

# Cancer service delivery in regional and rural Australia – problems and prospects

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**STEVE ACKLAND:** I'd like to welcome you all to this workshop, which is facilitated by the Clinical Oncological Society of Australia, on the subject of "Cancer service delivery in regional and rural Australia – problems and prospects". I'd like to acknowledge the traditional owners of this country for allowing us to be here and also acknowledge NRHA for facilitating this workshop.

During the course of the next hour and a half, six speakers will provide a little backgrounding about where the cancer health professionals, who mainly live and work in big cities, think that there's the possibility of enhancing cancer services in rural and remote Australia, and what we have individually and collectively done in that regard. The main purpose of this workshop is to get feedback from people who actually live and work in rural and remote communities, about whether this is on the right track, what we could do better and what components are good and bad about the way we're thinking about delivering cancer services. Ultimately, we want to engage you with us to promote improved health services in relation to cancer.

At the end I propose a panel discussion for about half an hour, so I'm asking each of the speakers to try and be as brief as possible. Now, we're going to kick off with some statistics because it's always good to start with data, so Rajah, from the Cancer Council in New South Wales is going to tell us about Cancer Incidence and Survival Rates, Rural Versus Metropolitan. Thanks, Rajah. I forgot to mention, Peter Brown from NRHA is our scribe and at the end of the session, we will formulate some recommendations that can be taken further, ultimately towards government, in the hope of promotion of this issue.

**RAJAH SUPRAMANIAN:** Thank you. Good afternoon, ladies and gentlemen, on this beautiful Alice Springs day. As Stephen has said, I'm here to just give you a brief outline on cancer survival and the differences, or the contrast, between regional and rural experience versus metropolitan. I'm going to talk a little bit about New South Wales data, because that's what I'm most familiar with and then I'm going to also have a look at the Australian data as well. Then I'll also, if there's time, discuss a couple of papers that were just published very recently; one from Michael Coorey in Queensland, but his national data I want from Darcy Holman's group in Western Australian.

The New South Wales data comes from a report that we did a few years ago, looking at remoteness and cancer incidence, mortality and survival. We used data from 1992 to 1996 from the New South Wales Cancer Registry and we followed people up to the end of 1999. We looked at the 20 most common types of cancer and we also allocated a case, a cancer case, to be either rural or remote, according to the ARIA group, based on the local government area of residence.

So, what is ARIA? Something you may have seen already in some talks at Adrian's conference, but it's a standard measure of remoteness. It has replaced the old RMA measure. We used ARIA 1, which was the only one available at that time, now the things up to ARIA 2.0 plus, and

it's based on road transport links, so the fact that you're in a small town, doesn't automatically mean that you're rural. If you're a small town just on the outskirts of Sydney, then it doesn't make any sense to call yourself rural. It's based on access to major service centres, populations of greater than 5000.

The scores are usually arranged into quintiles from highly accessible to very remote. So that's what New South Wales looks like when you do ARIA. You can see here these dark bits, they're the only very remote areas, according to ARIA, in New South Wales, and that's Bourke and Brewarrina and you can see most of New South Wales, seeing the population, is in the sort of highly accessible/accessible sort of areas. When you look at it by population, you can see here that 83 per cent of the population of New South Wales is in what we call highly accessible areas and only 0.1 per cent is in very remote and 0.5 per cent in remote. Sorry, that should say moderately accessible. So they're the five categories; highly accessible, accessible, moderately accessible, remote and very remote.

So, a little bit about incidence of mortality, for all cancers. You see here, for incidence, across the five quintiles, it's pretty straight, not much there for males, and for mortality, similar, maybe a slight dip there but certainly no trend as such. For females, there is a slight kink here for very remote people, in term of incidence, so slightly higher there and maybe a similar sort of kink as well in mortality. But, on the whole, if you look at each cancer individually, by type, in the top 20, there's 14 cancers here and there's no difference there for either incidence or mortality, across the state. So it's pretty standard across the state in terms of diagnosis and mortality. But there are a few that do differ.

The ones that differ are lung cancer in females. These that are above me, these are higher in rural and remote areas. Sorry, I'm forgetting my terminology. Remote and very remote areas. Prostate cancer in males, also higher in remote and very remote areas. Head and neck cancer, also higher in males. Now, lung cancer and head and neck most people realise are smoking related, so there may be some sort of risk factor there, underlying these rates. When you look at mortality, cervical cancer, much, much higher in remote and very remote areas and it's perhaps because of higher rates in Indigenous people. Prostate cancer also very high, sorry, higher. Stomach cancer, strangely enough, lower in remote and very remote areas. Not sure why.

Usually, when people say "There's a difference in mortality and difference in incidences", certainly to do with mortality and survival, it's because there's a difference in the stage at which people present. So people that are presenting at a more advanced stage in remote areas is the reason what we expect. But you can see here, pretty much across these top nine cancers, not much difference. The only differences are actually in prostate cancer, where it's actually the per cent is presenting with a lower – with localised disease, is actually a little bit lower. So that's sort of what you will say, but it's also lower in stomach cancer which is a bit strange when you consider the mortality is actually lower. So, not sure what's going on there.

Okay. What I'm going to talk about now is survival and we use what we call relatives survival in registries and that's where we use – we don't just get look at – get a hundred people, put them in some sort of vacuum and then come back a couple of years later and say, "Okay, how many are still alive?". We actually divide that number that are alive by the number we expect to be alive, so we get a true indication of what the cancer's actually doing to those people. So we match each person who is diagnosed with a cancer, by age, with someone of the same age as if they didn't have cancer, sex, and also ARIA group. So we're really isolating the cancer, not looking at any other effect.

When we look at all cancers combined, you can see there is a slight gradient here, certainly for males, in terms of survival, so it's going down from almost 60 per cent for all cancers, combined in the highly accessible areas, to probably around the 50 per cent. Females, it's not as

clear, there's a little bit of a bump here, but in general you might say there's still a downward trend. Most cancers, whether statistically significant or not, most cancers the survival rate is lowest in remote areas. In this case, I've combined remote and very remote because the very remote numbers are quite small.

When we summarise it and we look for the ones where there are differences in the risk of death. You can find here that oesophagus, for rural people, actually has a lower — people on this left hand side, means that they've got a lower risk of death for oesophageal cancer in remote and very remote areas. Pancreas higher, pancreas, as we know is a very deadly disease and more than twice the risk of dying with pancreatic cancer. Head and neck, a little bit higher, but head and neck, in general, are pretty high surviving cancer, as is prostate cancer. And cervical cancer and also rectum cancer, I guess, to an extent. So, even though these are much higher rates, in terms of relative risk, the actual number dying probably is not as great a difference as it would be of pancreas cancer. It's hard to tease those numbers out, but certainly these are the ones with the differences.

So, in summary, when we published a paper on this, in 2004, we found that it's not just distance that is the problem with survival, but it's also the fact that there's also variability of services once people actually get to those places. So you'll find that people will make the effort, obviously, or the doctors will make the effort, to get people to hospitals but perhaps sometimes when they got to those hospitals, the quality of care or the variability of care sometimes is there. There's also maybe some socio-economic factors involved here which we don't know about and it's very hard to determine, in rural areas, because say, sometimes a million acre farm in Griffith is classified as the same socio-economic status as the person who works on the farm. So it's harder to determine whether there's any socio-economic factors playing a part.

The solutions we thought and it's probably something you've heard a lot over the last couple of days, is that we need to look at the education and availability of health workers, which everybody knows about. Also, look at transport and accommodation needs, they were the sort of barriers that people identified as getting treatments and getting better survival, and these two papers here address that issue.

I'll go now to Australian data. This is from the Australian Institute of Health and Welfare. This now looks, blowing this data up for the whole of Australia and obviously there's a bit dark spot in the middle of Australia, which is essentially all very remote and very lightly populated and all the heavy centres are around the coast. Now, this is data from the AHW. They did a study from 1992 to 1997 and they followed people up to the end of 1999. They used the old RMA classifications and they used sex specific, but they only adjusted for age, they didn't adjust for ARIA classification. So their gradients are going to be a little bit steeper probably they're comparing them to the whole of the population which most people live in the cities. So they're not comparing them like with like, so their data will be a little bit different, but the same story sort of comes through.

Again, we look at all cancers across Australia and again, definitely a trend in males across from capital cities, all the way down to other remote centres. Not so clear-cut in females, not so clear-cut in females. Not sure why that is. Sorry, today I'm giving you lots and lots of data, and lots and lots of results, I'm not going to give you too many conclusions, because I think that's what this discussion forum's for, so I'm just going to throw it all out there and hope someone else will have some ideas. Colorectal cancer, again some slight differences but really probably the big difference is again in males. It may be that males, as we do, don't go to the doctors as early and so we don't present as early and so we get poorer survival outcomes. That's been discussed a lot this week.

Lung cancer, a very deadly disease, so you don't see as much a difference, you know, because most people are going to die, no matter where you're from. So that's the sort of thing we've got there. Breast cancer, surprisingly very good across all classifications. Maybe not surprisingly, we've got maybe the effective screening, this study was done after screening has come in, so there's a lot more standardised care, a lot more common care across all areas. So perhaps that's why this data is like this. Prostate cancer, again a slight trend there, I'm not sure why there's no one diagnosed in remote areas over a five year period, but you would have to ask AHW about that, but certainly definitely a trend overall.

I'll just quickly go, have we got time to go through – yes. Two papers that were published recently. This one's from Michael Coorey and Peter Bard from Queensland, just published only a couple of weeks ago. They looked at Medicare benefits and AHW, looking at correlations between PSA testing and prostate cancer rates and also radical prostatectomy rates, to try and tease out some of these issues about treatments and monitoring. They looked at all people diagnosed across Australia, from 1985 to 2002/2003. They did it by financial year. You can see here, over that time period, mortality is slowly rising.

Okay, sorry, should explain this probably a little bit differently. Up here, this is the relative risk between rural and regional areas, compared to capital city rates, so the thing goes up here, the trend goes here, it means the differential between urban and rural areas is getting larger towards the regional area, so that's what all these things are. If you look at the PSA tests in that time, it's sort of almost mirrored, in that, this means that the differential is getting slightly lower. It's hard though to say.

Incidence, not sure what's going on there, it's a bit of wiggling around. Prostatectomy rates though, certainly they were getting closer over this time period, but still quite a large differential, almost about 80 per cent here and just popped up again there. So this means that more prostatectomies done in capital city areas. So, yes, those differentials suddenly gets a bit wider now.

So the conclusions they make, were that men in rural remote areas had excess mortality from prostate cancer, they had less PSA testing, fewer radical prostatectomies and lower access to urologists, which is something we knew about. The other article is published by Sonia Hall and Darcy Holman in British Journal of Urology, at the end of last year. They looked at the West Australian link data which is fantastic data, there's a lot to be said for lottery money, because their data is amazing for that, great for monitoring and stuff like that. I'm not sure everyone knows, but every time you access the health system, you go into a big loop and people are able to then see what your whole medical history is and it's very good if you access cancer services or you access treatment services, then you get a real true picture of a person's cancer journey or any other health journey for that matter.

They looked at between 1982 and 2001 and they looked at only three years survival, which is possibly a little bit short for prostate cancer, but that's what they did. The conclusions they came were that men from remote areas tended to go to metropolitan areas for treatment, so people in the far north west of Western Australia, went to Perth. Whereas regional men went to regional hospitals, so they found that differentials were not as big as they thought because of this reason, that people in remote areas were actually getting quite reasonable treatment, quite similar to people in urban areas. So there was no differential over all the ARIA groups that they had.

They said also that people who went to rural hospitals, though, had lower surgery rates and higher mortality, so people that actually lived in larger rural areas, actually fared worse than the people in the most remote areas. The other thing they heard, they also found there was differentials in surgery for people with no private cover or private hospital cover, and lower

socio-economic groups. So there's a lot of data there, lots of results and hopefully they'll cause some discussion later. Thank you.

**STEVE ACKLAND:** We've probably got time for one or two specific questions about Rajah's ... (inaudible) ...

**FEMALE SPEAKER:** I have a question ... (inaudible) ...

**RAJAH SUPRAMANIAN:** ... (inaudible) ...

**MALE SPEAKER:** Certainly, there might be just one concrete manifestation of access to care which could be measured. Anyone else?

**MALE SPEAKER:** Rajah, I'd like to suggest perhaps provocatively that the New South Wales data has limitations because of the percentage of the population that actually lives in remote and very remote areas. Would you care to comment on that?

**RAJAH SUPRAMANIAN:** Well, that's certainly true. I mean, I think also as part of ... (inaudible) ...

**STEVE ACKLAND:** Okay. Now, the next is this guy, Steve Ackland, who works in Newcastle and does a clinic up the road at Muswellbrook, which is 160 kilometres west of Newcastle and I think that's still highly accessible, isn't it, according to your map. And I'm going to talk to you both as an individual and as the President of COSA, on matters relating to mainly medical oncology because that's my specialty.

Now, I guess, the specialty oncologists, of all types, wanted to know what the current problems are in trying to understand resource issues in rural and regional Australia and they have undertaken a forum, which was conducted in Canberra, in 2001, to try and investigate what people thought the current problems were. From that, I'm going to talk about what the resources and gaps in services that currently exist or were perceived to exist in 2001, and what has been done to address them, and what else is currently being done to address the problem, which is two surveys or projects that are ongoing in various parts of the country.

So, the current problems are perceived as being differences in outcomes between cancer sufferers from major metropolitan areas and those in more remote areas, which are presumed to be due to differences in access between those two areas. This Cancer in the Bush Conference (2001) was convened by a few people there, including a bank and the Australian government and the Cancer Council of Australia. It arrived at a number of recommendations which, for probably most of the audience, are patently obvious in what you do everyday. For example, the IPTAAS scheme is variously applied over in different states and territories of Australia.

There's a perceived need for more patient support in rural areas, where it's apparently deficient. There's a need to improve national co-ordination of health professional training, particularly as it relates to rural and regional professionals. Workforce planning needs to be brought into bear. There needs to be better established regional networks to provide this sort of care, so it's a "who you're going to call" type arrangement, and knowing who you're going to call when the problem's sitting in front of you in your office.

There's a need to compare cancer experiences between the rural and the urban settings, to make sure that there are actually gaps in the rural sector that we can deal with. People are inadequately reimbursed, it is believed, for services they provide, often on a visiting basis, to rural and regional areas. There are concerns about drug and radiation availability in these settings.

But there is a paucity of evidence, we don't currently know what services currently exist where; private versus public, resident versus visiting. We haven't yet identified what the gaps in these services are, at least in an organised manner, and so until we've done so, we can't lobby for any improvement. Now, one thing that's happened since 2001 is that the National Breast Cancer Centre has co-ordinated a series of workshops on the subject of Breast Cancer and Chemotherapy in the Bush, which was designed to allow or facilitate the involvement of regional and remote health professionals in the management of women receiving systemic adjuvant therapy for early breast cancer.

Support for this was provided through the RHSET of the Commonwealth Department of Health and Ageing, and a few pharmaceutical companies (and you'll see that the names have changed since 2003), and various regional co-ordinators, including representatives from rural and regional health areas and so on.

The objectives of this project were to provide or facilitate improvement in the knowledge and confidence that GPs, nurses and other health professionals had in dealing with early breast cancer, to facilitate communication links between local health professionals and specialist services. In other words, the issues that Cancer in the Bush identified. The approach used was to try and provide an educational framework, enhanced communication with a resident or visiting medical oncologist and allow local adaptations of evidence-based guidelines.

What was done was initially a needs assessment survey of the medical oncologists who provide services in rural and remote areas. An evidence-based workshop program was worked through. There was a pilot workshop and then five regional workshops to determine whether this approach had validity in the regional and remote setting. It was evaluated and a kit was developed. So the areas where the workshops were done, were Cairns, Bundaberg, Grafton, Wagga – where there's a resident medical oncologist, a solo practitioner – and Nowra.

What has resulted is a kit which I can show you an example of in relation to the next study and this basically allows local health professionals to conduct a workshop in their area, in conjunction with the visiting or resident specialists. In each kit there's a suggested program, there's some pre-prepared evidence-based presentations on the CD-ROM and suggested reading material. If anybody wants a copy of this one for breast cancer, it's available at the NBCC and this slide indicates the ways to get it.

Now, the next workshop that was done was very similar, but in colorectal cancer, and this was done by the Medical Oncology Group of Australia. Again, with sponsorship from the Commonwealth and some newer pharmaceutical companies. The process was similar – it was piloted, in six centres, mainly on the eastern seaboard in rural and remote areas and was conducted in 2002 and 2003. If you want a copy of this kit, which looks like this, and it comes with a CD, that's got all the presentations on it there in PowerPoint. You can get it by giving MOGA a call or through one of those mechanisms.

Now, there's a couple of other things that are still ongoing that are being done to address issues and problems related to rural and remote cancer care delivery. One is a survey that is being done by the Clinical Oncological Society of Australia to compare non-metropolitan and metropolitan cancer service delivery. The second is the BCCCP project which is being conducted out of Albury-Wodonga, and I'll speak briefly to them.

The COSA survey is a mapping exercise. The survey will target chemotherapy nurses, because they're believed to be the linchpin in identifying providers of cancer care in rural and remote areas. Tell us if we're wrong there. The chemotherapy nurse will be the person who we think should be most knowledgeable about what's available in that particular area and be able to co-ordinate the area's response to the survey. We aim to document current practice in all the

areas indicated there, both in public and private sector, as well as residential and visiting services. It's going to be bench-marked against three metropolitan sites, Peter McCallum, Royal Prince Alfred and our place in Newcastle. Currently the data collection is nearing completion but not yet analysed. It's being supported by an unrestricted grant from Mayne Pharma.

Now, the BCCC project is trialling a co-ordinated approach to treatment and support of cancer patients and families/carers in the border area. It's funded by the Commonwealth and Victorian governments and it's run under the Upper Hume Community Health Service. There's a local steering committee and a national expert advisory group and it aims to facilitate and evaluate improvement in care co-ordination across the state border – I think there's some issues there – in all health sectors. This project is still going on and hasn't yet got to the point of providing any data for the rest of us.

What they're going to look at is the employment of cancer care co-ordinators, one a nurse and one a non-nurse, with the aim being to determine whether a cancer care co-ordinator needs to be a nurse or can some other allied health professional or perhaps even a non-professional functioning in that capacity. There's an oncology social worker and psychologists and they aim to establish a multi-disciplinary clinic in colorectal cancer, using the same model that's been established by the National Breast Cancer Centre for Breast Cancer. They will involve GPs either face to face or by phone-link, and arrive at some costings in relation to conducting multi-disciplinary clinics or meetings, so that we can promote the idea of a specific MBS item number for oncology case conferencing.

There'll be a website with information on it about local treatment protocols, referral links and pathways, advice on managing side-effects, which will be available to people in the health area. It's believed that this should be adaptable in other health areas. In the process, they intend to document service gaps and funding issues and barriers and any other bumps along the way. I'll stop there and invite any questions about these specific projects.

Okay. If not, we'll move on and hear from Fred, the local guy, about how things are done in Alice.

**FRED MIEGEL:** Thank you for that and I'm glad it's a nice Alice Springs day for everybody today. When they said 28 degrees on the email the other day, I thought, "I think people are in for a bit of a rude shock".

I'm the local chemotherapy nurse, I'm working out of Alice Springs Hospital and I've been asked to speak about a nurse's perspective on chemotherapy within a rural remote area. Firstly, Central Australia covers the southern half of the Northern Territory. It includes the Barkly Region, Pitjantjatjara lands of South Australia, which are down here, and the Ngaanyatjarra lands of Western Australia.

It covers a population of about 45 000 people and within Alice Springs itself, it's quite a young transient population within the non-Indigenous population. An example of this is the fact that for 26 000 people, we actually have 11 primary schools. 4000 people are in Tennant Creek and then you have about another 16 000 people covering the 45 communities across Central Australia and Barkly region. Alice Springs Hospital is the tertiary health point for this region, it has about 125 beds, depending on whether we've got rota virus or something like that, at the time. But also Tennant Creek Hospital has about 20 beds.

So, within the Northern Territory, there's two major cancer treatment areas. Darwin covers the top end and that's chemotherapy done out of Darwin Private Hospital and they have a dedicated day unit, they have three nurses and an oncologist available on staff. They actually cover a bigger population than Central Australia, so they have a bigger unit for obvious

reasons. Here in Central Australia, chemotherapy is done at Alice Springs Hospital, and it's done by a small part of the day procedure unit, I've got four recliner chairs right down the back end of the day procedure unit; it's a nice area.

One nurse, supervised by a medical team. We have our visiting oncologist, four monthly, and we have video link-ups with Professor Olver fortnightly as well. We treat, on average, about 10 patients at any one time and of those 10 patients, we're probably seeing one to two Indigenous people. So the role of chemotherapy nurse here in Central Australia, to liaise with patients and their families. The reality for our patients are that they may go down to Adelaide, or to Melbourne, or to other tertiary places, to follow up on diagnosis and have initial planning for people, which means they'll start their treatment within that tertiary centre.

Quite often, the families may not be with them for several reasons, and it means that the families need education, they need follow-up down here about what to expect from their family members when they come back and that's quite often the case. I also liaise with the medical staff and the GPs within town, the medical staff do the scripts for me and do any medical reviews that I need done on patients, as they come through. I let the GPs know what's happening with their patient, so that they can be aware of what's going on as the treatment goes on. I liaise with oncologists, so with Professor Olver at the Royal Adelaide, and also with gynae-oncologists in Adelaide and some people choose to go to private oncologists, or go to another interstate tertiary institution.

Pre-treatment education; some of the patients we actually do start here in Alice Springs, so the role is to do the pre-treatment education. Referral to other support services around this region and to give treatment and organise the follow-up. We have some non-government organisation supports; we have the Cancer Council of the NT and they have a co-ordinator and a breast care nurse. These guys run support groups for cancer sufferers in general and also for people with stomas. Within the Northern Territory, stoma supplies are actually distributed by the Cancer Council.

We've just got some funding from Dragons Abreast and we get to get brand new magazines every week. I don't know if anybody saw the Dragons Abreast program on Australian Story, towards the end of last year, but we're grateful for that and the patients and staff are very grateful for update information on the stars. We also can link with private psychologists for referrals, unfortunately we don't have funding to follow that up.

Some of the disadvantages we have, and some of these will be covered by other speakers this afternoon, probably the biggest one is no radiotherapy in the NT. Realistically, here in Central Australia, even if Darwin had a radiotherapy unit, it would still mean travelling 1500 kilometres for treatment and we get a very good deal out of Adelaide. We have a lot of transient staff, even the registrars are here for about three months and then move on. Nursing staff, it can be shorter.

Staff knowledge; at the moment in Central Australia, we have a handful of nurses who are cytotoxic experienced and generally the medical staff, unless the registrars work in oncology unit or palliative care units somewhere else, they don't generally have that experience. It's something we're trying to build on at the moment. We're lucky at the moment, in Tennant Creek, that there is a cytotoxic experienced nurse and we can liaise to get some single agent palliative chemotherapy done there but, at this stage, we haven't had to do that. We did offer it to one person, but they declined it.

Also, there's the issue of distance for the people to travel interstate for treatment, but also the distance for remote community people who come in for treatment. Quite often, these remote communities only have a plane once a week and if it means somebody's coming in for

treatment for a day procedure treatment, they'll fly in on that day, but then they're in town for another week sitting around, unless they want to risk a car journey back to a remote community when they're probably not feeling in top shape. There's very limited private health cover here in Central Australia and that prevents costs recovery to actually build on the service.

Problems for providers; chemotherapy drugs going astray. Now, that's not within the hospital, that's actually out of Melbourne, is where we source our cytotoxic drugs and, for some reason, the couriers have trouble identifying Alice Springs and Bendigo and Perth and Darwin. This generally tends to happen with the short expiry date chemotherapy and on two occasions we've actually had people come down from Tennant Creek, 500 kilometres, to be told, I'm sorry, but it hasn't turned up, it's gone to Bendigo, or it's gone to Perth, or it's gone to Darwin, you know, but there'll be some here tomorrow, so that means putting them up for an extra day before they can travel back to where they come from.

Remote patients missing lifts; if that plane only comes in once a week, it can delay treatment by a whole week. Cultural language difficulties; if we're dealing with Aboriginal people, you know, English is a second, third or fourth language for some of these people. They deal with, depending on their urbanisation, their whole disease understanding is of a spiritual level and not a physical level. Also, you have law commitments for Indigenous people. If there is a funeral on, it is their responsibility to attend that funeral, even if they're due to have chemotherapy.

Understanding the aim of treatment; now I think this is probably across the board in Australia, but the reality is, it's harder when you have some of those cultural difficulties. It's also harder when people are taken out of a rural area, into a city area, have the explanations without family members there. It makes it harder for them to understand, "Okay, I'm going back to have chemotherapy. Chemotherapy cures everything doesn't it?". And that's a hard one and that happens in the city, I know, and that's why I do a little bit of work with families before patients come back, if possible.

Patient issues; I did a bit of a straw poll with patients over the last couple of weeks, when they come in and out for that and the biggest problem for people is, they really appreciate being able to have chemotherapy in their home town, it means they don't have to leave their home, they don't have to leave their family for interstate treatment. It means they don't have to close their business down. There's less disruption to their life. We have an idyllic life up here, a little bit hot at times but we're happy with it.

The cost of being interstate, the PAT scheme is supportive but can get a bit tricky when you're trying to get escorts with people with cancer into interstate treatment. Also the cost of, you know, if you have young children, it means packing up the whole family and taking them interstate. People going to Adelaide, having to rent a unit for a period of a couple of months, while they're having treatment.

Also the city versus Central Australian lifestyle or the rural lifestyle. A lot of city hospitals like to put PIC lines into their patients. Now PIC lines are great in an urban area but unfortunately you don't have a lot of PIC trained staff within rural areas. Also PIC lines which sit under the arm here, have a tape over it to hold it in place and in a hot sweaty environment, you know, that's not very pleasant; people like to go for swims, people like to be outside. We actually encourage our patients and, if we can, here in Alice Spring actually get an infuser port put in because it means it's out of the way, it's self-enclosed.

We have limited access to oncologists and some patients will take the bull by the horns and ring Professor Olver, or their oncologists, but some people will actually sit their for the four

months and wait to see them again, even if they do have a problem. We've got some very interesting people in Central Australia, so they don't always come out of the woodwork until they're told to. One of the good things and Professor Olver will talk more about this, the video linking, and I've actually had two occasions where I've had patients, at vital times of decision-making with their treatment, we've been able to link them in a video link-up to actually help them make that decision of treatment.

Alice Springs Hospital is a busy hospital with an acute focus. A&E is generally never quiet and you dare not say "It's quiet today" as you walk through, because you know someone's going to follow you in. But for oncology patients, with a febrile neutropenic patient, it's not a place to have them sitting, waiting to be seen by a doctor and that's one of the issues we're trying to deal with at the moment.

I guess, in closing the patient's grateful that they can have their treatment in Alice Springs, for the above reasons and I'm thankful for the support that we get from the Royal Adelaide Hospital from Professor Olver, but I'm also grateful for the goodwill of rural communities to help keep people at home. In the last six months, we've probably had three or four options to help people with, not just cancer, but also motor vehicle accidents, just to help support the financial issues of living in a rural area. Thank you very much.

**STEVE ACKLAND:** Any questions for Fred before we move on? Okay. Ofra, palliative care.

**OFRA FRIED:** Hello. I'd like to thank COSA and the conference organisers for inviting me to speak on palliative care service provision in rural and remote Australia. What I was actually asked to speak about was being so far away from treatment and I guess, in this talk, I'd like to try and help you refocus on service provision in rural and remote Australia, so that instead of seeing only remoteness from the care available in the urban centres, you can appreciate the realities of what's on offer in the bush and that's basically as good as the care planning that we put into it and the resourcing.

For those of you who aren't familiar with palliative care, there's a definition there. It's not in fact confined to the treatment of the terminal stages of malignant disease, although that's what we're focusing on today, however, historically contemporary palliative care services have developed mainly in response to the needs of cancer patients and many of our services patients have non-malignant conditions, about a third of them in fact. So palliative care is actually a concept of care on an approach to practice that's holistic and multi-disciplinary and client focused and that's the bottom line. Palliative care services have a specific skill-set, which I would encourage you all to access, but palliative care can be provided and generally is provided by non-specialist practitioners and in settings other than hospices and hospitals.

I'd like to introduce to you the concept of a web of care supporting patients with cancer. We often talk about providing our patients with a seamless passage between different care services and clearly, it can't happen without a lot of willingness and effort and good communication and I was really interested to hear from Dr Ackland about the sorts of projects that are being got up to address that. It's really important that all care providers involved in any given patients care, share the project of that care, that is they're actively co-operating to provide it and work towards the same goals of care and clearly those goals may need to change as the patient's disease progresses.

It's generally recognised now that palliative care is an integral part of comprehensive cancer care, whereas in the past it was only really something provided at the very end of life when active cancer treatment had stopped and good comprehensive cancer care centres, such as those of the Adelaide, have their palliative care services fully incorporated in with them. We find it's must more practical to provide good palliation of symptoms and proper psycho-social

support and appropriate multi-disciplinary approach to management in parallel to active cancer treatment, not something that's at the end, after active treatment stops. I would also consider palliative care to be a part of the primary care of most patients with cancer and other life-ending illnesses.

I think that I view cancer as being a chronic illness with remissions and relapses, best managed by community care workers and specialist cancer care services working together and many patients will also have their palliative care provided either in the primary care setting, or in fact by cancer care practitioners who are not palliative care specialists. Finally, it must be remembered that patients with cancer continue to be a part of their families in their communities. This is really important in the planning of their cancer care and Fred's alluded to some of that. The family and the community life of a person determines much of what they experience as their quality of life, which as you may remember from the definition was an important part of palliative care. So family concerns are integral to making good treatment decisions. The family and community is also the source for much of the care and support the patient needs.

So, what's different about delivering palliative care in rural and remote areas? There are a number of practical difference, including the availability of trained staff and ease of access to various services, such as health care facilities, psycho-social supports, practical home care help and personal care services. In addition, patients in regional areas may have unique clinical and other characteristics that will impact on the sort of treatment and care they need and how it's best provided. These differences then influence the practicalities of care planning for patients, that's regardless of whether you're planning at the curative or at the palliative end of the spectrum, or anywhere in between.

Much of the focus of our palliative care services work is therefore to help guide appropriate treatment decisions and to bring to that knowledge the unique situations of our local patients. Whilst such decisions need to be individually tailored, the most useful when they're embedded into what I like to think of as a public health or population based approach to care, which I'll talk about a little bit more.

Now, good treatment decisions will of course incorporate the practicalities of delivering treatment and care. Fred's alluded to the enormous area that we cover from Central Australia, we've actually got 2.5 staff in our palliative care service, so clearly we can't be at the bedside of every patient in the million square kilometres of territory that we cover, so how do we do it? Now, much of that's about having a good network, accessing patients when they actually come through Alice Springs for treatment or on route elsewhere and, frankly, we just use whatever we can, the phone, the fax, electronic means, to remain in communication with and support the primary care providers who are in the front line of care. So you might think I'm on the front line but if any of you are remote area nurses, you probably know the difference.

Talking of people at the front line, I want to focus a little bit more detail on the area of staff and services. Basically, in remote areas, the absolute number of health providers is low and you're multi-disciplinary palliative care team, if you're a patient living on a remote Aboriginal community, might if you're lucky consist of one or two remote area nurses. We talk about all these terms is what I'm saying. So you might get one or two remote area nurses, perhaps an Aboriginal Health worker, perhaps a doctor visiting once a fortnight.

Their skill levels are going to be variable but, more often than not, bush workers area really highly skilled in the various domains of practice that they need to be, in order to provide care and they often have considerable post-graduate training. They're capable of working in isolation and taking in an enormous amount of responsibility. Additionally, they're sources of invaluable local knowledge. So, whilst they mightn't have specific palliative care skills, if you

support them and guide them, even from a distance, they're going to be able to provide their patients with excellent care and support and they do. As Fred mentioned, staff turnover can be very high, that impacts on the quality of local knowledge but also on the sort of education that we provide, it's time consuming, it has to be repeated.

I'd like to focus a little bit on care relations, it's not all bad and the closeness of small town community life, and Fred did mention this, it impacts on the quality of our care relationships and we tend to meet our patients and their relatives in the supermarket or when we have our house painted or our car fixed or whatever.

Fred and I have both been working in Alice Springs so long that we're accessing multiple family members coming into our care over time and, if you request Aboriginal liaison or interpreting services, you're more likely than not going to have these workers in some kind of a kin relationship with your client and these things impact on workers, both emotionally and culturally. So the closeness can make things difficult, but it can also be an absolutely wonderful resource. It can reduce alienation, it can make the patient feel safer and it can maximise service networking.

Fred's alluded to some of the difficulties of access to high tech facilities, so we don't have lots of diagnostic facilities such as MRI, nuclear medicine, bone scanning, here in Alice Springs, let alone on a remote community and we're distant from any treatment facilities. Fred mentioned radiotherapy, there's also specialist surgery, even specialist pain management. So, as a result, the decision to transfer a patient for any of these things, palliative radiotherapy, a stent, intrathecal analgesia, whatever, it can be very difficult and you have to help the patient weigh up the potential benefits of these things, with the burdens of being maybe hundreds of kilometres away, often in a completely alien environment, where nobody speaks your language or understands your needs, often for a very long time.

If things go wrong, they might spend much of their remaining precious time in that situation and they might even die there, far away from home and kin. So, it's a really difficult thing. So timing and stage of illness and informed consent and the respect for individual and family and cultural concerns, are all of vital importance in making these important decisions. Such treatment decisions can become unstuck if all these things aren't attended to.

Apart from the high tech and tertiary treatment facilities, our patients also need access to a whole range of services in the local context, from medical supervision to personal care support, from psycho-social and bereavement support, home help, child care, securing pharmacy supplies locally, perhaps getting special dietary needs, continence needs, you know, a whole range of things that you wouldn't think about, even access to a wheelchair or to electricity for home oxygen, cannot be taken for granted.

So, once again, good care choices must be made in an informed way and some effort has to go into strengthening that web of care. We sometimes find that the treatment given to a patient, when they go interstate with their cancer, and their resulting special needs, may make it impossible for them to return to their home communities and that can be an enormous source of grief. On the other hand, we've cared for patients with very complex needs on remote communities.

So this next slide is an approach to what I previously described as a public health approach to care and what I mean by that is that we try to understand our client base, and their environment, so we can provide better targeted services and there are various disciplines that contribute to such an understanding. I'm not an expert in any of them but, you know, you have to have some sort of a grasp of it. So, epidemiology is the study of disease and disease

attributes in defined population. It's equally applicable to disease requiring palliation as it is to any other.

Demography is the social science of people considered collectively, for example, by their ethnicity or where they live. Geography, obviously, is the study of the surface of the earth, its natural features and how these interact with the lives of its inhabitants. The reason I've put these up is, you need to ask who your patients are, where and how they live, how do they do things, what's important to them, what illnesses do they suffer from. Now, half our patients are Aboriginal people from about a dozen different broad language groups and many living on remote communities.

I haven't got time to talk about specifically Indigenous issues and I haven't been asked to do that, but the rural Health Education foundation has asked me to draw your attention to this CD, which contains some information about providing palliative care for Indigenous people and I've got a few copies here and there's also some other resources out on the Commonwealth Department of Health and Aged Care table out there, which have been developed about Indigenous issues in palliative care.

Really important in terms of epidemiology to recognise that the range of illnesses local Aboriginal people suffers, is not the same that you would find in an urban setting, even the types of cancer they get are different. High premature mortality in our population, frequently extensive co-morbidities and so we have a relatively young clientele and that has an enormous impact on the provision of home care and also in issues of grief and loss.

In dealing with access issues, these vast distances here do impact on health care; there's little public transport, roads can be long and rough, variable weather can close in suddenly. Whether you're Aboriginal or non-Aboriginal in Central Australia, the likelihood is that your family and supports are going to be far away, so you can't easily, for all of these many reasons, transfer an urban style of practice to a bush setting while still meeting people's real needs.

Nevertheless, care planning can be done really well in remote Australia. In this slide, I've tried to unpack the way we do our care planning. I think we need to pay attention to three broad areas; the process itself, the way we do it, the social and cultural domains determining our care choices and the practicalities imposed by the patients clinical condition and their care environment. I've put them in this order for a reason. We doctors generally plan treatment in accordance with clinical scenarios only and we leave others, perhaps social workers, nurses, maybe the patient themselves, to take care of these other areas.

When our plans fail, we fail to understand why. I think without due process, you can't make holistic treatment decisions based on adequate information and true informed consent and I believe the social and cultural domains of a person's life underpin everything else, so if you ignore them, you always get problems. I think care planning elsewhere is probably done similarly, maybe its elements are a bit less visible in an urban environment and where you think patients' lives are a bit closer to yours.

So, the first element process, primary ingredient in good care planning is good communication. Trust and mutual respect are prerequisites for that. Important to use plain, non-medical language and, if needed, language interpreting services, all important clinical consultations and we also find it useful, with our Aboriginal patients, to consult the Aboriginal Liaison Services to make sure significant cultural issues are addressed and provide advocacy support and what sometimes are overwhelmingly difficult clinical interactions. In order to facilitate decision making, it's really important that doctors source enough clinical knowledge about the condition obviously, its treatments, but also the patient's prognosis so that they can provide

meaningful input. I'm saying that because often we don't talk about prognosis, I think, well enough.

Regional networking means that you know your regional referral care environment, your services and care providers well enough so you can help your patient negotiate these. For our palliative care patients, but particularly with Aboriginal families where the cultural significance of the kin network is generally so important to decision making, family meetings provide very useful forums for information sharing and providing a culturally appropriate means of decision making.

Social and cultural dimensions of care; I can't go into in any detail again because of limitations of time. I wanted to mention the concept of cultural safety. I'm actually not going to describe it, for lack of time, but if anyone wants to ask afterwards, we can talk about it. I think it's absolutely vital to care. I think the most important aspect of many patients' lives are family and community considerations and these may take precedence over other considerations and we have to respect this, but patients also depend on the family's care and support them, so they've got to be included.

Aboriginal kin networks can be very extensive but there are cultural rules determining which people can and should provide certain sorts of care. This can govern everything from who might travel as an escort interstate with the patient, to where they will receive care at the end of life. For many Aboriginal people in our region remaining on and returning to, or even in fact dying in their traditional country, is a prime consideration determining their treatment in care choices and it just makes it that much harder, I think, when they have to travel for care in situations where they might not make it back.

The practicalities are basically, on the one hand the patient's disease and the other side their care environment. Clinical conditions are obviously vital in care planning and, in my experience, despite the advent of wonderful new diagnostic techniques, we sometimes fail to properly understand at what stage the patient's illness is in and what their prognosis is. I'm saying "we" as all care providers.

So, we don't factor that well enough, sometimes, into our clinical advice and additionally we might fail to tell patients clearly enough what to expect and that means they can't give fully informed consent to treatment plans and they can't make their own personal end-of-life plans. I think we all try to do this but, in my experience, people sometimes come to me, sometimes after years of treatment, still not understanding where things are going and therefore how that's going to impact on what's ahead of them.

Treatment plans need to take into account issues of distance and transportations, care and carer requirements and available support services. Then the potential benefits of any treatment needs to be weighed against adverse outcomes. Just as an example, it's not much good prolonging someone's life for a few weeks by means of the miracles of modern surgery, if the outcome of that is that their care requirements confine them to a hospital bed, far away from their family and country, for the remainder of that time.

So, I'd like to summarise then with these three take-home messages. The first is not to make assumptions about care in the bush. Remoteness is relative and you might find it helpful to just try and turn things around, look at things from your patient's point of view and hopefully understand where they're coming from. Secondly, with good planning, good care planning, it's absolutely essential, excellent care is possible. Thirdly, the guide and the key care planning is good communication with all the parties involved. And that's really all I had to say. Thank you.

**STEVE ACKLAND:** Any questions for Ofra? All right, while Ian's coming up to the podium, I might just mention that the Department of Health and Ageing views cancer as a chronic disease now, so while it might be a terminal illness, the term is often very ... (inaudible) ...

**IAN OLVER:** Good, thanks, Steve. I'm medical oncologist at the Royal Adelaide, I actually do the oncology clinic up here, which I've just spent the last two days doing. In between times, we have a fortnightly video conference with Fred and the physician and communicate by phone and email and letters in between times as well. So that's how we manage the patients up here. With Darwin, I don't visit Darwin more than sporadically but we do it all by tele-medicine with a weekly tele-medicine link, so I've been asked to speculate on the role of tele-health in the diagnosis and treatment of cancer in rural and remote Australia.

I think we've got to start by asking what the purpose of wanting to do tele-health is and what we're needing to do is to try and export expertise to rural and remote areas to achieve an equity of access. You've got to be very careful with the term "equity of access" because if people interpret it as that there's going to be a linear accelerator at the end of every street, there isn't, but there should at least be equity of access to the expertise that drives the treatment choices. We also are using tele-medicine in this sense, to deliver multi-disciplinary opinions, where in rural and remote areas there may not be all the members of a multi-disciplinary team that we'd have in urban areas, for example, if there's no linear accelerators in the bush, there won't easy access to radiation oncologists.

Tele-medicine also may increase the efficiency of being able to deliver care by reducing travel time for clinicians and, as Ofra said and Fred said, the minimising of time away from home, family and their workplace for patients, is extremely important. So we did a couple of experiments in developing this and the first experiment we did is to establish a tele-medicine link between the Royal Adelaide and Darwin. The purpose of that was Darwin wanted to be able to present their patients to a multi-disciplinary meeting and we reviewed all our medical oncology patients in a multi-disciplinary meeting each week, so we simply put that all in a tele-medicine room and Darwin switched into it and presented the patients. When they first started doing it, they just presented their patients and then switched off. Now they stay for the whole hour comment on ours and use the whole thing as a sort of continuing education experience.

The other experiment that we did was right at the level of the patient, where the tele-medicine link requires special digital equipment and digital phone lines and we wanted to explore the use of ordinary video phones over the plain old telephone system. We used some rural areas in South Australia to see if we could use video phones to extend the outreach of palliative care in areas where we knew the palliative care nurses, or in fact the regional nurses, couldn't visit as often because of remoteness. So, if we could supplement that in between times, how well did it do.

So in the first of these, we established the digital video conferencing link, we built a video conferencing room at the Adelaide and had some portable equipment at Darwin and then we evaluated that. This is our tele-medicine room. You can have a multi-disciplinary meeting. If somebody switches their microphone button, the camera automatically zooms in on them, so they can actually talk one to one with people at the other end and we can display slides, we can display pathology and radiology back to the people when we're presenting the patient.

What we found in this research was the advantages in tele-medicine was if did enable the remote clinician to be able to participate in a multi-disciplinary team and reduce their sense of professional isolation, if you like. There was clearly better communication between the tertiary and remote clinicians for all aspects of care, but it included palliative care. There was clearly a decrease in patient and clinician travelling time because, even if the patient had to come to Adelaide for radiotherapy, the radiation oncologist had already seen, discussed their case, seen

their x-ray and you could virtually see them and plan them on the day that they had hit the unit and that saved a week.

It enhanced the education of remote clinicians, not only sitting in the clinic, but if we have a visiting speaker in Adelaide and we can hold it in the tele-medicine room and Darwin can join in, it certainly enhanced peer review. Not only was it giving second multi-disciplinary opinions, but there was also the ability to send x-rays and path down and have that reviewed as a second opinion as well.

The disadvantages in the early days, particularly, were technical, with breakdowns and movement artefact which made it a bit artificial. Now things are so much faster, it's almost like watching television. There are problems in personality of the interaction and we've found that what you've got to do is you've actually got to meet the people some time, and then that makes the tele-medicine link go better. So I might end up going to Darwin once every two or three years and Sid will come down to Adelaide and we'll meet the whole team and then we can communicate better over tele-medicine.

I guess one of the troubles was the inability to examine remote patients but you've got to trust the team to provide you with accurate information. There are other blocks though that are legislative. There's lack of reimbursement for a video conference, so this is very hard to do in the private sector and there's lack of reimbursement for each member of a multi-disciplinary meeting. There is some attempt to reimburse but I gather only one clinician can be reimbursed out of a multi-disciplinary meeting, so somebody gets paid and the rest do it for nothing, which is almost unfairer than having nobody getting paid, in my opinion.

Initially, when we set this up, the quality of the link was not good enough to give a professional opinion on x-rays or pathology. It now is probably, but one of the rules that we'll talk about later on is that we can't change the practice of these people. And I'll talk about that. The patients actually thought it was great, they were quite satisfied that their case had been discussed by a whole range of clinicians and those that travel for treatment, believes that because their case was already known, they didn't spend as much time. We actually did a little survey and found they spend an average of eight days less in Adelaide when they came for radiotherapy and we saved a lot in accommodation costs and so on.

So, what lessons did we learn? We learnt that to establish this thing, there had to be a champion of this type of technology at either end of the link. The teams should meet, as I've said, and the use of the technology must not disrupt normal practice, so we put our multi-disciplinary meetings in that tele-medicine room, whether Darwin switches on or not. It's a place that's easy to access. There's a lot of centres that have their tele-medicine equipment in a boardroom and there's invariably a board meeting when you want a link with them. You can't change practice, so if it is the practice of a radiologist and a pathologist to sort of mull over something in advance of presenting it, and to discuss it with their colleagues, then even if you do it digitally, you'd send it down a couple of days earlier to let them do that because otherwise the tele-medicine becomes intrusive.

So the next step was this other program of looking at video phones and we used palliative care nurses in Port Pirie and that was the last sized town where there was a palliative care nurse. Beyond Port Pirie in South Australia, there were regional nurses with no specific palliative care training and these video phones, which I'll show you, are sort of hand-held. So you have a town of about 15 000 that's 230 kilometres from Adelaide and they needed to liaise with their more distant nurses. So, we looked at the more distant nurses in Peterborough, which is a further 95 kilometres from Port Pirie, and Boolaroo Centre which is 65, and we provided analogue phones to the palliative care nurses and the remote nurses.

Now, I said to them, "Why can't you just get on and drive 65 kilometres?", and that's the sort of thing that sort of turned up round every corner, so it took them some hours to get from Port Pirie to Billaroo Centre and some hours back again. So they simply couldn't visit these patients very often. And then we actually used questionnaires to look at the satisfaction. That's a little video phone, it's highly portable and it just plugs into the phone line.

The potential barriers to conducting this sort research is that people that work in remote communities, usually have not done research before and you need to sort of up-skill them in what that means. The other thing is, if you want to get large numbers, you can't get it in a remote area because you don't have large numbers of interactions, so you end up doing descriptive studies, rather than quantitative studies and then there's no literature on what you should be measuring anyway.

What we actually encountered was just that, they were inexperienced in conducting research, there was this high turnover that others have talked, so just as you got someone trained to the video, they had sort of missed the sea or something and go off to somewhere else and you'd have to train someone else. Even with simply analogue phones, they weren't compatible with the local hospital's PABX and there were some remote farm houses that actually didn't have phone lines at all. So, that was one thing.

Now, the palliative care nurses actually found they were very useful to have, they used them to communicate with the outreach nurses, but they also used it to communicate with the outreach nurse when one of their own clients was being visited, so they put in an extra visit by using the video phone and they also used them to communicate back to Adelaide to the oncologists. They made the comment that they knew these clients and some of these people were reluctant to talk on the telephone but when you used a video phone, they talked as if the person was in the room, so they felt that they were far more comfortable.

The project was sporadic, there was only the odd patient every month that was available to do this and the equipment was easy to use but it was extra time to set it up, particularly when we had one high tech nurse that set it up so you could view it through the television to make the image better and I thought that was pretty good stuff, but I bet he spent half an hour figuring out how to do it, because I can't.

Now, the perceived advantage of video phones was the reduction in travelling time, the reduction in social isolation and the better rapport with the phone. The disadvantages was some of the nurses were actually techno-phobic and didn't want to use this new technology and when they got it set up with Telstra, you know, if an incoming phone call came into the house that knocked their call off, then they had to go through the whole business of establishing it again. So using the phone line wasn't such a good idea.

So, what of the future? I actually think we're now exploring web-tape based technology to talk with some of our international collaborators and this would seem a far better, there's some polycom equipment that gives you almost video type images and when you have on your computer one to one conferencing is easier. So, what I do with Fred, instead of needing the big room, I just do from my office, using digital equipment, but in future we may just use internet. The quality is now adequate for diagnosis, but you'll have to send them earlier, and we need to work out these reimbursement issues. I'm happy to take any questions.

**STEVE ACKLAND:** Any questions for Ian?

**FEMALE SPEAKER:** I just want to make a comment, as I think rural New South Wales in seen is a remote area on the map and it just seems to me that more and more of the technology has to be put in place with the high cost of fuel and added difficulties with travel applying here as

well. Certainly for the people that I see, where I work, you know, it's a long, long trip, and always by road to where they go for primary treatment.

**IAN OLVER:** Well, I would agree with that. Once people get used to it, it's actually easy and the quality of the technology just leaps ahead year by year. I mean, now everyone's carrying video phones on their mobile phones, so you might do it a different way now, but the proof of principle is there.

**FEMALE SPEAKER:** Yes.

**STEVE ACKLAND:** Okay. Michael, radiotherapy and milk.

**MICHAEL PENNIMENT:** You've seen the slides. You've spoilt the surprise. Yes, thanks. I'm Michael Penniment, a radiation oncologist in Adelaide. I had confidence in the speakers that would go before me, to really go for a lot of the key issues that we have talked about in terms of accessing oncology treatment, so what I thought I'd try and concentrate on is knowing the limitations.

How do we rationalise the distribution of oncology services, in particular radiation oncology, it's fairly easy to understand that to start a radiation oncology centre, it's a capital intensive organisation that will need decisions to be made. So, we always are faced with decisions. Clearly, there's some product, such as milk, where clearly you don't have to drive to a capital city to get milk, that's provided and you can get that in a facility that's close to you, although that also is not always the case.

But what about this, this is a radiation oncology machine, a linear accelerator, where just what you can see there is basically a couple of university trained physicists, biomedical engineers, technicians that have done years of specialised courses. That's just essentially routine maintenance on one linear accelerator, quite a lot of significantly trained staff and we're not talking about radiation oncologists, nurses, other support services, it's purely the technical people. So that's linear accelerator again and, as I say, it's fairly capital intensive to put even just one linear accelerator into a unit.

Once you look at the lifespan of a linear accelerator and the number of patients that you can treat over a period of 10/15 year lifespan, the actual treatment per patient is quite cheap and there's now quite a lot of data that says that, basically, about 50 per cent of patients with cancer would benefit from radiation oncology. That's data that WHO, the NHMRC and just recently, Delaneys group in Liverpool have accurately put the number at 52.6 per cent, but basically about half the people with cancer would get some benefit from radiotherapy. Most of that's done as an outpatient which clearly, if you live near a centre is great. If you don't, well, it's not necessarily a major benefit.

So then if you're talking about radiation oncology, there's different levels of radiation oncology as well. What this shows is really, I suppose, the simplest way you can give radiotherapy, that's a patient too who had a lump in the groin, I've put a wire mark around where the lump was. I didn't want to treat certain areas here, so I've shielded that out and I've just put on a field, I could have done that with text on his leg. Then I could have taken the patient to the machine and put them on the machine, lined up the radiation unit according to the marks, and give the treatment and use a fairly basic linear accelerator which would only have cost about one and a half million dollars, in a bunker that probably only cost about another million dollars. Basically that's pretty straight forward simple radiotherapy.

But what about if you want to do computer plan radiotherapy to try and cure somebody with a six or seven week course to lung treatment. Well, this has opened up another degree of complexity in terms of CT simulation. We've got a CT scan that specifically plans our patients

in Adelaide. Certainly not all centres in Australia have CT scans, only a couple have reached that level of complexity. You need people that are obviously trained in operating a CT, you need people that are trained in working out the dissymmetry and utilising the technology to the nth degree.

We're actually, as I've presented in this conference a couple of years ago, we're able through our research to link in to other CT scans such as the one in Darwin, where we can import the images from Darwin, down to our CT simulation packages in Adelaide and save patients a week or so of coming to Adelaide for the planning, but the treatments another issue. Even then, then there's more complex treatment such as a patient with a head and neck cancer, where they need custom-made mobilisation devices and they need even more technical aspects to their treatment. So this takes the treatment to a level where, as I say, Royal Adelaide, Peter McCallum, a couple of centres in Australia at that level, so there's clearly different levels of radiation oncology.

I thought, just to sort of go off on a bit of a tangent, this is essentially a slide from University of Adelaide marketing, it's got nothing to do with cancer and all and it's pretty late on a Saturday, so I thought we could go into distribution graphs. What this shows is, in essence, it's pretty self evident and that is, if you want to actually get whatever your product is to the people that are the customers and here, let's say the clients are the patients. We know that the distribution costs of actually getting your product to those patients will increase according to the number of people that you want to get something to.

So, in other words, with the milk, if you want to set up a shop in the centre of Sydney that sells milk, and that's the only place in Australia, well, you know, you will sell milk and there'll be some people that will probably live in Newcastle that might drive down for their milk. But then there's going to be people in Alice Springs that are going to look at substitutes in terms of powdered milk or buying a cow, although it will be damn hot for a cow today I must say.

And so how do we work out — how do we rationalise those decisions. Well, we know ultimately in terms of radiation oncology there's things you can do along that line where you can bring your service to the client or to the customer. You're never going to get to the point where it's going to be a hundred per cent access and equity of service. And you know that this line here which is lost sales, well what we can look at with radiotherapy we'll come to. It's not as much lost sales obviously, but it's loss of patient care, and that has equity points of discussion.

So again, just pinching something from the University of Adelaide Business Studies, the distribution objectives, what we're saying is basically if you've got something that you want to get out to people you've got to look at how you can get it out in as easier and as efficacious way as possible. And Ian's talked about things we've done with some of the technology in terms of at least simplifying the root of service, in terms of getting the clinical opinion to the community. And obviously you want to know what the customer wants, and I think Ofra said a lot about that in terms of that there are specialised needs for everybody that lives in different centres, and that's Adelaide versus Sydney versus Alice Springs, versus Katherine versus a community centre.

Now, in order to try and put that a little bit more in terms of cancer, this is just my way of trying to start a discussion in terms of looking at that cost curve, but looking at it from the point of view of a cancer patient. And we know if we have one radiation oncology centre which costs X, the people will use it, the people — we don't put any effort into trying to get the message out that radiotherapy is useful for cure and palliation, we do nothing. And there will be still people that will know about it and will come to it.

If we actually pay to make sure that people go to various centres, so myself to Darwin, and Ian to Alice Springs, then we're putting a little bit of cost in but we're getting a better number of patients that are going to be accessing the service. We can build local infrastructure which costs money and gets – again, gets more people into the service. We can go for a full radiotherapy centre, a cancer centre like at the Royal Adelaide. But again, we're never going to, no matter how much money we put into the system we're never going to get the situation where everybody has absolutely complete full access to treatment.

And looking at that previous curve that had about the loss of sales, well we know obviously the more people that access cancer treatment, there'll be clearly the socio-political benefits we've talked about in terms of the psycho-social and other aspects, but just pure cost of hospitalisation, years of life saved. And as we say, the other things we've talked about. So if we take that intuitive stepped approach, how can we actually put some numbers around that to say, well where should we be, how much money should we be putting in to service fulfilment.

And some of the basic points that are going – that would help us to work out this would be there's been a number of New South Wales studies that have shown a lot of Michael Barton's work from Seacorp, show that radiation utilisation patterns, as we'd expect, are highest near a major radiotherapy centre. Again, if we're looking at the utilisation rate of 50 per cent as a sort of gold standard, if you get close to a centre, and this is replicated in Adelaide where I think metropolis and utilisation rate is of the order of 40 per cent.

In an area where an oncologist visits, and I know Michael Barton's figures show a big blip around Broken Hill, which is somewhere I go to. The utilisation's less, but it's clearly better than somewhere such as Northern Territory where the utilisation rate is really quite significantly below all the other national averages. And we also know that, as I said with milk, if you can't get milk you look at substitutes and you look at powdered milk or whatever. Well, it's the same if you're faced with a decision where you have breast cancer and you've got a choice between a mastectomy and post operative care, and that that may be able to be done in a large rural centre versus coming to Adelaide or Melbourne or wherever for post operative radiotherapy and have six weeks of treatment.

Even if you're told that a number of studies have shown there's a slight survival benefit as well as the cosmetic benefit of having the radiotherapy, it's still no surprise that there's a 20 per cent higher mastectomy rate away from radiation oncology centres. And that's for a variety of reasons, but clearly people faced with the choice of going away for six weeks, or more than that really, eight weeks, will elect to go for a mastectomy. And we know that utilisation numbers that we've talked about will go up as soon as the new centre begins, and that's again pretty straightforward. Again, the milk situation, if you put a milk shop in they'll sell milk. Well, Geelong and Townsville where I work, the utilisation rate went up quite significantly, a lot above what the expectations were.

And in terms of looking at those centres and other work that's being done, if you do population projections as has been done in a forthcoming report into territory oncology services it's not quite released, but it basically would suggest that in 2001, 340 patients in the territory would have benefited from radiotherapy, and that looks to rise – the figure looks to rise to 440 in 2010. And in general what is thought to be a reasonable number for – one linear accelerator working in a very busy centre in say Sydney, would treat basically 350 to 400 new patients a years. So this 440 figure in 2010 is a little bit more than a busy radiation oncology centre.

So where's the research taking us? Well, I think there's two ways that we could look at the research. One is what about putting small radiotherapy units in as many places as possible, and there has been a trial that started in 2002 in Victoria, the single machine unit trial, which put a

single linear accelerator in major centres just away from Melbourne, and linked them quite intimately to major Melbourne centres, Peter Mack Austin and the Alfred.

And that trial unfortunately the data from that trial's not due to be released for a few months, but what it looked at was four things, basically was putting a linear accelerator in these places, did it improve access of patients to their treatment, did it improve the utilisation rates we've talked about, was it economical, how much did the service cost compared with the funding of patients to a major centre without a linear accelerator. And also was it providing a quality service. And basically without the full results being available I can certainly say that it obviously did increase utilisation, but it was expensive, and it's being looked at.

In regards to some other work I was doing a couple of days ago, I'm just in the process of preparing something that I thought I would put in this talk. Now, it's Adelaide-based and if anybody comes from a centre that doesn't have a dot that should have a dot, well that's just because it's a work in evolution. But what this basically looked to show was if level one I called centres – oncology focuses that had a visiting oncologist and had some ability to deliver oncology care. Level two was where there was a medical oncologist or a cancer physician or of course a radiation oncologist then came in at level three where there was a single modality unit, so there was a radiotherapy unit. And level four and level five was where there was really a full cancer centre.

So in other words, there was radiation oncology, there was the ability to give high dose chemotherapy, or more than just average chemotherapy. And there was also other factors such as high level radiology support in terms of maybe pet scanning or at least CT and MRI. Now, Perth, I don't know much about Perth, so anybody from Western Australia, apologies, apologies for – but what this is really I only meant to say, is exactly what we saw in the first presentation, and that is a lot of dots up the east coast.

Basically – and certainly Queensland where I have worked for a few years, I wasn't even going to put all the dots in for Queensland because I thought, well let's just go with the big red ones just to give you the impression that the capital centres have high level oncology centres, and at least some access to radiotherapy. And it's clearly the rural and remote areas that certainly lack radiotherapy, but they also lack those extra levels of cancer care. And just in terms of Adelaide experience, again there's level four and five, there's radiation oncology and major oncology centres in a couple of areas in the urban region of Adelaide. And there should be a yellow dot up here which is what I was working on the slide for, but we can come back to that.

Anyway, so should there be – what should we do in terms of – should we have these single units in a variety of places around Australia, or should we have big units that concentrate expertise? Well, I think again we've talked about a number of advantages of having a centralised unit. And there's no question that a big centre certainly has a concentration of people that have seen a lot of – a particular type of cancer. There's, as I said in the first slide, there's a need in a radiation oncology department to have quite a lot of very highly trained staff, and it's expensive equipment that needs to be – we need to rationalise the use of that.

But also the last point, the patterns of care study from the UK from 1988, which was Lester Peters and Rod Withers, looked at a number of radiation oncology units and found that there was quite a significant safety and quality deficit in terms of the outcomes of treatment in small radiotherapy centres that were not adequately linked to a main centre. So basically what they found was, especially in the private sector, if there was a stand alone single linear accelerator that wasn't intimately connected with a major centre, it was really giving service that was of a clear lesser quality to a major centre.

But that was 1988, and what's happened since then? Well, I think we've talked a lot about IT and video conferencing, but there are ways that you can use the technology to improve at least the linkage between a major centre and a small satellite linear accelerator. And that's not only in terms of, as Ian said, keeping in contact with the people in the outside centre for tele-medicine. But also we can do a lot of other things, as I said, we can plan patients from CTs remotely. We can even service some machine faults from a major centre without sending technical staff to the machine. And we're increasing our access through specialist rural clinics.

And if we're going to take that any further and work on that, well, just some of my thought to try and start the discussion. There's in particular the – it's all very well to say that if we put a phone line in and talk to the people, or if we put a phone line in and have our technical staff see if the linear accelerator is working properly, that's good. But there's really a lack of careful evaluation and research to say that that still comes up to the point where it's as good as having your technician in the same centre and walking down and looking at the machine.

Similarly, so we need to do more research in terms of that. I've put the transport costs in just purely because of the issues of – the Darwin centre I think is on hold in terms of the decision of sending people to major centres, costing less than sending – than having a centre so that there's a weigh up of economic issues.

Now, what I wanted to sort of probably just highlight the advantage of a specialist centre is that there's always, no matter what level of care you give, you're always going to have procedures that are going to be best done in a centre that does all of them basically. What this is is brachytherapy in a patient at Royal Adelaide, and there's only a couple of us around Australia that do brachytherapy for head and neck cancer and other certain cancers. And clearly there's ways of bringing a small – bringing the linear accelerator to smaller areas that are currently services, and the single machine unit study in Victoria is going to help with that.

And I'm sure if there was a centre in Darwin that was linked to a major centre with things like the remote access with the CT scan with the IT links, we would be able to deliver state of the art treatment to patients having linear accelerator treatment. But you don't want to have treatment like this from a practitioner that's done one or two in their life. So there's always going to be the need to travel for a specialist centre for certain things.

So I suppose again just to stimulate discussion, in terms from a patient's point of view being very simplistic, what would we want? Well, in terms of diagnosis you want to make sure the diagnosis is accurate, which means consultation with experts, you want histology, the pathology slides, the radiology, all those things to have been evaluated by people that are dealing with a lot of cases and that know the cancer disease. You want to be able to discuss that diagnosis and have a good relationship in terms of deciding on what treatment that you ultimately will have. And that's, I think we've already seen there's a lot of advantages in the way we're moving in terms of getting people into communities and getting the communication links better.

But in terms of treatment, certainly if it's simple you want it close to home. But the more complex it gets the more it becomes a question of should you have it in a major centre, and that's always going to be a hard question. But you want safety and you want experience, but you also do want the ability to stay close to home. And indeed as a radiation oncologist that spends three or four days in Darwin every couple of months with a young family and patients in Adelaide, I quite like staying at home as well. So it works both ways basically.

And follow up, well, follow up's not too hard because obviously if I do a clinic in Darwin and see 20 patients in an afternoon or whatever, that's 20 people that have had a saved trip. And so follow up again, I think we can look at without too much difficulty. So getting back to that

distribution objectives, well I think we're working on the physical distribution logistics, we're looking at the care that we want to give and the cost that's involved, and we're looking at the customer in terms of the patient and what they need, and what they should be able to access in terms of an equitable society. And as far as the specific issue of a radiotherapy centre in Darwin, well, I think it's just one short step really. Thank you.

**STEVE ACKLAND:** Okay, thanks Michael. Any specific questions for Michael? One down the back there.

**FEMALE SPEAKER:** Staff shortages, there's a shortage of medicos coming out at the end of placement training ... (inaudible) ... What's happening in terms of number of them coming through the radiology, the speciality area of radiology, there's not enough. How do we ensure that following – also the number of shortage of nurses, the turnover there, staff issues ... (inaudible) ...

**MICHAEL PENNIMENT:** There's a number of issues with staff, and that's from every aspect basically. A few years ago we had a major critical staff problem with the radiation therapists who are tertiary trained and who were in very short supply. And part of that was a failure to appreciate the time of training these staff and anticipating the projected needs of cancer services, so that they were shutting down courses and then in five years' time they ended up having a scarcity. And that's to some extent been fixed, but there's still – there's centres around Australia that have very critical staff numbers where you really only require a couple of people to move, and they're in strife.

And that's particularly another aspect for why ...(inaudible)... have a oncology unit with radiotherapy, let alone with other aspects. It's good to have at least a main centre because all of the radiation oncology centres that are linked ...(inaudible)... linked to major centres seem to be able to deal with those staff and do reasonably well because of the major centres ensure the other areas work well. Whereas the centres that aren't intrinsically linked to a major centre are the ones that are ...(inaudible)... continually has ...(inaudible)... problems of, oh my God, the radiation oncologist has left there, therefore we can't train registrars there.

They're short a couple of radiation oncologists. One place that I worked in Queensland had a couple of people leave, and they had to bring one of the radiation oncologists up from Brisbane, on a weekend, to handle their patients. It was a fantastic deal for them because they made it look worth his while. But it was quite an expensive effort to do that, it was bad planning, it wasn't to do with bad planning but it wasn't as the ultimate in terms of having centres ...

**STEVE ACKLAND:** Can I cut you off there?

**MICHAEL PENNIMENT:** So, there's issues.

**STEVE ACKLAND:** Yes. And those issues are being addressed by various reports from AMWAC, Australian Medical Workforce Advisory Committee. They haven't got down to other health professionals besides doctors, and they make reports and it's up to governments to acknowledge them and act on them and there's still an issue there. There was a question in the corner I think.

**FEMALE SPEAKER:** ...(inaudible)...

**MALE SPEAKER:** ...(inaudible)...

**STEVE ACKLAND:** While this question is being answered, would the other four speakers like to sit out the front?

**FEMALE SPEAKER:** I'm a radiation therapist ... (inaudible)...

**STEVE ACKLAND:** Again, it's a workforce issue and that's one of the things that's been pointed out, even three or four years ago, as being a major issue in delivery of cancer care to the bush.

**FEMALE SPEAKER:** Can I just make a comment that I think we all ... (inaudible)... it can have a really direct effect.

**STEVE ACKLAND:** So, it's really efficiency of use of the workforce, as well as the number.

**FEMALE SPEAKER:** Absolutely.

**MALE SPEAKER:** Can I just say that ... (inaudible)...

**STEVE ACKLAND:** So really, there's a lot more to provision of a high tech service like radiation oncology than just putting them under and switching on the machine; it's doing it in a holistic, caring manner. Question up the back.

**FEMALE SPEAKER:** It's not a question, it's a comment ... (inaudible)...

**MALE SPEAKER:** ... (inaudible)... patients like that that have a fantastic relationship with the radiation oncologist ... (inaudible)... And it's not a criticism. I think that we have to look at ways to make it work smoothly.

**FEMALE SPEAKER:** The only time that ... (inaudible)...

**STEVE ACKLAND:** So I'm getting a sense from you guys out there that another issue is to look at ways of improving the efficiency of delivering some of these high tech services, but taking into consideration the quality of the care delivery that goes along with it and the respect for human dignity. Is that what you're saying?

**FEMALE SPEAKER:** ... (inaudible)...

**STEVE ACKLAND:** Okay. Has anybody else in the audience got any ...

**FEMALE SPEAKER:** I've just got another comment. I'm three and a half hours out of Perth and ... (inaudible)...

**STEVE ACKLAND:** Any other comments?

**MALE SPEAKER:** Yes. Michael, I'm from Darwin and I'm the convenor of the Prostate Cancer Support Group there. I'd be interested if there's any possibilities ... (inaudible)... we could work together. I am sure that I am on the government's current blacklist of people not to be sponsored. I'm locked in battle with ... (inaudible)... at the moment over the possibility of a radiation therapy unit and we're also ... (inaudible)... patient travel — assisted travel scheme because that's becoming more and more inequitable all the time and several of our members have really had very severe financial ... (inaudible)...

**STEVE ACKLAND:** I'd like you all to be prepared to provide comment on — I mean, I think all of the speakers have addressed most of the issues on this slide and indicated that they're something of a priority, but I guess I'd like a sense from the audience of whether anything's got a higher priority than another point, or whether there are points off here that you think should be on there. Your question.

**FEMALE SPEAKER:** It's a comment really. I think ... (inaudible)...

**STEVE ACKLAND:** Just as badly as we are in the bush, or possibly worse.

**FEMALE SPEAKER:** And I think – and some of that ... (inaudible)...

**FEMALE SPEAKER:** Transport is up there.

**STEVE ACKLAND:** What's that? Transport is number one and four years ago it was the main issue that most of the providers of care in the bush identified. Yes. It was really reimbursement for transport costs, it was something that we thought the federal government or the national bureaucracy could address at the time. Ian?

**IAN OLVER:** In some areas, local communities and NGOs are addressing. I mean, in Adelaide, for example, the Cancer Council runs motels on a cost recovery basis, with mini-buses, run by volunteers across their treatment and that's one of our great resources and yet it's done by the sort of generosity of a non-government organisation.

**MALE SPEAKER:** Several Darwin people are very appreciative of ... (inaudible)... and the Territory government doesn't go anywhere near enough.

**FEMALE SPEAKER:** Is there a need ... (inaudible)... education to ensure that their expectations are not unrealistic, so that they actually do understand that some particular types of malignancies, the best treatment is available in – and it may only be Adelaide, Melbourne and Sydney – but we will need to actually do something to alter the perception of the community and educate the community on what is best practice for particularly the more difficult and complicated and complex malignancies.

**STEVE ACKLAND:** I think that's a good idea. You can't do brain surgery in Tennant Creek. Some people intuitively understand that but they don't understand that simple chemotherapy shots also can't be given in Tennant Creek, for a whole variety of reasons that Fred pointed out. Ian?

**IAN OLVER:** In the single radiotherapy machine unit trial in Victoria, that Michael talked about, that was limited to certain tumour types, so that complex head and neck cancers were treated in Melbourne. But there's always a graph – the report we didn't release – but there's always a graph we have of what's treated outside of those groups because of patient demand. But some people say "You either treat me here or I'm not going to be treated". So patient education is very important.

I think they stop using the term "equity of access", in terms of equity of physical access, and start talking about access to the expertise to treat you in the same way and I think it would be more realistic. Because there are advantages to living in remote and rural areas, and there are disadvantages, just like in urban areas, and one of the disadvantages are physical access to high technology treatments. So, I think that's why transport's on top because that's a very practical solution for that.

**STEVE ACKLAND:** So it sounds to me like recommendation number two might be for the cancer health professionals, as an organisation, to state clearly what can be done in what sort of setting, what sort of cancers can be managed adequately in what sort of setting. Do you agree? Okay. I was going to ask Michael and perhaps Ian, and Fred first. In Newcastle, at our hospital, we have an area called the Villas, which are like live away from home accommodation, almost motel/dormitory style, \$20 a night, on the hospital campus, for cancer patients and sometimes their carers. Do you have such a thing in Alice Springs?

**MALE SPEAKER:** We can't get accommodation for nurses.

**STEVE ACKLAND:** I mean, I know in Perth, someone's here from Perth, a facility like that's funded by the Cancer Council?

**FEMALE SPEAKER:** Yes, it is.

**STEVE ACKLAND:** Yes.

**FEMALE SPEAKER:** And donations.

**STEVE ACKLAND:** And donations, yes. So, I mean, could those sorts of facilities be provided in places like Alice Springs and ...

**MALE SPEAKER:** There's real accommodation problems in Alice Springs. I mean, you've got the renal problems which probably take precedence ...(inaudible)...

**STEVE ACKLAND:** So when Joe Bloggs comes from way out west and his chemo isn't here and he has to wait a week, do you ask him whether he's brought a tent, or what?

**MALE SPEAKER:** Sometimes there is some low cost accommodation through some of the hospital services called ...(inaudible)...

**STEVE ACKLAND:** So perhaps one of the things, I'm hearing recommendation number three here, maybe. In the COSA scoping survey, one of the things we might look at is low cost accommodation near treatment centres, for patients and their families, as maybe a gap that could be relatively cheaply filled, with a patient co-payment, of course, I suppose.

**FEMALE SPEAKER:** Perhaps I could put an addendum to that. Which is, that if we're not looking only, but I suspect that there's whole floors of patients with cancer illness, then the accommodation ...(inaudible)...

**STEVE ACKLAND:** Yes. You had a question or comment?

**FEMALE SPEAKER:** ...(inaudible)...

**STEVE ACKLAND:** So is that a fairly widespread perception that people struggle, I mean, I know in Newcastle people struggle with accommodation a lot of the time. Yes?

**FEMALE SPEAKER:** Can I just make a comment on sitting up there ...(inaudible)... and I do have a fear in central Australia that it could fade out, the services that we currently ...(inaudible)...

**STEVE ACKLAND:** Yes. And I guess that comes under the workforce issue. I mean, as I said earlier, I go to Muswellbrook, I have one nurse who does chemotherapy and palliative care up there. I support her for the chemotherapy but the palliative care guys in Newcastle support her for the palliative care side, and her mum died – or her mum got ill and died – and she took three months off. We didn't have anybody for three months.

**FEMALE SPEAKER:** ...(inaudible)... the workforce.

**STEVE ACKLAND:** Well, it's workforce planning, isn't it? That's what you mean, and it's an overall workforce planning.

**FEMALE SPEAKER:** ...(inaudible)...

**STEVE ACKLAND:** Yes.

**FEMALE SPEAKER:** ...(inaudible)...

**STEVE ACKLAND:** So I'm hearing recommendation number four, define what a cancer patient anywhere could expect.

**FEMALE SPEAKER:** Yes. ...(inaudible)... but that kind of thing, you should be able to articulate that ...(inaudible)...

**STEVE ACKLAND:** Do you agree with that one?

**MALE SPEAKER:** Yes. The Victorian Cancer Plan that they're implementing at the moment looks a little bit like that. They've got cancer streams but they're trying to identify what each small rural area can do and they're trying to link it with the next one up the chain so you might be able to do say, breast surgery, but not rectal surgery, you'll have to move on. And you need to know what sort of support services you need if you're going to do breast surgery, and so there is an attempt, there's a model there that I think will be quite useful for the rest of us.

**STEVE ACKLAND:** All right. We might refer to that and try and enhance and embellish it.

**MALE SPEAKER:** I guess it comes under improved co-ordination of health professional training in recent methods. I think rural GPs can ply out that more aptly and a greater role and earlier follow-up of cancer patients than happens in many places. And there are some places where the GPs have tried to be more actively involved, it needs to come from both sides. To be more actively involved, they need to be better educated on what they're going to see in early follow-up after treatment. So that is something I think is important for people to look at, to keep them from having to trace back for what effectively are well-checks.

**STEVE ACKLAND:** I'm not sure how we can actually address that, except perhaps by establishing regional networks which really means the thing that Ian expressed is the specialist in the major centre having confidence that someone out there can act, on his behalf, with a reasonable degree of confidence. Frankly, those workshops that are available in breast cancer chemotherapy and colorectal cancer chemotherapy are aimed to provide a level of confidence and expertise by local health professionals to do those sorts of things, including giving a bit of chemotherapy here and there.

**FEMALE SPEAKER:** It's not really about providing education to professionals though, it's about starting the process to ...(inaudible)...

**MALE SPEAKER:** It would be very useful to have, from a specialist's point of view, to have enough people that are prepared to take on that role ...(inaudible)... where in other places it's pretty clear there's people that I know well but that I wouldn't do anything other than let them know what was going on, because I know they want to know and they can certainly follow people up and there's no issue about that ...(inaudible).. So I'd be keen to know who is interested where and I would also be keen to know what things could stimulate that interest in terms of obviously, one, we've got to just be interested for all the right reasons, but I'm sure there are other aspects in terms of primary care, reimbursements and other issues that would stimulate them.

**STEVE ACKLAND:** So I guess in the process of establishing regional networks, there needs to be an understanding by their specialists of which rural and remote health care professionals are interested in participating in shared care.

**IAN OLVER:** And the high turnover there, is another issue that makes it difficult. I mean, I was trying to work out, I've been doing the clinic up here for about 14 years and I think there's only about two GPs that are still the originals. We've been through six medical directors in the

hospital, at least, and probably that number of physicians, so just as you establish a relationship, things change and it's a real challenge. I mean there's no GP in Tennant Creek, and the major GP in Tennant Creek left a couple of weeks ago and there's a whole community of 4000 people wondering what to do next.

**FEMALE SPEAKER:** So it sounds like ...(inaudible)...

**IAN OLVER:** So that – but maybe ...

**MALE SPEAKER:** ...(inaudible)... GPs have been in a place for years.

**IAN OLVER:** And that'd be the easier way.

**MALE SPEAKER:** ...(inaudible)... drawn on as well as they ...

**IAN OLVER:** No, I agree with that and that would be the easiest thing. So, we need to be aware of it and maybe if they were drawn on more, there'd be more professional satisfaction, like I was talking about with Darwin and the retention may go up as well, I don't know.

**MALE SPEAKER:** Absolutely, no question.

**STEVE ACKLAND:** I was told that the average age of a working nurse now is 47. We've got a serious workforce planning issue in nursing in this country. Any other comments or suggestions?

**FEMALE SPEAKER:** ...(inaudible)... and that's just going to increase as – it's like how long is a piece of string, but it is going to increase, so there is evidence-based ...(inaudible)... protocols that are available to any practitioner in New South Wales ...(inaudible)... available to any practitioner anywhere.

**IAN OLVER:** Actually, it's a very good point but probably everyone in every state, I mean, Fred uses ours, and I've talked to Robyn Ward (medical oncologist, SVH Sydney) who did this work in the last couple of weeks, because there is no reason why there can't be a national centre for protocols and that would save an enormous duplication of work, as currently every state upgrades their treatment policy guideline pretty much annually. So we actually perhaps ought to take advantage of the boost that the New South Wales Cancer Institute has given that project, and it may be important to have hundreds of people actually updating that as well, to keep it viable and up to date.

**STEVE ACKLAND:** Yes, I think all of us, Ian, and I don't know whether this is the case in radiation oncology and palliative care and cancer nursing, but I think we all develop our own local protocols and they're probably all very similar.

Well, people are gradually wandering off to have a beer down the road, which I think is appropriate, and I'm running out of gas and I suggest most of you have. But I can see we've got at least a few extra recommendations to reinforce these recommendations of a few years ago and I'm hopeful that NRHA will promote these through a little bit of dissemination in the next few months and certainly ...

**FEMALE SPEAKER:** ...(inaudible)...

**STEVE ACKLAND:** I think so. I think the plan is to make the deliberations of this workshop available to all the registrants of the meeting. Certainly, I'll be taking these back to COSA and the Cancer Council as reinforcement.

**MALE SPEAKER:** Specifically, the recommendations that we'll knock out at the end of tonight's session, will be fed into the communiqué process for the conference itself.

**STEVE ACKLAND:** Okay. I'm thirsty. Thank you all for coming.

