COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Services and treatment options for persons with cancer

WEDNESDAY, 20 APRIL 2005

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Wednesday, 20 April 2005

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

Substitute members: Senator Cook for Senator Hutchins

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

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

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BURNS, Mrs Sarah Judith Imogen, Music Therapist, Bloomhill Cancer Help 14

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KNIGHT, Associate Professor Rosemary, Department of Health and Ageing 74

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LYONS, Ms Margaret Patricia, First Assistant Secretary, Health Services Improvement Division, Department of Health and Ageing 74

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PITT, Mr Matthew David, Member, Brain Tumour Australia 24

PITT, Ms Susan Louise, Executive Committee Member, Brain Tumour Australia 24

STRANGMAN, Mr Denis, Chair, Brain Tumour Australia 24

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VIVIAN, Ms Bernice Clare, Executive Committee Member, Brain Tumour Australia 24

Committee met at 9.09 a.m.

DANE, Ms Margaret, Member, Australian Council of Community Nursing Services

FOLEY, Ms Elizabeth, Director of Policy, Royal College of Nursing, Australia

GREALISH, Ms Laurie, Fellow, Royal College of Nursing, Australia

CHAIR—The Senate Community Affairs References Committee is continuing its inquiry into services and treatment options for persons with cancer. I welcome representatives from the Royal College of Nursing Australia and the Australian Council of Community Nursing Services. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions. I now invite you to make an opening presentation, to be followed by questions from the committee.

Ms Foley—The Royal College of Nursing, Australia, welcomes the opportunity to appear before the committee today to assist you in your inquiry by providing additional information or clarifying any points raised in our written submission of March 2005. I advise that RCNA has been requested by Ms Jill Iliffe, the Federal Secretary of the Australian Nursing Federation, to represent on their behalf as they are unable to appear before the committee today.

Nurses are the primary care givers to persons with cancer, whether that care be provided in acute care health settings or in the community, such as in the home. Nursing care is generally provided on a 24-hour basis over the full seven-day week. Nurses work well in multidisciplinary teams where their skills and unique knowledge of care for people with cancer makes a difference to care outcomes and the quality of life for their patients. However, there needs to be a clear definition of ‘multidisciplinary’ amongst health professionals in the care of persons with cancer so that it is clear as to whether it means ‘many different disciplines’ working together as a team to effect better health outcomes and/or quality of life for the person with cancer and assistance for their family, or whether it means ‘many different specialist medicos’ conferring amongst themselves exclusive of other health professionals. This distinction is important for the smooth delivery of care for cancer patients and to ensure that all members of the health care team are fully informed of all treatment options at each stage of progression of the illness and can share aspects of that care from their perspectives, thereby enabling them to fully engage the patient and his or her family in that care and decision making.

CHAIR—Would anyone else like to make a presentation?

Ms Dane—I would like to pick up on a few points. I represent a community nursing organisation, and I would like the opportunity to discuss a few points around the rural community nurse, who often works in isolation, often does not have the option of a multidisciplinary team and has to tap into already very minimal resources in country areas. What the service looks like in a metropolitan area is completely different from what it looks like in rural Australia. I work in the Greater Southern Area Health Service, which is a huge area that goes from the south coast of New South Wales almost across to the South Australian border and then down to the Victorian border. A figure that popped into conversation recently was that 97 per cent of the care of cancer patients is actually provided in the community, within our area health service, so there is a huge burden on community services. If there were one point I would like to make about cancer care, that is the one I would make. We pay a lot of attention to the tertiary care that is provided but most of the ongoing care and support is provided by the community nurse and the GP.

I will quickly mention the story of one person who lives in a country town, who was a senior nurse in our organisation. She had sarcoma of the face and underwent radical surgery. Her nose was removed and a flap was put in its place. This lady is very intelligent and has worked in nursing for many years. She told me something that I have not forgotten—how abandoned she felt by the medical and health service and the lack of continuity in care. This was from a person who actually knew how to get herself around the health care system. So I keep that in mind and think: what of the people who do not know how to navigate our complicated system?

Senator HUMPHRIES—Ms Dane, you touched on an issue that I was going to ask about—that is, the extent to which it is possible for us to push cancer related treatment further down the medical hierarchy and closer to the grassroots. Is the figure of 97 per cent for treatment of cancer—

Ms Dane—No, that is for care—for supportive services. I think the tertiary sector would do the three per cent—the chemo, radiotherapy, surgery and that sort of thing—and the majority of the ongoing care is provided in rural areas by a GP, community nursing or the allied health within that area.

Senator HUMPHRIES—Recently, there has been the capacity for a number of activities in GP surgeries to now be performed by nurses and for a Medicare rebate to be payable. Are there any cancer related treatments or activities being done in rural settings, for example, which you think might be susceptible to the same kind of treatment?

Ms Dane—The multipurpose service model, which we have in some of our areas, which combines acute care, post-acute care and aged care, is a really good utilisation of services. That is the type of capacity that I think could be built up. The country hospital that people work from and which is seen as the support service to the whole community—

Senator HUMPHRIES—So that is a hospital based activity that you are talking about?

Ms Dane—In most of those country areas, there would be only one doctor and he would work very closely with the hospital. He would have a general practice but also would be the VMO—the visiting medical officer—for that service. Often in these smaller country areas, there is just one doctor.

Senator HUMPHRIES—I have a question for the Royal College of Nursing. In your submission you refer to models established in England with regard to rehabilitation of cancer patients. Can you tell me a bit about those models? What do they actually do?

Ms Grealish—The two models that I am particularly aware of are in radiotherapy and in the management of breathlessness. In those models, the nurses have identified that there are some symptoms that patients have secondary to their treatment that have been medicalised. For breathlessness, it is called dyspnea. When they went back and looked at those symptoms from the patient’s perspective—based on some qualitative data from studies that were done previously—they came to understand that the experience of being breathless was actually much more than a physical experience. So the strategies that they engaged in with clients in that particular service were around the medical treatment for dyspnea but also around supportive strategies in terms of thinking about what was happening during the course of their disease, what was happening with their family et cetera. So they are changing the meaning of practice from medical practice to much broader supportive care.

In our submission, the point that we want to make probably the most is that, if we continue to have our services offered in cancer care based around medical treatment, we will continue to have patients feeling abandoned. When the treatment finishes—once you have had your surgery for your face and the sarcoma is removed—people are abandoned by the system. Once they do not access medical services, the other supportive services are not available. We really do need to be looking at some sort of self-referral system for our patients or setting up these kinds of nurse-led services where people can continue to come in and talk about the effects of the illness on their lives.

Senator HUMPHRIES—Is that primarily a sort of psychosocial service to cancer patients or is it medical?

Ms Grealish—I think you combine them. Nurses can offer a combination of an understanding of the body and the pathophysiology of the disease and the kinds of medical treatments that are available and they can refer patients to those services. They also bring an understanding of what the illness experience is about, and it is that kind of understanding that I think is absent from a number of the systems. Calling it psychosocial is okay as long as we remember the social side. My concern about the literature that is emerging in Australia around psychosocial care is that they are usually talking about psychological interventions, which again do not capture the rich, meaningful experience of living with a disease like cancer that patients and people around this country are having to wake up to and confront every day.

Senator HUMPHRIES—Turning to complementary treatments, your submission says that the college:

> ... supports the concept that patients should have access to oncology physicians and surgeons ... who would be prepared to discuss all options in regard to less conventional and complementary cancer treatments without judging or intimidating them.

I infer from that statement that you feel that there is a problem with specialists and even GPs taking an inflexible or not very broad-minded approach towards the potential of those sorts of treatments to affect the path of a patient’s cancer.

Ms Grealish—To suggest that would be a generalisation. I do not think that any individual GP, physician or surgeon intends to lead people to feel hurt by the kinds of things they suggest. They are working within a cultural system that values survival and, when you value survival, treatment becomes most important. When the work that you do is about treatment and you work in a system that values survival, the rest of the stuff becomes invisible to you. It is not an intent on the doctor’s part at all. I believe that they offer the best services they can within that kind of framework, but the rest of the things that are available are invisible if that is the only point of contact that patients have with our health service.

I do not know what it is like for you but I know that when I have been labelled—and I have been the receiver of cancer care; not directly but as a family member—it is a very painful and hurtful experience, more so when you have been part of that system. In the work that I have done with patients and families through the Cancer Society in the ACT as well as some research work I have done in a living with cancer course, people continue to tell me that they experience a sense of abandonment—and you will hear that from people who present submissions later today—and that the system is failing them.

Senator HUMPHRIES—Is that related to the training of doctors? Is it related to a lack of support for patients?

Ms Grealish—It is related to the way we have conceptualised our health service around a medical focus. When we talk about health services, we talk about treatment, we talk about nursing work in GPs' offices around the delivery of medical treatment and the way that nurses can deliver that treatment, and we relate it directly to funding, because obviously that is important to us. But, when we do that, we forget the other work that GP nurses can offer, which is about some of that social support or directing people to services that provide them with the breadth of support that they probably require. So, when we talk about their work only in relation to the kinds of medical services they can deliver, we continue to have this paradigm view.

Senator HUMPHRIES—We have heard evidence that many patients who undertake complementary or alternative treatments for cancer often will not reveal that to their doctor because they feel that the doctor's paradigm—as you put it—is different. Do you think they tend to be more forthcoming with nurses who might deal with them in the same treatment regime?

Ms Grealish—Sadly, nurses work within the same system as the doctors and some nurses adopt the same values. So patients choose which nurses they share that information with and they make that judgment based on the kinds of interactions that they have with those individuals. Nurses, like doctors, can also be seduced by the survival model that exists in cancer care in particular and the medical model that exists in our health services in general.

Ms Dane—I think there is a different perspective in the community—and this is only anecdotal from 17 years of nursing in the community. I think there is greater exposure of what is happening within the family, within the home or within the treatment of a client who is with a community nurse or a palliative care team.

The approach we would take is one of balance. I have seen the families that struggle to pay $2,000 a month for X treatment but they are unable to eat anything that they enjoy. You know that time is very precious but, as Laurie said, they are so seduced by that survival—they will do anything to survive. I have also seen the same sort of drive in people who are having the fourth or fifth line of chemotherapy, radiotherapy or surgery, so I think it is about balance and a respect for where the person is at. I have seen lots of alternative therapies, such as touch therapy, aromatherapy and massage, and we use them in nursing. Complementary therapies are sometimes part of our mainstream nursing practice. When looking at quality of life and comfort, which is part of that psyche approach—that strengthening of within and that healing—there needs to be balance with both and respect for both. As long as the client is well informed, the road they take is their decision.

Senator HUMPHRIES—Given that nurses and doctors come out of that same educational tradition about focus on survival, what do we do to change the assumptions about what is best for a patient and how the patient’s overall needs are addressed?

Ms Grealish—At the end of the day, survival is the most important. The difficulty with the way we have structured our health services is that it renders everything else invisible. We need to explore other paradigms of care delivery, which I understand is the purpose of the inquiry, such as models that incorporate nurse led clinics and palliative care and that encourage rehabilitation. To have facial surgery of the kind that was described earlier has some long-term implications, particularly when returning to the work force. Supportive staff should be available to work with people as they try to transit back into a normal life without being normal again. I think you have to run these in parallel, which is what people today call ‘integrated’.

Senator HUMPHRIES—In an integrated model, in a multidisciplinary approach, do you think that a nurse will invariably or even generally be the best case coordinator for a particular patient?

Ms Grealish—Firstly, I would like to comment on multidisciplinary approach and how it is being used in the literature today. We would like it to include disciplines other than medicine, but in the documentation that is emerging from some of our medical communities, particularly *Optimising cancer care*, the implication is that ‘multidisciplinary’ refers only to surgeons, radiotherapy specialists and chemotherapy specialists et cetera. If you are talking about multidisciplinary care being about other services, I would suggest that the nurse is in a good position but, sometimes, particularly in the rural sector, another discipline could take that role. The important thing is that the person who takes the role has a good understanding of the cancer experience from the patient’s perspective, of the ethics of supporting people in making decisions that may be different from decisions they would make for themselves and of what the treatment options and the non-medical options would be.

Senator HUMPHRIES—I do not know whether you have had a chance to read any of the other submissions to the inquiry. There is one from the Pharmacy Guild, which talks about a model of pharmacy based treatment or a maintenance regime of drugs for patients in the community. I suppose you cannot comment on it if you have not read it but do you think those sorts of community based models might be more effective than hospital based or GP surgery based models?

Ms Dane—I think it would be really difficult to comment without knowing the details. There are pharmacists who have a history there, and I would leave it to the pharmacists to discuss. They have come out of the same education process as our medicos and our nurses. I have had a bit to do with some of the pharmacists relating to the prescribing of drugs—I am trying to think of the name of the Commonwealth program—and the same of the pharmacist doing a medication review for a client in their home. It is a Commonwealth funded service. It became evident that a lot of pharmacists are not used to dealing with the public. They are in the business of dispensing but we are expecting them to extend their roles without providing them with that back-up education. I am not talking about cancer care but about aged care, which I have been involved with, but I think they would face the same types of challenges that the rest of the health care professionals face.

Ms Grealish—Shifting our health services out of medically dominated surgeries and institutions such as hospitals could offer us an opportunity to explore other ways of dealing with health care. I think it would be worthwhile exploring multidisciplinary collaboratives that are non-medical, if you like—for example, working out of a pharmacy, which is a very well-respected community organisation—and perhaps doing some sort of trial. They have introduced nurses into my local pharmacy. Some of my neighbours have accessed those services and feel quite satisfied with them. Although it is anecdotal, I do believe there is an opportunity there to extend some of our health services.

Ms Foley—Senator Humphries, before we move on, can we go back to a question you asked earlier about the Medicare items for nurses in general practice? We suggest chemotherapy management should also be included. Wound care is an area that should obviously be included with cancer care, but nurses also deal with people with nausea and vomiting, which are side effects of the chemotherapy management.

Senator HUMPHRIES—Those things hang off GP care, and that is the way that other Medicare rebates work, so that would be in the same model.

Ms Foley—A person with cancer could actually go to the GP’s surgery and just be seen by the nurse for that particular aspect.

Senator LEES—Can I pick up on that and ask what happens now? Where does someone go who is going through the process of chemotherapy, particularly in rural areas, if they are experiencing nausea, vomiting and other side effects?

Ms Dane—Either the community nurse would visit them and liaise with the general practitioner in the area or they would go to the hospital.

Senator LEES—It is generally now up to them to find their way through the system?

Ms Dane—Yes.

Senator LEES—I would like to try to develop the ideal model. I realise it would differ from patient to patient and from place to place, but what do you see as the ideal multidisciplinary approach or team? Do you think that the patient should have any input as to who is part of that team?

Ms Grealish—In terms of the ideal team in cancer care, I think we need to go back to the data that has emerged from people’s experience of cancer. There have been a number of qualitative studies done here in Australia as well as overseas, and we need to extract from that data what people are saying is important in their cancer journey. We then need to take a step back and look at not only what we are doing well but what we are not doing so well and what we can construct in our health services to support people with these particular aspects and concerns. That is the kind of work that we talked about in our submission on nurse-led clinics—they are looking at that data and that data is informing the way that they are offering service.

Senator LEES—In that team would you include the nurse, the specialist, the GP and perhaps someone in the complementary area if that were the patient's wishes?

Ms Grealish—Sometimes you have to include the people who are available. If you were talking about a rural or an Indigenous community, you would include the Aboriginal health worker. It is about the people who are in that local community. The difficulty with talking about models is that the context changes depending on where you are at. I think there is a framework or a philosophy about all views having an equal weight and related to that is that the person chooses which areas they want weighted more heavily—and that is going to change over time. Our work might be more around educating patients, clients, people with cancer about what is available and talking with them about what is most important right now and then directing them to those kinds of services.

Senator LEES—Would nurses be comfortable, for example, referring someone on for reiki or referring someone on to a dietician? There is a range of people and services who have talked with us. I wonder how people find them. Do they get on the net? Do they talk to their nurse?

Ms Grealish—I think it has become more of an issue recently because of the internet and the World Wide Web as people are finding these services and using them more.

Senator LEES—And coming to you and saying, 'What's this about?'

Ms Grealish—That is right. People are making those choices whether or not we want them to. The difficulty for the nurses working in the current model is that they have adopted the same paradigm view as their medical colleagues. So, when we look to change the system, we have to be working with the staff about what these changes mean because it will mean changes to their practise, particularly around supporting decisions made by patients and clients that are different to their own decisions. I think health care professionals find that the most difficult.

Ms Dane—Going back to the original case that I spoke about, that person comes from a small country town and her supports were her family, her friends, the community nurse, the staff at the hospital, her GP and the naturotherapist in the town. When she got back from the metropolitan area where she was having her radiotherapy they were her support mechanisms.

Senator LEES—So, in that case, you would include the family or her primary carer as part of the team?

Ms Dane—Definitely.

Ms Grealish—Absolutely.

Ms Dane—She had had facial disfiguration and, when they took the dressings off, her husband told her that he loved her. She makes a point of saying that he said, 'You look great,' and she said, 'I know I don't look great but at least I can see in your face that I don't look that bad.' We can talk about systems but, sometimes in country towns, people have those supports when, in a metropolitan area, they can get lost. I do not want to be saying, 'You're better off in a metropolitan area than a rural area,' but there is the ordinary human support care that will help somebody like that who has returned to the nursing work force.

Senator LEES—So, basically, we need to keep an open mind and very much start listening to the patients as to whether they want, for example, the local pharmacist involved as well in the process?

Ms Dane—That is right. I think that way we will get a balanced perspective rather than a top-heavy perspective.

Senator MOORE—Ms Dane, that support network sounds pretty damn good in terms of some of the things we have heard about the isolation that people feel. That kind of community based support involving a range of people in a country town sounds quite positive. I want to talk about the work force issues. I would not have a group of nurses if I did not have to talk about the work force issues, but I would like to hear from the college in terms of the situation with specialist cancer nurses and the training and need across the community. Ms Dane, my own experience with community nurses in Queensland is that there is a real issue about recruitment and retention, particularly in regional areas. For the record, it would be useful to have a statement about that and, at the same time, the support network for the nurses. It is a very difficult career at all levels, but what kinds of things should be around to give support to the workers in this particular speciality?

Ms Grealish—Preparing people to work in specialist cancer care services is very different to preparing nurses in general. You have to remember that people living with cancer present in all health services. We see them not only in specialist cancer care but also in surgical areas—like the earlier example we had of the woman. We also see people presenting in medical areas, maybe with complication of their cancer. It could be a diabetes related or a hormonal related complication.

The thing with cancer education is that you cannot train everybody up to specialist standard. If we are talking about specialised practice, we probably need to continue to be funding some postgraduate education in specialist cancer care so that nurses can manage the complicated treatments that occur. But I think there is something broader than that that can happen, and that is where we start getting all nurses and probably all health professionals to talk about their practice.

One of the things that I have witnessed from my 20 years of nursing experience is that we talk about treatments and we talk about outcomes but we are do not talk about the practices that get us there. We are not talking about the kinds of things that happened on the way to getting to this woman’s home. The stories that Margaret is telling you today and these kinds of conversations do not happen very often in our practice settings. They happen over coffee and they are not open to analysis. That kind of discussion about practice and critical thinking, in supportive environments that allow that critical debate to occur, with health professionals and within nursing and across disciplines has to happen, and it is not happening now. We need to be looking at ways to structure that kind of support, because that is educational work within the workplaces. The college is very keen to promote that kind of thing, and we are doing it through the lifelong learning program.

Ms Dane—What you were talking about with respect to the community nursing work force is certainly an issue with the ageing work force especially. I worked in the ACT for the last five years before taking up my current position. The statistics showed that something like over 50 per cent of the work force could retire within the next couple of years. That is huge. We formed a strong bond with the university. We looked at bringing undergraduates into the community, which was always thought of as a specialist area. We said, ‘We might think we’re special, but we are not going to be too special if there is none of us around to do the work in a few years time.’ So we have worked in a collaborative manner with the university to introduce undergraduate nurses.

We have also developed new grad programs completely within the community. We used to have new graduates only for a couple of months to expose them to the community, thinking that they would need more acute care under their belt before they came back and worked in the community, but we have changed our thinking—and I think that is fairly out there. I cannot say whether it is not commonplace, but I have not seen that sort of initiative on any large scale.

We have to be more open and to be more creative about attracting people to the work force. The support that you mentioned goes hand in hand with that. In some ways it is a burden for the one community nurse working with the one GP in a country town, doing everything from the babies through to palliative care, but in other ways there is the support around. They are able to go into the hospital and have a cup of tea. I guess the linkage is much easier in country areas in that regard. In a metropolitan area, you would find that the hospital is the hospital and the community is the community. I think it is about bridging those gaps and providing people with opportunities to debrief.

I also think education is incredibly important—and not just specific to cancer, as Laurie was saying, but wider. Education helps us understand that we cannot save the world, which is a lot of the problem with us. We think if we work harder and longer we are going to do it. We have to realise that we are part of a team and a system and we do what we can. I think education helps us understand that we can call on the other people within that team to help.

Senator MOORE—Taking up that point about the team and the kinds of issues that Senator Lees was raising about the various models for multidiscipline teams, that kind of support network that you were talking about could operate in that focus as well, could it not? It could be part of the whole process.

Ms Grealish—That is right. But, again, that requires some change to the paradigm.

Ms Dane—It does.

Ms Grealish—At the moment, we have a paradigm in practice where there is right practice and wrong practice. I know from working with patients and their families that it is not about right and wrong; it is sometimes the best decision that we can make on that particular day because of where we are at the time. We need to have greater acceptance within the health community that it is about finding the best fit as opposed to right and wrong. It has taken me a while to learn that. I do believe that that is the kind of conversation we need to start having.

It is not about best practice. Best practice is only an average. If you look at randomised clinical trials, you see that best practice is the average. It does not necessarily capture the richness of the experience of cancer or the variety of experiences people can have. When you get into the field, you could be working with someone who was in a trial whose data sat over here when the line was over here. They are very different so the practice has to change; best practice will not fit for that particular client. Those are the conversations we are not having.

Senator MOORE—There is a proliferation of studies and reviews, and one of the things we found through this process is that most jurisdictions are doing something about cancer. There are working parties and reviews and all those things. Ms Grealish, you mentioned the report, *Optimising cancer care in Australia*—the recent bible. Are your organisations involved in those different research activities, community consultation activities or specialised working groups? There are all different things. Is the college and the specialist group for community nurses involved in those study programs and ministerial advisory groups both at the federal and state levels?

Mrs Foley—We are involved in some of them. Sometimes we get bypassed, which is an issue for nurses. We try to encourage people to include us in their deliberations, but it does not always happen. Some of it is simply due to the sheer workload and the impossibility of responding to everything. We do have members with specialities, like Laurie—and Margaret has also been involved in the past—who represent us on various committees.

Ms Dane—I think there is an overlay. I am just talking about New South Wales now and the Cancer Institute. There is an overlay there. We are not representing our organisation but we are nurses involved in some of those decisions and some of those committees that are governing the work being done by the Cancer Institute.

Senator MOORE—I have one last question, which goes to telemedicine, particularly in terms of the community situation and also for nurses generally. Telemedicine has been around for a while and thrown into the discussions. For the record, would you like to make any comment on the role of telemedicine and the role of nurses in that stream?

Mrs Foley—I will make the comment first off that we prefer to call it telehealth.

Senator MOORE—Okay. I like that a lot.

Ms Grealish—Again, if you change the paradigm to include health, I do not think the opportunities for using these kinds of technologies have been fully explored. I have recently become involved with the Rural Health Education Foundation, which is also federally funded, and I have had an opportunity to look at the programs that they have offered in the past and I am getting the opportunity to be on one in the future. The quality of the discussion, the opportunity to hear real people talking about their practice, is the kind of education we should be pushing. It is the kind of continuing education that can reach a large audience, and I know I will be using it for my work with undergraduate students.

Ms Dane—In the Greater Southern Area Health Service it is used because of the distance and it is often used at the practical level. The nursing unit manager of a team might be located in Moruya and will have a session every morning to discuss with the people at Eden and Pambula what the workload is for the day and those sorts of things. It can be very practical. It is also used for communication between the clinical nurse consultants and clinical nurse specialists in certain areas. So it does bring us together. On the next level, it is also there for education. Sessions can be televised and conferenced across a whole area. There is another level, but I have forgotten what it is. It is of great use on many levels. The cost of the technology is the biggest problem in rural areas. It is very costly, but a lot is being done to try to reduce the costs.

CHAIR—I do not think we have heard anyone tell us that they do not support the multidisciplinary care model, but you do not believe it is really happening to the extent it should be happening. Is it because we are really talking about ‘multi-multidisciplinary’ care models depending on the phase of the patient’s treatment? I am just trying to come to grips with all this myself. We heard that at the Peter Mac they have a number of different multidisciplinary teams that analyse where a patient may be at the different periods of treatment, and none of those teams seem to involve the patients themselves. You are talking about a community support multidisciplinary team model. Is it impossible to bring all the people together who need to be involved in it? Are we really talking about different multidisciplinary teams for each stage through to diagnosis, treatment, recovery and support type issues? How does that work and how do you see it working?

Ms Grealish—‘Multidisciplinary’ is an ambiguous term. It is not being used in a clear way. If you talk about ‘multidisciplinary’ being an approach, which is a philosophical position, that is where you get general agreement amongst all of us. We all believe that, philosophically, there is a range of services that people want to access, so we should be working together to make them available.

When you talk about how they are actually structured operationally, then you have a different picture. If you went into a large tertiary centre here in Australia at the moment and you heard the medical community talking about ‘multidisciplinary’, I suggest they would be talking about sitting down in a meeting with the surgeon, the radiotherapy oncologist, the medical oncologist, their medical students and whomever else happens to be there. That is multidisciplinary because they come from three different disciplinary views. When nurses talk about multidisciplinary, though, they are talking about doctors, nurses, physios, pharmacy and nutrition. I suspect, not having looked at the other submissions, that allied health people would use it that way.

I have not had an opportunity to look at the literature on what people with cancer call ‘multidisciplinary’, but I would be really interested to know that. What do they expect when they say ‘multidisciplinary’? I am not sure, and maybe that is a question you can ask others today. I think the difficulty is that, if we want to have a multidisciplinary team and name all the members of the team operationally, we are not going to get there because, although philosophically it is a good position, maybe it looks different in different settings as opposed to different stages of the disease.

CHAIR—But how do we get there? The committee could make a recommendation to say the multidisciplinary care model is the right model. Everyone agrees with that, and we should keep going on that, but it is meaningless unless we define the patients’ needs and put some meat on that. Can you offer us any guidance?

Ms Dane—In palliative care, we talk about an interdisciplinary team. I cannot give you the definitions but I know what an interdisciplinary team looks like. I think it is about all of us having a shared goal of where we are going, how we will get there and who the best person is to case manage for this client. An interdisciplinary team would include the client, the family, the doctor, the GP, the nurse, the specialist and whoever else is important. The naturopath and the home care people would be part of that team. That is an individual thing. The whole idea is that it is built around that person—as a support through that time in that person's life. When we talk about 'multidisciplinary' in palliative care, often what we think of is grabbing an OT from somewhere, pulling them in and getting them to do whatever, because that is all that is available at the time. They are not actually sitting there working towards the goals that have been outlined. I am not trying to clarify anything, because I think it is very complex. We can see what is needed, but how you get there is quite complex.

Ms Grealish—I would suggest that it is a step-by-step approach and that we first accept that 'multidisciplinary' is the way we want to go. I think we need to do research into how patients and families see 'multidisciplinary'. If we are going to define a multidisciplinary approach, it must include some reference to the need for supportive care. Any multidisciplinary approach should have a supportive care part to it so that it effectively stops us from excluding supportive type care activities from any definitions that the medical community might promote through documents like *Optimising cancer care*.

CHAIR—I want to talk a little about what you said about best practice—that it is something we cannot really grab hold of and is meaningless at the end of the day. They were not your words though.

Ms Grealish—I suggest that we cannot throw away a clinical judgment—that clinical judgment has to continue to be prized more importantly than guidelines and best practice standards et cetera. We need them—do not get me wrong—but it is problematic when they become more important than clinical judgment. When there is no opportunity for people to talk about the judgments they made clinically and to talk about why they deviated from the standard, the standards tend to dominate.

Mrs Foley—The best practice guidelines should be used as a tool in conjunction with other things like clinical judgment and not as a be-all and end-all.

CHAIR—There has been talk about an accreditation process for cancer treatment centres and about whether, for example, the centre will have psychosocial support, specialised nursing support and information provided to everybody about complementary therapies. Those are the sorts of things that you can then tick off to get to what might then be described as best practice. The list may be a dozen or 50 but, whatever it is, it is agreed. That does give us something hard, and people know that there is a best practice model to go to. I think I understand what you are saying, but I also see a practical need to get to a level or standard where we say that all these things as a minimum need to be provided to have proper care in the first place. The second question is whether it is delivered appropriately et cetera.

Ms Grealish—I would support that. I think you need some sort of standard, but my concern is that, when these services are set up, there is an expectation that people will have to access all parts of it. Whenever you set those up, we always have to be guided by the ethical position that people are free to make their own choices in light of all the available information. What patients and families have been telling me is that, sometimes, they either have not been offered a full choice or, if they choose something different from what is the 'best' treatment, they are either excluded or they feel bad or they do not get any more appointments with their medical oncologist. All kinds of things happen. So I think you have to have both, but we always have to have that ethical or moral position underlying it.

CHAIR—The final issue I want to cover is about empowering patients with knowledge about who they are seeing and the quality of the treatment they are getting, which relates often to the skill of the person who is delivering the treatment. How do we make that information available to people in a proper way? When we talked to other witnesses about this, they have said that if you are talking about a league sort of teams table—who is on the ladder, who has treated the most people, who is the most successful—that often can be very misleading. It will depend on the type of people you are treating, the extent of the development of the disease et cetera. Do you see a need and would you be supportive for that information being available to patients in a proper form?

Ms Grealish—Absolutely. I think the success of the New South Wales cancer services directory for breast cancer—I think it is on the web site of the New South Wales Cancer Council—has proven that people find that helpful. Again, though, that is not for everybody. People who are IT literate and people who want that level of information will access those services. Other people will not want that much. Having that information available in one place—and the non-government organisations, particularly the cancer societies, is a good place for it—is a starting point for patients and families and we would support it.

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

Proceedings suspended from 10.00 a.m. to 10.15 a.m.

BUICK, Mr Patrick, Volunteer General Manager, Bloomhill Cancer Help

BURNS, Mrs Sarah Judith Imogen, Music Therapist, Bloomhill Cancer Help

GARGAN, Ms Margaret Ann, Founder/Manager, Care and Education, Bloomhill Cancer Help

MORTON, Mr Geoffrey Alfred, Secretary, Bloomhill Cancer Help

Evidence was taken via teleconference—

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

Mr Buick—Thank you for giving us the opportunity to share further in the inquiry into services and treatment options for persons with cancer; we believe it to be both very important and timely. I will make a few opening remarks and will be followed by Margaret Gargan, our founder and manager of education and care. Sarah Burns, our music therapist, who is currently undertaking her PhD on evaluative research into the impact of music therapy on a group of recently diagnosed breast cancer patients, will then make a short presentation. Finally, Geoff Morton, our secretary, will make a brief statement. This should leave about 15 minutes for questions.

We have a very positive organisational culture here, with management processes that are fully participative and transparent. You probably need to have a vision of the four of us in front of this conference phone. In this room are several of our therapists, patients, clients, volunteers and friends—about 20 people. Being on the Sunshine Coast, of course, it is a lovely sunny day—you need to know that. Physically the main Bloomhill Cancer Help centre is a large residence placed amongst 10 acres of beautifully maintained garden and mainly virgin rainforest at Buderim on the Sunshine Coast. We have two therapist rooms, which are regularly used for counselling, massage, music and art therapies, Bowen therapy, reflexology, reiki, and client and patient assessment; and we have larger rooms that are used for group support discussions for patients, carers, volunteers and staff, and for meditation, relaxation and other meetings. Additionally, we have a couple of open-plan office areas and a library. Also, of significance, we have a wonderful large covered deck, which is used for things such as our fun and friendship club, art classes, various Bloomhill socials, individuals' celebration of life, other activities and fund raising functions.

We have four cars, which are mainly used by our volunteers to help in various care roles: driving patients to and from chemotherapy, radiotherapy and dialysis; as buddies, visiting people in their homes, taking clients and patients to assessments, meetings, hospitals, doctors and specialist appointments, giving relief to families and carers and bringing clients to and from Bloomhill for therapies and participation in some of our group work and fun activities. We have five opportunity shops located on the Sunshine Coast and we raise additional income from a variety of other fund-raising activities to support all the services for patients and clients at Bloomhill.

I will illustrate by relating my own experience. Nearly 2½ years ago I lost my wife Zoe to ovarian cancer. We participated in some of the group support services for carers and patients at Bloomhill and we had Zoe’s celebration of life here. Zoe had what I can only describe as a close to perfect death, both for her and for me. She died in my arms at home, which seemed to be more than just symbolic of the loving environment in which she had spent her journey dealing with living and dying of cancer. In the last nine weeks, I worked at home with the palliative BlueCare nurses; that included giving Zoe 21 injections each day, most of which I administered. This was very much our choice.

During the last year of her life, Zoe was in and out of hospital. She had operations and chemotherapy and tried many complementary medicines and therapies. I would like to have my experience, along with that of hundreds of other individuals, accepted as fact and, therefore, as evidence and not just dismissed as anecdotal. My background years as a management consultant, psychotherapist, counsellor and masseur have been invaluable in applying my skills and knowledge in a voluntary capacity at Bloomhill and in giving back to an organisation that has given me so much. I am actively involved in all aspects of Bloomhill’s development. All of us at Bloomhill are very privileged to be working in a context of humanity at its best. Zoe, in her final message to us, said that she had a life of conscious living and was then in a state of conscious dying, with conscious loving as the bridge.

Bloomhill is a wonderful model, but we still have many challenges. No specific person, modality or organisation has all the answers. We have a lot of fun here. Volunteers, patients and staff often hug but, of course, it is always optional. We are dealing with issues of life and death and quality of life and quality of death. At the end of the day, we are aiming for a spirit of unconditional human love. Looking around at the happy faces in this room, I would acknowledge that at times we come pretty close to achieving it.

As founder of Bloomhill, Margie Gargan has been building on her extensive experiences here and elsewhere and, in fact, is applying them in the near future to another site in the Blue Mountains. Personally, I do not like the terms ‘patient’ and ‘client’ because I believe they are both limiting, but at this stage they are all we have; at least we know to whom we are referring. I would like to embrace more appropriate terms.

One point I would stress is that a multidisciplinary approach not only should be the way but also must be the way. However, the model must be inclusive of both traditional Western medicine and complementary medicines. Our challenge is to educate and integrate these two aspects of our resources. Every patient’s journey after diagnosis is totally different, as indeed is everybody’s process of grieving. All patients should be able to choose from a range of support modalities and have the opportunity to access whatever level of information they require. We need to proceed with compassion and integrity, with the needs of the patient being paramount. The alternative is to foster a self-defeating fortress mentality. I will now hand over to our esteemed founder and manager of education and care, Margaret Gargan.

Ms Gargan—Thank you, Patrick. Having breast cancer whilst in charge of a cancer ward has been an incredible gift. It was a gift of insight and has been the motivation for the development of four models of care, the ultimate of which is Bloomhill. I have specialised in the area of cancer care for the last 25 years. I vowed 17 years ago, when I was diagnosed, that I would set up an organisation that would support not only the person with cancer but the whole family. I developed Bloomhill Cancer Help because I became aware that people were diagnosed, treated and then left out in the wilderness. No-one provided the psychosocial aspect of care. My intention was to fill the gaps and to complement the roles of other agencies. There is not enough recognition or understanding of how difficult survivorship is. Every time a symptom occurs, the person automatically thinks it is cancer related.

I am passionate about providing care and support from the time of diagnosis, as this is when the existential crisis begins. I also believe that care and support need to begin at the time of presenting the diagnosis. Whilst at the Prince Charles Hospital in Brisbane after being diagnosed with breast cancer, I headed a multidisciplinary team that developed guidelines for presenting a diagnosis of cancer. If this is done with compassion and sensitivity, it is a totally different ball game. I have been doing work with first-year medical students from the University of Queensland and the guidelines are an integral part of the tutorial there.

The ultimate of how not to present a diagnosis occurred to a gentleman who, with his wife, came to Bloomhill in an absolute crisis. He was diagnosed with hairy cell leukaemia 18 years ago and, because he had refused to have his spleen removed, the surgeon proceeded to tell him in the most brutal way possible just how he would die. That man had been waiting to die for all of that time and had not been living at all. He had not worked and his family was breaking down. We rehabilitated him. He accessed everything Bloomhill has to offer and is now once again working full time as a town planner.

Bloomhill is a model that is way beyond palliative care. It is an integrative body, mind and spirit model of care. There is a concept within our society that palliative care is about death and dying, which evokes fear. Cancer Help is all about quality of life and living. It is about empowering people and encouraging personal responsibility regarding their disease process. We have had a lot of people access our services because we are not about palliative care or hospice care. We encourage all of our people to go down the medical model path and utilise complementary therapies as well. This enables them to give it their best shot and ensures that they do not have any ‘if only’s. Within the Bloomhill model there is also a potential to have people fall through the gaps. To prevent this happening we have second monthly reviews for all of the people we are caring for. We contact people that we have not heard from in some time.

I believe that the key to implementing the appropriate changes in our health care system lies in acknowledging the fact that integrative medicine can be practised effectively and efficiently. I also believe that the way we go about doing this is reliant on educating all of our young professionals in the formative years of their study. The beauty of the Bloomhill model is that it is a transportable model. I can teach others how to adopt the model, which is what I will be doing in the Blue Mountains very soon.

Mrs Burns—I am a registered music therapist and a young breast cancer survivor of 20 years now, who has lost her husband to cancer. I have been a part of and involved with Bloomhill Cancer Help since its inception. Music therapy in Australia is a professional occupation and, as such, all practising music therapists are required to be registered with the Australian Music Therapy Association and to adhere to a strict ethical code of practice.

During my university training here in Queensland to be a music therapist, I was fortunate to do a three-month internship at the internationally renowned Bristol Cancer Help Centre in the UK—a centre which promotes holistic mind, body and spirit health care alongside orthodox medical treatment for cancer patients. This is more commonly known as integrative medicine. It was during my time working as a music therapist at the centre that I witnessed the positive impact on the quality of life which music therapy and the other complementary therapies gave to patients attending either the daily or weekly residential programs at the centre.

It was this anecdotal evidence which led to my inquiry and fed my desire to carry out evidence based music therapy research in the area of cancer care. I did this initially by accepting an invitation to return to the UK upon completion of my undergraduate degree to carry out a pilot study at the Bristol Cancer Help Centre with a team of scientific researchers. This research demonstrated that even a one-off music therapy session boosted the cancer patients' immune systems, lowered their stress levels and increased their energy levels, which is a very important factor, as the main symptom of cancer and its treatment is fatigue. Music therapy also decreased tension, and all the patients involved in the study experienced an increased sense of wellbeing and, thus, an overall enhancement in their quality of life.

I have been fortunate enough to be awarded an Australian Postgraduate Award scholarship to carry out evidence-based music therapy PhD research at the University of Newcastle in New South Wales, where I am investigating and evaluating the impact of an eight-week group music therapy program with women who have recently been diagnosed with breast cancer. In this research I am utilising both quantitative, psychosocial and physiological measures and qualitative, in-depth interview and focus group methodology in order to capture both the objective and subjective outcomes of the music therapy intervention.

My initial research findings are showing that music therapy can indeed positively impact on all aspects of a breast cancer patient's life, because music therapy, along with many other complementary therapies, aims to treat the whole person: their body, mind and spirit. It is and always has been my belief that the way forward in the treatment of cancer and other chronic illnesses is to bring into practice an integrative model of medicine, as is being increasingly adopted in the major medical centres throughout the USA, the UK and Europe.

Bloomhill is at the forefront of integrative medicine and as such it is the premier model of how such an integrative medical model works in the treatment of cancer. I am very proud to be associated with Bloomhill as I see it as the ultimate way forward in the treatment of cancer. I am now very much looking forward to carrying out postdoctoral research here at Bloomhill in order to evaluate the effectiveness of the model.

Mr Morton—My background is very different from that of most of those you have heard from during these hearings. I spent 39 years in the Royal Australian Navy. I will firstly address some financial issues and then comment briefly on accreditation or what could be viewed as standardisation.

On the financial front, the committee might benefit from some information on what it costs to keep Bloomhill delivering the services to the community that it does. This year our total budget income is projected as approximately $990,000. The bulk of this income is generated from our five opportunity shops and their associated warehouse—that is, some $725,000. Our other major sources of income are donations and fundraising functions. They are expected to yield $233,000 this year. Our expenses this year are expected to be just on $900,000, which should provide us with sufficient surplus to pay off half of the $130,000 we still owe on the land we occupy. We need to discharge this loan before we can start increasing the services we provide. As you will be aware, there is an ever-increasing need for these services. We currently find that our ability to provide assistance is being stretched to the limit. The biggest limiting factor is our ability to raise funds. As an aside, I would observe that some 80c in every dollar we raise goes directly back into client care.

You also need to factor into the above budget figures the fact that the bulk of our non-professional services are provided by our over 250-strong volunteer force. Without their efforts we simply would not be able to operate. All but one of our management committee of 10 are volunteers. Many of them devote 20 hours a week or more to Bloomhill activities. It is very difficult to capture the total effort put in by our volunteer force. However, on the basis of the data available to me, a conservative estimate of the hours put in by our volunteers last month was 1,500. The figures I just gave you reflected our budgetary position as developed in October last year. But overseas catastrophes such as the tsunami have markedly affected the inflow of donations to us. Currently we are looking at not being able to pay off our loan as quickly as we would like to or, indeed, need to.

So is there a case to be made for community based organisations such as Bloomhill to receive some kind of financial support from government? I think there is. But this support needs to be provided in such a way that it does not increase the bureaucratic workloads placed on organisations such as ours as this would inevitably divert us from our primary role. A possible formula might be for government to provide grants on the basis of $1 for every dollar contributed by the community up to a maximum limit to be defined. I would suggest to you that this cost would be more than offset by the reduction in the reliance on government funded traditional services which would occur.

I turn to the potentially contentious issue of accreditation. This in itself costs money to implement and administer. I will not make any comment on the need for formal accreditation for those organisations providing hospital and clinical care. However, for organisations such as Bloomhill which provide complementary care and work closely with the mainstream providers, a regime of clear oversight or standardisation might be more applicable and certainly less expensive. If you like, this self-regulating model is akin to what occurs across industries and in the sports aviation field. This reduces costs to government but still gives the public confidence that standards are being set and maintained. We could go on, but it might be more productive if we were to take questions from you.

Mr Buick—We are open for questions, folks, if there are any.

CHAIR—It is interesting that you described Bloomhill as an ‘orthodox medical model providing complementary therapies’. Does this mean you are officially acknowledged by organisations such as the Queensland Cancer Fund and the oncology departments in public and private hospitals?

Ms Gargan—We definitely are. Nambour hospital is developing a cancer centre that is actually doing outreach as far as Rockhampton and west of Rockhampton. We are going to be an integral part of everything that happens within that cancer centre. So they are definitely recognising us as a very viable and important model.

CHAIR—The other question I have, if it will not take too long for the answer, is: what actually is music therapy?

Mrs Burns—There are several different modalities of music therapy, but basically we can play live music to patients for relaxation or use pre-recorded music to help patients to relax and to create imagery, or we can use another technique called improvisation. Improvisation uses a number of tuned and untuned percussion instruments. I am carrying out research on that at the moment because it is proving a very valuable and powerful way to actually help patients to express emotions by using instruments in a group setting creating different themes or feelings—all sorts of different things happen. It is a non-verbal way of expressing emotions and being able to release anger, frustration and a lot of different things. It does cover a very wide range of music therapy techniques. Often patients will use imagery to help them during their radiotherapy or chemotherapy treatments by creating their own image through music to help them during that particular phase of their treatment. I hope that has answered a little bit of your question, but we could go on for a very long time.

Mr Buick—You have to give credit to a PhD student for summing up in a short space of time like that! We are very honoured to have Sarah here. Music therapy is a significant modality. There are of course other things, like art therapy which, at the end of the day, have similar aims.

CHAIR—Thank you for that.

Senator LEES—How do you get your referrals? Do local GPs refer? Are there specialists that refer? How do people find you?

Ms Gargan—People can self-refer. We do get referrals from surgeons, hospitals and doctors but one of the main things that happens is that people just drop in here. They come in in a crisis and if they are in a crisis we see them immediately. A registered nurse sees them and does an assessment and then together we plan whatever they are going to access through Bloomhill. I guess it is my greatest joy that people are now contacting us as soon as they are diagnosed. We can start to teach them coping skills. Once a person has been assessed by Bloomhill we then send letters to their treating doctors—the GP and the specialist—saying, ‘This is what we are offering your patient’ so that they understand that we are working together as a team.

Senator LEES—So there is no reluctance on the part of your patients to have their doctors informed? We have found in other centres as we have moved around the country that some patients are very reluctant for their doctors to be involved because they are rather concerned about their reaction or response.

Ms Gargan—No, we do not have a problem with that at all. Initially, when I first started Bloomhill, there was some suspicion and they were not sure what I was trying to do or what I was actually on about. But now we have got the respect of the medical profession and when we do an assessment with our people we ask them to sign a consent form so that we can send letters to their doctors. I have never had anyone refuse to do that.

Senator LEES—If you are so well respected in the local area—and obviously you are—and as you are part of the new cancer services unit, is there no regional funding or state government funding at all for your centre?

Ms Gargan—To be honest, I do not want to go down that path because it is too restrictive. We are the one organisation that can be completely flexible. For instance, we had a gentleman who was in an absolute crisis. His daughter was 13 years old. He had been in the too-hard basket for all the other agencies. As soon as I saw him he became part of Bloomhill and he had a buddy that looked after his daughter and him. I think the key is to absolutely have flexibility, to not be caught up in paperwork and to not be taken away from what the core business is, and that is caring for people.

Senator LEES—So you have not even applied for any establishment funding or, for example, funding to pay off your loan or any specific grants to re-establish in the Blue Mountains—or is that a totally separate organisation?

Ms Gargan—The organisation in the Blue Mountains will be Blue Mountains Cancer Help, based on the same model that I have set up here. But we do take gambling money. We have had a lot of that. In Queensland we are fortunate that we have Jupiters Casino Community Benefit Fund. I have actually accessed $230,000 of gambling money in the time that we have been going.

Senator LEES—And how is the expansion to the Blue Mountains being funded?

Ms Gargan—It is going to be self-funded as well. A lady who recently died left a trust of $100,000 for a very special program. I am sure that they will be accessing that money. Also they are setting up an op shop. They already have a lease for six months rent free.

Senator KNOWLES—I would like to explore this funding thing, because I understood Mr Morton to suggest that you would not be opposed to some form of government funding.

Mr Morton—Yes, that is exactly what I said. I think we have to look at how that comes to us. There is some responsibility and some need for governments to be able to fund organisations such as ours. But the point that Margy was making was that the strings that inevitably come with the existing arrangements create such a bureaucracy that it diverts us from our ability to provide help. So we have to look at a mechanism of being able to receive government help and government funding, perhaps for particular purposes, but allowing us then to apply that in a good and sufficient way. I understand clearly that there is financial accountability through the government system, but for situations as important as this and the work that we provide we ought to be able to find a way of making this happen. We ought to be able to be innovative enough to meet the requirement without getting bogged down in bureaucracy. I think that is what Margy was really getting at. We need to be free to pursue the things in the way we do it. We do not want to employ administrative staff just to administer funding, because that would be self-defeating. As I said to you, we have a very high return rate on the donations that we get, and we would like to maintain that.

Senator KNOWLES—I understand that. I have to say that there would be not an organisation in Australia that would not like to adopt that model, particularly when we get into areas of nursing homes and so forth. But, unfortunately, governments need to have accountability and scrutiny so that the public can be assured that the facility is running according to what they consider are appropriate rules and standards for their taxpayer dollars. In that context I ask whether or not you have explored with any level of government—state, federal or local—the model that you are suggesting.

Mr Morton—No, we have not explored it, but I would be very happy to work with you as you go through this process to try and come up with something that meets your requirements—which I fully understand—and helps us do our job.

Senator MOORE—Could you just expand a bit on the basis of the family focus that your organisation has and the fact that it is open for a range of help for the carers as well as the person who actually identifies with the condition.

Ms Gargan—We recognise that the carers go through equally as much as the patient does but that their needs are different, so we focus as much on carers as we do on the patient. We have a carers group that meets once a month, we have a carers retreat once a year and we also have massages for carers. Another aspect often left out of the equation is children. We focus on the whole family, so if children are struggling because their parents have cancer we have the children see our art therapist. Children with cancer also see our art therapist, who specialises in looking after children. It is also important to say that when we are looking after children we never talk money. We sponsor children, because people who are going through a crisis do not need extra financial burdens as well. We are passionate about caring for the whole family.

Senator MOORE—I have another question to do with money. I know that Mr Morton and Mr Buick would have views about this, being on the board. There is a fee component, isn’t there, for people who want to go and spend time there?

Ms Gargan—Yes. Do you want me to tell you what that is?

Senator MOORE—I think it would be useful for the process. You are in an extraordinarily beautiful part of the world. What is the possibility of getting people who might not have access to good incomes—if you were in Brisbane, for instance, in an area that is not well off—to attend your centre to experience the Bloomhill process?

Ms Gargan—I will explain what we do charge, firstly. We charge $25 for a single person and $40 for a family, and that entitles them to have a free massage, free counselling or free complementary therapy. We keep all of our fees really low. If people are on a health care card and they access any further therapies, it is only $15. If they are not on one it is $30. For our support groups, such as Fun and Friendship, it is only $5 for meditation and those sorts of things.

Also, when people are genuinely financially disadvantaged we sponsor them. We do not charge money and we do not talk about money if we know for certain that they cannot afford it. You talked about people coming from Brisbane. We do have quite a few people coming up from Brisbane now, and the number will increase the more we become known. We are also involved with Angel Flight. We flew a young mother with two daughters, aged 13 and 10, up from Adelaide. They accessed everything that Bloomhill has to offer for two weeks. That really changed their lives. The two daughters did art therapy twice and wrote letters to their mother saying that they were going to be okay, knowing that she will die some time. The staff come to me or to Patrick and say, ‘This family genuinely needs sponsorship,’ and we do that.

Senator HUMPHRIES—The committee has been looking at this distinction between complementary medicine and alternative medicine. The definition we have been given is that complementary cancer medicine is meant to be in conjunction with, or supportive of, the conventional treatment that a patient might receive, but alternative medicine is in substitution for what a patient might get in a conventional sense. Are you conscious of whether any of your clients, for want of a better word, are accessing your services in substitution for conventional cancer treatment such as chemotherapy or radiotherapy—that is, they might have given up on those other things and are relying on the sorts of therapies available in your centre and not undertaking the other sorts of treatment?

Ms Gargan—Very rarely does that happen, because we really encourage people to access orthodox medical treatments. I will share with you one example. The husband of a lady fell in through the door in absolute crisis about his wife. He said: ‘I don’t know what to do. We think she’s got cancer; she’s never been to see a doctor.’ Normally I would never invade someone’s privacy, but I went around with him immediately. She let me through the door because I was from Bloomhill Cancer Help. She had been accessing alternative therapies. She had been having colonic irrigation twice a day, seven days a week for months and had never seen a doctor. Her breasts had gone, had disappeared from the cancer. Her arm was enormous and her lungs and liver were involved. It was the most horrendous situation. Ultimately, we did get her to see a doctor and she ended up having palliative care at home. But we certainly do not encourage alternative therapies. People access them and they are certainly entitled to. We do not interfere with that, but we do promote orthodox medicine.

Mr Buick—The concept of alternative, of course, goes back to the fifties and sixties, when it was widely used. Some aspects of those areas got bad names. Today sometimes people use ‘complementary’ and ‘alternative’ synonymously. We are very clearly complementary. People come to Bloomhill as patients because they have had various medical treatments, experiences and so on. Then it goes on from there. Probably they have a new hat of becoming a client. I just want to stress that we are specifically complementary medicine.

Senator HUMPHRIES—I think you were saying, Mr Morton, that you did not believe that a strict accreditation system would suit the things you do at Bloomhill—you would rather have a more flexible model that allowed you to self-regulate.

Mr Morton—That is correct. There are plenty of examples out there where this happens. I happen to know very well the sports aviation field. They—the Gliding Federation, for example—are delegated by CASA, which has the overall responsibility for administering the standards using a peer assessment process. That kind of thing is appropriate to a complementary organisation such as Bloomhill—that way people do have confidence in what they are getting. But you do not put regulations, bureaucracy and expense on top of that. It is horses for courses. It is different in hospitals, obviously, but for our organisation and for organisations like ours some other model may well be more appropriate.

Senator HUMPHRIES—With the moves that are happening at the moment towards an accreditation system for cancer centres and the credentialling of therapy providers, you at this stage—although obviously you have not seen the details of the scheme—would be unlikely to seek that accreditation or credentialling for your staff.

Mr Buick—I am very familiar with the processes of accreditation across different industries, where you have to go through measures of competencies and everything else. More important is the actual process of arriving at accreditation. Arriving at accreditation provides a good opportunity for integration of the industry. It is definitely healthy to explore, in the same way that we can explore the formula that a different site or organisation needs to adopt. That needs to be an ongoing, very carefully integrated process.

Senator HUMPHRIES—I understand that. Mrs Burns, did I hear you say that it was a requirement that music therapists be registered with the Music Therapy Association nationally?

Mrs Burns—Yes, the Australian Music Therapy Association, whose head office is in Sydney. There are quite a number of music therapy courses, with four-year undergraduate degrees, two-year postgraduate degrees and master’s degrees offered at universities here in Brisbane, Sydney and Melbourne. The Melbourne course has been going since 1978, I believe.

Senator HUMPHRIES—So a person who practised as a music therapist without registration could be prosecuted.

Mrs Burns—If they are working without registration then they would be subject to prosecution, possibly, yes.

Ms Gargan—All of our therapists are registered within their own modalities. They also have to have insurance. They cannot treat anyone at Bloomhill without having their own private insurance.

CHAIR—Thank you all for taking the time and effort to put in a submission and to link up with us today for what is a very important contribution to our inquiries. I thank you for that.

Mr Buick—Thank you very much, senators. We are very keen to listen to the outcome. Do you have a timetable?

CHAIR—We will report by the end of this financial year. Thank you again.

[11.01 a.m.]

ARGALL, Mr Dennis Walter, Private capacity

PAICE, Mr John Christopher, Member, Brain Tumour Australia

PAICE, Ms Sue, Member, Brain Tumour Australia

PITT, Mr Matthew David, Member, Brain Tumour Australia

PITT, Ms Susan Louise, Executive Committee Member, Brain Tumour Australia

STRANGMAN, Mr Denis, Chair, Brain Tumour Australia

VIVIAN, Ms Bernice Clare, Executive Committee Member, Brain Tumour Australia

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

Mr Strangman—Thank you, Chair and senators, for this opportunity to appear before the Senate inquiry. I trust the size of our group—six people—is not too intimidating, but between us we have a range of experiences and knowledge. I am the foundation chair of Brain Tumour Australia, the only national consumer advocacy group for brain tumour patients and carers. My late wife Margaret died from a glioblastoma multiforme malignant brain tumour in 2001 and I became fired with a desire to help people in a similar situation to have easy access to reliable information and resources. I am also involved in various cancer and palliative care committees, including the Cancer Alliance Network, whose representatives are to appear before you this afternoon and which was helpful to Brain Tumour Australia in our formative stages.

My colleagues include Ms Susan Pitt, an executive committee member of Brain Tumour Australia Inc. and the mother of Matthew, who also appears today. Matthew is a four-year survivor of a benign brain tumour that was diagnosed in his late teens. Ms Clare Vivian is an executive committee member of Brain Tumour Australia Inc. and the widow of Anthony, who had a brain tumour and had many and varied experiences with alternative/complementary therapies. Ms Vivian is a self-employed information technology and business development consultant. Mr John Paice is a former public servant and now a statistical consultant. John has a glioblastoma multiforme brain tumour and appears with his wife and carer Sue Paice.

When someone is diagnosed with cancer they, their family and friends will often go in search of information. Not always, but often they do. People want to help. They may know of ‘something’ that helped a friend or might not be widely known that might be useful. They will turn to anything and everything, sometimes with good results and at other times it is a disappointment and a disaster. People who are diagnosed with cancer are prompted to take a look at where they are at, what is important to them, what is ahead, their relationships and even their beliefs. I do not know if many of you watched the interview with journalist Geraldine Brooks on Andrew Denton's television show on Monday. At the end of the interview, he asked her about her diagnosis with breast cancer and she replied:

> There were really a lot of good things about last year. The incredible kindness that comes from your friends, all the prayers and Lourdes water, and somebody actually hired a monastery full of Tibetan monks to pray for me for a day … Somebody else trudged into Kurdistan and tied a scarf around a holy rock. My atheist friend in Denver said, "I can't include you in my daily prayers, but I'm including you in my daily anxieties."

I thought that was a great comment. My late wife Margaret was fully prepared to be the first miracle to prove Mary MacKillop's elevation to sainthood, but her attitude was also a mixture of being positive but realistic: positive to accept anything beneficial in treatments and therapies that might come her way—the neurosurgery, the radiation therapy, the chemotherapy—and realistic to know that we were on the roller-coaster ride of our lives and the prognosis did not look good. I would like to acknowledge my 19-year-old son Gregory in the audience. Gregory was 14 when my wife was diagnosed in 2001 and he was a carer with me as we travelled this journey.

My colleague Matt Pitt is able to talk about how a well-meaning friend steered him in the direction of a shyster multilevel marketeer, peddling you-beaut nutritional supplements. Matt also believes strongly in the need for a point of contact in the treatment continuum. My colleague Ms Clare Vivian can talk about how her late husband Anthony spurned standard therapy and tried the alternative therapies on offer and what effect they had. Mr John Paice can tell you how he nearly had to go interstate for his radiation therapy because the local facilities were fully booked. My colleague Ms Susan Pitt is not only the mother of Matt—and, by the way, she is the daughter of Rob Chalmers, the longest-serving member of the parliamentary press gallery—but also has a more personal experience, and I am permitted to say that Susan had recent treatment for breast cancer.

I need to say at the outset that we are not doctor bashers. There are inadequacies in the health delivery system in Australia, but there are many staff in the oncology area who are well aware of these inadequacies and are trying to bring about change. For example, I was privileged to serve on a committee with medical staff to establish a cancer resources centre and library at the Canberra Hospital, and that project is now up and running with a library of 700 resources which are borrowed at a steady rate by patients and their carers who visit for treatment. It is very well supported by staff. But they can only do so much, and let me instance this example where no amount of good intentions prevailed in the end.

Last year there was a proposal from staff for the creation of special nursing positions whose occupants would act as a common reference point for cancer patients undergoing treatment. They would be knowledgeable people who could answer unusual queries—not queries at the acute level or emergency level—that were troubling cancer patients and their carers. The money for these positions was diverted in the end to funding clinical audits. While that may be important, so were those positions. I do not actually know what a clinical audit is, but I do not think it is very relevant to a cancer patient on the end of a telephone line wondering why they have suddenly come out in bruise marks.

As another example of problems that exist in this area, I happen to know that each year there is now an average of 200 patients in the ACT and its catchment area—the southern region—who cannot receive radiation therapy in an acceptable time frame and must travel interstate, despite the extra cost and inconvenience. To my knowledge, only a couple of brain tumour patients have had to do this because their needs are usually recognised as being urgent. The staff are doing their best, but it needs a concerted effort to train and recruit sufficient qualified radiation therapy staff. I am old enough to remember that years ago in New South Wales and Queensland, when there was a shortage of teachers, education departments introduced attractive teacher-trainee bonded bursaries, which competed with Commonwealth matriculation level scholarships. Maybe we need to think along contemporary but similar lines today.

But what irks me the most is that it becomes a case of who can yell the loudest in competing for scarce resources, and, personally, I find this demeaning. In order to prove our point and to attract attention, I find it embarrassing to say that more children under 15 years of age now die from brain tumours than do children with leukaemia. Why is this the case? It is because there has been a great improvement in treatment protocols for leukaemia and a virtual standstill for brain tumour treatments. One new therapy, which we are all sweating on and waiting to see if it will receive a listing on the PBS, has been hailed as the first advance in 30 years for the treatment of malignant primary brain tumours. I find it embarrassing to have to say that, while brain tumours are 14th on the incidence list of all cancers, they jump to fourth place on the table of person years of life lost. Why does that happen? It is because brain tumours do not discriminate. They hit the elderly and the very young—males and females—and a great number of years of anticipated life for a young person are lost forever, and their parents and siblings carry that grief for a long period.

‘Prevention’ and ‘early detection’ are not in the brain tumour lexicon. You cannot scan the brains of the entire community. If you did, you would find—according to a study released in the United States two weeks ago—that 18 per cent of us already have some kind of anomaly in our brain, and two to eight per cent should be sent for clinical analysis of this anomaly. You would have to repeat the scanning process for everyone at least yearly. The cause of brain tumours is unknown, so you cannot embark on any preventative program. A cancer treatment policy of ‘one size fits all’ or ‘one approach suits most patients’ just will not help brain tumour patients in the main.

I would like $10 for every person who has spoken to me and said: ‘Denis, why did this happen to me? I exercised regularly, I didn’t smoke and I led a healthy life. What did I do wrong?’ There is no answer for these people. Mobile phones have not been proven as a cause, and for people of my and my late wife’s generation, mobile phones were not even part of our lifestyle—until my wife became ill. The only plausible epidemiology study shows some kind of connection between brain tumours and former employees of the Pratt and Whitney jet engine manufacturing plant in the United States—and my colleague Clare Vivian also has comments about the possible connection with certain solvents used in certain industries—but there are not too many former Pratt and Whitney employees in Australia amongst the 1,400 new cases diagnosed each year.

We need a focus on brain tumours—their treatment and causes—equivalent to the focus that AIDS and HIV attracted 15 to 20 years ago. AIDS diagnoses in Australia peaked at 952 cases in 1994 and declined to 290 in 2003. This was because of the decline in HIV incidence in the mid-1980s and the use, since 1996, of effective antiretroviral treatment of HIV infection. This only came about because of a massive concentration of public attention, research effort and government resources. We want the same attention for brain tumours, please. Thank you.

Mr Argall—Having had the privilege of listening to your conversations earlier this morning, I thought I would put aside the prepared remarks I was going to make and address three things. Firstly, I would like to say something about myself and my background. Secondly, I would like to take up the issue of abandonment and isolation, which the nursing groups focused on. Thirdly, I heard you speaking in various ways about interdisciplinary models, and I have jotted down some points I think might be useful there.

On my background, I should say that we have Denis and Dennis here. It was to our great astonishment, as people who had been nodding acquaintances and friends in this building 10 years before, around 1990 or so, that we found in the latter part of 2000, over the internet, that we were both still in Canberra. I am not here anymore; I live elsewhere. But at that time we were in Canberra. Both our wives were called Margaret and, within a short period, both had been diagnosed with the worst kind of brain tumour. We had both set up web diaries on that matter, and we were embarked on internet discussions. Many people out there in the world still confuse us and think we are one very strange and composite person, despite our best efforts, and we endeavour to remain friends.

My wife was diagnosed in April 2000. Indeed, this day, five years ago, her Canberra sinus pain—she was a chronic user of antihistamines and every allergenic plant in the world that survives frost—had become extremely severe. We waited through a period of having Easter and Anzac Day packed together at the end of the month. We knew that she had the world’s worst brain tumour, and she finished an operation for that in Canberra Hospital. It was a usual brain operation—about 10 people, about five hours, and it cost nothing, thank you very much. A most important thing to record here is that we live in a country where you get that attention and it can hopefully happen quickly for people.

I went on from that, and Denis and others joined too. We established an internet group called OzBrainTumour. Over five years I have shared the lives of hundreds of people struggling with this, living and dying with this, and it has been a very great privilege. I met some of the people here, but others have been friends for a very long time, even though we may not see each other.

I had a prior career in public policy advice. This week as I prepared, coming through the icebergs, ocean liners and aircraft carriers of major institutional submissions to you, I was reminded of having the temerity in 1974 to make a submission to the Coombs Royal Commission on Australian Government Administration when I was young senior executive. I put to them some things which were found a bit too radical at the time, such as that we should have strategic planning, program budgeting and, indeed, that we might put the senior executives on contract. I have watched some of these things instituted subsequently and, to my chagrin in many ways, I have seen the way things which I thought would produce better outcomes have tended, nevertheless, to be subjected to the problem with all bureaucracies and big organisations: things inevitably become part of process. In whatever we do in developing new systems, we have to get things which do not get stuck in process and constantly maintain focus on outcomes. I notice that in some places in the health area the word ‘outcome’ has been hijacked as a part of process in many ways.

I will discuss the abandonment and isolation matter. We were essentially abandoned right at the jump, after the big operation. Several days later, after pathology had been confirmed, the radiation oncologist came and saw my wife at 5 o'clock in the afternoon in the public ward. That is the worst time. If you have any kind of knock on your head, that is your most stupid time of the day. But that is when he came and said, 'We'll fit you in the queue when we can.' She rang me from the ward desk, and I said, 'Can I speak to him?' He was there and she passed him the phone. I said: 'Is there consent involved? Is there a briefing on these matters? What is this about? We don't know the path.' He said: 'Oh well, if you want to know about it, come along to the first session. Do you want to come with her?' That was the manner of it. There was no discussion of any other treatment.

Hence, I went to the internet. As an intelligent person, I was conscious that I had resources and background which many other people did not have to do these things. We found that there were much better options available in Sydney and we were able to get into a queue of treatment with the Sydney Neuro-oncology Group, affectionately called SNOG, which meant that Margaret, having been told that she had three to nine months, in fact lived for 16 months, but it was a very hard process for us as a family and for her. We supported her desire to fight and survive. I am also informed by having spent more than 100 days in public hospitals and hospices and seeing it, as well as sharing the lives of others.

Margaret died in September 2001. There was another historic event that particular week, a couple of days later: the attack on the World Trade Centre. I am aware that 2,726 people, according to the US Centers for Disease Control and Prevention, died in the World Trade Centre attack. I should note that, in the time since then, the number of Australians who have been told by a doctor that they are going to be killed quite quickly by a malignant brain tumour is much greater than the number of people killed that day in New York. It says something about our social perspectives, and I urge you to look at those things. I have made recommendations in my submission which go beyond cancer. Cancer, of course, is a large part of the health services subject matter. It is also a huge part of all of our mental apparatus: our focus on our greatest fears. I think it is important to try to do those things.

As regards the interdisciplinary model, I wrote down six points just now on what I think is important. Firstly, an interdisciplinary case management system needs to be understandable and seen as positive by all users. Secondly, it has to be launched at the front of the process—that is, at the earliest consultations with the person with the diagnosis. Thirdly, it has to be subversive of medicalisation and the commodification of what is done to people; that is to say, fourthly, it needs to shape actions in support of the individual, of that person's empowerment and of making the best quality of life for the days they have left. Fifthly, it must be simple, flexible, inexpensive and effective. Sixthly, it needs also to support the family and validate their rights. If you do not support the family up-front while the person is dealing with cancer, you will, from a crude budgetary perspective, see those people back later at much greater cost.

CHAIR—Mr Strangman, I invite you or your colleagues to make a brief contribution before we move to questions.

Mr Strangman—Is it okay if we move straight to questions from the committee?

CHAIR—That is fine. One of the things you mentioned was the process Mr Pitt had been steered into by a well-meaning friend. That is an issue that has overlapped with some of the things we have been exploring in this committee. I think that would be a useful experience to be relayed to the committee briefly.

Mr Pitt—As you can understand, when I was diagnosed with a brain tumour, it was a very frightening prospect that I faced. There was a lot of uncertainty and I had a lot of fear. It was very swift between diagnosis and being operated on—it was only about 10 days. There are things that I would like to say about the medical establishment, but that is aside from the alternative complementary therapies I think you are asking me about. After I had the medical treatment, the process called, I think, ‘a feeling of abandonment’ happened to me. I also went onto the internet, like Denis. There is no end on the internet to people trying to sell you things or promote their own therapies for whatever cancer. It does not matter; they treat them as the same sorts of things.

When you have nothing else to grab onto these things are the end of the line. There are calcium treatments and sugar treatments. There are all sorts of products—algae and all sorts of things—that are available. There are people making money off these; there is a lot of money being made, especially in America. Most of these sites seem to be American sites, but it is not limited to them. May I stress that brain tumours, in my opinion, are worse, in most cases, than any other cancer in that they take away the ability to think clearly. In a lot of cases a tumour does not get detected until it makes an impact on the person’s life. Typically, that impact is neurocognitive problems. It is hard for someone with a brain tumour to be able to choose intelligently what they should be doing. It is very easy for them to be falling into the cracks of the shysters, if I can put it that way.

I have tried lots of different things. There are Chinese medicines. The Chinese doctors are fairly benign, but there are lots of less benign characters out there. There are multilevel marketing people. One of them was a colleague of my friend’s mother. He wanted me to buy $1,000 worth of supplements every month. The group he is an associate of is an Amway-like multilevel marketing scheme called Mannatech. He wanted me to buy $1,000 worth of products every month and he said it would cure me. This was basically going to be the cure for all tumours and it was a great advance. He spent two hours with me. He had a PhD in chemistry from Melbourne University. I was convinced. I asked my mother, and she said no.

Ms Pitt—He rang me at midnight and asked me for my credit card number.

Mr Pitt—He had worked me over fairly well: he was a saviour. I would just like to point out the vulnerability of people with cancer—particularly those with brain tumours—to characters out there like this guy. He was working for profit—he was getting money from it—and he was actually trying to reach sales targets. He even told me as much.

CHAIR—Given the state of your mind at the time, would it have mattered if the complementary medicine approach organisation that you might have been dealing with was accredited or certified in any way, or wouldn’t that have made any difference?

Mr Pitt—I am a cause-and-effect type person and, with a lot of these treatments, I tend to focus on the chemicals, sugars and things that they might be giving me. As you know from the drug industry, it is very expensive to do clinical trials for any of these things, so I think it is impossible for anyone to give a clearly defined clinical outcome of what he is trying to sell to me. I could not ask, ‘Where is the clinical trial information?’ I would ask a lot of those people, ‘Show me the proof,’ and they would tell me every time that they could not afford to run clinical trials—‘But please trust me: these work; we just can’t afford to do clinical trials.’ So it would be very hard to tell someone, ‘No, they don’t work,’ because you have to run a clinical trial; they are too expensive. It is always going to happen.

Mr Strangman—Senator Marshall, Ms Vivian also had a similar experience.

Ms Vivian—My husband had family bowel cancer, and he always used to be worried about that. He had colonoscopies. He came across a group out of England called Campaign for Truth in Medicine. They do roadshows, and they are associated with a company called Neways. We joined. This was before his diagnosis. He bought the theory that B17 laetrile was going to be the cure for all cancers. We were already vegetarians long before this. We did a lot of healthy meditational lifestyle stuff.

When he was diagnosed with his brain tumour, he said, ‘I’ll take the surgery,’ because that was pretty much compulsory to survive, but he refused radiotherapy. We launched out. We got TGA approval to bring B17 into the country. Nine weeks later, the brain tumour, which was three centimetres by five centimetres, had completely regrown and gone deeper—that is the speed at which this thing could grow. He had to have more surgery. He had to have radiotherapy. He continued the B17 therapy as complementary therapy at that stage. I tried to work on him on this basis, because I had done the research, and I said, ‘I don’t think B17 is going to help this kind of cancer; it might help nice, slow-growing ones.’ There are all sorts of things like that.

While we were doing this, he wanted me to go off and get the sales training from Neways. I am a salesperson in the IT industry, so I am already quite well versed. There are books written on the wellness revolution and the $3 trillion, or whatever it is. There is money to be made on it. The methods that we were trained to do were not particularly ethical.

It does not mean there is no role for B17; there is a role for any number of these treatments. I have had good experience with Chinese herbal treatments for a range of things. However, getting back to what you said about accreditation, even if there is evidence that says this is what you can reasonably expect based on anecdotes—this is a typical anecdote—the trouble is that, when you hear the suggestion that this is a conspiracy on the part of conventional medicine and you go to the doctor and they pooh-pooh that, it sounds like a conspiracy. So you actually play into their conspiracy theory when there is no conspiracy. I think everyone has the best intentions, but they have some rather dubious ways of going about it.

CHAIR—I want to hand over to some of my colleagues, but, Mr Pitt, I would be interested in your view of how you were dealt with by the medical system. If we get time and my colleagues do not ask about that anyway, we will come back to you.

Senator KNOWLES—Does Mr Paice have any stories about complementary medicine to tell as well?

Mr Paice—I am based in Canberra. One of my contacts is in the Chinese community in Canberra, and they recommended a particular Chinese herbalist. I have taken advice from this Chinese herbalist and she said I should feel a lot better after three weeks. I have just started and after three weeks I will see how things stand. So I am doing my own little experimentation.

CHAIR—The herbalist is not offering to cure you, though, is she?

Mr Paice—No.

CHAIR—They are offering to complement your treatment by making you feel better—would that be how it is described?

Mrs Paice—John had a brain tumour removed, followed by radiation therapy. The doctors say, ‘There is nothing more we can do for you. We have to wait and see when the tumour recurs.’ They say ‘when’ the tumour recurs; we try and think ‘if’, which is a different mental approach. We have gone away and thought, ‘What else can we do?’ Apart from diet, meditation and those sorts of things that we have looked into, people have talked about Chinese herbs. Regarding your point about the accreditation, we thought, ‘How do we find out who is a good person to go to?’ We were lucky—we had this contact. Canberra is a small town and we thought this person would be reasonable to go to, but we would have certainly been helped if there were some form of accreditation. We were comforted by the fact that this person had several diplomas and Chinese stuff on her wall—I am not being very coherent, but—

Mr Paice—One of the links along the way is that her husband is an accredited Western medicine doctor, so that gave us extra reassurance.

Mrs Paice—For somebody with John’s condition—this glioblastoma multiforme tumour—the Western doctors say, ‘It’ll recur; go away and enjoy yourself.’ So you either accept that or you look for complementary treatments. As I understand a lot of these different complementary things, they are aimed at boosting your immune system so that you can at least fight.

Mr Argall—I have more to add on the Chinese matter, but it might be better to pass it to others if you want to go onto that at the moment.

Senator KNOWLES—I would be interested to hear your comments, if you would not mind.

Mr Argall—My wife was very determined from the jump. We had been living in China and we had Chinese friends. She had a sense of what Chinese medicine was about and was very concerned to pursue that direction. It happened in somewhat serendipitous circumstances, in fact. In Sydney we met a professor visiting Australia from the biggest cancer hospital in Asia at Guangzhou and ran off a prescription of hers, which considerably boosted what had been offered by a very well-qualified local practitioner.

We finished up in the hospital in Guangzhou. We did that in consultation with Dr Helen Wheeler, whom I would regard as, and few would question is, the best neuro-oncologist in the country. She works at the Royal North Shore Hospital. Dr Wheeler had worked with herbal material in laboratories with Chinese colleagues and seen extraordinary reactions to some of the Chinese traditional remedies. These reactions occurred in the Petri dish, so they are not necessarily going to happen with people, of course. I spent a year or so cooking strange teas with centipedes, scorpions and fungally altered caterpillars as well as other materials.

Senator KNOWLES—Your house must have smelled nice!

Mr Argall—It did. We were dealing then with a remedy which was deemed to support the immune system and give a person greater strength but it was also specifically anticancer. We brought that back into Australia from Guangzhou in an instant tea form. Subsequently it was not possible to bring more in because it was subject to a clinical trial in the hospital in Guangzhou. In Guangzhou we also saw doctors from M.D. Anderson and McGill who were qualified in Western medicine and were promptly offered treatments which were not accessible at the time in Australia in Western medicine.

Mr Strangman—Ms Pitt has some examples if anyone is interested.

Ms Pitt—I have a script for Chinese medicine and some Chinese herbs that I will show you. I will also show you the herbs that Matthew took and his script. When I went through my experience I went to see him and he gave me some needles so I could perform my own acupuncture, which I still have not got around to.

Senator KNOWLES—Is that because of a fear of blood, a fear of needles or a combination of all of the above?

Ms Pitt—I am a bit squeamish. That script is from a Chinese medicine place in Sussex Street. I can take it down to Dickson in Canberra and the Chinese medicine fellow there can read it and dispense it. I have no idea what most of the ingredients are. As Dennis said, Matthew was on a script that included things like centipedes, seahorses and fungi. I stopped taking the Chinese medicine when I went on to chemotherapy because I know that the liver can be overloaded by toxins. Matthew, can you remember what the fellow said to you?

Mr Pitt—He leaned back in his chair and said, ‘Herbs can help. But do not give up on Western medicine.’

Ms Pitt—He said, ‘Go and see the neurosurgeon.’

Mr Pitt—He was quite good.

Senator KNOWLES—Can I come back to something in your submission, Mr Strangman, that surprised me as a layperson. It said there are very few neurosurgeons who specialise in the treatment of brain tumours. Silly me, but I thought that brain tumours were encompassed in most neurosurgeons’ specialty.

Mr Strangman—There are about 100 qualified neurosurgeons in Australia. There are only about three or four that do a high volume of brain tumour specific neurosurgery. I would say that only about five per cent—that is an educated guess—of a typical neurosurgeon’s workload in any one year would involve brain tumour work. Therefore, there is no accumulation or repository of expertise and ongoing educated knowledge about the latest developments in the area.

Senator KNOWLES—Piggybacking on to that, can I ask you, Mr Pitt, to tell the committee about your experience with conventional medicine?

Mr Pitt—I was not feeling very well for a period of probably four years, but I felt particularly bad in the last three weeks before my diagnosis on 10 February 2001. I took myself off to a GP, a Dr Gupta at the Garema Place surgery. She no longer works there. She diagnosed me fairly swiftly and diagnosed that there was something wrong. She thought it might have been meningitis or a brain tumour.

I went to Calvary Hospital and was given a CAT scan. By that stage my mum had turned up, and she was there with me when I received the news from the radiologist. From there, there was a 10-day period. The type of tumour that I had was a very slow growing benign tumour that had reached a critical mass in my brain and was causing massive swelling and displacement. The tumour itself was five centimetres by five centimetres by five centimetres. I do not know the amount of brain fluid that was pooling up, but I was told afterwards that I had a couple of weeks to live. That is only significant for what I am going to say now. After having the scans I was sent to Canberra Hospital. I think there were three neurosurgeons at Canberra Hospital. I spoke to one of them, Dr Chandran. He said that he could operate on me but that he was going away and would be back in two weeks.

Senator KNOWLES—Having been given two weeks to live, you were told, ‘I’m going away’?

Mr Pitt—I had not been given two weeks then; it was only later that I was told that. He was going away and he said he could help me then. I was pretty much left to think about it on my own terms—as much as I could think at that stage; I was very sick. It was up to us. No-one at any stage came up to me and told me that there were far better places to get my tumour operated on—it was deep in the brain—than Canberra Hospital. At no stage did any medical person tell me that. If I did not have my family around me acting on my behalf—namely, my mother and my stepfather—I could well have had surgery at Canberra Hospital, two weeks after I could have been operated on in Sydney or Melbourne, by an inferior procedure that is the equivalent of taking a hammer to your brain compared with the things I had done in Sydney. No-one in the medical establishment told me that. It was a serendipitous connection, similar to Dennis’s and other people’s. I had a private medical connection of my own—my mother’s partner is friends with a paediatric surgeon who knew the people in Sydney. She sent a list of the five best neurosurgeons in Australia. It was only through those means, which the general public would not have access to, that I was given a list of the people who I should be seeing and I was able to find what I would call the best surgeon for me in Australia who does endoscopy, a minimally invasive procedure that only came about in 1997. I was operated on through that means.

I hasten to add that I was able to cover that with private health insurance. Most people would not be able to afford that on the public system—I don’t even know whether they could choose it. It had a huge effect on my outcomes. I have met patients who had the previous surgery—the surgery I would have had at Canberra Hospital—and they are in far worse condition than I am now. The fact that I can talk to you now, and even have my memory intact, is all due to the serendipitous connection and my private health insurance.

Senator KNOWLES—Forgive a personal question, but do you have any side effects post-surgery?

Mr Pitt—I had many side effects pre-surgery and a few side effects post-surgery. Most of the damage was caused not by the surgical procedure but by the growth of the tumour itself. Without getting into too much detail, I have a lot of memory deficits and personality differences. Every area of my brain was affected due to the size of the tumour and the pressure on the brain. Everything that we are is basically our brain, so I was affected in every way.

Ms Pitt—What we were offered at Canberra Hospital was someone to hold the slides up and basically shake their head and say: ‘Maybe we can do a biopsy and put two shunts in, but I’m going on holidays. Maybe my colleague will see you. Go back and sit in the ward.’ For many tumours you can have a neurosurgeon who is not the top, but if you have a low-grade tumour that is deep in your brain, you will get a much better outcome if you can access a surgeon with the sort of equipment and training that Matt was able to access. That was Dr Charlie Teo at the Prince of Wales in Sydney.

Senator LEES—Is there anywhere on the net or through your organisation where these five names can be passed on?

Ms Pitt—As to Denis’s list that he talked about, we in Brain Tumour Australia do not ever say, ‘See this surgeon,’ or ‘Don’t see that surgeon.’ What we do try to do is recommend that people get a second opinion or a third opinion. Dennis can comment on the list.

Senator LEES—It has some of the best in the world.

Ms Pitt—Yes.

Mr Argall—We have two groups really involved in this area. Denis was concerned to establish the activist organisation of the brain tumour association. I decided I would not follow that but would stay to maintain the integrity of the support group, OzBrainTumour. People who come in do have to be IT literate. They have to be a little bit down the track with that usually. The wonderful thing these days is that it is not necessary as a moderator to know what the latest things are. I am not up-to-date like many others. For example, a woman wrote in two weeks ago and said: ‘I have an eight-year-old and I want to go to the United States because in my state certain things are not available. Who else can I see?’ Somebody will write and say, ‘Charlie Teo in Sydney,’ although I am aware of a great deal of hostility in the conventional neurosurgery business towards him because he will attempt things that others will not and he seeks a little publicity. But then out of the woodwork the other day came a message from somebody who said, ‘I have been in a wonderful group since July last year. I have a child who is in a situation almost the same as yours and I have done these particular things.’ I have never written to this group before. I am a listener. But each time you find that, when somebody comes in and you think, ‘That’s not the mainstream GBM stuff that everybody talks about; this is an odd one,’ there is always nowadays somebody else. My view is that community is going to be more important in this.

One of the things we need oncologists to be aware of, especially when they are in areas which are remote from brain tumour centres, in places even such as Royal Melbourne or St Vincent’s in

Sydney, is that the remoteness begins very close to the big cities. The arrogance of thinking they know everything when they do not starts very close in sometimes. They need to be aware that intelligent patients are going to find information and be ahead of them in some matters. I have included in my submission a wonderful email with the permission of a building worker in Perth. He managed to influence his oncologist to get him down a particular line of treatment by virtue of meeting people and then having the confidence to talk about the things he knew which the oncologist did not have knowledge of.

CHAIR—But it should not be a lottery. That is something we have to turn our minds to. If people are in a position to access information for a whole range of reasons, it should not mean that some get better care than others.

Mr Argall—I can only agree.

CHAIR—Their care should be suitable. People who ought not to be providing the care should not be providing it.

Mr Argall—Your interdisciplinary case management needs to start up-front with people being given their rights. I would say that, 30 per cent of the time, conversations with patients in hospitals are wasted because people do not know what an EN, an RN, a CNS or a CNC is. They do not know what the intern is supposed to do or what the junior resident, senior resident or registrar do. They do not understand the relationship between them and the visiting consultant, so they ask the wrong questions or they do not get the chance to. They are terrified because they think, ‘If I ask the wrong question, I’m going to upset the man—he won’t like me and he’ll go away.’

Ms Paice—I wrote that down as one of the things I really would have liked. One day John was fit—he was riding his bicycle and running—and the next day he was in hospital with a brain tumour. I had never been in a hospital. We brought up three kids and we had never been in emergency. If somebody had given me a brochure saying what a registrar is and what an intern is, I would have known. I would have had a much better idea of how the hospital system worked. It would have been brilliant.

Mr Strangman—We now have resources.

Ms Paice—Yes, but I wanted something from the hospital that listed the hierarchy so that I knew who to complain to or who to say thank you to.

CHAIR—Yes. Mr Strangman, people still have to find you to get the resources.

Ms Paice—I just needed a map of the hospital on the very first day.

Mr Strangman—I want to say for the record that we now distribute this handbook called *100 Questions and Answers about Brain Tumors*. We imported 500 copies with the assistance of the American Brain Tumour Association and a sponsorship grant from Schering-Plough in Australia. We are very grateful for that. We established a toll-free line—1800 282 912—and we distributed 243 copies of the book to every neurosurgeon, radiation, oncology and cancer therapy centre in Australia. People ring that number if they come across the book in the treatment centre, and we provide a free copy directly to them. That will soon be running out. We have now imported 700 copies of *A Primer of Brain Tumors*, which is a basic 68-page handbook telling people who are newly diagnosed about elementary facts and giving explanations of the terminology of brain tumours. So we are trying to redress the kind of dreadful information underload that still exists around the place.

Senator KNOWLES—Ms Paice has raised a very interesting point about who is who in a hospital.

Ms Paice—If you have never been in one you just have no idea.

Senator KNOWLES—Do not think I am being rude, but that is such a simplistic problem, and you would not be the only person experiencing it.

Mr Argall—It is not just the hospital; it is the social workers, the entitlement to carer support and the whole works, which is why my second recommendation is that the opening discussion should essentially give people a portfolio. It should not necessarily be a 100-page book. I am much more interested in people knowing what they can get from Centrelink. Their whole lives are threatened by this. They need to know that the system is going to help them get through this one way or another. We are going to help the person with cancer to try to survive, or we are going to help the person down whatever pathway we can, and we are going to help that family to stay in one piece. Whatever literature you go to, you find that if you have a neurocognitive problem such as Parkinson’s or Alzheimer’s you have high incidence of marital or relationship problems. If you have a problem with cancer, you have a high incidence. If you put the two together in a brain tumour you have the world’s worst, frankly, on the research evidence. You are seeing people who are sensible here. We also need to be aware that there are a lot of people who need a lot more practical support out there in the community, as you say, Senator.

Mr Strangman—Ms Pitt has seen the contrast between what is available to her as a cancer patient and what was not available to her son Matt as a brain tumour patient.

CHAIR—I think that is important information for us to have, because the breast cancer model is being held up as something that is about a dozen years ahead of where everyone else is in the different cancers. But the concern is that that is still not where it ought to be. We do not want to hold that while everything else catches up; we need to move forward everywhere. If you could share some of those experiences that would be useful to us.

Ms Pitt—My first experience was with Matthew and the brain tumour. There was nothing—no brochure, nothing. Like Sue, I had no idea that the person we were speaking to was a registrar who would defer to the neurosurgeon. When I was diagnosed last July I got an enormous amount of information from BreastScreen, in the ACT. I was going to bring in the material today, but it is about a 13-centimetre high stack of information. There is an enormous amount of knowledge and a large awareness about breast cancer in the community. I think ten times the number are diagnosed with breast cancer than with a primary brain tumour. That does not include tumours like my son’s, which is not a malignant tumour. Those stats just cover those who have a malignant tumour, a cancer. But the support for brain tumours is just not there. We talk about it as an orphan disease or a Cinderella disease.

I got support from Breast Cancer Network Australia, Bosom Buddies, community nurses and the breast cancer nurses in the ACT. I think I stopped counting the number of people I saw here in Canberra as I went through surgery, chemotherapy and radiation therapy at about 100. It was such a contrast in the level of service, knowledge and expertise given to the person with the brain tumour. I still spend my time dealing with with brain tumours, and there are others doing a wonderful job with breast cancer.

Senator MOORE—Mr Strangman, the advocacy group got the documents from the states. I know everything comes from the states. You got the books and the other things and sent them to the specialist people in your area and the radiologists. What feedback did you get from those professionals to the activity you were doing?

Mr Strangman—They were very grateful for anything that was given to them for free. They were grateful that at last they had something they could genuinely refer patients to. We sent the book for review to a senior neurosurgeon, an oncologist and a radiation oncologist, including Professor Barton in Sydney. Naturally enough—we did not expect them to say it was a hopeless book—they wrote favourable reviews. We included that with the free copy. That reassured the specialists that they could refer it to the patient with confidence. Having said that, American things are American things; I am afraid, Denis, there is nothing in this about Centrelink. It probably has some reference to whatever the equivalent is in America. That is an area that we certainly do need to address. We are having a national workshop in Melbourne at Royal Melbourne Hospital on 16 to 17 July. Ms Vivian is one of the key organisers of it and I know she has people from the finance and assistance areas, all these practical things, coming along to tell our people everything about it.

Ms Vivian—It goes back to what was said before about not knowing who was who in the zoo. You know there is a social worker at the hospital but the private hospitals do not have as many social work facilities because they are not recoverable costs. You go through this whole thing and, in the end, in the first few weeks afterwards, you are in such a spin. I had to give up my job and become a full-time carer. I earned twice the money my husband did. He had sick leave, which was a blessing, that lasted most of his illness. However, you are in this constant spin. There is not one thing in your life that remains the same. It is a complete up-ending. I had to deal with psychological problems, practical problems. He had gone from being a very fit and able person to a person who had only half his visual field. He could not find words. He was no longer able to articulate things. I had to be his champion. I think that is a bit different from the normal thing. I have watched other people with cancer where their brain is still pretty much intact. You may not be an assertive type, but if you want to you can go out there and fight for yourself. But, with a brain tumour, if there is nobody there to fight for you, you are going to get handballed around by people in unnumbered jerseys.

Mr Pitt—No-one needs a case manager more than someone who has just been diagnosed with a brain tumour.

Senator LEES—Don’t the neurosurgeons or the people in the hospitals give these brochures immediately to anyone who is diagnosed, so they at least know where to start on the path? Isn’t there a pile of these at Canberra Hospital—or even with GPs?

Mr Strangman—We do our best, Senator.

Senator LEES—It is not up to you; I am saying that particularly the specialists—

Ms Paice—It was given to us by an enrolled nurse in the neurosurgical ward who was interested. I think he is a member.

Senator LEES—But there was no official process in the hospital?

Mr Argall—It is not an evidence based piece of paper. I state a fact. It is a very serious problem. I think there is a major problem with what is evidence based in that it grows around the money pots. I think we have to face the fact that people go to alternative options in treatment, and people come to organisations and form organisations, because of the awareness of the inadequacy of understanding the nature of cancer. I do not think we will get the urgent stuff solved at a professional level—leaving aside the case manager—in the long term until people recognise that doctors do not have all the answers and doctors recognise that they do not have all the answers. We need to start trying to find out what causes all of this.

Senator LEES—But surely doctors understand that they are not really providing any of the psychosocial support that people need; isn't that their brief? I just do not understand the reluctance, even of GPs, to at least give what is pretty concise and valuable information.

Ms Vivian—It is the lack of a whole person approach and a whole family approach that leads to that. I am here just to address that because I had to constantly ask for information, and still I found out so much by accident and from other people making a comment.

Mr Paice—When I was told in August last year that I had nine months to live—it was nine months on average I could expect to live with this type of tumour—there was, I thought, no understanding of what the averages were. That was the feeling I got. From my viewpoint I am not average, but that viewpoint did not seem to exist. So, while the information seemed to be conveyed to me and my family—fortunately, they were all present—as sensitively, I think, as possible, that understanding of the scientific basis of what was being said did not seem to exist.

Senator HUMPHRIES—Some of you have mentioned the internet as a source of information; I think you talked, Mr Argall, in your submission about support groups being valuable and, Mr Pitt, I think you said that some of the information you got about these dodgy cures came from the internet as well. What is the net benefit or disbenefit of the internet in these circumstances? We cannot regulate the internet, obviously, but should we discourage people from looking it up or should we be providing recognised alternatives? It is an impossible situation, but what do we do about it, given the misinformation and confusion on the internet?

Mr Strangman—Matt, do you want to answer that?

Mr Pitt—I think we have all got—

Mr Strangman—We have got 15 dozen opinions!

Ms Vivian—I have worked in the infotech environment: I worked for Oracle for 6½ years, up until Anthony's diagnosis, and I have done a lot of work with the internet. I am sure you are aware of the profile of Oracle Corporation. The bottom line is about being able to certify a site and maintain that so you can say, ‘This isn’t all a load of codswallop’. I think that is an important thing. And it has to be a fair and transparent thing, and it cannot be as evidence based as we would like it. However, you do need that thing, because when somebody says, ‘You’ve got a conspiracy,’ or ‘This is going to be a miracle’ type thing, people need to know that the site has had a bit of review and has a rating of some sort. I think this is important.

Mr Strangman—Can I just add to that. As a kind of sideline, I have established a web site relating to Canberra cancer services, called the Canberra One-Stop Cancer Web-Shop—we had to get a catchy title to attract people.

Senator HUMPHRIES—Don’t say it too quickly!

Mr Strangman—It has attracted 6,000 visitors in the last two or three years, seven or so a day. Now, the way that I get authorisation or verification is that I have an advisory board of five specialists, including Professor Reaby, the head of nursing at the University of Canberra; Dr Desmond Yip, an oncologist; my GP; and a scientist at the ANU. I have given each of them the absolute right to advise me to take down a link or any reference to anything that they personally believe is inappropriate for a person with cancer to be accessing or have access to.

The other thing is that there is a facility located in Switzerland called HON, Health On the Net, and you can submit your web site to that organisation. They will go through all the links and all the content within it and, if you are lucky, they will give you an imprimatur—a stamp that you can have on the end of your main web page. So Health On the Net is a useful guide for people. There is also a very good source in America called Quackwatch. You can punch any proposed treatment et cetera into its search engine and it will often bring up verified and scientific evaluations of the efficacy of that kind of treatment. I have found that quite useful.

Mr Argall—Could I just add that I am more of an internet anarchist or libertarian, if you like, and less dependent on endorsements and I think it is very instructive that, in a world where we seem to be much more consumers and fighting and competitive individuals, you are actually able to establish community on the internet. I am very impressed by the way in which you can get a sufficient number of people together to address something seriously and they provide advice to each other which is on balance very sensible, measured, up to date, constructive and mutually supportive. I do not think the internet differs from anything else. I can go into a newsagent and find pornography. I can look at the tabloid’s headlines outside the newsagent and see much worse news than I find on the internet. I contribute, as it were, to international development matters, to sustainable agricultural matters, to all sorts of things on the internet. I have a life there, in some ways, of doing things. I also try and get out in the sunshine. We are here with the invention of the street light, with the invention of the internal combustion engine. The internet is a new way of doing things which has made it possible, for example, for me to browse every one of your submissions and read your transcripts as they come up.

Senator MOORE—We could go on for days.

Senator KNOWLES—We could ask you many questions

CHAIR—We could. Thank you for what will be, in my view, a very critical contribution to our inquiry. Thank you for the efforts you have made and your participation today.

Mr Argall—Thank you very much, Chair, and members.

[12.09 p.m.]

TALMATZKY, Mr Stefan Sebastian, Vice-President, and Chairperson for Naturopathy, Australian Natural Therapists Association

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

Mr Talmatzky—I also speak as a practitioner.

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 Talmatzky—Thank you very much for the opportunity to appear before the Senate committee today. I will introduce the Australian Natural Therapists Association, ANTA. It is a national body that has been in existence since 1955 and represents about 4,000 practitioners. They are practitioner members from all disciplines of natural and traditional therapies, ranging from traditional naturopathy, herbal medicine, homeopathic medicine, nutrition, massage therapies and ayurvedic medicine to acupuncture and traditional Chinese medicine.

In order to be a member of ANTA, each practitioner is required to meet the high minimum standards set by the accreditation board, ANTAB. Members are obliged to comply with a democratic constitution, in effect signing up to the principles and ideals of our profession. There is a requirement for strict adherence to our code of ethics and professional conduct. Members are also obliged to attend continuous professional education. It is through mechanisms such as these that we strictly self-regulate our members for the common good. We were the first association to discuss with governments some models for government registration and to have recommended a coregulatory model to the New South Wales Department of Health. I am ANTA's vice-president and chairperson for naturopathy. Please remember that all executive positions are on a voluntary basis. I am a Heilpraktiker, which is a traditional natural therapist, also specialising in classical homeopathy. I fully trained in Munich, Germany, and have been practising in Australia since 1982.

I thank you for accepting our submission and I simply emphasise three key points. Firstly, for a real free choice for the public, one would really have to give the public a chance to attend some form of hospice or clinic where they could access natural and traditional therapies practised by accredited therapists and away from a dominating influence of mainstream medicine, if so chosen. Secondly, in order for such therapies to be effective, natural and traditional therapists must have greater access to their full range of remedies, to their tools of the trade. At the moment we are being asked to practise our crafts and arts with an ever-diminishing range of remedies, because either they have never been made here or the TGA has seen fit to prohibit the access to and use of some of those that have been made here. This leads to the third main point, which I know has already been the subject of discussion in this committee. I refer to the unacceptable use of the mainstream medical paradigm to assess natural and traditional therapies, including their remedies. With the greatest respect and with great hopes for your arduous work, may I suggest that you include these points in possible recommendations.

It is important that members of this committee see the fundamentally different paradigm from which we work. For instance, one talks about multidisciplinary teams. Mainstream medicine requires multidisciplinary teams just so a collective of specialists can treat a person. In natural and traditional medicine, it is impossible to practise our disciplines without considering the whole person: the individual constitution and of course the clinical state, their psyche, their environment, their family, their medical history and the spiritual realm—every aspect of their lives—in order to come to a proper, individualised and effective treatment. I will highlight the difference with an example. If I see 20 patients with the same or a similar illness, they might receive 19 different treatments or remedies. Ultimately this means, for us, that the patient really and practically comes first. Even when we are treating chronic disease we treat the whole person, and the diagnosis—even of cancer—is, practically speaking, secondary. Yet this already empowers the patient and prevents them from being just a consumer or object.

CHAIR—Let me ask a very direct question first, so we can get it out of the way. Will members of your organisation offer an alternative cure to cancer patients, or complementary therapy to the conventional treatments?

Mr Talmatzky—Our members are held to remember that the basis of their treatment is the patient, that they are to treat the patient in the state that he or she is in, and the diagnosis is secondary. In particular—and this may be the direction of your question—the difficult state of cancer is something which is really excluded; it is even considered a bit of a taboo for our members. The main reason for that—apart from what I could call the negative popularity of it, the sensational and the money aspects that are unfortunately associated with cancer—is that there is a legal uncertainty. Some states have legislation where cancer is not, as such, allowed to be treated other than by the medical profession. There is legislation in South Australia which we understand has been revised, but in spite of legal advice the situation is not very clear. So our members are advised not to treat cancer, and our members normally are not in this realm of offering cures or propagating alternatives. Has that answered your question?

CHAIR—I would like you to be a bit clearer than that. We heard evidence yesterday in Sydney from the Australian Traditional-Medicine Society’s Mr Khoury, who was very clear about the role that his members would play. It was one of supporting wellness and supporting general health as a supporting role to conventional treatments for cancer. His members would never—and he was very clear about this—advise someone that they have a cure for cancer and that they should not take their therapies in conjunction with conventional treatments. Is what you were saying? Because we have this ongoing argument about who is a quack and who is not, and it is fairly easy for others who want to be critical of complementary therapies to bunch everybody together, I want to get a very clear and concise position about what your members stand for.

Mr Talmatzky—As I said, we do not treat cancer. We see the patient in his totality. We assist in the situation the patient is in, including his pathology, in chronic ailments, including cancer. The most common scenario in the practice is that a practitioner would be approached by a patient who has gone through many treatments and then seeks some recourse from effects of the actual ailment or effects of some treatments. That would clearly be a complementary situation, although it might be confusing for us here because our disciplines are so autonomous, as opposed to the ones I read about that were mentioned in Perth—the more hands-on therapies. However, we never would and we cannot make a claim of cure; we would not wish to. Speaking from practice, you do not really know when you treat a cold whether you will be successful, so there is not an absolute certainty. The patient is almost always in a vulnerable situation so, from an ethical point of view, you do not make promises because they can turn out to be false.

CHAIR—Thank you, that does clarify it for me. I think it was important to do that. We heard from the last set of witnesses about an acupuncturist who provided acupuncture needles to the patient to self-administer. I think you were in the back of the room. That is not a practice your organisation would support, is it? I assume that acupuncturists are members of your organisation.

Mr Talmatzky—Yes, we do have acupuncturists and traditional Chinese medicine practitioners. Considering the difficulty of this discipline, I do not think anyone would advise or want to endanger his own patients by doing that.

CHAIR—So those sorts of people would not be welcome in your organisation?

Mr Talmatzky—No. We have the highest entry standards of training, and they would not make it.

CHAIR—I want to ask you about the TGA, which you referred to. I think you were being a bit critical about their being so restrictive that they stop you practising to the full extent that you would like. An argument that Mr Khoury used yesterday in his defence was that there are those with more traditional approaches who want to accuse complementary therapies of interfering with their treatments, such as doses of vitamin B. Mr Khoury was relying on the TGA clearly removing or putting out warnings on anything that might interfere with those sorts of treatments. I guess what you are saying is reinforcing that the TGA actually plays a very interventionist and proactive role in controlling natural medicines and natural therapies.

Mr Talmatzky—And will do more so after the recommendations of the expert committee have been accepted and interpreted in one way or the other. The Therapeutic Goods Administration is in a difficult position as it is now, I hear, nearly exclusively funded by the pharmaceutical industry. It is a government body. However, that might lead to a certain conflict of interest later on. I am saying this out of great hope for the TGA, but mostly in the hope that it will not be able to exert double standards, which to some practitioners it seems to do. You might remember the issue of comfrey, which has not been allowed to be used in an ingestive way since I came here 20 years ago due to an evidence study, which I would call bad evidence or science used badly, which actually castigated it as being carcinogenic. Over many hundreds of years we have used comfrey as the remedy of choice for the treatment of difficult fractures, even in the case of non-union of fractures. So we obviously have very different evidence there.

We have an ever-growing list of herbal and homeopathic medicines that are restricted and not accessible to us practitioners. I come from overseas and I may be a bit spoiled with the armamentarium of natural medicines we have there. It is very frustrating for all of us, especially when treating chronic diseases, that there are medicines that you cannot get here and that, with the present criteria, you will not get here. The trouble is that the qualified, accredited and registered practitioner is treated somewhat like a shop customer. There is no separate ruling for medicines to be made accessible to a practitioner.

Senator MOORE—In your paper I was impressed by the comment:

> If the practitioners themselves co-operate (traditional and mainstream), this reduces considerable stress for the patient.

That leapt from the page at me. We have some evidence that a large number of people who are having treatment do seek complementary treatments as well. As part of their journey they are seeking the two. On what evidence do you base your statement? Do you base it on patients telling your practitioners that the relationship between mainstream medical practice and your medical practice is so fraught that it is causing them more stress during their journey with cancer?

Mr Talmatzky—In Australia the experience is related in a small part to the accessibility of medicines but also to the non-existent or difficult communication. Again, the experience in Europe, where I was a bit spoilt, is one of a very normal relationship that every Heilpraktiker—registered natural therapist—has with one or two local GPs, internists and others. That is just a normal, smooth and proper working relationship for the patient’s sake. Here it simply does not exist. The few contacts I have had were private. In difficult areas, particularly with a few patients with cancer, contact was made via the patient, with sometimes a very good response and sometimes an adverse one.

Senator MOORE—There is no professional respect.

Mr Talmatzky—I could not even say that. There is no professional communication or relationship.

Senator HUMPHRIES—You say that it is not appropriate to submit the philosophy or the regime that your members work under to what you describe in your submission as an unsuitable mainstream approach. You say that it is absurd to imagine that remedies like herbal medicine, homeopathy and traditional Chinese medicine should be subjected to that mainstream approach. The mainstream approach advocates say that they live on the basis of evidence and that, if a treatment or remedy can be proven to actually improve the condition of a patient or address their medical problem, they will accept it. For example, they say that acupuncture, which was once very much ‘out there’, has moved much closer in to mainstream medicine because it has demonstrated its capacity to do that. Why is the paradigm that you work under not susceptible to that evidence based approach? If you have a remedy for a particular problem, why can’t it be put to a test to show whether it affects positively or not a particular condition, illness or disease?

Mr Talmatzky—I understand that statement might sound a bit radical if it is not explained. It is one thing to test a remedy. It is another thing to test a discipline or modality such as acupuncture—to put the whole modality under a test. The difficulty lies in what are the scientific parameters to which I will subject either this object for testing or the other? It is the question of which questions are asked before you conduct a test. Do you test this herbal remedy for its ability to destroy tumours or for a part of it being able to destroy tumours—and if you do not find it do you say it is rubbish? Or do you look at the ability of this herbal remedy in increasing phagocytosis or stimulating macrophages that can then indirectly be gently stimulated to literally gobble up tumour cells or debris from tumour cells? It depends on the parameters you put on a test. You cannot test a herbal remedy under the same criteria that you test a cytotoxic chemical.

Senator HUMPHRIES—Why can’t you do it? Surely at the end of the day the same question is there—that is, is this therapy or treatment efficacious in dealing with that problem? It seems to me that it is not a different paradigm. You are asking whether this can cure a patient of this disease or can it destroy the tumour. Obviously, if you pose that question, you have to submit both radiotherapy and a therapy that you might recommend to the same regime. But we are not generally talking about that. As I understand it, most of the therapies that your members would administer are not about curing people of cancer; they are about managing their condition and alleviating pain and things like that. If you take that as the test, why can’t your therapies be submitted to the same regime? In conventional medicine, we have painkillers designed to relieve people’s suffering, improve their condition, increase their longevity, relieve symptoms of nausea or vomiting or whatever it might be. Why can’t those tests be applied equally to a conventional drug and to a therapy that your members would administer?

Mr Talmatzky—They actually can. On the basis of what the question is—that is, whether there is a potential of influence on the tumour—you can. I have a stack of literature about it. There has been much research done and evidence gathered on the effect on tumour events and the immune system et cetera with more biological agents, herbal substances, enzymes and organ extracts. There is a vast amount of evidence and literature, so I must excuse myself—it must have been very misleading. If one wants, one can create that evidence. However, you can also create evidence to the contrary. Science can be used in this way or in that way. Why am I saying this? Because scientific evidence has been used to discredit natural therapy disciplines as such and has been used to discredit single remedies, such as the humble comfrey I just mentioned.

Senator HUMPHRIES—You have nothing to fear from properly administered science though, do you? Science which is properly and objectively assessed and applied to remedies should not be feared but should be embraced and used.

Mr Talmatzky—I honour your trust, Senator, but there is no such thing as an objective science. That does not exist. Science and medicine have always been used by power and politics, and they are being used. You can use science. There is ‘scientific evidence’ of a person being a subhuman. There is ‘scientific evidence’ by professors, by anthropologists and by universities supported by government that I myself am a subhuman. It happened many years ago—before my time—but, as you know, in Germany there were racial laws supported by science that led to the destruction of many people. Maybe I have to destroy a myth here. Science can be used for this and that. Look at what the Soviet Union did with science.

Senator HUMPHRIES—It was about misapplication of science or the use of selective evidence from science, but we do not have the time to go into it here.

Mr Talmatzky—It happens in medicine. You have evidence for this and you have evidence for that. I am saying this because we have sometimes been exposed to the misuse of science re our remedies. It is constantly said that herbal medicine is totally unscientific and homeopathic medicine is unscientific, but they are based on totally different parameters of science. But to get back on a practical point: there is present scientific research which supports the use of certain biological agents, including herbs, in the supportive treatment of cancer.

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

[12.37 p.m.]

GREGORY, Mr Gordon, Executive Director, National Rural Health Alliance

PHILLIPS, Ms Anita, Manager, Policy, National Rural Health Alliance

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 a brief opening presentation to be followed by questions from the committee.

Mr Gregory—Thank you for inviting the National Rural Health Alliance to appear before the committee. In our written submission and here today we concentrate on term of reference (a)(iv), ‘differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians’, and term of reference (a)(v), ‘current barriers to the implementation of best practice in the above fields’.

There is much that could be said about the epidemiology and incidence of cancer in non-metropolitan areas, and others with specific clinical and technical skills are well placed to inform the committee. The Alliance’s focus is not on epidemiology but on cancer as a powerful reminder of the difference it makes living in a rural or remote area and of the vital need to work with social and economic determinants and impacts of disease. The evidence relating to cancer in regional areas is summarised on pages 20 to 24 of the joint submission from the Clinical Oncological Society, the Cancer Council of Australia, the National Cancer Control Initiative and the National Aboriginal Community Controlled Health Organisation. The last of these, NACCHO, is one of the 24 member bodies of the National Rural Health Alliance, for which we work.

In summary, the incidence of certain cancers is higher for men in regional areas than in major cities but, unlike the situation with other conditions, as you well know, not worse again in remote areas. For females the rates of incidence are not markedly different between country and city. But what swamps the differential rates of incidence are the different rural and metropolitan rates of survival and the different amounts of grief that flow from an equivalent number of cases due to the characteristics of country areas. The chief villains are distance, levels of education, attitudes to self-care and to risky behaviours, and social and economic status. Overall, people in rural and remote areas are relatively vulnerable on all of these.

There can be no better case study than cancer of the need to treat the same rate of the same illness differently when it occurs in a rural or remote area. It is the archetypal instance of where rural and remote people have an urgent need for different consideration than their city cousins, due not to a higher rate of disease but because the greater rate of difficulty, the more serious sequelae from an apparently equivalent burden of disease. Everywhere we look in rural and remote areas, cancer reminds us that preventing an illness, intervening and treating it, require consideration of all aspects of life, not just health services narrowly defined.

The issue of travel is always cropping up in considerations of health services—and here it is again, writ large. The absence of cancer specialists and the immobile nature of some of the necessary equipment mean that travel and accommodation will always be required by cancer patients who live in rural and remote areas. According to another of the Alliance's member bodies, the Rural Doctors Association of Australia, the need to travel becomes a major determinant of poor cancer outcomes, as many people have to make their health care choices on the basis of financial and social cost, rather than optimal health care. One of the 10 key recommendations from the eighth National Rural Health Conference in Alice Springs last month was:

> There should be an immediate national review of the state schemes that assist patient and carer transport and accommodation. The purpose would be to introduce a uniform approach which provides people from remote and rural areas with reasonable reimbursement for accessing services that are not available in their own communities.

I would like to leave with the committee a four-page document which is the communique and set of 10 recommendations from the conference we held last month. With 1,100 delegates, it was the biggest meeting ever held on rural and remote health in Australia.

The recommendation I have just quoted echoes the proposal in the submission to this inquiry from COSA and others for a collaborative Commonwealth, state and territory task force to address the problems associated with the existing travel and accommodation subsidy schemes for people from rural and remote areas. The Alliance supports this recommendation in the strongest terms.

Another of the Alliance's members, Health Consumers of Rural and Remote Australia, has proposed that, as part of a holistic approach to health care, local requirements for transport should be included in individual care plans for patients which are prepared by their medical practitioner or allied health professional. HCRRA has also suggested that information on health related transport be collated to form an information database and should be better disseminated. Hospitals should be able to provide transport for patients without other means of travel to get from one service provider to another. Transport collaboration between local government authorities and the district health services could be strengthened.

On the Isolated Patients Travel and Accommodation Assistance Scheme or its equivalent—even the name is not uniform, as you well know—the characteristics of an improved scheme would include: more information about it; less variation within and between jurisdictions; carers and escorts being eligible; assessment being based on psychosocial needs, not merely medical grounds; consideration being given to those on low incomes and who incur a major loss of income; and attention to boundary issues and eligibility issues relating to a second opinion and treatment of choice.

There is some good news where rural cancer services are concerned. More comprehensive cancer services are evolving in some larger regional centres, and the success story at Albury-Wodonga is described in COSA's submission. The number of patients treated locally has risen from 150 to 750 a year, with an eight-fold increase in chemotherapy day treatments performed locally and the establishment of multidisciplinary clinics. There are also regional cancer centres at Ballarat, Bendigo, Wagga, Port Macquarie, Lismore and Townsville.

As is often the case, though, the good news is offset by the situation for Indigenous Australians. Evidence from the Northern Territory and South Australia shows that Aboriginal people and Torres Strait Islanders with cancer are twice as likely to die from the disease as non-Indigenous people with the disease. The causes of this differential include poorer access to prevention programs, later-stage diagnoses, higher rates of deadlier cancers and a reduced likelihood of completing a treatment program. Also we can assume that Indigenous patients experience greater language barriers, poverty, and institutionalised racism. The Australian Institute of Health and Welfare reported in 1998 that Indigenous women die eight times as often from cervical cancer as other Australian women. Much is still unknown about these differences, however, and Indigenous cancer is one of the areas in which it seems to be agreed that more research is needed.

So the rates of cancer may be similar for country and city people but not its impact. What this all adds up to is an alarming statistic: people in country areas who are diagnosed with cancer are 35 per cent more likely to die within five years than cancer sufferers in the city. This is what the Rural Doctors Association calls a timely reminder of the enormous inequalities embedded in our health system. The overriding causes are more advanced conditions at diagnosis and poor access to treatment subsequently. There is no shortage of concrete proposals to improve the situation and we have attached some to the evidence from which I am now reading.

The Alliance is aware of one of the special stimuli for this inquiry, and we note term of reference (b) which talks about ‘how less conventional and complementary cancer treatments can be assessed and judged’. The Alliance does not have evidence on this matter. If nothing else, this serves as a reminder to us within the organisation that the whole question of complementary therapy is one on which we have as yet no representation and no expertise. However, rural areas are short of vets and accountants as well as doctors and podiatrists, so we can safely assume that they are short of alternative and complementary therapists as well.

Australia has a shortage of health professionals relative to demand. As we have said previously to this committee, the Alliance is concerned that Australia is relying to a large extent on overseas trained health professionals as a means of overcoming our local shortage. This is not because of the sort of problem highlighted recently in one adverse case in Queensland as the normal rule is that the OTDs we have in rural areas give great service and are warmly welcomed. Rather, it is because we should not be taking professionals from resource-poor nations. This is an inappropriate position for a small developed nation to be in. Australia’s responsibility is to make a net contribution to the international health work force. We need to train greater numbers of professionals across the board.

Where overall professional shortages exist, the worst deficits are in rural, regional and remote areas. This has an impact on persons with cancer. The Alliance supports measures to increase our national supply of doctors, nurses, allied health professionals, dentists, pharmacists and managers. The recent conference in Alice Springs proposed that our universities move immediately to incorporate interprofessional education for health students as a means of helping to build a multidisciplinary health team.

The process of Senate inquiries is an important part of the ability of special interest groups to be heard at the highest level and in policy formulation. We hope the Senate will continue its strong role as the house of review so that the voices of people in more remote circumstances will continue to be heard in the work of parliament.

CHAIR—Do you have anything to add, Ms Phillips?

Ms Phillips—No, I do not.

Senator LEES—Thank you for your evidence. You mentioned multidisciplinary teams and multidisciplinary clinics. In rural parts of Australia, who would they involve as a typical example?

Mr Gregory—Senator, you probably know better than me. The situation is that it is currently very hard to put together the necessary multidisciplinary team for cancer care. One of the implications of what we have said here about general work force shortages is of course that it is very hard to provide a team. What this means is something with which you would all be very familiar—so much more depends still on the doctor. This means that the treatment one gets as a cancer patient will depend on the propensity of the doctor to understand it and the time the doctor has—many of them do not have much time. What it falls back to after the doctor is the psychosocial support one has from family and community.

There is an assertion made in a number of places that social support is better because you are in the bush. That is something which I think is a generalisation and is not always true. So the multidisciplinary cancer support team is something which is pretty rare in rural and especially more remote areas, as you know.

Senator LEES—Would teleconferencing be a way of at least informing people about their options? Are those sorts of things being used?

Ms Phillips—Yes, they are to some extent. But, without going outside professional boundaries, in some experiences people do things in addition to what they might normally be trained to do. For example, even in support there might be unqualified people who are part of a team and who are part of a local hospital who provide that sort of support and have the expertise coming in via telemedicine through computer links and things like that. So a hospital that normally would not be able to provide that level of service or treatment is able to do that with a team that is partly made up of people who are not even at that particular location.

Senator LEES—Over recent years, I have been unable to understand why in my own state it is so hard to get chemotherapy outside of the metropolitan area. I had a friend a few years who had problems. That has now been sorted and it is available in that particularly large hospital. Is it a work force issue? Is it a reluctance on the part of doctors both in the metropolitan as well as the country areas to take responsibility for treatment in rural areas? What are some of the barriers? To ask someone to travel for five or six hours by car, get their treatment and then go all the way back feeling absolutely awful—

Ms Phillips—And then do it again next week.

Senator LEES—The trauma that builds up with both them and their families must surely set the process back.

Mr Gregory—One of the recommendations we have listed here is that indeed chemotherapy should be more frequently administered by an advanced practice nurse with a protocol put in place and under the supervision of a GP.

Senator LEES—Is it the doctors’ reluctance to do that or the nurses’ reluctance to train?

Mr Gregory—On behalf of the Alliance, I would like to be a bit positive about this because, as you well know, the situation now in terms of the relationship between the general practice profession and the developing advanced nursing practice discipline or profession is much better than it was five years ago. I expect it will be much more practicable in years to come to have this sort of system where that is working. That implies good communication and good links between the advanced practice nurse and the GP or the specialist who is in a regional centre or the city.

You have mentioned also teleoncology or telemedicine. In one of the submissions to you, I think, or an earlier report, reference is made to at least three of the difficulties that need to be overcome in order to have teleoncology in a more widespread fashion. The first is the technical difficulty of having decent working phones, working internet connections, email and, potentially, transmission of images down the line. The second is remuneration difficulties—that is, whether the person who is doing the teleoncology or the telemedicine is remunerated or not. We have made some steps down that track as well. The third is legislative difficulties whereby the person may be operating over a state border and they need, therefore, to be registered in more than one jurisdiction. But going back to chemotherapy and advanced nursing practice, we in the Alliance are working as we speak on a revised position paper on advanced nursing practice. We have to say that things are much better now than they were five and especially 10 years ago.

Senator LEES—I have a question relating to detection and to actual screening processes. Is your organisation looking at how to get men in particular to report more regularly to or, if they are in any way suspicious, to appear at the local GP surgery? Are there any programs? I know there are some being run in Aboriginal communities based around things like men’s groups, barbeque groups and those sorts of thing.

Mr Gregory—It is that sort of innovative approach to public health campaigns, whether they be screening or something else, that we need to be more clever at adapting and adopting for rural areas. You just mentioned the need to use men’s groups—plus sporting clubs, carers, local shires, libraries and all those places and times that will get to rural people better than we have done in the past.

Senator LEES—Do you know of any particular campaigns out there that we could use as examples?

Ms Phillips—One of the ones in Queensland is breast screening for Indigenous women, which has been developed out of the public health area at James Cook University by Craig Veitch and others. That has been very successful. It has been very much on the ground, working with people. If you have not got the work force on the ground then it is very difficult to be able to do it. Just driving the mobile van into an area is not going to get the women to come along. It needs innovative and different kinds of approaches. That is one of the things we are recommending government looks at. The programs and initiatives that are promoted on our television screens in cities just are not applicable to people living in the bush. They do not learn the same messages, they do not hear the same messages, they do not change their lifestyle, they do not go along. Evidence in the most recent *Medical Journal of Australia* shows that in general people in the bush come to their doctors with a much later diagnosis than city people. So that is why we were saying that non-survival rates are much higher—because they come at a very late diagnosis. Part of that is because of ignorance, because of not wanting to bother the one GP who is in town and a lack of knowledge and education about the symptoms or signs.

Mr Gregory—In the submission to you from the Australian Nursing Federation they express surprise at the huge gap between breast screening operations as a whole—how that is all working so well—and screening for other cancers which is so far behind, particularly for some of the male ones.

Senator MOORE—The attachment to your submission from the Alice Springs conference mentions a couple of seminars that happened in the program. Were they popular in terms of the participants at the conference?

Mr Gregory—They were popular enough. Do you want a number?

Senator MOORE—No. In the range of issues that your organisation covers, particularly in that conference, was the cancer focus one that people were interested in?

Mr Gregory—Yes, but not more so than some of the other issues that were run. It was a conference where we considered all manner of issues. Certainly the cancer workshop was very successful in Alice Springs.

Senator MOORE—We have been hearing that just about every state jurisdiction and the federal government have put a focus on cancer research, cancer reviews and cancer consultation. From your experience, are the national health organisations plus practitioners and people living in the bush being involved in the various consultations and processes that governments are putting in place?

Mr Gregory—Particularly in relation to research?

Senator MOORE—The whole gamut. At the moment just about every jurisdiction has got something happening on cancer. What I am trying to find out is whether the voices from the bush are being heard in those processes.

Mr Gregory—The National Rural Health Alliance are certainly well connected and well consulted at a national level on most things. We do not have a lot of capacity as a national body to be involved in state-by-state initiatives or consultations. I am not even clear—Anita may know—about the extent to which states, in their consultations on health, are succeeding in consulting with rural and remote people. The general comment I would make is that many governments and other agencies many times fail to recognise the costs involved in genuine consultation with rural and remote people. It costs time and effort in your state. If you have a consultation in Brisbane and one in Rockhampton then it is going to be a significant effort for people from Central Queensland, the Cape or wherever to be involved. Often community groups as a whole complain about being forgotten in that regard. I cannot say anything specific about the state jurisdictions and their consultation on cancer with consumers.

Ms Phillips—I have recently come from living and working in North Queensland. It is certainly my experience that a lot of the areas outside metropolitan cities do not get the same amount of service. I think that goes back perhaps to one of the questions you brought up, Senator Lees, in respect of whether doctors are reluctant to upskill to be able to do the diagnosis and the treatment of cancers. I do not think it is a reluctance. I think they are very busy, terribly overworked and they just do not have the capacity to go into the metropolitan centres and do the skilling. Even the access to telemedicine is problematic in many areas where broadband and other more sophisticated lines are not available. It means that those professionals outside the metropolitan areas, in whatever state it is, are not hearing the same message about cancer, along with a lot of other things. I think, Senator Moore, when you say that a lot of the states have got this on their agenda—and it is certainly on the agenda of the Australian government—that it is not getting out to the people or to the professionals in the bush.

Senator MOORE—And it is just one more major issue to cope with.

Ms Phillips—Yes.

Senator HUMPHRIES—I am sure you are aware of the proposals to provide accreditation for cancer treatment centres around the country to formalise administration or delivery of services. We were told yesterday in Sydney that there would be a hierarchy of these centres. In the major metropolitan areas you would get major cancer treatment hospitals and it would range down to base hospitals in small centres where accreditation levels would be much lower because they only offer basic kinds of services. Do you have any fears or concerns about that arrangement? Do you think that a lower level of accreditation in the bush would in some way damage the capacity to deliver services to people there who have cancer?

Mr Gregory—This is the big question, isn’t it, for rural and remote health services, and therefore it is the big question for us in the National Rural Health Alliance: what is it we are after? If we were to have our druthers now, what would we be after? One starts from the obvious premise that everybody agrees with: you cannot have dialysis units in every village in Australia of 20 people where it might be needed. That tells you something straightaway; that tells you that one’s expectations have to be realistic. The other extreme—and this is the implication of your question—is whether rural people will be satisfied at having a second-rate or a less high-quality service than people in the cities. As I say, this is the vital issue with which we deal every day in the Alliance.

Our answer would be along these lines. Access to good health is a human right. Therefore, access to health services should be seen in that light—as a human right, not a luxury and not something one should have to pay for. Therefore, everything should be done to achieve—and this is the phrase that has been coined in the past which seems to sit well with some people—equivalent services for equivalent need. That is a bit of a play on words and really does not answer the question you pose. It is true that people anywhere are willing to make known, explicit trade-offs—for instance, about things like birthing and dying—between the quality of the professional they have and their psychosocial experience. By this I mean that some women will knowingly take higher risks than they might be advised to take in order to birth on their own lands or in their own home. This is well illustrated by a quotation from the front page of the Cancer in the Bush Conference report from three years ago which is the story of a family who knowingly took a child with cancer home to die. From memory, I think that child was not seen for the last four to six weeks of its life.

People will always be willing to trade off knowingly, and that is fine, because they are doing it as human beings and with choice. I guess that last word, ‘choice’—or access or options—is one thing that we can be fairly categorical about. Rural and remote people should have choice. They should have options. What this means is that, whether it is a question of taking the service to them or taking them to the service, it should be possible for them to exercise that choice at no greater cost than for someone in a city, where the costs are low. Sorry, that sounded like a bit of a lecture, but it is the key issue with which we grapple every day.

I would like to add something else. One of the extremes is that people sometimes say that rural and remote people choose to live in a rural or remote area and therefore have no right to demand anything. That is something with which the Alliance does not agree. Rural and remote people are not only human beings with equal rights but also productive elements of Australian economy and society. If we did not have people in mining towns and on stations we would not export. Every which way, one can justify maximising access and options for people—even in more remote areas.

Senator MOORE—Can I follow up on that, Mr Gregory and Ms Phillips. I know that Senator Humphries has been following this through. We have heard evidence about a model which has had a fair degree of publicity, and that is having very large, well-resourced cancer centres, on the basis that recent reports have said that people who work exclusively or for a long time in one area are more expert. So you are going to get better treatment and better outcomes if you go to someone who works in the area a lot. That is come out in the breast cancer process in particular. The real guts of it, though, is how you get that service to everybody. You have the centre and you have all the grafts going out. In your report, you talk about the cost of people coming from rural and remote areas to the city once they have made the choice to do that. I do not see any option, if people are going to have the choice to go and have the best service, other than relocating for periods of time. It is a question of how we balance that expense. Has your organisation come up with any recommendations about just how the cost of travel for services that cannot be done well locally? For example, chemotherapy can be; radiation will not be done in every part of the community, as you said in the case of dialysis. What is your recommendation for the cost imperative for people who sometimes have to leave home for months on end?

Mr Gregory—I guess this is where the recommendation which we are supporting in relation to IPTAAS or PATS, or whatever it is called in a particular jurisdiction, comes in. We believe that reasonable costs should be reimbursed for those who have no choice but to travel in order to access a service. Their carer or consort should have some cover as well. We have a firm view on that. The PATS or IPTAAS has been an issue—a sore—for a long time. I think the proposal which emanates from COSA that there should be a national task force involving states and territories to look at the whole thing is a strong one. I add that there is a recommendation to you—I forget who it is from—that you can also subsidise the services to go out. So outreach services obviously can be subsidised. Some people have suggested that the cost of specialists and other carers who are travelling from a regional centre, say, to do home visits and small clinics should be covered as well under the same sort of subvention.

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

Proceedings suspended from 1.09 p.m. to 1.47 p.m.

CUTHILL, Mr Harvey William Graham, National Councillor, Pharmacy Guild of Australia

EMERSON, Mr Lance Ian, Director, Professional Development, Pharmacy Guild of Australia

MAY, Ms Khin Win, Policy Officer, Pharmacy Guild of Australia

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

Mr Cuthill—I thank you for the opportunity to address the committee in its inquiry into services and treatment options for persons with cancer. The Pharmacy Guild of Australia is an employers' organisation servicing the needs of independent community pharmacies. Our members are owners of community pharmacies. Community pharmacies are the principal distribution points for prescription medicines, scheduled over-the-counter medicines and complementary medicines in this country. In addition to supplying medication, community pharmacists provide a wide range of services, including drug information, quality use of medicines information, clinical interventions, medication management services and preventative care services such as the monitoring and compliance of drug therapy. We participate in proactive and therapeutic decisions, and we provide information and advice on minor ailments and over-the-counter medication.

Community pharmacies have also been very successful in running government funded programs, namely medication management reviews and medicines information for consumer programs. Community pharmacies are currently working in consultation with general practitioners to provide medication reviews for patients with complex needs, both in the residential aged care setting and in people's homes. These review services help avoid medication related problems and optimise medication use. Residential medication management reviews have been provided by accredited pharmacists to residents in nursing homes since 1985. Eighty per cent of residents within aged care facilities in this country receive these services, which is 130,000 reviews per year. Home medications reviews is a collaborate service between doctors and pharmacists and is provided to consumers living at home and in the community. As of February 2005, we have performed 67,238 of these reviews. The program has been a great success, and the Department of Veterans' Affairs has adopted it as their model for home medication reviews for veterans.

The medicines information service for the community was introduced as one of the quality use of medicine initiatives in 2002. Four thousand community pharmacies are registered for this program. The findings of the evaluation of this program show an overall positive result from both consumers and pharmacists. The consumers who have received CMI report a high level of satisfaction with the information they have received.

Today I would like to highlight some of the areas in which the Pharmacy Guild believes community pharmacy might become involved in the enhancing of delivery services and treatment options for persons with cancer in Australia. The first recommendation of the Pharmacy Guild of Australia is that, as part of the patient care reform, a program be established for community pharmacists to provide domiciliary pharmaceutical care to patients who are able to access specialist cancer/drugs treatments in their home. This proposed model aims to integrate the activities of pharmacists, physicians and other members of the health care team, sharing their responsibility for patient outcomes. Following the patient's consent to participate in the program, an individual care plan would be developed in collaboration with the physician, the GP, the pharmacist and the patient who requires chemotherapy suitable for administration at home. The pharmacist could then regularly meet with the patient to assist in optimising their treatment plan at all times, in consultation and cooperation with the patient's medical advisors. Review and monitoring of the treatment care plan would be undertaken through ongoing face-to-face sessions in the patient's home.

During these visitations, the pharmacist would assist in monitoring and managing the symptoms of their key therapy by providing counselling, advice and treatment support; ensuring that prescriptions for patients are understood and that the medicines are used to optimal effect; and ensuring that over-the-counter and complementary medicines do not have any adverse interaction with patient medicines. It is interesting to note that there are a number of interactions—and they are widely reported in the press—between complementary medicines and cancer therapy. There are a couple I could quote to you today. Dong quai is a complementary medicine that is widely used in the community in postmenstrual treatment to ease the symptoms. That particular over-the-counter medication in fact interacts and has a competitive nature with oestrogen antagonists such as tamoxifen, which is probably the most widely used drug for the treatment of breast cancer. It is a significant interaction that patients who are undergoing current cancer therapy ought to be aware of when they are using complementary therapy, and possibly the only place they would get that information would be a pharmacy, because, uniquely, pharmacists are in the situation where they have training in both conventional medicine and complementary medicine. I am aware that you have had a number of submissions from that area, but certainly pharmacists are uniquely placed with their knowledge of both complementary and conventional medicine to advise on such matters.

We see another common interaction with patients who are taking saw palmetto for the relief of the symptoms of prostate enlargement—and then they might well consult and use the PSA, which I am sure many of you in parliament would have heard of at various times as a means of monitoring treatment for prostate cancer. There is a degree of interaction there, and you can in fact get false negative results if you are taking saw palmetto and you have PSA testing. That is a common interaction. It is widely described, and it is in a counselling handbook that the guild and the Pharmaceutical Society have recently provided to all community pharmacies in Australia.

CHAIR—Is that information on the supplements that are sold? Isn't the TGA responsible for looking at those interactions and either providing warnings or—

Mr Cuthill—Those specific warnings are not provided on the packs at the moment. As an organisation, we do provide shelf talkers, if you are familiar with those. In the case of dong quai, it has four questions on it, including whether you are taking any other medicines and whether you are pregnant or breastfeeding. Whether you have had breast cancer is another one that is specifically mentioned. In the case of saw palmetto, one question asked is: have you spoken to your doctor about the problem? That would lead you into the question about the PSA testing. But they are not on the product. I am not here to talk about the labelling of complementary medicines in the country, but I would say that it is certainly something that has been addressed. However, the Pharmacy Guild believes that some of those medicines ought to be sold in the right place so that that advice can be given, with the appropriate reminders, shelf talkers and so forth that do complement this.

CHAIR—It is relevant to the extent that a previous witness has relied on the thoroughness of the TGA to monitor any interaction between what might be considered complementary therapies and traditional therapies. You are saying that it is obviously not in every case but, in any case when there are interactions, they should be published in some form.

Mr Cuthill—In a form readily available to consumers. There is great evidence that labelling is one aspect of providing consumer medicine information, but verbal and further written amplification is demonstrably a much better way to get it through to the consumer. A classic example in that area would be St John’s Wort, which is used in many cases for the treatment of depression. A significant number of cancer patients, particularly in their terminal stages, are being treated for depression with medication. We are aware of that from statistics that are widely out there. That is another interaction. You would have had other submissions that indicate that up to 64 per cent of patients who get a diagnosis of cancer do seek some form of complementary medication. I think it is a significant area that pharmacists can and should be involved in to provide the appropriate advice for conventional and complementary medicines.

In addition to providing information about those matters, we would be providing advice on medicine delivery systems and ensuring that patients comply with the treatment regimes. In some of the treatment regimes for cancer the protocols used are quite complex, and the patients certainly need additional information. If we are also involved with the patient in the home and the use of chemotherapy, there is an additional requirement for the disposal of both the drugs and the equipment that have been used. There are special protocols that need to be in place. You do not want those finishing up in the normal rubbish chains of the world. Clearly, there are special needs there and the patients need to be aware of them. If that is delivered in the home, that is the case.

Through the third pharmacy agreement—as I am sure members of this committee would be aware, currently the guild and the government are involved in negotiations for another agreement—it is proposed that these professional services be continued. Both sides of the debate—which is an ongoing and robust one, which we are involved in other places—at the moment are indicating that they believe that the professional services I have alluded to above will continue in the next agreement and be funded, particularly the areas of home medication and domiciliary medication reviews.

It is envisaged that facilitators, GPs and pharmacists would collaborate on other primary health care initiatives in this area of home based chemotherapy. We realise that this would be a change. At the moment the community and the pharmacist would need a change in their mind-sets to introduce such revolutionary concepts in this country as providing chemotherapy in the home. We would propose that there would be a large-scale pilot demonstration project that would see pharmacists providing pharmaceutical care to patients who are able to access cancer care in their homes, with an aim to implementing a national roll-out of this patient care reform.

In recommendation 2 the guild recommends that a program be established for pharmacists to provide medication management of palliative care patients at home. Community pharmacists can make a valuable contribution to the provision of palliative care to terminally ill patients. Palliative care is aimed, as we are all aware, at the highest possible levels of comfort to the patient during his or her last days. Home treatment is very often possible and should be the preferred method as it is more comfortable for the patient, allowing the patient to lead as normal a life as possible. Patients wishing to stay with their families for as long as possible should be encouraged to do so. Along with all other health professionals, pharmacists can support the family and indeed the patient in making the decisions more acceptable and in taking the right decisions. Due to the combination of severe illness and emotional difficulties, the delivery of good palliative care presents a complex challenge. As the most accessible health care professional for many patients, their carers and families, the community pharmacy should be an integral member of any interdisciplinary palliative care team.

Good palliative care depends enormously on teamwork and effective symptom control. Most of the patients in need of palliative care already have a long and trusted relationship with their regular community pharmacist. In the difficult circumstances of palliative care this relationship becomes stronger. Pharmacists are aware of the valuable contribution they can and should make in consultation with the patient’s medical practitioners, particularly in the area of medication management. This requires both traditional and expanded pharmacist activities, including a variety of education support roles. The Pharmacy Guild proposes to establish a program where pharmacists would provide medication management at home for palliative care patients and families by assisting them with medication use; dosage forms; compounding extemporaneously, which is our way of making dosage forms more palatable, in many cases; or, indeed, in innovative ways, of achieving effective symptom control and maximum comfort for patients in the terminal phases of their lives.

For recommendation 3, the guild recommends that the range of medications used in palliative care listed on the Pharmaceutical Benefits Scheme be broadened to assist in providing wider access to medications at an affordable price for patients who wish to remain in the community during the terminal phase of their lives. The guild acknowledges that recent listings of several medications used in palliative care on the Pharmaceutical Benefits Scheme provide some access to medications at an affordable price for those patients who wish to remain in the community. However, the guild is concerned that the preparations currently listed which may be prescribed for those patients receiving palliative care are not adequate and need refinement. To this end, the Pharmacy Guild recommends that the initial supply of medications provided under the palliative care schedule be provided without an authority prescription—you may have had some representations on this already. There is a new palliative care schedule; it has only been on the PBS for a short time. For the majority of the drugs listed on that schedule you still need to seek an authority prescription. This is not always appropriate, particularly for the urgent needs of those patients receiving palliative care. We suggest that the initial supply for those patients be made without an authority, and that ongoing supply would need an authority. This would provide ready and easy access for those patients who need these drugs in an immediate sense. There are already, within the guidelines of the palliative care schedule, quite a number of prescriptive elements as far as their usage is concerned.

These authorities would also not be needed for patients who are under the care of a palliative care team within a hospice or, indeed, within a nursing-home environment. It seems to us somewhat ridiculous that patients are admitted for palliative care and then need further authority from the Commonwealth to provide the drugs that are needed for their care. Authorisation is not generally withheld and we are not saying that that has been the case; we are saying that we believe that there should be an easier process in place—it already occurs within other parts of the Pharmaceutical Benefits Schedule. There are some medications that are registered for other uses and indications, but are commonly used for the care of palliative care patients, and these anomalies need to be rectified. For the committee’s purposes I can name two drugs that are widely used in palliative care in this country: one is called Midazolam and the other is called Ketalar. They are not listed on the Pharmaceutical Benefits Schedule. The reason behind that is that they have been initially approved for use mostly as short-term anaesthetics, but they are amongst the most widely used drugs for palliative care in this country. However, there is little incentive for the manufacturers to apply for PBS listings for these drugs for innovative uses, such as in palliative care. There needs to be some care taken with that. You would be aware, of course, that the Pharmaceutical Benefits Advisory Committee is the gatekeeper for products to be on the Pharmaceutical Benefits Scheme but, in some cases, these drugs will not be sponsored by them although they are widely used and community use would say that dual listing of medications used in palliative care should be investigated. The guild also believes that there needs to be better education about drugs that are listed on the schedule of pharmaceutical benefits for general practitioners, pharmacists and practice nurses.

In conclusion, community pharmacists have a well-defined and well-placed role to assist the care team to provide maximum comfort for the patient, in both cancer therapy and palliative care. We certainly believe in a multidisciplinary approach involving community pharmacy, which would deliver improvements in the coordination of cancer and palliative care services. That will benefit patients’ families.

This model of community service delivery, which makes effective use of case conferencing, health assessment and multidisciplinary care planning, would provide convenience and flexibility. It is cost effective and it is sustainable because it develops and extends existing services that are already in place. It assists the general practitioner and the pharmacist in their primary care coordination roles. The Australian National Health Strategy has identified the vital role that community pharmacies can play in the provision of health care—a role which we sometimes feel is underutilised by the government.

International literature also shows that pharmacist interventions could provide huge savings to the health care system and benefits to consumers. A review of literature clearly shows there is strong evidence across a number of settings for the effectiveness of pharmaceutical care services, continuity of care services post hospital and pharmacist education for improving patient outcomes. There is sound evidence that when pharmacists implement continuity of care services post hospital there is much better follow-up for high-risk patients. This leads to reduced hospital readmissions, a reduced number of medication related problems and improved medication knowledge and adherence.

Overseas studies of pharmacies providing pharmaceutical care to cancer patients in the home—including chemotherapy—demonstrate that, if a pharmacist is allowed to be an active participant and encourage patients to administer their own therapy, patients regain some of their control. They have reported that they are able to cope better, that it has enabled them to feel more in control and that it is less stressful than hospital treatment. There are also reported benefits to family life. Therefore, the Pharmacy Guild recommend that such models be established in Australia to achieve best practice outcomes, and we are willing to assist the government in initiatives where community pharmacies are engaged and utilised in this area.

CHAIR—What sort of training would be needed for pharmacists to be involved in using chemotherapy drugs?

Mr Cuthill—Some community pharmacies are already involved in the delivery of chemotherapy via hospital networks and would readily move into this role, I would think. They would already be familiar with the methods of reconstitution of the drugs involved and all that goes with providing chemotherapy. I note in the preceptors guide that is used for pharmacy students now—and all pharmacy students in Australia are under the guidance of the pharmacy boards—there is a module where the students are tested on their knowledge of chemotherapy. At the moment it is an optional area of the course and is one of the least utilised, so I think the point that you make is a good one: certainly, additional training would be needed.

Most pharmacists who have worked in the hospital network—and that now includes every pharmacy student—would have some background in chemotherapy services from there. I think those who have been in practice for a longer period of time would find it a greater challenge. We would have to offer additional courses through our societies for those who wanted to be involved. I would not consider that everyone would be involved in the first instance. It would have an offtake. We would need some heroes in the start to get the projects up and running, but it would also have some economic impact on the way in which pharmacies operate, and I think that would be a great driver as well.

Mr Emerson—There would also need to be some professional practice standards and pharmacy standards developed and implemented in order for that to occur in every pharmacy. Obviously, we achieved that through the implementation of the Home Medicines Review program, so pharmacies are quite used to incorporating new standards as part of their usual practice.

CHAIR—The model you have described to us is fairly comprehensive. I wonder whether pharmacists have the capacity to monitor treatment plans, provide counselling, meet with patients face to face in their homes and provide feedback to specialists and GPs. Those are all things you have talked about. It seems like a fairly onerous task.

Mr Cuthill—We are already doing that in the Home Medicines Review program, and that has had an evolving role in the last three years. There is not one element of that program that would not be described under the things that we have indicated there. These home medication reviews are only provided at the behest of the gatekeeper general practitioner, and in all cases the patients are on complex medication regimes. They are all visited in their homes, they all get a care plan at the end of the operation and the doctors also get a report at the same time. So that continuum of care is something we have seen unrolling in the Home Medicines Review program. We would see that the care of patients for chemotherapy, and indeed for palliative care, would be a continual roll-out of that program.

CHAIR—How are pharmacists funded to do that under the current program?

Mr Cuthill—Lance is the world’s expert on this, so maybe I should defer to him. Under the Pharmaceutical Benefits Scheme we allocated some money in the last round of agreements to roll out these programs. There was a degree of acknowledgment within the profession that, unless we involved ourselves in cognitive services apart from the mere supply of medication, our role could be diminished the future. That has been our great driver. We were able to convince the profession that some remuneration that would have come to us under the Pharmaceutical Benefits Scheme would be better spent on research and on rolling out some of these programs over the last five years. That is where the money came from. It is margin and profitability that the pharmacy has forgiven I guess in the interests of an ongoing role within the health profession.

Senator KNOWLES—I am a bit concerned about what you are saying about the adverse reactions of some complementary medicines with conventional drugs being used for cancer treatment. We had evidence as recently as yesterday afternoon to suggest that there no known, approved complementary medicines will provide an adverse reaction. A number of us questioned this witness extensively yesterday because we were concerned that other evidence that had been provided to the committee supported what you were saying—

Mr Cuthill—I am pleased.

Senator KNOWLES—about there being adverse reactions to some of the drugs. I am concerned that there is now further evidence to suggest otherwise. How comprehensive is the list that you have?

Mr Cuthill—The document that I have used today to provide evidence to your committee is an abridged guide. We call it a counselling guide for non-prescription medicines. It goes over a whole area of other activities and includes everything from mouth ulcer treatments to laxatives. One of the sections in this is our guide for complementary medicines. It tends to focus on those interactions that have been documented. I am happy to leave this with the committee. The references and the initial documents support what I am saying. The reference that I gave to you about breast cancer is a widely published and widely known drug interaction guidebook within the medical fraternity called *Stockleys Drug Interactions*. It is published by Stockley in London.

If somebody has said to you that there are no interactions, I would have to dispute that. I often use the guidebook when I talk to patients. I say to them: ‘Everything has interactions. If you drink enough water you will drown.’ It is a trite expression, but in this context it is not fair say that there are no interactions with natural products; there certainly are. They are evolving. As we see more complementary medicines used we will see more interactions. Many of you would be aware of the circumstances with Vioxx, which has been the subject of much review. The side effects and the problems with that only arose post marketing, when the drug had become widely used. The level of problems was low but once it became widely used in the community it was a different issue.

I am quite happy to get further evidence for the committee about the interactions that occur. There are schedules of drugs that are used. I would be particularly concerned as a male. You could be showing the symptoms I indicated with BPH. You would be taking saw palmetto, and quite reasonably so. Then you could seek medical advice and one of the first things most practitioners would do would be to take the PSA reading, which I spoke about. You could get a false reading. That is not an issue of interaction within your body; it is an interaction in the way testing is done.

Senator KNOWLES—Would it be routine for the doctor to first of all ask a patient whether they were taking any complementary medicine before the PSA was done?

Mr Cuthill—It could happen, but I had a PSA test done in recent times and I was not asked that question.

Mr Emerson—To add to that, one of the key things we are finding through the home medicines review scheme is that doctors who refer patients for a home medicines review are often surprised to find that the patient has been prescribed a range of other medications from another doctor, so often the patient does not actually tell doctor the medications they are taking. These complementary medicines are non-prescription medications, so patients are even less likely to inform the doctor that they are taking these medicines. I think the key issue we want to inform the committee about is that we think there is a strong role for the pharmacist here, who has the most up-to-date information on interactions between complementary medicines and other medicines, and it should be ensured that that pharmacist is involved in that health care team so they are in a position to provide that advice to the patient and, indeed, the other health care providers. We believe there is a strong role there, particularly through a case collaboration type of system.

Senator KNOWLES—Can I just be the devil’s advocate for a moment. If a lot of people go in, look along the shelves and say, ‘That sounds good, I’ll have that; and that sounds good, I’ll have that’—

CHAIR—And it looks good.

Senator KNOWLES—That is right. They put it in their little basket, go to the counter, pay for it, walk out of the shop and consume it. They do not ever come in contact with you; they come in contact with someone on a cash register. So how do we actually get to the point where what you are suggesting, quite properly, does actually happen in each and every case where someone buys a complementary medicine?

Mr Cuthill—I guess one aspect that I could comment on is that the majority—in fact, it is now over 90 per cent—of pharmacies in Australia have some sort of quality assurance program in place. One of the elements of that quality assurance program is that you are obliged to have the additional information that I have mentioned today—the so-called ‘shelf talkers’—within your health care section. I still say to you that the ultimate model which I was proposing is not the model that could happen there, but there is at least some opportunity for those products to be sold with some advice. I would agree with you that maybe—and at the moment we have not come to grips with it—some scheduling of complementary medicines in this country needs to occur.

At the moment, complementary medicines as we know them are sold without any sort of poison scheduling whatsoever. In other words, there is no classification. One of the strongly held views of the Pharmacy Guild is that we believe in scheduling, and there have been a number of inquiries into that in other places. That allows a stepwise opportunity for a significant number of complementary medicines that have no adverse effects known to man and beast at the moment to be sold in open sale. However, it does mean that those medications that have got a known side effect profile—and the two I have mentioned today would surely fall within that classification—ought to have some level of scheduling. That is a stepwise approach. If there is a scheduling involved, the sale that you talk about, Senator, has to occur in a different manner. So there may well be a case for complementary medicines to be included in that arena. I think that would certainly be something that the Pharmacy Guild would be advocating if we were in front of a Senate committee inquiry into the scheduling of medicines.

Senator KNOWLES—Which would attach itself to reimbursement, obviously, for the pharmacist.

Mr Cuthill—It does not happen with schedule medicines as we know them at the moment. I think it would be fair to say that in some cases schedule medicines do attract a higher margin because of the extra level of advice that we do and are expected to provide for those medications. However, I would not expect that there would be remuneration from the government or anybody else for those sorts of things; it would simply mean that there would be additional checks and balances put in place in their sale.

Senator KNOWLES—I understand what you are getting at and in an ideal world that would happen, but for the pharmacist to leave the dispensary every time someone wants to buy a complementary medicine—

Mr Cuthill—Only certain complementary medicines. If there were only six, eight, 10, 15, 20 or whatever—and I would not like to make an estimate in this place where I am being recorded—I would say that, if that is the case, in the same way that it is with other schedule medications you have to get off your bum and go and do it.

Senator MOORE—I only have two questions. The first is regarding accreditation for pharmacists who would be involved in this kind of process. Would that be done at the pharmacy level or through the individual pharmacist?

Mr Cuthill—At the moment we have not—

Senator MOORE—Would you accredit a pharmacy?

Mr Cuthill—No. As we do with home medication reviews, we accredit individual pharmacists.

Senator MOORE—So locums could take their accreditation with them as they go from place to place?

Mr Cuthill—Absolutely and categorically, and be employed by community pharmacies to provide that service. The model that we use for home medication reviews at the moment is that some elements—for example, the coordination, the timing, making appointments and so forth—can be done through the community pharmacy, but the report that goes to the general practitioner in this case, and indeed the interview in the home, has to be performed by an accredited pharmacist, not a pharmacy.

Senator MOORE—The other point was about the workload impact. It seems that the need and the demand for effective home based services are getting larger, and most pharmacies, from my observation, have the model where the pharmacist is in the dispensing area. If that person is on the road as much as this kind of workload could imply, what would that mean for resources?

Mr Cuthill—I think you are absolutely right, and we have certainly had workplace issues in our profession. However, with the home education review we have found that we do have a significant number of pharmacists who want part-time or casual work, and those sorts of things. I would have to say that many of those are female pharmacists, and they would find an ideal role. In fact, it would be—dare I say it—complementary to their current work practices to fit in with this. That has often been the role that we have found. It certainly has put strain on us. It is one of the issues with home medication reviews. At the moment, the requirement is for those reviews to occur in the home.

Senator MOORE—During standard working hours?

Mr Cuthill—Indeed. However, it does provide its challenges. In certain circumstances—in a rural environment, for example, where there is an accredited pharmacist who is also the only pharmacist in the community—some innovative practice programs have had to be put in place. However, the cost of providing chemotherapy services in rural and regional areas could well be offset by providing additional support. Also, I think it is fair to say that the profession has also reacted. A number of other pharmacy courses in rural universities in Australia have been established within the last three years. We are not seeing the results of those at the moment, but fortunately, as I alluded to in our preceptor program with respect to pharmacy students, they are at last being challenged about their knowledge of chemotherapy, and I think that is admirable.

Senator HUMPHRIES—Is there a forum or an opportunity for interaction between pharmacy in Australia and the complementary medicines industry as a basis to discuss the issues of adverse reactions between the two medicine regimes?

Ms May—I do not think there is a formal mechanism at the moment, but it can occur through the organisation level.

Senator HUMPHRIES—Do you think there is value in stepping up that level of interaction in order to address the issues that Mr Cuthill has spoken about?

Ms May—I would think so.

Mr Cuthill—I think that is right. The whole concept of the scheduling of some complementary medicines strikes fear and pain in some, quite clearly. Obviously, as Senator Knowles indicated to us, even from the evidence that you have received at this forum, that would be difficult. I think that there ought to be enough common ground. We are not suggesting that these products be available only on prescription. What we are suggesting is that there ought to be better supervision and that, in some cases, pharmacies are the appropriate to place because of our knowledge of chemistry and our knowledge of the other drugs that the patients are taking—

indeed, the medication histories that we are involved with. In recent times we have been involved with the government in research projects with respect to Health Connect and MediConnect. One of the essential elements of those programs has been to enter the use of complementary medicines in the patients' profiles. Quite frankly, if other practitioners who are in the sale of complementary medicines want to get involved in those health networks, they are going to have to get aboard the train.

Senator HUMPHRIES—I think we would prefer to recommend that there be cooperation between the two sectors to achieve that rather than regulation brought about by government.

Mr Cuthill—I accept what you are saying.

Senator HUMPHRIES—If you think you could do that then that is obviously worth while. Perhaps we could accelerate that a bit. I have one last question. Have you costed the scheme you propose in recommendation 1? Do you have any idea what sort of cost would be associated with that?

Mr Cuthill—No. I think I did suggest there that we would be proposing a trial program. It would be exactly the same as the one we did with the home medication review program. We rolled out some trial programs in consultation mostly with divisions of general practice in order to do the costing model. I would not have thought at this stage that there would be a general roll-out until those trial programs had gone ahead. Maybe this committee could see some worth in commending some of those to other people to foster, support and, indeed, finance.

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

[2.26 p.m.]

BAUMBER, Mr Donald Eric, Director, Cancer Alliance Network

MCGOWAN, Mr Russell James, Board Chair, Cancer Alliance Network

CHAIR—I welcome representatives from the Cancer Alliance Network. 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 McGowan—I am happy to make a presentation from the perspective of consumers of cancer services. Thank you for the opportunity to do so. The Cancer Alliance Network has been an opportunity to form a network of cancer consumer groups at a national level to provide consumer perspective to the providers and funders of cancer services in Australia. We fill a space that we believe has not previously been filled by any other stakeholder. There have been national consumer groups for specific cancers and there have been state-wide networks attempting to cover the range of cancers, but before our existence we do not believe anyone had tried to connect all cancer groups together at a national level to try to provide consumer perspective. That is why we came into existence.

We want to stress that we do not consider ourselves to be a peak body. We do not dictate to consumer groups what their reaction to things should be. There will be individual consumers who have quite different views. Our submission has attempted to provide a range of those views which are not necessarily held by all consumers by any means. Our current board consists of six members from four different states and territories. We have been represented in the past by two other states and territories as well. So we are trying to bring together perspectives from all parts of Australia.

We try to network the opinions of a broad range of consumers and consumer groups and express them in a way that will optimise the outcomes for people living the cancer and their families. It is a very difficult process to manage a network like this and we have had some difficulties in operating. At this time we are under some stress. We have no paid staff and the members of the board are largely people who are suffering from the effects of cancer themselves. They have variable health and variable amounts of energy to put into this. Despite those handicaps, we believe that we are able to put together perspectives that may be of value. We will get onto those in a bit more detail in relation to the specific terms of reference. As we have done in the submission proper, we will try to highlight some of those.

We have mentioned other groups that try to cover a broad range of cancer issues—in particular, Cancer Voices NSW have been around for some time and do a very good job of presenting consumer perspectives in that jurisdiction. But we believe that they do not necessarily have a full awareness of what is going on elsewhere in the country, which is one of the reasons we continue to put these perspectives. We also know that there are organisations like the Breast

Cancer Network of Australia, Brain Tumour Australia—whom you heard evidence from earlier today—and the Prostate Cancer Foundation of Australia, which are organised nationally and can give a quite useful perspectives on those specific conditions. But sometimes the needs in the specific conditions are not across the full range of needs of cancer consumers. We have been attempting to support the development of tumour specific groups at a local and national level for cancers that are not well represented. We have worked with the Australian Lung Foundation to help develop a cancer support network for lung cancer patients. We have also sought to help people suffering from colorectal cancer and to organise and produce support groups and a consumer voice in that area. I believe we were helpful to the Brain Tumour Australia group when it was formed.

We want to turn to the specifics of the inquiry, and my colleague Don will speak to some of the terms of reference and I will speak to others. The first area that we want to talk about concerns the pathways within cancer and the guidance that we believe is useful in producing good outcomes, so I will hand over to Don.

Mr Baumber—Thank you, Russell. I will explain my biases and where I am coming from, firstly. I was diagnosed with prostate cancer in March 1994, and I still have prostate cancer. I have been asked to speak about the efficiency of the multidisciplinary approach. My personal experience is that, when I was diagnosed, the urologist said: ‘You’ve got prostate cancer. You have a choice of surgery or radiation.’ He reached for his diary and said, ‘I can fit you in in two weeks.’ This still goes on today and does not provide the range of options for most men who are diagnosed with prostate cancer. We often hear of the multidisciplinary approach to breast cancer, and that is now considered the normal approach. However, during the time I have been involved through the support group movement, clinical guidelines have been developed for localised prostate cancer. Those guidelines say that one of the things that should be done is to seek a second opinion. We eventually developed a localised prostate cancer guide in consumer terms, with those particular clinical guidelines. That has made a huge difference because it addresses the problem of the range of particular options that might be available for patients, and it particularly emphasises the point of getting a second opinion.

The problem is that, even with that terminology and that limiter, new technology comes along regularly and certain areas have specialty treatments available. But not all patients hear about all those treatments, and not everyone knows the decision pathway to follow to map out their particular journey. The thing I often have to say to people who ring me is: ‘This is not a single, urgent decision that you have to think about. It’s a plan that you have to make over a 10- or 15-year period, and knowing which pathway you will have to follow is probably pretty important.’

Mr McGowan—That sort of introduces the next term of reference, which is about identifying somebody who could help people along that pathway. The point that we want to make about these case managers or system navigators, or whatever term you want to use for them, is that they must have the appropriate skills, and those skills are not necessarily directly related to the clinical skills necessary to provide individual services. We will come back to that later, as we did in our submission. We believe that this is often overlooked and that the social context of the person suffering from cancer and their ability to access services, as well as the availability of individual services, need to be taken into account.

Term of reference 3 talks specifically about psychosocial guidelines. We believe it is useful to have these, and useful work has been done by the NBCC in relation to breast cancer and, subsequently, that is being adapted to all adults receiving cancer services. The task is to promulgate and implement these guidelines rather than just to write them. We have struggled to find ways to do that effectively and to ensure that the whole context of the person is taken into account. Don is also going to comment on term of reference 4, and we want to stress in particular rural and remote access.

Mr Baumber—We all know that men die younger, but rural men seem to fare worse, particularly when it comes to cancer, especially prostate cancer, which is again my particular interest. In rural and remote areas it is more likely to be detected at an advanced or a metastatic stage, whereas in metropolitan areas there is a higher percentage now of more localised disease. With localised disease, there is potentially curative therapy available. When it comes to the later stages, there is no potential curative therapy and you are looking at controlling the disease, perhaps with hormone ablation.

From the rural point of view, the other aspect is that in a clinical practice where you have a clinician doing a particular treatment or particular forms of surgery in large numbers—whether, for example, it is for breast cancer or prostate cancer—that often shows the best outcomes for the patients, either in controlling the disease or in minimising the side effects. People in rural and remote areas do not necessarily always get access to that particular treatment. So finding a way of perhaps providing that equally to people living in rural and remote areas is going to be a problem.

Senator KNOWLES—How do you suggest we do that?

Mr Baumber—I do not have a good answer to this, except we could start by supplying the money to make it economic for a person to go to a major centre, rather than them having the treatment in their local area. The biggest issue in relation to this is when it comes to radiation therapy, where you are talking about a treatment that will go over six or seven weeks. If you are having four or five treatments a week—the treatment itself takes only a couple of minutes—you have to go back every day and be near the unit that is available to give the treatment. For a person whose job or farm, or whatever it might be, is in the country and who has to be away on their own that length of time from their family, that is a real problem. If they have to get somebody to run the farm while they are away, it is a real practical problem. If we can overcome the economics of it, that may be one way that we can deal with that particular problem.

The other way is to look at perhaps more advanced treatments. Instead of just having external beam radiation therapy that takes seven weeks to deliver, low-dose brachytherapy is now available. This treatment involves the insertion of radiated seeds into the prostate, and the man is hospitalised for only 24 to 48 hours and can go home after that period of time.

It is the same when you look at the surgery situation. If a person has a radical prostatectomy, they normally spend about a week in hospital and have a catheter in for up to 21 days. Now there is a robotic arthroscopic procedure and it requires about 24 to 36 hours hospitalisation. People can fly to the centres of excellence and have these treatments and go home. But what they need when they go home is fairly intensive treatment, or at least looking after when they are away from the actual clinical procedure. That is the real problem to overcome, their after care.

Mr McGowan—There are incentives to provide services in a way that is convenient for the system rather than to get the best possible solution, which may, in fact, be more cost-effective and certainly produce a better long-term outcome. There are different players in the game. Often the state governments are responsible for providing support for people to get from rural areas into treatment centres. These schemes are variable across the country, so it is easier in some jurisdictions than in others. It is a difficult problem to deal with. There has been an attempt more recently for the jurisdictions to come together and standardise and to provide more support for people who have to do this, but it is a slow process. We would like to encourage that to continue.

Mr Baumber—Basically, that is it. From a practical point of view, you do not have to be that far away from a major centre for it to cause a problem and disruption in your life. I come from the Gold Coast area. We do not have a public radiation unit on the Gold Coast, so the Queensland Cancer Fund arranges a bus that runs from Tweed Heads up to Brisbane, taking people for radiation therapy. That bus does the route, but it means people are tied up using that service virtually all of the day when they are only getting treatment for about two or three minutes.

Mr McGowan—Moving on, the fifth term of reference was about barriers to best practice service. We would like to highlight the work force shortages and the skill mixes that are available in various places. There is obviously a need for this to be planned on a more systematic basis, and one of the areas we have mentioned in the submission is the shortage of radiation therapists, which is a worldwide shortage. That is well understood, but a more integrated approach is going to produce a better ability to provide these therapists. The other area that we are particularly concerned about, which seems to be a poor cousin, is the oncology social worker. We really do believe that they can play a vital role in maximising and optimising outcomes for people with cancer and yet they are often not available to be attached to treating multidisciplinary teams, which we fully recommend. The second item that you wanted to look at was the less conventional therapies area. We have got a few points to make on that before taking any questions.

Mr Baumber—Perhaps I have got to make another declaration. This morning I had my three Brazil nuts and chewed a vitamin E capsule and took some other odds and ends, including eating some blueberries. The research is there on some of these things, but it is pretty distant sort of stuff. This is the problem with this particular area. Most of the research that we consider as good for evidence based medicine, for example, follows guidelines that are on a Cochrane systematic review, where you look at all the evidence and so forth. The tendency is to look at a particular aspect of a treatment or a drug and come up with an answer to that individual thing. What we are looking at here is more of a whole-of-life issue and the way people address that to control the situation themselves. I think this is why people get involved in this area, simply to try and take back control of their life after it has been lost to a particular diagnosis or treatment. The problem is that there is no system available to look at the range of things that people may be doing. The way research is done is to look at one or two things and perhaps compare those two things and see the way they come out. That is one of the complexities. The other issue is that a lot of these things are about matters that are not going to be patentable. There is not going to be commercially resourced funds to be able to provide real research.

Within our particular area we had a classic example: a thing called modified citrus pectin. A well-qualified researcher in the USA did some work on it, took it through to the stage of doing small animal studies on it, found it was quite good in relation to prostate cancer and other particular things, then went applying for some money to get it into clinical trials and found that no-one put up any money because this thing could not be patented. That is the problem. You are looking at either individual things or the mix. From the patients' point of view, they want to see the mix of things. Most people would look at it as a complementary approach rather than a simple alternative approach.

Mr McGowan—That leads into the second thing under (b):

(ii) the efficacy of common but less conventional approaches ...

The point we want to make here is that it is often hard to demonstrate efficacy, particularly if you do not have a sponsor for the particular intervention through MSAC or the PBAC. We would rather hope that it was possible to provide support for promising treatments with the proviso that there would be surveillance of what was occurring to see whether that support needed to be continued. I understand that this is happening with some treatments with the Medicare program in the US. I think that our mechanisms at the moment are a little too rigid. The standard of proof that is required before you can start utilising promising therapies is too high for many who might benefit. Certainly many of the consumers we deal with who are not risk averse would like to have quicker access to things that may well make a difference. They need to be fully informed of the risks, but that then needs to be monitored. If it is proven over time that it is not cost effective and efficient then the subsidies can be withdrawn, but we think rather than waiting till you have full proof before providing the subsidies it would be useful to have alternative mechanisms.

Finally, in relation to the role for government in these complementary or combination therapies, we would like to say that there is a role for government to disprove the value of some of these therapies as well as to prove value. We are concerned, as indeed clinicians are concerned, that some people jump into therapies for which there is no evidence base and for which there is in fact potential for harm. We would like regulation—I know that is a difficult thing to be involved with—or at least strong endorsed advice from authoritative sources that these treatments are going to produce the outcomes that are claimed for them. We think government needs to have mechanisms that will do that and also support for research in the area that will prove one way or the other whether these sorts of interventions are occurring.

CHAIR—In relation to what you have just said—that if there is no profit motive for clinical trialling to be done somewhere, there is not enough money to prove something—would it be a better approach to try and prove things rather than spend scarce resources disproving things?

Mr McGowan—Depending on the risk to patients that are undertaking these—

CHAIR—If there was an endless bucket of money, we could do both. The reality is that there is not, and there is not going to be.

Mr McGowan—We think that the bias at the moment is entirely towards waiting till you get a sufficient proof before you endorse things. I understand the economic imperatives for that, but there would be value in having the capacity to do some smaller scale things on a trial basis where people were fully informed of the potential risks and where there was the capacity to close them down effectively if they were proven to be not effective. So that was what we had to say in support of our written submission. We are happy to answer any questions.

CHAIR—Thank you for that. I think there was a lot of valuable information in your submission and presentation. I want to ask you something which probably does not go to the content of your submission. Yesterday we heard evidence that Cancer Voices are on the way to setting up state branches in every state and that the intention then is to become a national organisation. One of the things that has bewildered nearly everyone on the committee is the number of different organisations involved with this disease and the offshoots of it. Are we going to end up with two organisations representing consumers of cancer services, advocating the same thing and duplicating themselves?

Mr McGowan—We would think not.

CHAIR—I am making no judgment about who should do it or who was there first or anything like that. It is just a point about scarce resources being duplicated.

Mr McGowan—We understand that difficulty. At the time that we were established there was only one Cancer Voices, and that was in New South Wales. We were wary of that body being seen as the national voice, because there are things specific to that jurisdiction that do not apply in other jurisdictions. We did not go to the model that is now being considered—that is, setting up a similar organisation in each jurisdiction as a means of finding a national organisation. We thought that it was better to try to tie in those national organisations that already existed in specific diseases, such as the Breast Cancer Network and the Prostate Cancer Foundation, together with local groups that might represent consumers with other specific forms of cancer or combinations of forms. There were groups in Western Australia and the ACT which have since renamed themselves as Cancer Voices groups but were networks of cancer consumers that pre-existed with different names.

We believe that, with the growing acceptance of that terminology—it is being used in the UK, for example, with CancerVoices UK, and Don has recently visited that group, and in New Zealand—maybe this is a better mechanism. But what the structure will be to form a national organisation we are not sure. There are difficulties inherent in any national organisation. People want to work either with the disease they are familiar with or within the jurisdiction they are familiar with. To rise beyond that into a national group and to put your time into that rather than into the thing that hooked you in in the first place is quite difficult. So it is an emerging thing. We certainly do not want to set up a parallel universe. We want to see a merger of these two things, but there are inherent difficulties whichever way you go.

Senator HUMPHRIES—You say in your submission:

> The current governmental approach to cancer services signals a narrow clinical and epidemiological view of what cancer services are.

Can you explain what you mean by that?

Mr McGowan—I guess it is the medical model that we are getting at. It is all a matter of points of service: putting people into an episode of care and moving on, rather than looking at the journey across the care continuum. There has been an attempt to remedy that with the development of the National Service Improvement Framework for Cancer, which I am sure the department will talk to you about soon. We had input into that, and we think things are going to improve. But there is a concentration of resources in the tertiary sector, so most of the treatments are provided in a hospital setting, when often the experience of cancer extends over a much longer period of time and a much broader setting. Regarding the resources that are available in the community setting, people often have to go and find alternative or complementary support because it is not available in mainstream clinical care. We would like to see that change over time, with more of the services being provided across the experience of cancer in a way that produces better outcomes. That is particularly relevant to psychosocial outcomes.

Senator HUMPHRIES—What you say certainly makes some sense, and a number of people have made similar comments in their submissions, but we have not yet heard any practical way of actually achieving that. You say that the medical model needs to be influenced by a multidisciplinary approach. Yes, that is a good point, but how do you get medical schools, doctors or organisations to engineer that kind of change? What exactly is the mechanism for that?

Mr McGowan—In most of the jurisdictions they are now starting to look at the cancer streams that will integrate the various services that are delivered—in New South Wales it is the Cancer Institute—and will at least have the different clinicians who are providing the services talking to each other more regularly. In the ACT, which is where I have been involved since I had a bone marrow transplant 10 years ago, I have been involved with the local hospital, advocating for a better range of services. We have looked at trying to locate some of the supportive services outside of the hospital, recognising that the problems people are dealing with are beyond just that acute treatment phase. The breast care nurses, who we have mentioned in our submission, are obviously one example of that which has worked pretty well. But nursing staff by themselves are not the only clinicians that need to work in that broader context; we think social workers and psychologists can also provide support. They can also help people navigate through the system to make decisions about what their next treatment option is, including no treatment at all. Those resources really are very thin on the ground in most jurisdictions. Getting people to recognise that it is a much broader experience and journey than just that intense acute sector episode and providing resources across the spectrum to help optimise the outcomes is what we are getting at. Most of the consumers we talk to are feeding in that sort of perspective.

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

Proceedings suspended from 2.56 p.m. to 3.00 p.m.

CHOI, Dr Ching, Head of Division of Health, Australian Institute of Health and Welfare

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

COOK, Dr Jane, Senior Medical Adviser, Medicare Benefits Branch, Medical and Pharmaceutical Services Division, Department of Health and Ageing

DAVIES, Mr Philip Keech, Deputy Secretary, Department of Health and Ageing

HORVATH, Professor John, Chief Medical Officer, Department of Health and Ageing

HUNT, Dr Leonie, Acting Principal Medical Adviser, Department of Health and Ageing

KNIGHT, Associate Professor Rosemary, Department of Health and Ageing

LOPERT, Dr Ruth, Senior Medical Adviser, Pharmaceutical Benefits Scheme, Department of Health and Ageing

LYONS, Ms Margaret Patricia, First Assistant Secretary, Health Services Improvement Division, Department of Health and Ageing

CLUTTON, Mrs Cathy, Acting Executive Director, Centre for Health Advice, Policy and Ethics, National Health and Medical Research Council

CHAIR—Welcome.

Mr Harding—In support of our written submission, we have brought along a set of key summary statistics that may assist the committee; I have simply documented our databases.

Dr Choi—The Australian Institute of Health and Welfare is a statutory authority in the health portfolio and it reports on health and community services statistics and research.

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 remind officers that they will not be required to answer questions on advice they may have given in the formulation of policy or to express a personal opinion on matters of policy. I now invite you to make an opening presentation, which will be followed by questions from the committee.

Mr Davies—We will take this opportunity to make a brief opening statement. I start by thanking you for the opportunity to address the committee this afternoon. We hope you have had a chance to read our written submission; I am not going to repeat, largely, the material that is in there.

The Australian government has a proud and outstanding record of achievement in services for people within the Australian community who are affected by cancer. Those services cover the whole spectrum of cancer, from prevention to treatment through to palliation. In these few moments, I will highlight some of those key achievements.

Firstly, the government recognises the burden of disease that cancer creates in our community. Most Australians, it is sad to reflect, will be affected by cancer, either directly or indirectly, through involvement with someone who has the disease. Cancer is a very common experience, with one in three men and one in four women being directly affected by cancer before reaching the age of 75 years. Each year an estimated 460,000 Australians are diagnosed with cancer. In 1996, in recognition of its significant impact in our community, cancer was identified as a national health priority area. The aim of doing that was to focus public attention and health policy on coordinated efforts to deliver significant health gains for our nation.

It is important that the committee appreciates—and I am sure you do—that the Australian federal, state and territory governments, non-government organisations and the community as a whole all have a role to play in the prevention and treatment of cancer. The Australian government's role primarily is one of national leadership in delivering improved outcomes through a wide range of areas, including research, policy formation and program implementation. Under the current 2003-08 Australian health care agreements, the Australian government provides substantial financial assistance to the states and territories as a contribution to the costs they incur in providing public hospital and community health services. Under the current agreements, the Australian government will provide funding of up to $42 billion to states and territories over that five-year period.

In addition, the Australian government has specific and direct responsibility for our two major national subsidy schemes: the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme. It also regulates and subsidises private health insurance. The Medicare Benefits Schedule ensures that all Australians have access to free or low-cost medical, optometric and hospital care. The Pharmaceutical Benefits Scheme, the PBS, aims to provide all Medicare eligible people with affordable access to a comprehensive range of cost-effective medications and is widely acknowledged to be among the best such pharmaceutical subsidy schemes in the world. These schemes, the MBS and the PBS, cover all Australians and subsidise patients for a wide variety of services from medical service providers as well as a high proportion of their prescription medications. They are obviously therefore very important for people who are affected by cancer.

In 2003-04, PBS expenditure directly on medications related to oncology amounted to just over $412 million, with a further $173.3 million of indirect expenditure, which would be for such things as drugs for bone pain associated with malignancy, laxatives and analgesics—a significant proportion of which are used in the management of cancer patients. Also, as of December 2004, 8.7 million Australians were covered by private health insurance and, of course, each of them benefits from a 30 per cent premium subsidy from the Australian government and can use their private health insurance to support the costs of treatment in hospital.

However, as well as these important and comprehensive entitlement based programs, the Australian government has made a substantial investment in cancer care through a diverse array of more directly targeted initiatives. For example, if we start at the prevention end of the spectrum, the Australian government has implemented a range of strategies under the National Tobacco Strategy to discourage people from taking up smoking and to encourage those people who already smoke to stop smoking. Smoking, as I am sure you need no reminding, is the major cause of lung cancer as well as a number of other cancers. So the National Tobacco Strategy supports education programs and campaigns, it supports pricing measures, it is bringing in the labelling of tobacco products with health warnings and it is banning most forms of tobacco advertising, promotion and sponsorship.

Adoption of this comprehensive approach to tobacco control has been remarkably successful and has made substantial inroads into smoking prevalence and, in turn, has contributed to Australia’s position as a leading international player in tobacco control. The most recent national figures on tobacco prevalence from our colleagues at the Australian Institute of Health and Welfare show that, for smokers over the age of 14, daily smoking rates have fallen from 19.5 per cent in 2001 to 17.4 per cent in 2004. That is a remarkable drop of 2.1 percentage points in just three years. It means we are now proudly among the lowest of any country in the world in terms of tobacco smoking.

The Australian government has also invested heavily in the early detection of and screening for cancer. For example, BreastScreen Australia, established in 1991, is a population based screening program that offers free biennial mammograms to women without symptoms in the target age group, which is 50 to 69 years. In 2001-02, more than 1.6 million women benefited from the services offered by BreastScreen Australia under that program. That is having an effect as well. From 1993 onwards, there has been a steady decline apparent in the age standardised mortality rates for women in that target age group. The mortality rate for those women fell from 68.3 deaths per 100,000 women in 1998 to just 56.7 in 2002.

We should also mention the National Cervical Screening Program, also introduced in Australia in 1991, which provides routine screening with Pap smears at two-yearly intervals for women without symptoms between the ages of 18, or two years after first sexual intercourse, and 69. The program aims to reduce illness and death from cervical cancer in a cost-effective manner through an organised approach to screening. Again, it is having an impact. In 2001-02 the participation rate was 61 per cent for the target age group and more than 3.34 million women had a Pap smear during that period. Our cervical cancer incidence and mortality rates have been declining steadily over the past decade. The incidence of cervical cancer has fallen by 57 per cent and mortality due to the disease by 58 per cent during that 10-year period. Over that period, cervical cancer has dropped from being the eighth most common cause of cancer death among Australian women to being the 18th most common cause of cancer death. That achievement, we believe, is directly attributable to the National Cervical Screening Program.

The Australian government has also shown strong leadership in the area of cancer treatment and care for people with cancer. The Australian government has a commitment to the application of evidence based treatment in cancer care and has funded the development of clinical practice guidelines that are summaries of the best available evidence and often the first step in encouraging evidence based approaches to service delivery. Guidelines are currently available or will soon be available for most of our priority cancers. In addition, consumer guides have been developed for several cancers to provide information for people with cancer in parallel to the clinical practice guidelines that are guiding their treatment. While we are speaking about people with cancer, it is notable that the guidelines for the psychosocial care of people with cancer have been endorsed recently by the National Health and Medical Research Council. In addition to best practice care, the government has funded the National Breast Cancer Centre to undertake substantial work in the area of multidisciplinary care, including a national demonstration project in breast cancer and a follow-up study focusing on the sustainability of those multidisciplinary models of care delivery.

I mentioned palliative care. The Australian government is also committed to improving palliative care. In the 2002 federal budget it announced $55 million over four years, 2002 to 2006, for national activities to improve the standard of palliative care offered in local communities. In those same health care agreements, 2003 to 2008, the Australian government has provided $201.2 million to states and territories specifically tied to the delivery of palliative care services. Of that, about $190 million is allocated on a per capita basis and the balance is for the Australian government to implement a national program of initiatives.

The government's national leadership and sustained investment through general health programs, as well as some of those targeted cancer initiatives that I have been talking about, is achieving results. As we outlined in our submission, we have one of the best systems of cancer care in the world. Our cancer survival rates are second only to the United States in international comparisons. The relative survival proportions are higher in the United States, probably due to the increased awareness and levels of screening leading to earlier diagnosis. Not only is Australia doing well in cancer survival rates by international standards but cancer deaths in Australia are also falling. They have fallen by an average 1.9 per cent per year over the past 10 years.

We cannot, however, afford to be complacent. Although there has been considerable improvement in cancer control, we recognise that there is always more work to do, even in areas where we have already made substantial progress. It is inevitable, given the ageing of the population and the fact that cancer is mainly a disease of older people, that cancer incidence will rise in the years to come, and recent trends support that view and suggest that that is already beginning to happen. Also, the gains that we have made—that I have outlined to you, and that we outline in our submission—are, sadly, not universal. Cancer incidence is increasing in disadvantaged groups. Aboriginal and Torres Strait Islander populations present particular problems. People in rural and remote areas and some patients with specific tumours are also areas where we believe there is still scope for improvement.

That work is under way. We are working to drive further improvements in cancer care. I think previous speakers here mentioned the National Service Improvement Framework for Cancer. That has been developed and places the emphasis on respecting patients and placing them at the centre of care. It identifies critical intervention points where most gains can be made.

In addition, the government has also reaffirmed its intention to reduce the burden of cancer by committing a further $137.1 million over the next four years, through its Strengthening Cancer Care initiative. That initiative will ensure better coordination of the national cancer effort; provide more research funding for cancer care; enhance cancer prevention and screening programs; and ensure better support and treatment for those living with cancer.

To summarise, the Australian government has recognised the burden of disease that cancer creates in our community and has a strong track record of substantial investment, with a diverse set of initiatives extending over several years and designed to improve cancer control. We are doing very well, but improvements can be made. They will be made through the systematic implementation of best practice treatments for people with cancer, at and beyond the point of diagnosis.

Mrs Clutton—Thank you very much for the opportunity to speak to the committee. The National Health and Medical Research Council has provided a written submission to the committee, addressing many of the terms of reference, but I just want to draw out a couple of points, if I may. The NHMRC has an interest in the subject before the committee in three ways in particular.

Firstly, the NHMRC provides funding for research: in 2004, a figure in excess of $51 million was allocated to research into a variety of types of cancers. This was an increase of some $5 million over the 2003 funding figure. Secondly, the NHMRC is responsible for developing the ethical framework within which research involving humans takes place. The National Statement on Ethical Conduct in Research Involving Humans includes guidance about clinical trials, for instance, and this document is currently under review. Thirdly, the NHMRC has developed a series of standards for the development of evidence based clinical practice guidelines. These standards have been used by the NHMRC and by other organisations, such as the National Breast Cancer Centre and the Australian Cancer Network, in the development of clinical practice guidelines in the field of cancer. You have heard about some of them this afternoon, and relevant guidelines were listed in the NHMRC’s submission to assist you.

The NHMRC has developed or approved evidence based clinical practice guidelines in the field of cancer treatment for some time now. The NHMRC’s authority to issue guidelines and to approve guidelines developed by others comes from sections 13 and 14A respectively of the National Health and Medical Research Council Act 1992. An issue that was not specifically included in the terms of reference for the committee is the treatment of people from culturally and linguistically diverse communities. I want to draw out that there are bilingual information workers who specialise in providing information on cancer in a range of languages, and in some states and territories the national Translating and Interpreting Service includes specially trained health interpreters. This was referred to in our submission.

Dr Choi—The Australian Institute of Health and Welfare, as I said before, is a statutory authority of the Health portfolio. We do a lot of work in monitoring all types of diseases, and cancer is one of the national health priority areas that we monitor. In our submission to you we described a work program that we do in the cancer area. We mentioned three important gaps in cancer statistics that we hope to improve on in the future. The first is the lack of nationally consistent hospital outpatient data. They service a lot of cancer patients with chemotherapy and radiotherapy. The collection of that data is starting on 1 July this year, with a lot of help from the states and the Commonwealth departments.

The second area that is lacking is data on the stage of cancer so that we can assist in the interpretation of the survival rates of cancer patients. I believe that there have been some submissions on the need for better clinical data on stages before your committee. We hope to be able to do some work on that, but that may take a bit of time because of the cost that could be involved in coding clinical data to cancer stages.

CHAIR—Are you saying that you are going to look at that as a result of some of the evidence that has been put before the committee, or is that something that has been in train for a while?

Dr Choi—That is something which has been on the table for some time. The state cancer registries have been working on a consistent data set with standard definitions and classifications of what cancer stages can be. We know that some states—I think New South Wales—already have some cancer staging data and that some states in the United States of America have some of that information, so we are not starting from scratch; there has been some work. It is just the standardisation across the states that will take some time. Also, the coding of it from the detailed data to an aggregated data set is very costly. I will leave it at that.

The third area with a gap is that, while we do have a lot of individual data sets from the MBS, the PBS and the HIC databases and we do have hospital records and death records, we have not been able to link them up in a way that we can analyse them together to understand, for example, the drugs prescribed in hospitals and in the community to the conditions that patients have. That also involves working with the states in terms of hospital data, because hospitals are the responsibility of the state governments. For example, the institute is working with the states on whether we can link up our death records and the hospital data, which we do have, a bit better.

CHAIR—We are interested to know whether you see this as an important priority.

Dr Choi—The outpatient data, the first one I said, is an important priority. Action is being undertaken to collect useful data from next financial year onwards. The staging data is also a priority. We would like to be able to decompose some of the improvements in survival rates which you have seen, for example, in breast cancer and in other cancers as well, to see how much of that is because of early detection and how much of that is because of improvements in treatment and care. I think that decomposition is quite important.

Senator MOORE—Is that going to cover the private as well as the public system?

Dr Choi—The staging data would involve all patients. The linkage between different data sets is really opportunistic: the more we can link up, with ethical clearance of the research projects, the better we can analyse. We do not know how many results we can get from linking data that way but the statistical community in the form of the state and Commonwealth government statisticians and the ABS are working on protocols on how the ethical linkage of data can be done. Different states have different privacy legislation. The Commonwealth has its own and we have to work within those guidelines.

We would like to work on the first and the last areas. We hope that the institute’s products will be able to serve the future requirements of the states and the Commonwealth. For example, I think Philip Davies mentioned the National Service Improvement Framework for Cancer. One needs to monitor how that is going. We would like to make our statistics useful to that process as well. I will conclude there.

Senator KNOWLES—Today we have had evidence from Brain Tumour Australia, who basically told us they felt that the whole issue of brain tumours was being left behind. Do you have any comment, Mr Davies or Professor Horvath, as to what could be done to not leave them behind in such an important area?

Mr Davies—I am not aware of anything structural in terms of the way the Australian government’s subsidy programs are designed that would unduly favour or hinder a particular form of cancer, but I am sure Professor Horvath is far more capable.

Prof. Horvath—It is a problem, largely because brain tumours are a class of tumour that largely has not fallen into the same sorts of categories as the ones that are commonly out there. There is very little known about prevention, there is very little known about risk and there is very little even in the way of drug therapy that does very much for them. I can understand their sense of frustration and concern. There is certainly nothing in the government initiatives that would disadvantage them, and all the other issues around palliation and around multidisciplinary care apply to brain tumours just as much as everything else. But I can see their concern that the large body of work in prevention and screening really does not apply to them, because there is not terribly much evidence that any of those really affect them.

Senator KNOWLES—They understand that the prospect of screening is just impractical, but there still remains a problem.

Senator LEES—They gave us an example—the comparison between what their people face and how breast cancer is treated. Just to get people to pass their leaflet on to newly diagnosed patients is, it seems, almost impossible. Doctors do not want to do it, and hospitals do not do it, so a person who is impaired in terms of being able to perhaps think for themselves in a strategic way is at a substantial disadvantage. What is there in your procedures or processes that can at least help people to know where the supports that do exist are?

Prof. Horvath—Most of the problems around that are really issues around medical science rather than health policy. The issues they bring up are around the multidisciplinary side of the management of their patients, and we take those on board as we do with the rest of cancers. I do not have any specific answers for them, no.

CHAIR—Maybe we should all have a go at this general issue—not just comparing brain tumours and breast cancer; let us compare breast cancer and the rest of the cancers. It would appear from all the evidence that we have had that breast cancer treatment and processes are way ahead of everything else. Why is that?

Prof. Horvath—You are absolutely right; they are. That is because they were the first off the block, and it has been of great value to the whole of cancer care that there was a very major investment, because the templates that breast cancer care has set are really the templates we are working from. The national improvement framework and a lot of the other strategies have, with modifications, been taken from the work on breast cancer. It just happens that it is a very common cancer and a very emotive one, and it attracted resources very early on. Fortunately, it showed a huge number of benefits to the community; therefore, governments, both state and federal, continued to invest in it.

CHAIR—It still appears that, for some of the tumour groups, the advocacy groups that are still driving a lot of the improvement especially about getting information out there to people who are diagnosed or to the general population about prevention, information for and empowerment of patients is still a major issue, even in breast cancer—and very little is happening elsewhere. It is consumer groups who are actually putting together digests about who can treat different cancers, the level of exposure that different practitioners have to different types of cancer and their treatment profiles. Why is that still happening at that level and not being done in an overall, coordinated way?

Prof. Hovarth—I might pass this to Dr Knight, who has been working with these various groups for some time.

Prof. Knight—I think that the consumers in breast cancers have themselves done a lot to support and provide material for the people affected by breast cancer. As I think Professor Horvath alluded, the science is more advanced in breast cancer but also we have had the opportunity for very strong consumer groups to put together a lot of pamphlets and information. The Australian government has funded the National Breast Cancer Centre to take forward some of those improvements and to provide an authoritative source for people affected by breast cancer. That is part of the reason why we have made strong advances in that arena.

Prof. Hovarth—To follow on from that, we hope a lot of the issues you raised will be addressed by the recent budget initiative of the Cancer Council Australia, which hopefully will work off the template and provide the benefits that the breast cancer community have got from those advances to all the other cancers.

CHAIR—That is where I was going. Maybe it is a timing issue. We accept that there are strong consumer advocates in breast cancer. The squeaky wheel has got a lot of attention, and that is terrific. We are not saying anything should be taken away or we should not continue to make significant advances in that area. But, in the absence of strong consumer organisations in some of the less well-known cancers, if they are not going to put some of this information together, produce it themselves and raise money to get it, do we just sit back and say, ‘Oh well,’ and nothing happens? We talked about the template and we know what works in breast cancer. Maybe it is a timing issue—maybe it is going to happen next month or next year—but it does not seem to be happening now.

Prof. Hovarth—I think it is starting. The national service improvement frameworks are being rolled out for all the other cancers. Similarly, Cancer Council Australia’s role is to address just the issues you have raised, to bring the other cancers to the table and bring them up to the level of the breast cancer awareness, involvement and management. I think it will be staged at different times.

Senator KNOWLES—There seems to be so much duplication in effort. Take breast cancer as one example—wherever you go there are these fantastic support groups who are providing so much information, but they do not seem to be talking to each other and avoiding duplication of that effort. There is only so much money that can go around, and one would hope that there would be a better way of coordinating all of that. Has that been considered at all?

Prof. Hovarth—It certainly has. I think this is a historical thing. Until 10 or 15 years ago, tumours were organ specific. The science or discipline of oncology is relatively new. Places like the Sydney Cancer Centre are only 15 years old. Brain tumours were treated by neurologists and neurosurgeons and gut tumours by gastroenterologists. Therefore they have their own support groups. The New South Wales Cancer Institute and the commission of cancer in Victoria are relatively new bodies, only one to two years old. There is a very clear acknowledgement that what you describe needs to happen. That is the philosophy behind the New South Wales and Victorian initiatives and certainly the philosophy behind Cancer Council Australia, to reduce duplication and try and get people to share.

Senator KNOWLES—Who is going to pull all that together?

Mr Davies—I think it is starting to happen. It is an issue that has been a frustration to us in the bureaucracy and also to the government. Professor Horvath has already mentioned the Strengthening Cancer Care initiative as part of the election commitment. As part of that we in our department will be commissioning the Cancer Council to undertake a review of that plethora of cancer support networks and also to look at overseas experience in the same area, because this challenge is not unique to us in Australia.

The idea of that will be to try and identify best practice approaches so that we are able to map across from those different support groups—each one of which is undoubtedly very passionate and probably in most cases very effective, but no-one has yet done what we are now embarking on with the Cancer Council—best practice models and promulgate those so that they can be shared amongst the organisations and we end up with best in breed rather than this somewhat disparate mix that we have at the moment. That is only starting, but it is a good—

Senator LEES—But the state governments are up to this as well. We have Western Australia going off with their own models now of multidisciplinary tumour networks. We have got Victoria going off with streams, I think they call them. Do you have an overview of all of this and how it is happening? Are states sharing information or is each one reinventing the wheel?

Prof. Horvath—The states in fact are talking a great deal with each other about it. It is not a matter of states, but the structures are slightly different to reflect the health networks and structures within the states. We are aware of many of these initiatives, working to ensure that the Cancer Council Australia fits in with them and is not in competition.

Mr Davies—I think we also need to recognise that in a sense a lot of the strength of these community groups or patient groups comes from their passion, and we have got to be very careful we do not crush that by trying to squeeze them into some bureaucratic model—

Senator KNOWLES—That is exactly right.

Mr Davies—and basically squeeze the energy out of them by turning them into little clones of the Commonwealth department of health.

Senator KNOWLES—Can I come to some of the specifics that were raised by the Brain Tumour association. One of them was removing some of the palliative care drugs from the authority list for the first dose. Or it might have been the pharmacists who raised it—

Senator HUMPHRIES—The medical oncologists.

Senator KNOWLES—Or the medical oncologists—maybe a whole lot of people have raised it. How practical is that? What are the ramifications?

Mr Davies—The restrictions required for an authority—for example, having to satisfy particular clinical criteria or get sign-off from a particular senior level of medical specialist—are generated as part of the listing process; you are obviously very familiar with this. That listing process is about ensuring the cost-effectiveness of those pharmaceutical therapies for particular groups of patients. So, to the extent that we have those approvals and those restrictions, they are designed to make sure that that pharmaceutical product is used in those areas where it will deliver an appropriate level of cost-effectiveness. We have got Dr Lopert here, who is our PBAC expert; I do not know if you have anything to add to that.

Senator KNOWLES—While you are thinking about it, if I may just add the other element to that which you may or may not have heard today—some of the drugs for palliative care not on the PBS include mild anaesthetics that eventually will be used by those people, but they are concerned that quick and urgent access to those drugs is not necessarily readily available. I thought that the authority process was pretty swift.

Mr Davies—The authority process in terms of phoning up the HIC to get an authority is instantaneous, but we had better ask Ruth.

Senator KNOWLES—I do not quite understand the nuance behind trying to get that first dose without the authority.

Dr Lopert—If I could just ask you to clarify, Senator Knowles, what you mean by ‘getting the first dose without an authority’?

Senator KNOWLES—It was put to us today that when someone needs that first dose for palliative care they should be able to get it quickly, without the need for an authority prescription—as I say, I was always of the belief that it was simply about ringing up and getting it ticked off—but that subsequent prescriptions be filled on authority. That is why I am asking the question; I do not quite understand why that would be an issue.

Dr Lopert—For most of the drugs on the palliative care list, with the exception of certain specific drugs, it is simply a telephone authority; therefore, I am not clear what the arguments in favour of enabling an initial dose without an authority are. I am not sure I can respond to that in a more helpful way.

Senator KNOWLES—Thank you for that. I am not clear about it either. I think we probably need to get further clarification from the Pharmacy Guild as to what their intention was in that. We did not pursue it.

CHAIR—I think it is actually in their written submission. You might have a look at that and if you can respond in writing to the committee that would be good.

Dr Lopert—Very well. Senator Knowles, you talked about some drugs which were not available on the palliative care list and I think you referred to anaesthetic agents. I am aware that there is concern over availability of some medications on the palliative care list, but their lack of availability on the palliative care list reflects the fact that they do not have marketing approval for the indications that are relevant to the palliative care setting.

Senator KNOWLES—That is right, and that is what was said to us today. But equally, I think—and I stand corrected if I misunderstood this—a person will eventually be on that drug for palliative care anyway in the case of, for example, a mild anaesthetic.

Dr Lopert—As I mentioned, if the drug does not have marketing approval in Australia for use in an indication which would be appropriate for use in palliative care then we have a problem listing it on the PBS for that reason. For example, there is one drug that I am aware of for which the marketing approval reflects use in the context of a procedure only. Therefore, it cannot be used for long-term therapy.

Senator KNOWLES—I wish I could remember the name of the drug I was talking about, but unfortunately the name was as long as my arm.

CHAIR—That was a general issue that has been raised with us. A drug that has gone through an approval process for a specific reason, where it may need to be used in a different dose or in a different treatment really needs to go through the process again. That is expensive, and there is marginal if any profit for the manufacturer doing that. As a result, it does not get done. We actually had the medical profession complaining about that. Again, we would have to go back through yesterday's *Hansard* to give you the detail of that. That was a general issue that has been raised.

Dr Lopert—The broader issue from the PBS point of view as opposed to the registration point of view is that it is inappropriate to provide reimbursement for drug for an indication outside that for which it is approved for marketing in Australia—that is one of the principles underlying the PBS.

Senator KNOWLES—It is a safeguard.

Dr Lopert—Yes. That is right. So there is that issue. The issue of approval for indications other than those for which it is registered is an issue for the TGA rather than the pharmaceutical benefits branch.

Senator KNOWLES—I have just been handed a note, and I think this might be the name of the drug: Midazolam.

Dr Lopert—I am aware of the drug. As I said, the approved indication is actually quite narrow. It is not approved for an indication that could be conceivably appropriate for use in a palliative care setting—it talks about use as an adjunct in anaesthesia for a surgical procedure.

Senator KNOWLES—I will maybe ask one more question and ask more if we have some time left over. On the TGA's role in approving the complementary medicines—Mr Davies, you have quite a comprehensive contribution here in your submission—we have had conflicting reports during our inquiry. On the one hand, we have the therapists who are administering the complementary therapies saying that everything is approved by TGA and everything is tickety-boo and so there is no problem with adverse reactions. On the other hand, we have had a whole lot of other people come before us saying that if you take that it is going to interact with that. How do we get to the bottom of this?

Mr Davies—We have colleagues from the TGA here who can probably give you chapter and verse, but fundamentally something either is or is not approved by the TGA. So that should not be a debating point.

Senator KNOWLES—It is approved by the TGA but its contraindications or adverse reactions are not known to a person who goes in and buys the bottle off the shelf and who is also receiving another therapy.

Mr Davies—Are you talking about drug-drug interactions?

Senator KNOWLES—Yes.

Mr Davies—I think we might ask the TGA.

Dr Hunt—Complementary medicines in Australia are regulated as listable medicines for the main part. That means that they are not allowed to make serious disease claims. For example, they would not be allowed to make a claim based on treatment of a cancer or a serious condition. If they wish to do that, then they are treated as if they are registered medicines and undergo a different evaluation route. The TGA is aware that some complementary medicines have the potential to interact with prescription medicines. One example would be St John’s wort, hypericum. In fact, there is a label on St John’s wort that advises people when they pick up the product from wherever they purchase it that it may interact with prescription medicines. Also, if the Therapeutic Goods Administration, in its regulation of prescription medicines, is aware of any possible interactions with known herbal substances, it will include the product information in the prescribing literature for health professionals and ask that the same information be included in the consumer medicine information for consumers of prescription medicines.

As part of the recent expert advisory committee that looked at the regulation of complementary medicines, there were recommendations made around the handling of adverse drug reaction reports for complementary medicines. In the government response to that, the government has agreed that it will work with some of the national medicines policy partners to increase the awareness of prescribers and health professionals to these interactions and encourage them to seek information from patients about concomitant complementary therapy use and to in fact report adverse events so that more information can be obtained and more interactions can be identified if they are causing significant problems.

CHAIR—When you say you advise health professionals, do you include the people who practise nutritional and environmental medicine, for instance? Do you advise their associations?

Dr Hunt—The prescription medicine program includes information in the prescribing information which is usually given to medical practitioners prescribing those medicines. For the complementary medicines such as St John’s wort, there was extensive consultation with the industry associations and linkages to the bodies that may be using those medicines. I cannot say that everyone would be aware of them but certainly St John’s wort products have warnings on the label advising, for example, of potential interactions with prescription medicines.

Senator KNOWLES—How about someone buying dong quai who is also on tamoxifen? Is there anything there, from either side? When someone gets their prescription for tamoxifen, is there a warning for if they are taking dong quai? Equally, if they buy a bottle of don quai, is there a warning for if they are taking tamoxifen?

Dr Hunt—For tamoxifen, I would have to check the product information to see if there is specific interaction with dong quai recorded for health professionals and consumers. In relation to dong quai, I am not aware of warnings on the label. Part of the government response to the recommendations of the expert committee was that the department would look at identifying the information needs of patients and health practitioners in relation to complementary medicines with a view to seeing what skills and information needs should be addressed as a priority. That could include identifying gaps and deficiencies.

Senator LEES—I know there is an automatic notification process for people who become aware of adverse reactions with specific medications as prescribed by the PBS, but what about for substances that may be approved by the TGA and their reaction if two items are being taken together? Is there some sort of an automatic process? We are not just talking about doctors but multidisciplinary teams, who often are the people, particularly nurses, who pick this up?

Dr Hunt—The adverse drug reactions system allows reporting by health professionals. That includes all health professionals—nurses, physiotherapists and any member—

Senator LEES—But does it include the TGA products as well as the PBS?

Dr Hunt—It includes all the products, and the adverse drug reactions database does contain adverse event reports on complementary medicines. Part of the response to the expert committee was an agreement that we would work with the national medicines policy partners to allow them through their education campaigns to increase the awareness of potential interactions by prescribers of medicines so that they can be more alert to questioning their patients and, if they are suspicious of an adverse event, to actually report it to the TGA. They use the same reporting system. The adverse drug reactions advisory committee looks at complementary medicine adverse event reports.

Senator MOORE—I have a couple of questions. I will start with some particularly relating to the area of breast cancer because, whilst I do acknowledge that advocacy groups have gone a long way, there is still a long way to go. Sometimes that has to be put on record as well. I am interested with the BreastScreen guidelines. Mr Davies, you mentioned in your opening statement the mammography service for women between 50 and 69. What is the basis for the cut-off at 69 for that and for cervical cancer examination? A number of older women have been coming to my office asking why, at 69, the services cease.

Mr Davies—Professor Knight is probably the best person to answer that.

Prof. Knight—The international studies and the randomised control trials that we have around cost effectiveness of mammographic screening show that there is a decrement over age. In fact, that is the arena where you get most cost-effective benefit for mammographic screening.

Senator MOORE—So if you are 70 you have to pay. Is that what it means?

Prof. Knight—No. My understanding is that if women over the screening age of 70 present to the mammographic screening unit they will still be seen by that unit but we do not actively recruit outside the age range which has been shown to provide most cost benefit.

Senator MOORE—My concern is that women think that they have no right to have the service over 69 because of the very good promotion out there that clearly says 50 to 69. So people are feeling quite concerned that they have been on a regular process of getting mammograms and then at 69 it drops off. Do I just encourage people to keep going to the clinic?

Prof. Knight—I understand that women are concerned but I think that it is probably the case that, with any particular cut-off where one is able to choose an age, there are always going to be issues about those on either side of that cut-off.

Senator MOORE—Exactly. My next point is about a cut-off in terms of a process which I know the Commonwealth does not run—that is, the issue of support for people who have to go from regional areas to other areas for various forms of treatment. I know that used to be Commonwealth; now it is state. I know it is a state issue and there is an issue there but, in terms of coordination of services and encouragement of services, is there any role for the Commonwealth in trying to change the cut-off points for people who can get support for travel expenses and accommodation when they have to go for services?

Mr Davies—The main area where this impacts really is radiotherapy because it requires repeated travel.

Senator MOORE—That is the main one, yes.

Mr Davies—There was the Baume inquiry and then there was a cross-jurisdictional group, which I actually chaired, bringing together the Commonwealth, states and territories, which looked at implementing those Baume recommendations. One of the things that specifically came up was this question of patient access schemes. As you have pointed out, they are primarily a state and territory responsibility. I think one of the Baume recommendations was that they should be aligned across the jurisdictions. Certainly there was an agreement—I think it was in late 2003—where health ministers agreed to the recommendation from our group that the responsibility for addressing those issues of patient access and transport schemes should still rest with the states and territories. The intent of the recommendation that they all signed up to in that group was that they would try to apply consistent approaches and consistent entitlements.

Senator MOORE—But the recommendation did not define what they should get to, did it? It was that they should be reasonable and consistent, if I remember the Baume terminology correctly.

Mr Davies—Yes, they were, and certainly at the time I was involved in looking at them they did vary greatly. The message is out there to bring them into some sort of consistent alignment, but I could not honestly put my hand on my heart and say that I believe that that is happening.

Senator MOORE—Going back to my two other questions; I got carried away with cut-off points, so I went straight to my other cut-off point. One is the issue of breast prostheses, which we have been talking about for a long time. I know that Minister Patterson was going to look at it, and I believe that it was being looked at by the department. The provision of support for women who need that service has been raised again in evidence, and I was wondering what the current policy is.

Mr Davies—Can I go back to your previous question because a colleague just reminded me.

Senator MOORE—They passed you a piece of paper.

Mr Davies—A very useful piece of paper. In regard to one of the things that did actually come out of that implementation group, post Baume, I can do nothing better than quote the heading of this particular appendix: ‘Possible values that jurisdictions could consider in improving physical patient access’.

Senator MOORE—Possible ones that they could consider!

Mr Davies—Apart from all those caveats. It looks at eligibility, transport benefits, mileage benefits, patient contributions, accommodation benefits—

Senator MOORE—Can we get a copy of that, Mr Davies? Is that a secure document?

Mr Davies—This report is available and we could certainly table it.

Senator MOORE—That would be good. It has come up in evidence in every state.

Mr Davies—This was the sort of package that that committee felt was a reasonable benchmark to aspire to.

Senator MOORE—If we could get that, it would be a good start.

Mr Davies—We can certainly get copies tabled.

Senator MOORE—What is the current state of discussion about breast prostheses?

Mr Davies—The fact is, as you have alluded, Medicare benefits are not payable for aids and appliances. Medicare benefits and the schedule are in respect of professional services, although funding for the implantation is actually available under the MBS for patients who go private. For patients who go public, the implantation and the prosthesis are covered under the health care agreements.

Senator MOORE—What if you have to go private because of urgency?

Mr Davies—Then it would not be covered, although obviously private health insurance would come into play there. I think I am right in saying that prostheses are on the schedule of funded items.

Senator MOORE—Yes. The other one in the same kind of area is the treatment of lymphoedema and the concern about the various aids that can be obtained for people with lymphoedema and the very expensive sleeve process that some women have. I believe that that was under consideration as well to receive some government subsidy, but I do not know and I did not know yesterday when the question was asked.

Mr Davies—I am not aware of any change to that. It is the same logic as applies in the case of the prosthesis.

Senator MOORE—If you are going public, can you get that free?

Mr Davies—No.

Senator MOORE—I did not think so. If it was the same as the prosthesis, would it follow?

Mr Davies—It is not covered under Medicare, but for a public patient in a public hospital—

Prof. Horvath—It is a jurisdictional issue.

Mr Davies—it would be down to the individual jurisdiction. Thank you.

Senator MOORE—Okay. I have one more general question. We have seen that there has been considerable documentation formed about appropriate guidelines for treatment. There have been national recommendations, agreements and that kind of thing. What I do not know is what authority the federal government has to request that those guidelines are followed so we have approved guidelines for multidisciplinary team approaches to treatment. We have it for psychosocial, which is a term I loathe, and all those things. What incentive is there, let alone directional ability, to get hospitals and practitioners to follow those guidelines?

Mr Davies—I think, as the name implies, they are guidelines. I do not believe there is either incentive for following them or sanction for failing to do so. Possibly at the hospital level they may be mandated, but again that is not something of which we would have a great deal of knowledge. I do not know whether my clinical colleagues have anything to add.

Prof. Horvath—As Mr Davies said, they are guidelines and guidelines have varying capacity for encouragement. Certainly the colleges, most importantly the college of surgeons, have been very forthcoming in encouraging their fellows, as do hospital quality committees. Guidelines tend to come into practice by professional pressure of a multidisciplinary sort rather than by carrot or caveat.

Mr Davies—I think it would be fair to say that the last 10 years have seen a bit of a cultural change in the medical profession, where what used to be dismissed as recipe book medicine is now actually seen as having value. Equally, I am sure, if you suggested to other bodies who may have given evidence that guidelines should be compulsory, you would have got a fairly hostile reaction.

Senator LEES—Some groups are now starting to take this into their own hands. The breast cancer group in particular now are starting to put together material, and I understand are planning to put that material on web sites, about which surgeon operates how often and I think also the results of surgery—some of the issues that women are concerned about. I think it is generally accepted that, where women know that there is a multidisciplinary team and they are going to get broad-ranging support, they are going to head in that direction. Some surgeons and some of the other practitioners are very supportive of this, but, as you can imagine, some feel quite threatened by it. Do you have a role to play in this? How do you feel about the whole issue of information on who is doing what and who has gone to which surgeon ending up on the net? We heard from the brain tumour network that they have a blogging site where people are sharing information and experiences and encouraging people to move around and seek other opinions.

Mr Davies—Probably the furthest we have gone is in some support we have provided to the Australian Cancer Network to look at the arguments for and against formal accreditation of cancer services. That would be the only movement in that direction coming from the centre. In terms of patient groups sharing their experience, which is ultimately what you are describing, I am not sure that is something on which we would have a view as to whether it is a good or bad thing.

Senator LEES—So there would not be any problem with groups’ funding or any other issues as far as you are concerned; it is really over to them to make decisions about how they share information with their membership.

Mr Davies—I are not aware that we fund that activity specifically. It has not been brought to my attention—

Senator LEES—But through the various support networks they have been able to pick up bits and pieces of funding here and there. So there are no worries about where they go with that side of the information?

Mr Davies—None that have been brought to our attention.

Prof. Knight—The Australian government did provide some substantial support to the Breast Cancer Network of Australia for the funding of their ‘My Journey’ kit, which provides women with authoritative advice and information about the cancer patient journey. Also, through the National Breast Cancer Centre there have been a number of reports and authoritative information for women about their journey and about the types of services which are provided.

Senator LEES—I guess this is part of where the other groups look to breast cancer and see all the additional information that is available there. Hopefully, that will spread and be dealt with in our report. When you talk about multidisciplinary teams, what is your definition of that? Who is in a team?

Prof. Horvath—The team is, I think, a very good example. It is everyone involved in the care of that patient.

Senator LEES—The patient?

Prof. Horvath—Yes, everybody involved, including the patient. The patient is central to it.

Senator LEES—And if the patient wanted a carer and, say, a dietician involved, is that possible—

Prof. Horvath—They are all a part of it.

Senator LEES—That is fine. That was just something that was—

Prof. Horvath—A multidisciplinary team is the surgeon, the medical oncologist, the radiotherapist, nursing staff, dietician and so on. It is a very large group of people with the patient in the centre. The frameworks we have been working on recognise that very clearly.

Senator LEES—Some concerns have been expressed to us by a number of witnesses about the funding of the process of getting together and taking people out of their daily schedules and out of hospital work or whatever. Is that something that you are looking at more broadly?

Mr Davies—The Medicare Benefits Schedule already has a number of items specifically for developing multidisciplinary care plans and for case conferencing, which is actually providing funding precisely to bring that team together. There are 18 case conferencing items for GPs to organise or participate in a case conference and there are also 18 case conference items for consultant physicians and consultant psychiatrists. So there is funding through the MBS for that. I think it would be fair to say that we are constantly reviewing approaches to practice and how well our funding approaches reflect desirable, contemporary forms of practice. If we became aware of any issues, I think we would look at them. We cannot on the one hand advocate multidisciplinary care and on the other put barriers in the way to its funding. So I think it is fair to say that we are continually reviewing that and considering new items to ensure that the schedule encourages appropriate practice.

Senator MOORE—Mr Davies, there has been consistent evidence given to this committee that one of the things working against having multidisciplinary teams, particularly in the private sector, is the fact that the current system does not allow that to be funded. We have heard that not from one set of evidence but consistently from a number of witnesses. The response you have just given is different to the responses very senior people have given to this committee. Is that because of a lack of knowledge or is it confusion or are they not talking to you?

Mr Davies—I suspect it may be a combination of all of those to some degree. Do we have anyone here from the Medicare Benefits Branch?

Senator LEES—Could we perhaps have both sets of opportunities?

Mr Davies—Certainly. They are in the schedule.

Senator LEES—I know of some of them under the Enhanced Primary Care program and that side of things for GPs, but one of the key issues seems to be that when someone gets into the hands of a specialist and is diagnosed with cancer then it is a case of, ‘I will treat you in the hospital,’ and then, ‘Goodbye; you’re finished with me now. Off to the next specialist.’

Prof. Horvath—That is certainly not the philosophy of the major cancer centres like the Peter MacCallum Cancer Centre or the Sydney Cancer Centre.

Senator LEES—We have found at least one or two in each state where it is not, but unfortunately—

Senator MOORE—Part of the Peter McCallum Cancer Centre's evidence was on that issue.

Senator LEES—Yes, it was partly on the funding issue, from memory. We certainly found some outstanding examples, but the consumer groups which have come before us—and the main one we heard from today was a brain tumour group—have raised that as a consistent theme.

Prof. Horvath—I have known the Peter McCallum centre well for many years. That then becomes an internal budgetary issue, for a very large institution, of how they are going to expend their dollars.

CHAIR—No, it was about consulting oncologists and others coming into the hospital to be part of a multidisciplinary team.

Senator MOORE—Professor, when you check the submissions we have had, you will see that this has been consistently raised by governments, hospitals and physicians. The key issue about MDTs has been that, particularly in the private area, the system worked against it. The Peter McCallum centre was one.

Dr Cook—As you know, there are case conferencing items for GPs and for consultant physicians, as well as consultant psychiatrists. There definitely are items for discharge case conferencing. So, when a private patient in a private or public hospital is going to be discharged back into the community, there is a payment system for consultant physicians and GPs to be involved in that transfer of care from the inpatient to the outpatient setting. There are items for when the patient is in the community and being managed in the community for those same groups to be involved, but there is no case conferencing for when the patient is an inpatient.

Senator LEES—This has been the key issue that has been raised in that, when the cancer diagnosis is made, people do not know where to go and do not know what alternatives there are. So it is a lottery; it is a raffle—it depends where your GP refers you. They may refer you to someone who is a specialist in that area. For example, one of the really positive things with breast cancer treatment now is that most GPs have at least a bit of a list of specialists and an idea of where to send you. If you are diagnosed with some of the other cancers, it is a case of, 'So and so is a general surgeon. Off you go.' There is no conference at that stage to look at alternatives with the patient or with their carer.

Dr Cook—The items only cover chronic diseases, so there are some restrictions around it, but they can be managed in the community, definitely.

CHAIR—But that is not the multidisciplinary care we are talking about.

Dr Cook—But you can establish a multidisciplinary care team in the community using a community case conference before the person goes to hospital.

Senator MOORE—We really need to have a look at this. It is quite critical.

Senator LEES—Yes, we need to have a look at the various options, if you could pass them over. Perhaps you have got someone, somewhere who can look at some of the evidence that has been presented to us on this issue and who can give us the answers as to what it is that these people do not know about.

Mr Davies—Just to be clear for our purposes as we go away and look at this, which we certainly will: your concern is really private patients undergoing—

Senator LEES—Not only private. Private seem to be the worst in that once they get into the private hospital system, it is very much a straight-line approach with no opportunities for them—and I go back to this morning's evidence—to even find out where the next stop is.

Senator KNOWLES—They go in, they get operated on, they get discharged and that is it: bye-bye.

Senator LEES—There were at least three or four people this morning who had personal experience with cancer who just came to a dead stop. For some people, they get on the net; for others, they are lucky enough to get hold of the right leaflet. But if there were earlier case conferencing and the ability and the opportunities to go through the process, and not just at discharge, people would be far better informed.

Mr Davies—Certainly our experience suggests that public hospitals in general are pretty good at organising and supporting multidisciplinary care.

Senator LEES—But which public hospital did the doctor send you to? This is part of the issue.

Mr Davies—Do you mean even on the way in?

Senator LEES—Yes. People are not being offered the opportunities and the choices. Their carers do not know what is going on or—as we look at the multidisciplinary teams—the opportunities available to have some psychosocial support. As you say, the department is very much involved in some of those—

Mr Davies—I want to take you back to when Professor Horvath was citing examples of private hospitals that do this very well. And I am sure others could cite examples of GP practices that do this very well. Somewhere in this mix are also the approaches and views and the experiences and the practices of individual clinicians, because the fact that you are seeing variation suggests to me that there are different ways of doing this. Maybe what we should be looking at collectively is how is it that it seems to work very well for private patients at the Peter MacCallum, but it does not work very well in others.

Senator LEES—In summary, it is patient ownership. Once a particular specialist or a hospital has a patient, it is very much an ownership issue: that is their patient and no-one else is supposed to interfere. A dietitian or a psychologist or anyone is not even thought of as someone who could help this person in the process.

Senator KNOWLES—It is also at every stage: on diagnosis, postoperatively and prior to discharge.

Mr Davies—But, from what you have told us, there are some shining examples where that works well.

Senator KNOWLES—That is exactly right.

Senator LEES—And where people are actually given some real opportunities. In Western Australia they can go to Brownes Dairy. Unfortunately it is mostly voluntary work, but there are places where they have the opportunity to feel somebody supporting them and understanding what they have gone through. In each state we are coming across examples, like Peter MacCallum, where people can get a breadth of support so they do not feel so isolated and get so stressed that they start undoing some of the good work that—

Mr Davies—What I am getting at is the fact that it does work well in some places. Maybe it is volunteers in WA, but the fact that some places can do it well suggests to me that it is not fundamentally a problem of how the subsidies and the benefits are designed. It is not a financial problem; it is an operational problem.

Senator KNOWLES—In some cases they say that it is a financial problem, because the doctors are so stretched. We heard today, for example, that there are so few neurosurgeons who actually specialise in brain tumours that they are stretched to the limit and to keep on allocating time to conferencing is a cost.

Senator LEES—Perhaps you could look at some of the evidence and point out to us how we, as we write the report, can make recommendations more generally to the various support groups. And perhaps you could point out what the department and other organisations can do, through the various things they are already doing, to help actually look at where these issues are for patients.

CHAIR—I want to clarify things. I think you might have made the assumption that we said it works all right in the private sector. I do not think we have actually received any evidence that it does. In fact we have received evidence to say that there is an in-built impediment in the private sector—

Senator LEES—There is an ownership problem in the private sector.

CHAIR—because effectively it is the specialist who owns the patient, and the private hospital just provides the facilities in which the patient is treated, whereas in the public sector the hospital takes charge of the patient and is much more able to apply a multidisciplinary approach.

Mr Davies—Our thinking is the same as yours: in general it seems to work better in public than in private, for the very reason you have described. Of course, there is patient choice whether to go public or private. We will certainly look at what is going on in the private sector and come back to you with any evidence we have found of obstacles, good practice and blockages.

Senator HUMPHRIES—Each year, there are very few complementary and alternative medicines evaluated, either in a clinical trial of some sort or in the TGA process, in a way that helps address this gap between conventional assessment of treatments—in this case treatments of cancer—and alternative or complementary treatments. We have heard that there is a level playing field and that a person with a particular therapy or medicine has the same opportunity to get that evaluated and approved as anybody with a conventional drug that does the same thing. We have also heard that there are other barriers, that things like the lack of an available patent for many natural therapies mean that there is no financial incentive to seek approval for the use of a particular drug or natural therapy and the fact that there is supposedly a higher standard of proof, in effect, for such treatments and therapies. What is your response to that argument? Incidentally, the other argument is that there is a financial cost associated with getting a drug or a therapy listed; it is a significant cost in many cases and not one that anyone other than a drug company would necessarily be able to afford. What is your response to that? Is there a level playing field or are there hidden slopes in that playing field?

Mr Davies—Are you referring to the approval for marketing, which is the TGA, or to the approval for subsidy, which is the next step, which is the PBS?

Senator HUMPHRIES—I am thinking more of approval for marketing.

Mr Davies—In that case it is a TGA question for Dr Hunt.

Dr Hunt—I will explain the regulatory system for complementary medicines. All therapeutic goods that can be generally supplied to the market in Australia must be included on the Australian Register of Therapeutic Goods. There are two classes of goods for inclusion on the register. There are listable goods, and many complementary medicines would fall into the characteristic of a listable good purely because of the substance they contain. But other components that make a good listable are whether the condition being treated is likely to be self-managed and self-diagnosed, and so the other component relates to the condition being treated. For a medicine to be listable the product must be assessed for quality and safety by the Therapeutic Goods Administration prior to entry to the market and the sponsor must hold evidence of efficacy, and that can be randomly tested by the Therapeutic Goods Administration. Listable goods are not allowed to make claims relating to the treatment or mention of serious disorders. So a listable good cannot make a claim that would allow it to say that it has a role in the treatment of cancer.

However, it is possible for sponsors of listable goods to have the goods included on the register as registrable goods if they can produce evidence to substantiate that the product has efficacy in the treatment of a serious condition. The goods then become registrable because their use is in a serious condition, and that takes them out of the low-risk listable category and they become registrable goods. The TGA can receive submissions from the owners of complementary products to have their goods included on the register.

The issue of encouraging research in this area was looked at by the recent expert committee looking at complementary medicines in Australia. That made a number of recommendations about the encouragement of research in Australia. In the government response to that, the government said that the Department of Health and Ageing, TGA and NHMRC would be working together to try to identify research needs, priorities and resources that are consistent with the national medicines policy and national strategies for quality use of medicines. Also, the government will ensure that the TGA consults with NHMRC and other stakeholders to make sure that centres of excellence that are able to do research into complementary medicines are identified and their work is facilitated wherever possible. In terms of research funding, the government does make funding available through the NHMRC. My colleague from NHMRC may be able to comment on recommendations in relation to encouraging funding for the use of complementary medicines.

In terms of the standard of evidence, because claims made about treatment of cancer are high-level claims about the treatment of a serious disease, the standards of efficacy that are required are consistent with the standards that would be required of a new prescription medicine for the same indication. That is, the medicine should be shown to be of acceptable quality and safety and also the label claims—the indications which are claimed—should be justified by the data that is produced. The complementary medicines office within the TGA produces guidelines currently to try to assist sponsors to undertake studies and understand the required levels of evidence. The expert committee also recommended that those guidelines be strengthened in coordination with the NHMRC and be made a compulsory part of the regulatory system through incorporation into legislation. The government has accepted those recommendations and will be undertaking further work in those areas at the TGA.

Senator HUMPHRIES—The sponsors that you referred to would almost invariably, I assume, be manufacturing corporations?

Dr Hunt—Almost invariably they would be manufacturing corporations. A sponsor does not have to actually manufacture a good. It is responsible for the export of the good from Australia, its import into Australia or its supply on the Australian marketplace as well as manufacture. So it does not necessarily have to be manufacturing the good in Australia.

CHAIR—But you are talking big bucks?

Dr Hunt—We have sponsors of small medicines. We have provisions in our legislation to allow products that are sponsored by small organisations which are low value and low volume, for example, to have a reduction in annual charges.

CHAIR—But the same level of testing applies and it is big bucks to get there, isn’t it?

Dr Hunt—Potentially it can be big bucks, but the level of evidence is required to be the same to create a level playing field and to ensure that claims—

CHAIR—There is no dispute about that. That is the point. To get to that same level it is big bucks.

Senator HUMPHRIES—The point I am making is not necessarily about a drug that might be viewed as a drug to cure cancer. For a drug that would alleviate symptoms or be efficacious in some other way or a treatment or therapy in that respect, the threshold is actually quite high. It is not likely to be reached by someone who is a proponent of, say, homeopathy as a treatment for cancer or the symptoms of cancer. You make reference in the NHMRC submission, for example, to microwave treatments. Normally speaking, those sorts of things would not get to those thresholds. Those things would not be likely to have the money behind them to get to the stage where they would be assessed. But the evidence the committee has received is that quite a few

Australians are in fact turning to those sorts of things either as complements to their existing conventional treatments or even as alternatives to those treatments.

Mr Davies—Just to be clear: I think everything that Dr Hunt has talked about applies to medicines and implantable devices. You mentioned in passing, I think, a particular form of treatment—

Senator HUMPHRIES—That is right. I am talking about—

Mr Davies—that is not covered by the TGA.

Senator HUMPHRIES—I know that; that is why I turned to the NHMRC as well. There are obviously other therapies and procedures that might be covered, presumably by grants that would be made available to assess those things. I see in the submission from the NHMRC, for example, that there was a decision made in August last year for Dr Holt’s radiowave cancer therapy to be assessed by an NHMRC grant. That is still under way, I understand. But the point I am making is that there are many of those procedures and therapies running around out there, and most of them do not make a threshold—do not get the capacity to be formally assessed by the NHMRC or any other process that certifies or disproves their efficacy. Given that we have had evidence that 60 per cent or more of Australians are accessing these sorts of things, that some of those complementary drugs, therapies or procedures potentially intervene on other conventional therapies, drugs or treatments in an adverse way, potentially cost a great deal money and can be very financially damaging to the people who take them, isn’t there a need for some kind of step to be taken to address this gap between these two sides of cancer medicine?

Mr Davies—In terms of therapies, as opposed to medications, anyone is at liberty to apply to have a particular therapy added to the Medicare Benefits Schedule. So, in terms of the cost dimension which you mentioned, if someone has a therapy that they consider to be effective but cost is a barrier, then they are quite at liberty to seek to have that added to the Medicare Benefits Schedule. I think I am right in saying there is no cost to the sponsor in applying to have a therapy added to the MBS.

CHAIR—So how many applications have you had and how many have been approved?

Mr Davies—For cancer related therapies or for therapies generally?

CHAIR—Let us say therapies generally, because we are specifically talking about complementary therapies for cancer.

Mr Davies—Any of those complementary therapies, if they are prepared to have it subjected to the scrutiny of the Medicare subsidy assessment committee—

CHAIR—We should also ask Mrs Clutton how many applications for grants for testing under the NHMRC there have been and how many have been approved. It is a similar question.

Mr Davies—One does not apply to the NHMRC for approval; one applies to the NHMRC for research.

CHAIR—We are talking about grants for testing. We are in the context of complementary therapies and medicines. We understand the different areas to do with how to get them on—where it is a PBS listing—but we are talking about proving whether things work or do not work as well.

Mrs Clutton—In the context of research, the NHMRC has received some applications for research into the use of complementary medicines, but the number of applications is quite low. The success rate is also fairly low.

CHAIR—How many applications have you received? How many have you approved for funding?

Mrs Clutton—According to the figures I have before me, the number of applications that we get ranges from eight in one year to 15 in another. They are very small numbers against, say, total numbers of applications for project grants of more than 2,000 for a particular annual cycle. I understand that the success rate in 2003 was 21.4 per cent, which is pretty close to the success rate overall for project grants, but in other years the success rate has been zero. Our belief is that the reason for the quite low success rates is that the applications are not as competitive as other applications that come in, so they do not make the cut-off for funding from NHMRC. What might we do about it? It is probably the case that people who want to do research in this field need some expert mentoring from people who are more qualified, if you like. I want to go back to Senator Humphries's comment about the review of Dr Holt's treatment. He mentioned that there was an NHMRC grant looking into that. It is not actually an NHMRC grant. It was a specific referral to the NHMRC from the minister for health. So it is something that we are doing, but it is not actually a grant.

CHAIR—Is that included in the 21.5 per cent?

Mrs Clutton—No, it is not.

Dr Cook—In terms of the access to the Medicare Benefits Schedule, I should note that it is for services provided by medical practitioners, so, if you make an application to the Medical Services Advisory Committee, it must be for a therapy that is provided by a medical practitioner.

Senator HUMPHRIES—Which most of these will not be.

Dr Cook—Yes. So there is that caveat on access to the MBS, which is provision by a medical practitioner.

Mr Davies—With a handful of exceptions in the past 12 months, the Medicare Benefits Schedule only subsidises services delivered by medical practitioners.

CHAIR—That is what we thought. I was wondering where you were taking us with that. I thought you were suggesting that there were opportunities that I did not think were there. But it is limited to the GPs.

Senator LEES—Through the Enhanced Primary Care program, doctors can refer someone with cancer to a dietitian.

Mr Davies—And gain a subsidy for doing so.

Senator LEES—Yes. There would be at least some subsidy for the patient for that. There seem to be quite a few barriers in terms of the enormous amount of paperwork involved with that process. Whether doctors are right about that or not, I am not sure. Perhaps you could supply us with some statistics and other information on how that is now being used since it was introduced for access to allied health.

Mr Davies—They are quarterly statistics, so we would certainly have them up until the end of last year. I think we presented them to the—

Senator LEES—We would like some idea of how many people are using that. It may be another thing that we should recommend GPs to look at more intensely.

Senator HUMPHRIES—Why don't women who are diagnosed with breast cancer have the same access to free mammograms as women who have not been diagnosed?

Prof. Knight—The mammographic screening program, known as BreastScreen, is for asymptomatic women. It is a population-screening program; therefore, it is not for those who have some symptoms such as a lump, a discharge or something of that sort.

Senator HUMPHRIES—I understand that, but the question was why.

Prof. Knight—Because the screening programs are predicated on the assumptions of the cost-benefit analysis and on trying to detect cancers in otherwise well women. It is generally held to be the case that women who have some suspicious symptoms should be seen by a medical practitioner and go through the normal referral system.

Senator LEES—The problem there is that the body of knowledge within the breast-screening program is that those people with the real expertise in reading mammograms are there. If woman goes back through the GP process, she might be referred to a radiologist who has seen three scans in the last month. There is a concern among women that they are going out of a very specialised, targeted program into a program that may not be as successful. In 1994, the Senate committee that looked at the breast-screening program found some very sad evidence of women who were picked up by the program, who had a family history of breast cancer and who had been getting the X-rays but who had been missed time and time again by radiologists who did not have any expertise in reading mammograms.

Prof. Knight—I guess the response to that is that there is variability across the country. I cannot recall any evidence that shows a difference in expertise among the radiologists who are employed by the BreastScreen program as opposed to those who are not.

Senator KNOWLES—What is the out-of-pocket expense for a mammogram?

Mr Davies—In the program?

Senator KNOWLES—No, for those who are not entitled to the screening process.

Mr Davies—Do you mean the subsidy? The out-of-pocket depends on what the radiologist charges.

Senator KNOWLES—That is right. But do you have any idea of what the out-of-pocket is likely to be?

Mr Davies—I will get you the average bulk-billing rate for diagnostic imaging.

Senator KNOWLES—You can take that on notice if you wish.

Mr Davies—The bulk-billing rate for imaging is about 60 per cent. So for 60 per cent of such examinations there is no out-of-pocket cost. The schedule fee for mammography of both breasts is $89.50 and for one breast it is $53.95. The rebate is 75 or 85 per cent of that, depending on whether or not it is carried out by a specialist. As to what the actual charges are, it varies between providers.

Senator KNOWLES—When is the final evaluation of the pilot bowel screening program likely to be?

Mr Davies—Do you mean when is the evaluation report coming out?

Senator KNOWLES—Yes.

Mr Davies—The evaluation finishes in July this year, then it is a matter of drawing conclusions and writing it up.

Senator KNOWLES—How long is that likely to be?

Prof. Horvath—I could not answer that off the top of my head.

Senator KNOWLES—Is it generally three months, six months or 12 months after the trial?

Prof. Horvath—It depends on the quality of the data and what the inconsistencies are. I have not seen any of the data, personally. I think we would have to take that on notice. I do not know the processes.

Senator KNOWLES—It is not a trick question.

Prof. Horvath—No. I do not want to mislead you by giving you a number.

Senator KNOWLES—Fine. Thank you.

CHAIR—As you are aware, we intend to report by 23 June. We would appreciate you reviewing some of the evidence we have taken. Where you can provide clarification or supporting or opposing evidence to the committee, we would appreciate you doing that as quickly as you can. We have effectively finished hearing from Australian witnesses. We do intend to hear from some international witnesses and we have specifically requested some evidence to be put before the committee. I say that in order to give you a picture of where we are going. Based on that, thank you for your submission and your evidence, and thank you in advance for what you may provide to the committee shortly.

Committee adjourned at 4.37 p.m.