

**Submission to  
Senate Community Affairs Committee**

**~ Inquiry into the Operation and Effectiveness of Patient  
Assisted Travel Schemes (PATS) ~**

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## Summary of Recommendations

The NSW Farmers Association (the 'Association') has raised a number of issues in this submission that must be addressed in order to improve the operation and effectiveness of Patient Assisted Travel Schemes ('PATS'). The key priorities for the Association in terms of required amendments to Isolated Patients Transport and Accommodation Assistance Scheme (IPTAAS) are to reduce the distance criteria from 200km to 80km (ie 160km round trip); allow patients a choice of specialist; increase the kilometre rate from the previous 12.7c/km (one of the lowest IPTAAS fuel subsidies in the country); and remove the patient contribution of \$40 per application

The Association offers the following recommendations as part of a national solution to these issues:

- 1) *That Patient Assisted Travel Schemes in every State and Territory recognise the importance of support networks in assisting patients – particularly rural and remote based patients – by ensuring assistance measures recognise the (often) required presence of family and/or carers.*
- 2) *That Patient Assisted Travel Schemes in every State and Territory remunerate fairly the family and/or carers of the patient for eligible costs incurred during chronic treatment episodes eg oncology treatments.*
- 3) *That the administrative requirements for patients utilising PATS be dramatically streamlined, particularly for those with conditions requiring regular medical attention, whereby subsequent claim forms should require only minor updating.*
- 4) *That the personal contributions towards PATS be uniform, with flexibility for patients requiring regular medical attention to contribute per treatment year rather than per visit.*
- 5) *That patients be eligible to lodge PATS claim forms within 12 months of the medical appointment.*
- 6) *That the accommodation assistance under PATS be increased, recognising the differing accommodation requirements of singles, couples and families, particularly those requiring medical attention in capital cities.*
- 7) *That minimum standards be introduced at State/Territory and national levels for PATS to improve flexibility for rural patient access to IPTAAS and specialist health services.*
- 8) *That patients utilising PATS be allowed a choice of specialist, particularly where the specialist has the support of a multidisciplinary team.*
- 9) *That an appropriately resourced PATS marketing campaign be introduced as soon as possible, with a target audience including rural doctors, specialists, Area Health Services, support agencies and rural communities.*
- 10) *That regular monitoring and public reporting principles be implemented at a State/Territory and national level to deliver continuous improvement in service standards ie benchmarking between the States/Territories.*

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## 1. Introduction

The NSW Farmers' Association (the 'Association') is Australia's largest state farming organisation representing the interests of the majority of commercial farm operations throughout the farming community in NSW. Through its commercial, policy and apolitical lobbying activities it provides a powerful and positive link between farmers, the Government and the general public.

Farmers and their families are also health consumers. Member surveys have highlighted that of all issues affecting farmers in NSW, poor access to health services remains a predominant concern. For this reason, combined with the fact that rural and remote Australians have poorer health than their metropolitan counterparts<sup>1</sup>, the Association is committed to addressing the rural health challenges facing non-metropolitan NSW.

The Association considers health a priority issue and has a long history of involvement in issues pertaining to the NSW Patient Assisted Travel Scheme (PATS), known as the Isolated Patients Transport and Accommodation Assistance Scheme (IPTAAS). Most recently, this has taken the form of targeted lobbying as part of the 'Less Distance for Assistance Alliance'. The Alliance's lobbying resulted in improvements to the IPTAAS eligibility criteria and a small improvement to the vehicle allowance, however, there are a range of outstanding issues. It is hoped that these issues – as outlined in the submission – will be addressed through this important inquiry.

Through its close ties with farmers and farming communities, the Association is in a unique position to contribute to the *Senate Inquiry into the Operation and Effectiveness of Patient Assisted Travel Schemes* and welcomes the opportunity to do so. The Association sought the feedback of members in preparing this submission, and their personal stories are quoted throughout. For privacy reasons, their names and locations have not been identified in the submission.

## 2. The Need for Greater National Consistency and Uniformity

The Association remains extremely concerned by the lack of consistency and uniformity between State and Territory versions of Patient Assisted Travel Schemes (PATS). Whilst minor improvements have taken place to key eligibility criteria in recent times, there remains a great deal of inconsistency in the composition and administration of the scheme across the country.

Despite the many administrative and operational problems outlined below, the Association is strongly supportive of the concept of PATS, and is keen to ensure the continuation of the Isolated Patients Transport and Accommodation Assistance Scheme (IPTAAS) in NSW – albeit with some significant improvements. The clear need for this type of scheme is indicated in the member comment below:

*"I am pleased to encourage you to petition for IPTAAS travel assistance to continue as we have a 32 year old son who has benefited from this scheme when he was diagnosed with a brain tumour in 1999. He has had partial surgery and goes back to his*

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<sup>1</sup> Australian Institute of Health and Welfare (2005). Media release "Poorer health, higher risks outside major cities" 13 May 2005.

*neuro-surgeon in Sydney yearly for monitoring of its progress and treatment. Our 26 year old daughter who had a stroke in infancy also benefited from this scheme for many years after she had a temporal lobectomy to correct epilepsy that resulted from her stroke. She travelled to Adelaide regularly for monitoring from 1981 to 1999. The medical costs were excessive so the travel assistance was much needed and appreciated.”*

## **2.1 Eligibility for Travel Schemes**

Prior to mid-2005, the Association had lobbied the then NSW Health Minister for a number of changes to IPTAAS to no avail. This lobbying was brought about by a number of inconsistencies between IPTAAS and other State and Territory versions of PATS. For example, until changes were made to the IPTAAS distance criteria in 2006 (see below), NSW had the highest distance rule in the country – requiring a 400km round trip in order to access the scheme. This distance criteria was twice that of the next highest distance criteria (Victoria and South Australia at 100km). Whilst acknowledged that the relevant Area Health Service did have the discretion to waive the distance rule, from anecdotal evidence, the Association found that this was rarely exercised.

The key priorities for the Association in terms of required amendments to IPTAAS are to reduce the distance criteria from 200km to 80km (ie 160km round trip); allow patients a choice of specialist; increase the kilometre rate from the previous 12.7c/km (one of the lowest IPTAAS fuel subsidies in the country); and remove the patient contribution of \$40 per application.

### Less Distance for Assistance Alliance

In mid-2005, the Cancer Council of NSW initiated an IPTAAS Forum following reports that a number of other health and rural groups were fighting similar IPTAAS battles. Following the Forum, eleven organisations (including the Association and the Cancer Council of NSW) formed the ‘Less Distance for Assistance Alliance’, agreeing to lobby on the most common and pressing issues, namely seeking urgent changes to the distance criteria and for patients to have a choice of specialist.

Following months of sustained lobbying by the Less Distance for Assistance Alliance, in March 2006, the NSW Premier announced that the distance criteria would be reduced from 200km to 100km, and the vehicle allowance would be increased from 12.7c/km to 15c/km. Whilst the Alliance had been lobbying for the distance criteria to be reduced to 80km, the reduction to 100km was a positive step forward. The increase in the vehicle allowance to 15c/km was also a positive step forward, but the quantum of the increase was very disappointing.

Unfortunately, in announcing these amendments to IPTAAS, the NSW Government did not even acknowledge the Alliance’s lobbying on the issue of choice of specialist. Separate correspondence has outlined that exemptions currently exist subject to the discretion of the referring doctor and the IPTAAS office. However, as was the case with Area Health Service discretion regarding the distance criteria mentioned above, from anecdotal evidence, the Association finds that this is rarely exercised. Clearly, national direction and consistency is required on this issue, particularly in light of the fact that the NSW Government appears unwilling to address the issue.

## **2.2 Level and Forms of Assistance Provided**

As stated above, the Association is extremely concerned by the lack of consistency regarding the level and forms of assistance provided under the various State and Territory iterations of PATS.

### Support Networks

The Association is concerned that IPTAAS does not fully recognise the importance of support networks for rural – indeed all – patients. The importance of family as a support network is highlighted in the member comment below, supported by a comment from another member who explains that carers and social workers are often required, not only for emotional and physical support, but also for assistance with excessive paperwork. The Association is keen to ensure that the loss of income for a spouse/carer during chronic treatment episodes, such as oncology treatments, is at least partially offset by the scheme.

*“It is important for patients to have their spouses with them when they are away receiving treatment and children need all their family not just one parent.”*

*“...we had a social worker who helped us out with IPTAAS and any other services available and also was our support network. Cancer patients also require carers to be with them whether they are 5, 15 or 50 and IPTAAS does not recognise that.”*

### **Recommendations:**

***That Patient Assisted Travel Schemes in every State and Territory recognise the importance of support networks in assisting patients – particularly rural and remote based patients – by ensuring assistance measures recognise the (often) required presence of family and/or carers.***

***That Patient Assisted Travel Schemes in every State and Territory remunerate fairly the family and/or carers of the patient for eligible costs incurred during chronic treatment episodes eg oncology treatments.***

### Paperwork

The issue of paperwork is raised by the vast majority of members who contact the Association regarding IPTAAS, ranging from criticism about the complexity of the paperwork through to resentment at being forced to lodge paperwork each and every time the scheme is utilised, even if the scheme is used on a very regular basis. The Association is extremely concerned by reports of members accepting inequitable financial burdens arising from medical treatment rather than applying for assistance due to the sheer volume of paperwork they are confronted by. This paperwork becomes particularly overwhelming during times of stress. The following member comments reflect these frustrations:

*“I applied to IPTAAS when we had to spend 7 weeks away receiving radiotherapy treatment. The bookwork involved was unbelievable. I had to gather all the receipts; referrals from the local GP (our local town is 56km away), the referring urologist and the treating oncologist; all receipts for travel including mileage and accommodation. [I then had to list] all these requirements which took some time and then apply to MBF for their contribution of \$100.00 which was taken off. I received a refund... after some weeks. We have had to return to our oncologist for a checkup where my husband also had to have a colonoscopy and endoscopy which involved another specialist. Needless to say I DID*

*NOT chase up another referral from our GP, oncologist or colonoscopy specialists. We paid for our own accommodation for two days and I am too exhausted by it all to chase everything up again”.*

*“While we received IPTAAS there were many difficulties with it not the least of which was the incredible amount of paperwork which needed to be filled in every time we went to Sydney, (which was constantly)”*

*“To claim \$20 back I have to have the form signed by the doctor, a copy of our health care card, a copy of our accommodation receipt and a copy of the doctor’s receipt. If you have been referred for the first time you are meant to have the referring doctor sign the form and the specialist you see as well. This is if you remember to take it with you then if you have a doctor who will sign it.”*

*“Having to duplicate the information you give them, in every claim form is a BIG bother and hassle, [particularly in light of] the time it all takes to get the 2 doctors to sign it.””*

*“I find the chasing up of referrals from the GP and specialists incredible when 1 referral should suffice for whatever the continuing treatment will be – in [X]’s case, his prostate cancer.”*

It was pleasing to note however that one member reported a positive experience with the administration of IPTAAS paperwork (as follows). The Association is disappointed not to have received more positive feedback about the scheme when it recently canvassed the membership for feedback (both positive and negative) on IPTAAS.

*“I had cause to use the IPTAAS scheme a few years ago when my pensioner mother needed surgery at Tamworth Base Hospital. It was a huge help to us financially and made it possible for me to take my mother to Tamworth for the surgery. When we returned I lodged my application (with relevant documents) and it was handled promptly and without any queries. It was excellent to have access to this assistance.””*

**Recommendation:**

***That the administrative requirements for patients utilising PATS be dramatically streamlined, particularly for those with conditions requiring regular medical attention, whereby subsequent claim forms should require only minor updating.***

Up-Front Fees

Members also regularly express concern about the up-front fees and the processing time of applications as indicated below. It should be noted that each State/Territory demands different personal contribution amounts for PATS, with some seeking contributions per trip and other seeking contributions per treatment year. NSW currently demands a \$40 contribution each claim. In the case of lengthy and repeat treatments, this quickly adds up.

*“Much of the time it took months (sometimes 6 months) for payment and each form that went in you had to pay \$40.00 up front”*

*“Processing of the forms is very slow – at least 2 months until you get paid. I am lucky I can drop them off in Dubbo. If you post them and forget a piece of paper by accident your paperwork is held up a lot longer.”*

**Recommendation:**

***That the personal contributions towards PATS be uniform, with flexibility for patients requiring regular medical attention to contribute per treatment year rather than per visit.***

Lodgement of Paperwork

Other members have expressed concern about the time necessary to complete the paperwork, arguing that forms should be able to be lodged within an extended period of time. This is reflected in a member's comment below:

*"Six months is not long enough to get the forms in. When our youngest was very sick as a baby, there were periods of time, usually right after seeing the doctor, when things were just too much to cope with. We weren't coping. Rural people already find it difficult to have needs met in such conditions and the IPTAAS forms were just one too many in the list of problems. There were a number of trips that I didn't claim because of the timeline, when we really needed the money."*

**Recommendation:**

***That patients be eligible to lodge PATS claim forms within 12 months of the medical appointment.***

Quantum of Assistance

The quantum of assistance was an issue of particular concern to many members:

*"We applied for a subsidy through [IPTAAS] and recently received around \$185 in rebate. This was for a 2 night stay in Sydney, round trip of around 600km. Not taking into consideration food expenses, the trip cost \$610. This was to take our two young children to their paediatric specialist (for allergy related consultations). Our youngest child needs follow-up visit every 6 months at present, so this is an ongoing expense for us. Because of the time the consultations take, and the age of our kids, we have to stay for 2 nights. The fact that you only get a subsidy for 1 night is a little poor. Perhaps it should be on a case by case basis."*

*"I think the government needs to raise the accommodation rebate more – maybe a family rate, couples rate and singles rate."*

*"We have been seeing a specialist in Sydney for our daughter for [almost 3 years]. The first year we went down 4 times, last year 2 times and this year will be 2 times. My husband has also had to have sleep studies done for sleep apnoea at RPA. If we don't have a hospital stay our private health insurance pays the travel and we can claim our accommodation from IPTAAS. We can claim \$40/night. We pay the first \$20 because we have a health care card. If you don't have that you pay the first \$40 on the claim. So for 1 night we get \$20 back!!! We usually only stay 1 night, see the doctor the next morning and head home. We travel as a family (2 adults, 2 children), so our accommodation costs about \$105/night."*

**Recommendation:**

***That the accommodation assistance under PATS be increased, recognising the differing accommodation requirements of singles, couples and families, particularly those requiring medical attention in capital cities.***

### 3. The Need for National Minimum Standards

As outlined above, there is a clear need for the immediate introduction of minimum standards to improve flexibility for rural patient access to IPTAAS and specialist health services. However, there is even a need for minimum standards at a state level, as reflected in the following member comments:

*“The administration of IPTAAS is very fragmented as each Area Health Service administers their own so the criteria are not standardised and what you get depends on where you live.”*

*“I don’t know how IPTAAS work out the travel. They don’t send an itemised invoice – just the total paid. You can ring them for an explanation if you need to. I find we are never paid the same amount twice but the costs are the same!!”*

**Recommendation:**

***That minimum standards be introduced at State/Territory and national levels for PATS to improve flexibility for rural patient access to IPTAAS and specialist health services.***

#### 3.1 Improved Flexibility for Rural Access to Specialist Health Services

The limited choice of specialist and difficulties in accessing specialists with the support of a multidisciplinary team is amongst the most common criticism of IPTAAS reported to the Association, as well as the Less Distance for Assistance Alliance. A number of members have expressed concern about this issue, as indicated below:

*“...rural and remote patients do not have the access and equity that all those in Sydney have already, and they are also restricted from receiving referrals to the best available specialists. The only reason my son is still here is that he was able to see the best specialists. While NSW authorities would deny it, there is a huge variation in outcomes between city, rural and remote patients and it is only common sense that all patients should attend comprehensive cancer care centres which includes multidisciplinary teams”.*

*“My husband has to return in June to the urologist for a checkup which will now be every 6 months. I also have to see a haematologist. The specialist in Tamworth is taking no more patients. He is swamped.”*

**Recommendation:**

***That patients utilising PATS be allowed a choice of specialist, particularly where the specialist has the support of a multidisciplinary team.***

### 4. Current Level of Utilisation of Schemes

Public reporting of PATS, as recommended above, would greatly assist in identifying the current level of utilisation of PATS, as this information is currently very difficult to obtain.

#### 5.2 Effectiveness of Marketing

NSW Farmers Association is disappointed by the poor general awareness of IPTAAS across the state; clearly a result of poor marketing of the scheme. Whilst members who have experienced chronic illness or serious injury requiring regular and prolonged

treatment and/or rehabilitation are generally aware of the scheme and have often utilised it, awareness of the scheme is generally poor amongst those in good health.

Those who contact the Association after developing an illness or incurring a serious injury to inquire about “rural health assistance” either have not heard of IPTAAS, have heard of IPTAAS but are confused by the acronym, or assume that they are ineligible because they do not consider themselves “isolated” geographically, despite living hundreds of kilometres from treatment centres. Others are not aware of the changes to the distance criteria made in 2006, indicating much more needs to be done in terms of marketing.

The following member comments reflect the issues raised above:

*“It is interesting that many rural patients I know often have never heard of IPTAAS and I know personally of cases where patient treatment has not happened because they are unable to afford the constant accommodation and transport costs”.*

*“Could specialist medical centres have a supply of the IPTAAS forms in view? Could someone educate the doctors about it? It is hard to have the form on hand and then get it signed at the visit when rural doctors are so busy”.*

*“I have been travelling from Alectown to Dubbo for monthly chemotherapy. The distance is 100km from home to Dubbo. As far as I know I am not eligible for IPTAAS as the distance is not far enough?”*

[This member is in fact eligible for assistance following the changes announced more than 12 months ago. However, information on the changes to the distance criteria was not made available locally].

Several members raised the need for improved marketing of the scheme to doctors, as indicated by the comments below:

*“Some doctors’ attitudes [are a problem]. Farming people don’t ask for anything easily and asking a doctor who gives you attitude about signing the forms, can be too embarrassing and another hindrance to the process. I think some doctors need to be educated about what IPTAAS is and that it is something we are entitled to claim. What about healing the whole person?! Less worry about money = healthier family.”*

*“We find IPTAAS difficult in that the form has to be signed by the doctor. If they would let the receptionist do it this would be easier. We have one specialist who will sign, the other hates doing them!”*

**Recommendation:**

***That an appropriately resourced PATS marketing campaign be introduced as soon as possible, with a target audience including rural doctors, specialists, Area Health Services, support agencies and rural communities.***

### **5.3 Monitoring to Inform Continuous Improvement**

The Association is keen to see the introduction of regular monitoring and public reporting principles in order to deliver continuous improvement in service standards, including benchmarking between States/Territories. This information should be readily available under the *Freedom of Information Act* or on the relevant Departmental website.

Recent improvements in the system have been welcomed by members, as indicated in the comment below, however, administrators of the scheme must continue to strive for excellence to ensure the best possible result for patients.

*“It is good to now be able to download forms if you have to. The improved form is a bit clearer and while I haven’t used it yet, I expect that the EFT payment option should make the payment time quicker, which it needs to be”.*

**Recommendation:**

***That regular monitoring and public reporting principles be implemented at a State/Territory and national level to deliver continuous improvement in service standards ie benchmarking between the States/Territories.***

## **5. The Role of Charity and Non-Profit Organisations**

Many members have highlighted to the Association the invaluable assistance provided by non-profit organisations in the provision of travel and accommodation assistance to patients. In the case of accommodation, Ronald MacDonald House has been identified as critically important for young rural patients in particular, as identified by a member below:

*“We were lucky and were able to be accommodated at Ronald MacDonald House which accepted the miserable \$30.00 per night allowance from IPTAAS.”*

The example above highlights the important role of charity and non-profit organisations in light of the negligible financial assistance available for accommodation under IPTAAS. A \$30 contribution towards accommodation in Sydney – whilst helpful – is relatively insignificant when hotel costs are generally well in excess of \$100 per night, further highlighting the need for a review of the accommodation allowance, as mentioned above.