

The Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Sir / Madam

**Inquiry into the Operation and Effectiveness
of the Patient Assisted Travel Schemes in Australia.**

Cancer Voices NSW wishes to express its appreciation that the Community Affairs Standing Committee of the Senate is to undertake an Inquiry into the Operation and Effectiveness of the Patient Assisted Travel Schemes in Australia.

Cancer Voices NSW is the peak coalition for cancer support and advocacy groups in NSW. It provides the independent voice of people affected by cancer, working to improve the cancer experience. Established in 2000, we are interested in the areas of prevention, diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard..

As the Committee would be aware, there have been a number of reports over recent years recommending reform within states and at national level. We very much hope, on behalf of cancer patients who need to travel for treatment, that the Committee's recommendations will be implemented.

Cancer treatment by its nature usually requires significant travel for patients living outside metropolitan or major regional centres. To be able to access the full range of treatment modalities – by specialist surgical, medical and radiation oncologists, working within a multidisciplinary team, there is often no option but to travel considerable distances. This in itself increases the pressure and distress of a cancer diagnosis, as well as posing major financial burdens on patients and their families and carers. Cancer patients, regardless of where they live, should be adequately and efficiently assisted to access best practice cancer care – there being a great deal of evidence now showing better outcomes for patients if they manage to access such treatment and care.

The situation facing cancer patients who need to travel for good treatment and care is summarised very well by the former Committee's major report "*The Cancer Journey: informing choice*" (June 2005, pages 64 to 69)

Cancer Voices NSW strongly endorses Recommendation 20 of that Report:

The Committee recommends State and Territories adopt and implement the consistent approach to the benefits for travel and accommodation recommended by the Radiation Oncology Jurisdictional Group (ROJIG, 2003) to ensure that benefits are standardised across Australia. These benefits would be indexed or reviewed annually for increases in travel and accommodation costs.

Cancer Voices would like to see uniform minimum standards for patient assisted travel schemes accepted by all Australian States and territories, with the opportunity to add to them where necessary due to local factors or by policy decision. We submit our current recommendations for changes to the NSW scheme, suggesting that these also be factored into national minimum standards. If national standards cannot be achieved across the states and territories, the Cancer Voices NSW recommends consideration be given to returning the PATS/IPTAAS schemes to the Commonwealth, to be administered by the Commonwealth for the benefit of all Australians.

Cancer Voices NSW's recommendations are outlined in the Position Statement below, which is posted on our website, www.cancervoices.org.au

Cancer Voices Position Statement re the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) in NSW

Background: Cancer Voices has been advocating for changes to the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) since 2002. With the assistance of the NSW Nationals, we collected 16,000 signatures to a Petition which was tabled by the NSW Parliament in 2004. We participated in the IPTAAS Alliance with other organisations (including NSW Cancer Council, Country Women's Association, NSW Farmers Association, NCOSS, Asthma Foundation) seeking at least a reduction to 100 km of the 200 km one-way criteria, which was patently out of step with other Australian schemes. *See Informing Choice Table 3.1 Summary of IPTAAS in Australia Senate 2005*

In March 2006, welcome but limited improvements were announced by the NSW Premier that as from July 1, 2006 the one way distance requirement to access IPTAAS would be 100 km; with a marginal increase in the vehicle allowance from 12.7 cents per kilometre to 15 cents.

However a number of issues of importance to people affected by cancer who need to travel for treatment remain unaddressed. These are:

1. Choice of Treating Specialist

A major issue is the ability of the patient to choose his/her treating specialist and still be eligible for IPTAAS assistance. This may involve a referral to a specialist who works with a multidisciplinary team at a recognised cancer centre – something metropolitan cancer patients can access with relative ease. CVN considers that it should be the most appropriate specialist not the nearest – which is the present requirement for claiming on IPTAAS - to ensure best practice treatment. Although not well known there is currently is an exemption allowing a GP to refer a patient to the most appropriate specialist rather than the nearest, if medically indicated. Patients should be advised of this, and that they can seek a second opinion. They should be aware that they can request their GP to use this exemption to ensure they remain eligible for IPTAAS. Ideally this should not be necessary simply as result of living outside metropolitan areas. Cancer Voices believes that the option of "most appropriate" should be the norm, not by exemption.

2. Fuel and Vehicle Rebate

CVN also considers the announced increase in the vehicle costs rebate of 15 cents per km to be grossly unrealistic. CVN proposes that the fuel rebate should be based on the ATO (Australian Tax Office) provision for vehicles driven for 5000km or less on business. If this system were adopted rural patients who need to use their vehicle (which would be the majority) to access treatment, would be more fairly compensated. *(For the 2005/2006 tax year this would have been at a rate of 66 cents per kilometre. These rates are updated annually following the federal Budget.)*

3. Complexity of Forms and Process

Our members call for major simplification of IPTAAS forms and of the whole process of application. There have been complaints from both clients and clinicians for its excessive complexity (see attachments). Cancer consumers of IPTAAS need to be consulted about a user friendly process.

NSW Health has undertaken a review of the administrative arrangement for IPTAAS, but without consultation with patient groups, the end-users. Cancer Voices would like to see the concerns of all those involved in an IPTAAS claim addressed. We understand that from 1 July 2007, new forms will be provided, including a travel diary to help in claiming assistance, available from the NSW Health website, but beyond the reach of many patients who need to travel for treatment. A streamlined national minimum standards format for claims would make a lot of sense.

4 Level of Accommodation Reimbursement

Another issue of concern is the level of reimbursement for accommodation costs under IPTAAS and the requirement that patients must bear the entire cost up front for a period of weeks or months, as the case may be, from their own resources. The current level of reimbursement does not, in CVN's view, reflect the commercial charges for even basic accommodation, except at subsidised Lodges built for the purpose by some cancer charities (one of these few facilities, the Blue Gum Lodge, Greenwich, is slated for demolition by Hope Health Care on whose land it has been built). CVN does not object to the patient being required to make a small contribution but considers that the reimbursement, currently fixed at \$30-\$40 per night, should be subject to regular adjustment by the Consumer Price Index.

5. Clinical trial participants denied IPTAAS

The NSW Health Department regards costs borne by a participant in a clinical trial as being the responsibility of the public or private institution undertaking the study. While this may be arguable in the case of industry funded trials when out of pocket expenses are covered, it should not be so for publicly funded trials. Unfortunately cancer patients are often unaware that they will not be able to access IPTAAS when they enter clinical trials. CVN believes participation in clinical trials should be encouraged by Government, not discouraged – in both the interests of individual cancer patients and the public good..

NSW Health IPTAAS Guidelines allow that Area Directors of Clinical Services may reconsider the merit of particular treatments in assessing a patient's eligibility for assistance, but we suggest this would not be something that referring GPs or cancer specialists, or indeed a country cancer patient, would know about.

6. Cross border anomalies

Cancer Voices NSW seeks that anomalies created by different criteria and administrative arrangements between states be reviewed, and recommends that this be addressed by a national minimum standard.

Discussion

Cancer Voices NSW continues to seek these improvements, and to convince the NSW Government to act on these issues which, if implemented, would make access to treatment for chronically ill rural patients in NSW, and particularly cancer patients, less of a financial burden and less of a disincentive to travel for treatment. We are keen for the IPTAAS Alliance to be re-established to pursue these reforms in a united manner with other concerned organisations.

We understand that our Department of Health is reviewing administrative arrangements for implementation of IPTAAS, but despite requests to participate in order to provide the cancer patient perspective, we have not been invited to do so. We recommend that cancer consumer organisations be invited to provide suitable informed consumer representatives to participate in the development of national standards, and in the reform and management of state based schemes.

While the above issues for reform are mostly NSW related, we suggest they may well be shared to various degrees by other jurisdictions. We recommend that the Committee includes them in its list of issues to be addressed by a set of minimum standards.

We have attached a range of comments and quotes from concerned patients and health professionals which bring attention to the issues of concern outlined above.

Thankyou for the opportunity to make a submission to this important Inquiry. We would be delighted to participate in the Hearings if this would assist the Committee's investigations..

Your sincerely

SALLY CROSSING AM
Chair 15 May 2007

SALLY HODGKINSON
Rural Issues Convenor

COMMENTS ABOUT NSW IPTAAS TO CANCER VOICES NSW FROM MEMBERS AND CONCERNED HEALTH PROFESSIONALS

(From letter to The Hon Frank Sartor, previous NSW Minister for Cancer, from a CVN member group)

“Re: Administration of the Isolated Patients Travel Accommodation and Assistance Scheme (IPTAAS)

I am a cancer survivor of 30 years (five primary cancers of kidney and bowel), and a member of the Southern NSW Regional Advocacy Network. Our group is part of a larger state wide network working towards improving cancer policy and services in NSW. Our group welcomes the recent changes to IPTAAS and acknowledge the positive impact these changes will have for cancer patients in NSW. We are however, still concerned about some of the administrative aspects of the scheme and ask that these be addressed in the upcoming review of IPTAAS by the Cancer Institute. We ask that:

- The form and **instructions** be simplified and more easily obtainable, generated by computer at doctors surgeries and treatment centres
- The scheme is administered consistently across the state with a travel or accommodation diary being a standard inclusion with the application to better cater for those undergoing block treatment (anecdotal evidence highlights that currently some offices allow patients to make just one claim for a block of treatment/travel by filling in a travel or accommodation diary while other offices insist on a separate application for each trip-
- Reimbursement for travel to be based on mileage with no petrol docketts required.

At the time of a cancer diagnosis people are at their lowest ebb, and confusion and bewilderment reign supreme . It is welcome and a comfort to cancer patients in remote areas to know that there is financial assistance available to see that they can access required specialist treatment. This information however should be readily available, precise, simple and consistent-regardless of where they receive the information. Through our research and talking to the staff at the different IPTAAS offices we have found them committed and helpful; genuinely trying their best for the patient. It is however, evident that each IPTAAS office administers the scheme differently and that this can have negative implications for already vulnerable cancer patients.

In conclusion we feel that these issues could be rectified at a minimal cost , not only resulting in administrative efficiency but most importantly in major benefits to cancer patients.

In order to work towards these positive changes we ask that we are able to participate in the up coming IPTAAS review. Having researched the scheme both nationally and at the state level we feel we have a lot to offer.”

IPTASS issues reported to Cancer Voices NSW from a rural NSW GP

The IPTAAS process is cumbersome, and many do not claim, as the paperwork is too much for them to cope with, especially if they are ill. The main problems seen by this GP are:

- ◇ The forms have way too much duplication
- ◇ They require the GP to fill in details, even though the GP could be left out of it altogether
- ◇ It should be enough for the specialist’s name and address to appear, along with the signature by the specialist to confirm attendance. The IPTAAS staff should then simply pay up if the distance is more than 100km
- ◇ The scheme should be expanded to seeing GPs and other allied health, as many people travel over 100km to do this too.
- ◇ The scheme should not be restricted to the nearest specialist, as clinical need, waiting times and continuity of care often mean patients need to see someone who is not the nearest.

- ◇ The onus on the patient to show petrol receipts is totally unreasonable
- ◇ The upgraded travel criterion is the only thing in which the GP need to be involved. For routine cases, the GP should not be involved (but see my point about the scheme's expansion to GP services.)
- ◇ The form should allow for multiple patient encounters, rather than a new form and new claim each visit.
- ◇ The forms state that only the doctor can fill them in – this is ridiculous.

Further comments: A simplified form, along the lines of the DVA travel claim forms, needs to be urgently introduced. This Rural GP indicated that he thought GPs and Specialists would simply refuse to assist with the forms unless they were simplified. He also said that in towns like his it means that every specialist referral needs an IPTAAS form, and he feels that this is totally unfair to all parties. He had seen instances of this problem in his practice.

Example of cross border problems

There is a particular problem for access to radiotherapy treatment in cross border regions. An example of this is where patients on the NSW far north coast (Tweed Area) have to travel north to Brisbane or south to access radiotherapy. Radiotherapy patients from the far north coast of NSW are often denied IPTAAS. A senior radiation oncologist has advised that IPTAAS needs to be reviewed as it penalises patients in the country: "It is unreasonable to expect patients / carers, most of whom are elderly and often unwell, to drive 100km each way every day for radiotherapy treatment over a period of weeks. The IPTAAS distance needs to be reduced significantly, and I would suggest 50 km (still 100km per day of travel)".

This cancer specialist reiterated that the reduction of eligibility distance for IPTAAS from 200 km to 100 km, although a good start, is nowhere near enough. It is inappropriate to expect that country patients should be driving 200 km per day on inadequate and dangerous roads. The patients and carers are elderly, and if having radiotherapy, fatigued.

Transport problems in a specific country region

A Cancer Voices member advises that areas such as Forster/Tuncurry and Gloucester (mid north coast of NSW) have difficulty in accessing not just cancer care but other medical care as well. "This is because there is either no appropriate public transport such as trains and/ or buses that run during daylight hours, not dumping people at the station at 3am".

"The Forster Health Advisory Committee has recently sent out an area-wide questionnaire re transport and have found that about 10% of respondents have missed a medical appointment because of transport problems getting to Taree or Newcastle..

The Cancer Council now has two cars, driven by volunteers, to transport cancer patients from Forster/Tuncurry and Taree or either Newcastle or Taree for treatment. Until recently there was only one, so things are looking quite good from this aspect.

Poor Gloucester has more serious problems. The distance to Taree is 84 km so IPTAAS cannot be claimed if treatment is given there. The trains go in the middle of the night and until recently transport for the disadvantaged was undertaken by a group of town volunteers. During the last 2-3 years there has been a lot of lobbying and discussion and finally the Cancer Council has agreed to reimburse the kms driven by the local volunteers by an agreed amount. So at present we seem to have sorted out much of the problem locally.

Smaller communities can sometimes do quite well themselves in situations like these. But every cancer patient should have access to appropriate advice and treatment without having to worry about transport,

or the expense of it, to and from treatment". *Advice from one of Cancer Voices NSW's Consumer Representatives on the mid north coast of NSW.*

A further example, not related to cancer: "I am aware of a child who had a cochlear implant fitted, in a rural area of NSW (Griffith) and was provided with IPTAAS for the implant procedure, but could not get IPTAAS to go to Wagga (then under the 200 km limit) to access adjustment facilities, as an attendance at an audiologist was not considered a medical procedure."

Clinical trial participants denied IPTAAS

(Communication from a NSW Director of Area Cancer Services)

"Firstly, (regarding the exemption cited by NSW Health for travel to treatment on clinical trials) "Directors of Clinical Services" (not Directors of Cancer Services) probably refers to hospital or Area Health Service CEOs. I very much doubt that our CEO would ever consider funding the costs of transport for patients in clinical trials. The facts of the budgetary crises are such that the CEOs do everything within their power to minimise costs and so for a patient in a rural area they would have no interest or compulsion to spend the hospital budget on such patients. So although the policy says that Directors of Clinical Services could approve assistance, I think in reality this is a unrealistic dream.

The NHMRC Statement on research states that it is the responsibility of the public or private institution undertaking the study to bear the costs. I could argue that the very fact that as patients are treated in a public hospital, and many patients are public patients, we, the public, are therefore partners in the trial. And since IPTAAS is just an arm of the public support process it is therefore legitimate for IPTAAS to fund trials. In fact it is a requirement of public institutions to participate in research and so I think it is ethically correct for the public purse to fund the research that public hospitals participate in.

Another argument is a practical one and revolves around equity of access to best treatment in cancer. In many cancers there are no effective treatments and the only potentially useful treatments are through clinical trials. In fact most of us would agree that the optimal management of many cancers is through participation in a clinical trial. If the experts agree that this is how some patients should be managed and rural patients are denied access (through denial of IPTAAS support) then rural patients are disadvantaged and this is a form of health service discrimination. The NHMRC Statement doesn't work in practice because Public Institutions and many privately sponsored trials simply will not fund the extra costs of transport from rural areas.

There are also many so called "trials" in which the primary aim of the trial is to allow access of new and effective drugs for patients in need but before the drug has been approved and available on the Pharmaceutical Benefits Scheme. For example we were able to supply the life saving drug Glivec to chronic myeloid leukemia patients 2-3 years before it became generally available.

The NHMRC guidelines are also there to help research for the greater good of the community and the practical consequence of the statement about bearing the costs is that research is inhibited and rural patients do not have access to research programs.

Finally there is a NSW Health mentality that connects clinical trials with "unproven treatments", hence the misleading term below in the policy statement "Clinical trials and unproven medical treatments". There is a perception I think behind the denial of IPTAAS for clinical trials, that patients are receiving unproven medical treatments. What is usually the case is that treatments are proven but there are options and the trial tries to determine which treatment gives better results. Another issue is that by "unproven" they mean "not approved by the TGA". We all know that strong evidence exists from randomised trials proving various treatments years before TGA approval is gained and in many situations TGA approval is never obtained because a company decides not to market a drug. This doesn't mean the treatment is unproven. Hence there are many patients receiving proven and very effective treatment on clinical trials, often with reduced costs to the health system because the drugs and diagnostic services are paid by the trials. In fact participation in clinical trials is often a saving to the health system

and at the same time patients are receiving good and proven therapy. It is anomalous therefore that IPTAAS denies rural patients access to this treatment.

These are just some of my thoughts on this issue and I would encourage the consumer groups to campaign for a fairer go for the rural patients."

Complexity of IPTAAS forms and process

(From a letter from a Western NSW GP to Cancer Voices NSW)

"Your request is remarkably timely as I come home regularly quite irate at the absurdly bureaucratic system developed for the IPTAAS especially for cancer patients who may have frequent visits and hence requirements for the system.

Briefly: I find the following issues either unnecessary or pointlessly repetitive:

1. The form keeps requiring someone else to write the same thing – why on earth should a GP enter information to be repeated by the patient and a specialist ? It is printed on unnecessarily expensive glossy paper.
2. Our Area Office requires the whole 5-6 pages to be filled out for each visit even when it is for the same condition. Cancer patients having weekly chemotherapy and feeling lousy have to tackle a mountain of paper work and make unnecessary trips to their doctors to get a signature just for refund. Heaven help them if they are too sick to remember to take it with them for the specialist to sign. Our patients do a round trip of 250 kms to have treatment or see a specialist and that is our closest centre !
3. The system does not pay a refund if the patient travels by Community transport. At a cost of \$70 they get nothing back but if they spend \$40-\$50 on petrol in their car they get a refund!
4. My biggest gripe – why require the GP to have to specify if the referral is to the nearest specialist. We make our referrals to the appropriate specialist for the patient and their condition (imagine the disaster if we send a mentally sick person to the wrong psychiatrist). Many country specialists still work in a broad field and the patient's needs can well be for a super specialist eg. in orthopaedics you really need a specific joint specialist> This means telling white lies or spinning an unnecessary yarn. If the IPTAAS is to assist country people it should be a given that the referral is appropriate and accepted. A top cap adequate to cope with travel to a major centre would stop rorting and paying without clerical double checking would surely save money!
5. So cut the paperwork, after all the specialist has a referral letter from the GP to prove the visit was needed. Accept the repeat visits without further form filling and pay for all visits whether or not the patient travelled by Shanks pony or Lear jet!

Hope I have not been too effusive; generally GPs are so resigned to wasting time on these issues that we just do what we are told for the patient's sake!"
