

COUNTRY WOMEN'S ASSOCIATION OF NEW SOUTH WALES



**SUBMISSION TO THE INQUIRY INTO THE OPERATION AND
EFFECTIVENESS OF PATIENT ASSISTED TRAVEL SCHEMES (PATS)**

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Senate Community Affairs Committee
Inquiry into the Operation and Effectiveness of Patient Assisted Travel Schemes
(PATS)

Introduction

The Country Women's Association of NSW welcome the opportunity to have input into this Inquiry. This matter has major ramifications for all of our country members. In our submission we refer to this scheme as IPTAAS as it is known in NSW.

With the down-grading of country and regional hospitals it is now necessary for patients to travel greater distances. In the past it was not unusual for specialists to regularly visit country and regional hospitals which meant that patients were able to access locally many of the services for which they now need to travel vast distances.

While we realise it is outside the scope of the Inquiry, we would suggest that a view of the "big picture" and improved facilities in country and regional hospitals, such as renal dialysis units would mean a better outcome for all concerned.

We realise that this scheme has a cost to tax payers and no scheme is a bottomless pit; however, we believe there is currently a vast discrepancy between the standard and opportunities of care available to city and country people because of their need to travel distances for their treatment. We believe that every assistance should be afforded them to address the inequity that currently exists between city and country access to medical treatment.

We address the terms of reference as stated by the Inquiry.

- a) We believe that this is a national issue and there should be national consistency and uniformity across all jurisdictions particularly with relation to eligibility. The level and forms of assistance provided may need to be modified depending upon the areas and availability of various forms of transport, but the eligibility should be uniform. The differing distance requirement – nil in some states, 50 km in others and the now reduced to 100 km in NSW, should be abolished. It seems unfair that people who live 100 km away are eligible but those who live 99 km are not. With the patient contribution, this would be self policing in most instances. For those who live closer distances, by the time the patient contribution was deducted they would not be due for an allowance or the amount would be so low as to make it unattractive to claim. However, by abolishing the distance requirement patients would still be eligible for the accommodation aspect. We further believe that a simple per diem, which is normal in the public service, to politicians and in the corporate world, would cut down the paper work, both by the applicant and the department administering it. Patients should be eligible for an accommodation allowance regardless of where they stay. It is normal if one stays with a friend or family member, to make some contribution to the host, either in the form of buying household items to replace those used or financial towards power and water. We believe that this scheme should be handled at a Federal level.

Currently there are vast discrepancies in NSW. Some patients in the North Coast areas are very happy now the distance has been reduced to 100 km and it enables many more to access the scheme. For example people from Coffs Harbour can now go to Lismore

(102 km) and from Ocean Shores (north of Byron Bay) to Brisbane. However in another area, a patient from Cootamundra had radiotherapy in Wagga Wagga, Canberra and Sydney in six weeks. His accommodation and travel expenses were \$12,000 and he received only \$300 back through IPTAAS.

The most important issue we believe is the requirement (in NSW at least) that the patient be referred to the nearest treating specialist. **This is totally unacceptable and must be abolished.** We understand that currently there can be "exceptional circumstances" where this requirement may be waived but it is further paper work and regulation. No patient would travel further than they need to. There is nothing more important to a patient than to have confidence in their specialist and treatment. This can be for any number of reasons, whether continuity of past treatment, cultural reasons, reputation or the support of a multidisciplinary team and the option to seek a second opinion.

The choice of treating specialist must be made between the patient and their doctor – no government department has the right to impose this restriction, simply to save a few dollars of tax payer's money.

We stress that no country person who is unwell would travel unless they had to. The stress of travelling in unfamiliar areas, heavy traffic, confusion and the added worry of finding someone to look after other family members or properties while they are away, makes travel a very unattractive option. We only do it when we have to.

- b) This is essential. As an example, for women in remote communities visiting the NSW Breast Screen Mobile van in Broken Hill there is no IPTAAS funding currently as the service is done in a mobile van, not a building! We currently have the bizarre situation of funds being spent on urging women to have regular breast screening but then being denied any financial assistance to do so. However if they fail to be screened, develop breast cancer, then they are eligible! As we all know, preventative maintenance is much cheaper than treating a problem once it has developed.

In the above situation women who travel from White Cliffs, Ivanhoe or Tibooburra, a journey to and from a screening takes at least 2 days but under current IPTAAS rules, they are ineligible for either accommodation or travel subsidies as they are not visiting a designated building.

It would appear that regulations and criteria are being set by bureaucrats who have never travelled the distances experienced by rural and remote patients. We seriously recommend that any person involved with policy making should be required to do an orientation tour to see exactly what is the impact of travelling long distances over (in many cases) very poor roads. It is normal in the corporate world for executives to know the areas they are dealing with, why not in the public service. Such trips could hardly be considered "junkets"! We suspect that some would experience difficulty in even finding the more remote areas on a map, let alone knowing how to get there. Our very remote members are constantly asked the question from departments as to what the nearest cross street is!! No idea whatsoever of what areas they are dealing with.

- c) We feel this may be different in areas. As already stated, the people from Ocean Shores NSW have no difficulty in accessing Brisbane. Broken Hill has long been considered part of South Australia for various purposes, including medical. We do not have any particular evidence that this is a problem; however other states may have some information.
- d) This again seems to be patchy. Many people say they know nothing of the scheme or think it is only for those who live in very remote areas. Others however, are informed through their GP or hospital. There needs to be better communication of the scheme. There are others who know of the scheme but cannot be bothered going through the ritual of signatures from referring doctor, specialist etc as well as completing the form. Some states have simple 2 page forms, NSW has a 6 page form – again, this needs to be made uniform. Very often the rebate is so minor that people who are very sick simply can't be bothered applying and waiting.
- e) Statistics clearly show that country people, while having a lower incidence of illness (particularly cancers), have a poorer survival outcome. It is generally believed that this is because of two main reasons – one being that for patients, even though they are receiving treatment, the need to travel means that the treatment is less effective due to the physical and in many cases the mental stress of travel. The second reason is that many people either do not have treatments as often as they should because of the travel aspect (including the cost factor) or worse still; simply decide to forgo treatment as the travel is just too much to contemplate. Several members of our committee have first hand knowledge of neighbours who simply decided it was not worth the effort and so stayed home to die, rather than continue their treatment.

At least a reasonable level of financial assistance would be helpful but improved facilities in regional hospitals would be an even better option.

- f) This is essential, not only to the patient and their family, but also to the medical fraternity. While seemingly unrelated to this Inquiry, we believe that part of the picture, is the problem that many doctors do not want to work in country areas because of the lack of multidisciplinary team members to confer with. This means that visiting specialists are not available, so patients must travel. This is an egg and chicken situation. We must address this problem and then we will surely have less need for travel schemes and better outcomes for all concerned. We would urge your Committee to take this aspect into consideration. We repeat our comment from a) that a patient must be allowed to access treatment from whatever specialist they and their referring doctor chooses. The requirement to visit the nearest specialist must be abolished. Again, we state, no one in the country who is unwell ever travels further than they need to. If this Inquiry does nothing else, we beg that this criteria be lifted.
- g) Reports on e Health outcomes are positive in the Central and Far West but the work is still in its infancy. Only some hospitals are currently using e Health so there would still be the need for travel and accommodation costs to be subsidised for the majority of rural patients. In speaking with various members, e Health has mixed acceptance (particularly amongst the older people) but we believe in time it will be better accepted.

h) We consider this is desirable and reasonable. Over and over again, we reiterate, country people do not travel for the pleasure of it and they are currently being denied many treatments freely available to people living in cities. We understand that originally the IPTAAS scheme was established and funded by the Federal Government. Responsibility was transferred to the states and territories in 1986 but as is always the case, each state and territory developed different criteria for assessing the eligibility and rebate levels.

We believe that once again, this scheme should be administered by the Federal Government, particularly as it is not uncommon for patients to cross borders for treatment, simply because of their geographical location.

i) The current involvement of charities and non-profit organisations in providing assistance is enormous. In one instance we know of a small country town where the Cancer Patient Assist Society paid between \$1200 and \$1500 per month for patients travel assistance and \$52,000 annually for accommodation. It is not unusual in some rural communities where such organisations are the only means of transport. There is no public transport, families are not living together intergenerationally and if a partner or family friend cannot drive the patient to treatment a voluntary organisation is usually approached for help. That provider of transport and/or accommodation in such cases whether an individual, family or organisation should still be eligible to receive the subsidy.

Summary

- We ask that the restriction that the patient be referred to the nearest specialist be abolished.
- We believe the system should be consistent and uniform nationally and preferably administered at a Federal level.
- We suggest that all distance criteria be lifted as the scheme would be self policing with the patient's contribution deduction.
- We ask that a per diem allowance for accommodation be paid regardless of where the patient stays, whether privately or in commercial accommodation.
- We ask that organisations that provide the service of transport or accommodation be eligible for the travel and accommodation allowance.
- We would further urge the Inquiry to consider recommending broadening the scope to increase services, such as renal units, at regional and country hospitals to avoid the need for some patients to travel vast distances.

Patricia Shergis
Chairperson
Social Issues Committee
CWA of NSW

10th May 2007