregistered therapy for their condition. The conditions under which the doctor can approve that therapy are that, firstly, they fulfil the criteria, secondly, they actually request the treatment and, thirdly, they are prepared to take the consequences of a negative outcome of that treatment to the point that they will sign a disclaimer and release the doctor from medical incompetence or misadventure associated with that treatment.

Because I am often working in the area of advanced cancer patients and palliative therapy, people are desperate and are looking for some way to extend their lives, create some stability or what have you. Everybody is looking for and hoping that a treatment will come around the corner that will be able to treat them. If they can stay alive for six months or a year, then that is what they want to do. You could say, ‘These patients have no hope. This is preying on them. This is an issue that you shouldn’t even get involved in.’ But what I used to see was that people, if they could not get help here, would go overseas to access it. They would pack up their family, spend thousands of dollars and go to Mexico or somewhere else. My view is that we can provide that kind of support and expertise within the town they live in. They do not have to move out of their current environment, they can maintain their other medical practitioners and the team approach and I can provide an approach for them which may not be fully recognised but, at some level, is the beginning of some form of therapy. If I monitor them and I am appropriate in the way that I treat them, hopefully there will not be a misadventure with regard to that. Does that answer your question?

Senator COOK—It does. It goes to the question, doesn't it, that often today's non-conventional treatments are tomorrow's mainstream treatments, once there has been sufficient evidence accumulated about the efficacy of them.

Dr Barnes—Yes. In a sense it is the beginning of the research process rather than the end.

Senator COOK—One of the things we are looking at here is a multidisciplinary approach—gathering together all the disciplines for someone with cancer to have all the options presented to them. Is your discipline called up from time to time in circumstances where someone is being offered a range of treatments? Do you get consulted in that way?

Dr Barnes—By whom?

Senator COOK—By hospitals or specialists.

Dr Barnes—No.

Senator COOK—The state government is proposing a multidisciplinary approach in this state as part of a plan it is yet to implement. Do you have a view on whether nutritional medicine should be included in a multidisciplinary approach?

Dr Barnes—I have an absolute view on that!

Senator COOK—I know it is a leading question. I take it the answer is yes.

Dr Barnes—Yes.

Senator COOK—I have a lot of questions for you, but, finally, one of the things that cancer patients are often enjoined to do is to be positive. Being positive seems to stem, at least in my experience, from taking charge or being responsible for what you do. Are you aware of any studies about positive attitude and its effect on the likelihood of life extension or improvement?

Dr Barnes—No. I am aware of a Stanford study that was done. In fact, when I was a medical student I went and stayed with a friend of the family and the woman was dying of breast cancer. She said to me, 'Come along to this meeting.' I was not aware of what I was going to and later I realised that I had sat in on a very important study. The study was looking at patients' attitudes in terms of the possible outcomes associated with three common approaches that a patient would have. One was an informed approach of taking charge, working, questioning, being proactive and designing their own treatment to some degree—a bit of DIY, as I said. The second group was the group that said, 'I don't have cancer. I'm just going to get on with life anyway'—the denial approach. The third group was compliant to the standard medical approach, where there was no questioning and they were not partners in their treatment; they were at some levels just recipients of the treatment. I cannot quote you the details of the study, but the general outcome was that the people who did best were in category 1, the people who did second best were in category 2 and the people who did third best were in category 3. So, in a sense, according to that study the people in the paternalistic model that we have—that of saying, ‘Don’t question, don’t ask, just come in and have this treatment; you’ll be fine’ and giving them a pat on the back—do the worst.

Senator COOK—This is a Stanford study?

Dr Barnes—Yes.

Senator COOK—Is it a reasonably well-known study?

Dr Barnes—Yes. I could probably chase it up and give you some information on it.

Senator COOK—It is argued—and there is some evidence for it—that a bit of quackery goes on in the less conventional fields of medicine.

Dr Barnes—I have been labelled that.

Senator COOK—My question is: how do you differentiate between serious medicos, like you, and ‘snake-oil salesmen’?

Dr Barnes—If you are going to work in oncology, which to me is one of the biggest challenges in medicine, and you have never done any training—if you have opened up a corner store because you had cancer, treated yourself with shark cartilage or something else and got well—or if you think this is this or that is that, then I think you have no place there. I do not think people should be involved in that. I think we have to broaden our approach and say that there are other disciplines which at some level have been out in the cold and need to come in, but we also need to make sure that the people involved have the necessary qualifications, have done their time, have developed their skills base, know what they can and cannot deal with and are connected enough to have a referral system so that, when they get in trouble or feel that they are potentially out of their depth, they can call in their colleagues to help them.

CHAIR—Where do you draw that line? From the evidence we have had so far, oncologists draw that line quite close to themselves—you would draw it somewhere else, and other people would draw it elsewhere. How do we, as a committee, come to grips with where that line should be drawn, based on training, experience et cetera?

Dr Barnes—For a start, I think there is a turf issue in oncological practice. There is certainly a hierarchy in terms of specialisations and what people are doing, but I am not sure that oncologists are the right people to decide where the line is, and I am not sure that I am either. I think that that needs to be done within a number of different disciplines. I do not even know who would do that, but I do not think it should be the people who have a vested interest in maintaining the status quo. I would have thought it could be a multidisciplinary team of people who have shown themselves to have expertise in those particular areas and not necessarily weighted towards oncologists, nutritional physicians or what have you. I do not know if I can answer that question any better than that, but my view is that it should not be left to oncologists—and it should not be left to me.

CHAIR—But you agree that a line needs to be drawn?

Dr Barnes—I am not sure what you mean. Who draws the line?

CHAIR—That is right. The quack is on one side of the line, and on the other side is someone who is legitimately practising something that is outside what may be considered mainstream.

Dr Barnes—The medical board should decide whether or not I am a quack. What has happened to me is that an oncologist has taken a complaint about my practice to the medical board. I was then required to answer the medical board's questions as to the basis of my practice. I submitted my answers and the medical board came back to me and said: 'Dr Barnes, we are satisfied with your level of expertise. We are satisfied with your practice. We are satisfied that you fulfil the requirements that we as a medical board have laid down for alternative medicine.' So I have been through that, and I have been defined as a practitioner of alternative medicine. One of my colleagues has asked the board a question and the board has scrutinised me.

Being a medical practitioner, I am beholden to the medical board of this state and I have to practise within the laws and the medical act that is laid down. If I were a naturopath, there is no such board. If I were a massage therapist or a range of other people, there is no registering board that is laid down by an act of parliament, as far as I know. So, in a sense, I can do that because I am a medical practitioner registered in this state. So I have started to find that I actually fall within the line as being able to practise within that area. That is something that the state may well have to address in terms of how they are going to register people in these other areas as to whether they are practising within their professional limits, and within considered guidelines and knowledge, or whether they are practising outside of that.

Senator KNOWLES—Dr Barnes, you do not have to convince me of your role within society—I am completely onside. What staggers me, I suppose, is that we are even having this conversation in 2005. That is the part that gets me.

Dr Barnes—It staggers me too.

Senator KNOWLES—Yes, and I understand why. I just find it absolutely astounding to think that there is still a reluctance within the medical profession generally to accept that nutrition, diet and all of those associated factors can impinge on one's health and wellbeing. I have been sitting here shaking my head for the last half an hour. I do not know how we turn that around and get a wider acceptance by the medical profession per se that this is an integral part, not a voodoo part, of health and wellbeing—not just for people with cancer, I might add, but for others.

Dr Barnes—As I said, I am 20 years into this. I have not had an idea of where it should be at any particular point in time. What I can say is that I do believe it is changing. I do believe that the fact that I am sitting here is testament to the fact that it is changing.

Senator KNOWLES—Is that generational change or is there something that has brought about a change in attitude?

Dr Barnes—I think the public is changing. Ultimately, we are all here to look after ourselves. We are not here to push our own particular agendas; we are here in service. That is our job: we came to serve. We serve in the way that we think is the most appropriate way for us to serve. That is what we do. In this whole area, we just go about our business and serve in the way that we do. If other people think that our service is not appropriate, not needed or what have you, that is their business; it is not mine. As a collective, you just need to see the numbers of people in the population who are coming to people like me and seeking out people like me.

Senator KNOWLES—Is that because people are a little bit more empowered, say through the internet or otherwise, and that they just do not accept on face value what a doctor says these days and they think, ‘What else can I do to help myself?’

Dr Barnes—Exactly. If you go along to your accountant, your accountant does not sit there in a paternalistic way and say to you, ‘I will solve every problem that you’ve got as far as your tax is concerned.’ If you have a problem with the tax department, they come looking for you; they do not go to your accountant. In a sense, what the accountant says is that you are responsible for your own business. Your discussion this afternoon about socioeconomics, access, education and all those issues relates to people’s responsibility for their own health. Talking as a doctor, I think that as a profession we have to see ourselves as consultants in the true sense of the word—as guides, as friends and as people who stand by the patient and help them to explore their own health issues and provide them with expert access to various resources and things. In a sense, we should not take a paternalistic viewpoint that we are going to cure people—nobody cures anybody; they only cure themselves.

We have to move away from this old, paternalistic paradigm into a new concept of people working with people to achieve health outcomes that the patient wants in the way they want to do it. Our role is to advise them, to help them, and to advise them of the dangers of certain things that they may be doing which we think may be detrimental to their health. That is what I see our role as being. Maybe that is something that will come. Obviously that goes right back to medical training. It goes back to medical schools. I am involved now with the new medical school that has started at the University of Notre Dame. I feel very strongly that they start with those premises right at the beginning with the medical students. So in a sense it is a cultural and a generational change that will be coming through. I think it is at that basic level. I did not train in Western Australia; I trained in New Zealand. Where I came from we actually had a bit of that 20 or 30 years ago, so I kind of got that. I do not want to be critical, but I did have a feeling that it was more paternalistic here. It was a bit of an old boy club. It was not so open.

Senator KNOWLES—It is terrific, from what you are saying, that the Notre Dame new school of medicine is taking that new cultural attitude. Are you seeing evidence of that at UWA?

Dr Barnes—I do not have much to do with UWA.

Senator KNOWLES—Have you tried to have anything to do with UWA and getting in at the ground level there?

Dr Barnes—No.

Senator KNOWLES—Too hard?

Dr Barnes—I think it is just the case that I have been doing other things. It is like a lot of things: you can look at your life and think, ‘Where do I want to place myself within it?’ I could have been more involved in medical education. I guess my last 15 years has been researching quacky therapies to see if they work and looking into the basis of these therapies and trying to understand them and trying to sort them out. I can then advise patients, ‘Don’t bother with that.’ If somebody comes to you and they want to take shark cartilage, for instance, I can say, ‘This research shows that shark cartilage is not really going to work for you. Why waste the last three months of your life using shark cartilage when there is something else here that is a lot better? We have researched this a lot more. We have tried shark cartilage. It doesn’t work. Don’t bother with it, don’t waste your money.’ They might say, ‘Oh, but I have been told such and such’, and then you can say, ‘Actually, I have got the runs on the board. We have looked at these things. We know that they are probably not of much value.’ That is where I have seen my role—much more within the interface of trying to help people to help themselves and find things that are going to be of benefit to them.

Senator KNOWLES—It is also passing that bank of knowledge on, though.

Dr Barnes—Yes. I recognise that, and one of the reasons I am becoming involved with Notre Dame is to do that. In my submission, I am hoping that they will start to look at things like nutritional medicine.

Senator KNOWLES—How did you get involved in Notre Dame?

Dr Barnes—Because I am in Fremantle, just down the road.

Senator KNOWLES—But it was not a direct approach from Notre Dame to you?

Dr Barnes—Yes.

Senator KNOWLES—It was?

Dr Barnes—I think they wrote to all the GPs and people in the area for their special interest to see if anybody was interested in being involved with them. As that came up, I wrote back and said, ‘Yes, I am. I am a GP but I have a special interest in nutritional medicine and I am happy to bring this knowledge and my expertise to the school.’ So they took me up on that.

Senator KNOWLES—Thank you. Good luck.

CHAIR—Dr Barnes, earlier you said that a lot of your patients come to you when traditional forms of treatment have actually already failed them and they are desperate. You obviously believe that the treatment you provide has some success in either prolonging their life or making their life more comfortable through that process. Do you have any evidence—I know it will only be anecdotal—that early intervention with your form of treatment, nutritional medicine, assists in treating people who come with an early diagnosis of cancer as opposed to later intervention?

Dr Barnes—I think the earlier, the better.

CHAIR—Do you have any evidence? We do want to collect evidence if it is there.

Dr Barnes—As I said to you, that is the area where we probably have least evidence. The previous speakers said, ‘We don’t have any evidence with regard to that because we are not collecting evidence in that area.’ I guess that comes down to me and my database and what I have gathered within my own practice. It also comes down to my collaborating collectively with all the other nutritional doctors that are doing this work and looking at what people are doing overseas. I can really say to you that we have not even got to that step; we need to start on that step. We probably need some grassroots funding.

As for the things that are happening, probably the best centre for this in Australia is Melbourne, where we have Swinburne University of Technology starting to look into some of the issues and starting to do some of the primary research—there is a lot of primary research—and more of the secondary research that is coming in. They are involving more nutritional doctors, they are starting to develop the programs that we think should be used and they are starting to look at the parallel processes that can be used alongside them. You can look at different cultures. For instance, if we always look at America in terms of research, which is what we tend to do, we can be very one sided and hoodwinked into thinking that there is no other research into these areas. If we start looking at some non-English-speaking countries, such as Japan and China, where these more traditional treatments have been combined with conventional therapies, we see that the research is actually there.

If we look at what the Chinese have got, we see they actually run two parallel systems. They run their traditional Chinese medicine system and they run their conventional Western system and they have hospitals that combine both. They have patient numbers in the thousands, but they are not publishing in a lot of the peer review journals that are coming out in mainstream medicine in, say, America and Britain. But the information is there and it is very important information. They are working with Chinese herbs in combination with chemotherapy and are getting better outcomes by doing that.

We need to start to broaden our viewpoint so that we do not just stick with English-speaking papers because they are easier to get and because they are in the peer review journals that we have always read. We need to start looking at, for example, very interesting research that has been going on in Japan into the use of mushrooms in immune support, particularly the shitake mushroom, which people probably have had when they have gone out and had Japanese food. The Japanese know how much shitake mushroom you need to have. There is direct evidence that if you use this in combination with chemotherapy you reduce the side-effects of chemotherapy, you improve the outcomes and you make the patient feel more comfortable. So from their point of view the shitake mushroom is now virtually becoming part of mainstream medicine. So in Japan that would be part of mainstream medicine; in Australia that is seen as a bit of hoodoo. Unless you read Japanese medical journals you do not have access to that information.

There is a lot of information coming out of Russia that we have not really given a lot of credit to. Germany is probably the best example. There is mistletoe therapy in Germany. I do not know if you know about mistletoe—Iscador—therapy and various others. It has been around for years. It was developed by Rudolph Steiner. Germany has a whole system of anthroposophical medicine. When you go to Germany, you can actually go to an anthroposophical hospital, where in fact you are given anthroposophical cancer therapy, which involves mistletoe therapy and other things. You can have surgery there, but instead of having chemotherapy you will have anthroposophical medicine. That will be paid for by the private health system, and it is a recognised and accredited hospital that provides that. If you go to London, you will see they have a homeopathic hospital. We know about it; it is already there. It will provide that kind of support. So there is information, but it is not just coming out in the *JMAA* and it is not necessarily coming out in the *Lancet* and other things. You have to go out to find it and it is a bit more diverse, but it is there.

Senator MOORE—How many environmental or nutritional physicians are there in Australia? Are there many?

Dr Barnes—Maybe a thousand, maybe 1,500 or maybe more. It is a question of how many have been trained.

Senator MOORE—So for these people to have that title they would have had to go through the process that you described earlier of the three levels of training?

Dr Barnes—You can be a member or you can be a fellow. The fellowship came out only in about 1995. Before that there were only members. What happened is that a group of us—maybe 40 or 50 around Australia—got grandfathered into being fellows because we had been the forefathers of the college. Then there are members, and a lot of members are going through. They are running maybe four or five courses a year for maybe 30 to 40 doctors.

Senator MOORE—So it is popular?

Dr Barnes—It is very popular. I was talking with Daan Spijer about nutritional doctors. Apparently Tony Abbott wanted to talk to all the doctors in his electorate. ACNEM got in touch with all the doctors in his electorate. He went along to the meeting with all the doctors in his electorate and he was staggered by the number of nutritionally trained doctors who were within his local electorate. It is there and it is growing. You have general practitioners who have some general knowledge around nutritional medicine. Then you have people like me, who have said: ‘This is an area that requires the devotion of all my time; I can’t be doing just sore throats and prescriptions for this and that. I really need to focus much more on this.’ I guess we have gone into it more as a subspecialty of general practice. We are not recognised as specialists but we no longer really fulfil the requirements of general practitioners.

Senator MOORE—But, as far as Medicare is concerned, you would be a general practitioner.

Dr Barnes—As far as Medicare is concerned, we are probably general practitioners. But we tend to get targeted by Medicare. We get targeted for two reasons.

Senator MOORE—Looking at your billing rate.

Dr Barnes—They scrutinise us in general practice terms. For instance, we get targeted on two things. There is an inquiry on me at the moment with respect to the time I spend with patients and also the pathology ordering. What I say to them is: ‘Go and have a look at my pharmaceutical profile, because you will find that my pharmaceutical profile is far less.’ They say, ‘Yes, you are not an expensive doctor but you stand outside the system. You are over here.’

Senator MOORE—The other point I have is that a lot of witnesses today have talked about complementary medicines as opposed to alternative medicines. We have had evidence to say that there is a growing acceptance of complementary medicines working with the traditional structure. How would you define what you do? Are you complementary or alternative? And how do other people define you?

Dr Barnes—We are the medicine of the future!

Senator MOORE—So do the mainstream people consider you more alternative?

Dr Barnes—Not really. I do not like those two terms.

Senator MOORE—I do not like them either but they are the ones that are used.

Dr Barnes—I will complement what people are doing, sometimes. I will provide alternatives for people, sometimes. If somebody comes to me and does not want to do conventional therapy, I am not going to be a complementary doctor, am I? I am going to be an alternative doctor.

Senator MOORE—By choice of the patient.

Dr Barnes—Yes. There are certain conditions, oncologically, that standard oncologists will not treat because they know that the treatment is worse than the disease. From a nutritional point of view, I might say, ‘I can try this. I don’t know if it is going to help you, but, from the side effect profile of these treatments, it is not going to make you any worse, so let’s give it a go.’ People will often be prepared to give it a go. I say, ‘All you’ve got to lose is some time and some money, and if you’re prepared to lose those two things in the process of exploring that then be my guest.’ Most people will say, ‘Yes, I want to do that.’

Senator MOORE—In those cases, people would get Medicare rebates.

Dr Barnes—Medicare rebates will pay for the consultation. Medicare will pay for all the pathology and radiology. Medicare and a lot of private health cover do not pay for a lot of the supplements that these people use. A lot of these people are self-funding to quite a significant amount. These things are not cheap.

CHAIR—Thank you very much, Dr Barnes, for your submission and your presentation today.

Committee adjourned at 5.33 p.m.