

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

Dear Sir/Madam

**Submission to the Senate Inquiry into the Operation and Effectiveness
of the Patient Assisted Travel Schemes in Australia**

This submission is made by Cancer Voices WA of 15 Bedbrook Place, Shenton Park, WA 6008. Cancer Voices WA is a consumer advocacy group whose members are cancer patients and carers. The Chair of Cancer Voices WA, Clive Deverall (a former Director of the Cancer Council of WA for 20 years), has had experience of both the IPTAAS and PATS programmes over many years.

All comments on the PATS programme included in this submission were provided by 23 patients currently undergoing treatment for cancer in Perth and 4 carers staying at AH Crawford Lodge, the Cancer Council's accommodation facility located in the grounds of Sir Charles Gairdner Hospital, Perth. The meeting was held on Wednesday 18th April 2007.

Background

The total PATS expenditure in Western Australia in 2005/6 was \$14 million, accounting for 51,000 individual trips for country patients attending specialist medical appointments, including, but not limited to, cancer patients.

The *WA PATS Review Report* released in 2002 provides a broad picture of PATS expenditure in Western Australia. The report showed that the total PATS expenditure in 2001 was \$10 million, and that there had been an annual growth figure of 10.7% over the period 1995/96 to 2000/01. The majority of trips made during 2001 were for patients to go to Perth, and accounted for 73% of the total, or 25,559 trips. Seventeen per cent, or 5,928 trips, were for patients to go to the 'nearest centre' or visiting specialist, while 0.6%, or 230 trips, were to go interstate, and 9.4%, or 3,302 trips, were classified as "unknown".

Again in 2001 84.5% of referrals were for outpatient appointments and just over 15% were admitted as in-patients. In terms of frequency of the trips, approximately 35% were one-off trips; 46% were repeat trips made at intervals less frequently than once per month; and 10% were repeat trips made at intervals more frequently than once per month; while the frequency of the remaining 9% was "unknown".

Over the last three years there has been an increase in trips made to the nearest regional centre and a decrease in trips made to Perth. In 2005/6 9,044 trips were made to the nearest regional centre – up from 6,323 in 2004/5, while trips to Perth in 2005/6 decreased to 41,770 from 45,459 in 2004/5.

The Cancer Voices WA position on the Patient Assisted Travel Scheme is the following:

1. PATS administration lacks coordination, consistency and flexibility

PATS/IPTAAS has been on regional and national cancer agendas for as long as can be remembered. It has been evident that since 1987 different states and territories have administered PATS in many different ways, and there has never been sufficient money in state/territory health budgets to adequately meet the demand for PATS in context of the needs and comfort of patients. One of the consequences of this lack of coordination is the 'patchwork quilt' nature of the way in which PATS is administered around the country. Whereas prior to 1987 (when the system was run by the Commonwealth) there was more flexibility and discretion in the decision-making process, today there is little or no flexibility, and too many of the decisions made by local PATS 'officers' are subjective and can have an adverse effect on a patient's prognosis.

This lack of consistency is highlighted by a patient from Derby (more than 2,000 km north of Perth):

'We have found over the long time my wife has been treated for breast cancer that the decisions about PATS alter according to who is in charge at the time. Some are very helpful but others difficult. We have had to pay excesses at hotels that PATS have booked us into in the city.'

A patient and carer from Albany (400 km south of Perth) commented:

'Our accommodation allowance was \$77.00 but the accommodation booked by the PATS clerk in Perth came to \$44.00 more which we had to pay out of our own pocket at the motel. In the Crawford Lodge adjacent to the Sir Charles Gairdner Hospital the PATS allowance covers the total cost.'

A patient from York commented:

'I live 7 kms outside York which makes the trip to Perth just over 95 kms but as the York GPO is 100 kms from Perth I was prevented from getting any PATS travel or accommodation allowance. I have raised the issue with several people, including my GP and cancer doctor, but they can do nothing about it. This has cost me a lot of money.'

Another patient from York expressed a similar opinion. The patient said it was just not possible for her (due to her type of cancer) to travel in a car or bus everyday due to the pain, discomfort, etc. Her husband travels down by car each day to help and support her.

In Western Australia there is a PATS travel grant of \$20 per day for patients who live between 70-100 km from Perth. However, there are often patients who daily travel 70 km for their treatment and become unwell afterwards. These patients need to stay in Perth, but the \$20 allowance is not able to be claimed directly by the accommodation facility and the patient has to meet the full cost of their accommodation at the time. This needs to be more flexible, otherwise more patients will need to be admitted to hospital.

2. PATS application process is complex and time-consuming

The administration of PATS for the South West of Western Australia is outsourced to McKesson Asia Pacific. Patients wishing to apply for PATS are required to ring an 1800 number at the time of referral to a specialist by their GP. They are then registered and sent a *Guide for Patients & Carers*. For the north of Western Australia, PATS is administered by individual PATS clerks/officers, usually based at the local hospital.

A patient from Bunbury (175 km south of Perth) commented:

'There is no PATS clerk at Bunbury and you have to dial an 1800 number. My wife and I have found it complicated trying to get information quickly and if you don't get things right at the start you will run into problems getting reimbursed later.'

Another patient from Bunbury noted:

'I had problems with PATS at the beginning. My GP didn't know much about it and I forgot to ring the 1800 number and by the time it came to go up to Perth I had not been registered but it was ok the next time.'

Also of concern is the lack of information on PATS, as a patient from Wagin (228 km south east of Perth) pointed out:

'I am being treated for prostate cancer and found that the information about PATS at the Wagin hospital was sadly lacking.'

3. Travel reimbursement is unrealistic

The type of transport allowed under PATS is important, especially in a state as large as WA. It is important to the patient and his/her carer in terms of comfort and time and important to the effect on the PATS budget. In Western Australia, the figures for 2001 showed that most trips were made by private

car (71% or 24,656); 18% or 6,435 trips were made by air; and 7% or 2,406 trips were made by bus or train, while 1,522 trips were classed as “Unknown”.

More recent figures show that in 2005/6 the trips by air were 9,401 (up from 8,984 in 2004/5), while the trips by car were 38,072 (up from 27,681 in 2004/5).

It is clear that every trip made by car saves PATS a significant amount taking into account the 13 cents per kilometer paid at that time – It took 3 years of lobbying to achieve an increase of 2 cents to the current 15 cents a kilometer. The rate per kilometer is unrealistic taking into account country fuel prices, insurance, etc.

A patient from Kalgoorlie (600 km east of Perth) commented:

‘In Kalgoorlie Hospital the PATS officer said I must travel by train though I wanted to travel by ute as it would give me transport in Perth. Using my own vehicle was cheaper as the allowance was very small. I can’t understand why the patient can’t select their method of transport – rail, bus or their own vehicle.’

A patient from Geraldton (450 km north of Perth) said:

‘I have one comment about PATS – there must be an increase in the travel allowance for cars – we are paying 127 cents a litre and more in the Geraldton area at present; it is costing my wife and I a lot of money and, as retired people, it is hard as well as being sick.’

Taking into account the low rate per kilometer paid for using a private car there must be a significant saving to the PATS system every time this allocation is made as opposed to other types of transport. **Are the patient’s comfort and needs fully taken into account when the decision is made in context of the type of travel to be funded?**

4. Referrals to regional centres save PATS money but may not be in the patients’ best interest

Of particular interest are the significant increases in trips to regional centres – 6,323 in 2004/5 up to 9,004 in 2005/6. This increase needs to be examined in light of the fact that the PATS system in Western Australia can only be used by patients to travel to Perth if there is no recognized visiting specialist to the nearest regional centre.

In the context of modern cancer management, automatically referring a patient to a ‘visiting specialist’ may well not be in their best interest nor relate to their clinical needs. At present multi-disciplinary cancer treatment is sadly lacking in regional Western Australia. It is essential that a cancer patient’s clinical needs are not compromised for the sake of the efficiency and frugality of the PATS budget.

In terms of a cancer patient's best interest, the majority should be seen by a specialist who has experience in treating the particular type of cancer that affects that patient. Modern, multi-disciplinary cancer treatment calls for surgeons and other clinical specialists to have volume throughput in terms of their specialty. Under the PATS system many patients are obliged to visit the nearest specialist who may be a regional surgeon or a visiting consultant. In some scenarios, PATS-funded patients referred to a local or visiting surgeon are operated on disregarding the surgeon's level of expertise in a particular type of cancer. As to whether patients are advised to have or offered adjuvant treatment (as most should be) is currently obscure, though some *Patterns of Care* studies have indicated that some women with breast cancer from rural Australia refuse adjuvant therapy.

A patient from Geraldton commented:

'I have cancer of the jaw and it took weeks for a decision to be made about who I should be referred to. A visiting specialist took one look at me, left the room and I never saw him again. Eventually I was sent down to Perth and have now made 11 visits so I know all about PATS which works ok for me.'

A patient from Bunbury pointed out:

'I complained about the delay to see an oncologist in Bunbury and was told I could not get PATS because you were not eligible if there was a visiting specialist. My GP had suggested two doctors in Perth who specialized in my type of cancer but neither visited Bunbury, so I was refused PATS even though my GP tried to insist. After 3 months of treatment in Perth it has been agreed to give me PATS but not for all the previous visits. I should have been allowed to see the doctor my GP suggested.'

5. Requests for funding for carers are being refused

More reports are coming to hand that requests for funding for a carer to accompany a patient are being refused. PATS relies on the assumption that all patients are ambulant, but in many cases there are patients who need a carer with them – especially during the sometimes lengthy course of treatment. In many cases, if the patient is admitted to hospital, PATS will cease accommodation funding for the carer for that period of time. Additionally, if it is known prior to arrival that the patient is to be admitted to hospital, in many instances PATS will only fund a carer for the night prior to admission and the night prior to discharge.

RECOMMENDATIONS

1. There should be a national minimum standard for PATS in terms of the different benefits provided. This was indicated in the intergovernmental “Radiation Oncology Jurisdictional Implementation Group” report released by the Department of Health and Ageing in Canberra on 28th November 2003.
2. PATS officers should be better trained.
3. An easy-to-access appeal system should be introduced.
4. PATS needs to become more flexible and user-friendly, especially in context of rulings based on where a patient lives versus ‘the distance from the nearest GPO’.
5. The policy of referring as many patients as possible to the nearest regional centre or ‘visiting specialist’ must be reviewed urgently. Whilst this may be beneficial to the PATS budget, it may well compromise a patient’s prognosis.
6. As Multi-Disciplinary Treatment (MDT) for cancer is developed in Australia, it is important that PATS facilitates each patient’s access to MDT.
7. It is essential that NGO providers of accommodation and transport be given every encouragement to maintain, if not expand, their services. As the population ages the incidence of cancer increases, which will increase demand for PATS. Accommodation services provided by state Cancer Councils are of exceptional standard and save the PATS programme money.

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