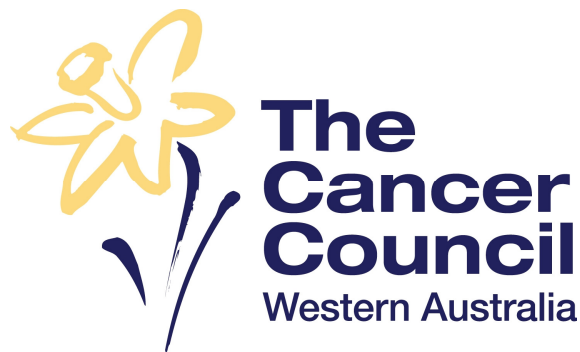


Submission from The Cancer Council
Western Australia to the Senate
inquiry into the operation and
effectiveness of Patient Assisted
Travel Schemes (PATs)



May 2007

OVERVIEW

This submission has been prepared by The Cancer Council Western Australia (TCCWA). The Cancer Council WA welcomes the Senates interest in the Patient Assisted Travel Scheme (PATS) which impacts significantly on equity and access to treatment for cancer patients and their families.

The Cancer Council WA has been the leading charity for cancer control in WA for 50 years and has a comprehensive understanding of the issues facing WA cancer patients and their families. TCCWA has provided, and subsidised, metropolitan accommodation facilities for country cancer patients since 1980. Since inception of a new accommodation facility (Crawford Lodge) in 2000 TCCWA has accommodated 16,000 cancer patients and carers. Providing this much needed service has required an in-depth understanding of the PATS system in WA and daily liaison with PATS administrators.

Additionally TCCWA has managed a cancer consumer participation program since 2001. Inherent to the program is ongoing identification of issues impacting on cancer patients. In 2006 the TCCWA Consumer Participation Advisory Committee actioned a local investigation into key issues related to the administration of PATS in WA from the perspective of country patients, their loved ones, PATS clerks and accommodation staff. The inequities and barriers of access to treatment, as a result of PATS, remains one of the most critical issues facing country cancer patients in WA.

There are a number of issues and discrepancies with the PATS scheme that require government led change and The Cancer Council WA makes the following recommendations for improvement:

RECOMMENDATIONS

1. PATS must acknowledge the unique psycho-social implications of a cancer diagnosis and review eligibility criteria, to allow country cancer patients the choice to be accompanied when accessing treatments;
2. PATS should have nationally consistent, simplified eligibility criteria in each state and territory of Australia;
3. Develop a simplified, standardised approach to interpretation of PATS rules and regulations;
4. Reduce the 'red tape' associated with PATS and enable non GPs to authorise the paperwork;
5. Review PATS eligibility criteria for zone allowances and petrol subsidies with increased allowances and flexibility;
6. Review PATS guidelines and criteria to address the current inequities between healthcare card holders and non-healthcare card holders in rural areas;
7. Increase PATS allowances for accommodation, travel distances and petrol to reflect the current economic environment;
8. Establish national standards for PATS administration and evaluation;
9. Establish a national minimum data set to enable future benchmarking for PATS administration and evaluation; and
10. State and Commonwealth governments should raise awareness and provide more information to the public about PATS

TERMS OF REFERENCE

1.0) PROCEDURES AND ELIGIBILITY

- **RECOMMENDATION:** PATS must acknowledge the unique psycho-social implications of a cancer diagnosis and review eligibility criteria, to allow country cancer patients the choice to be accompanied when accessing treatments.
- **RECOMMENDATION:** PATS should have nationally consistent, simplified eligibility criteria in each state and territory of Australia.
- **RECOMMENDATION:** Develop a simplified, standardised approach to interpretation of PATS rules and regulations.
- **RECOMMENDATION:** Reduce the 'red tape' associated with PATS and enable non GPs to authorise the paperwork.

"My haematologist/ oncologist wrote a letter stating I required a carer while in Perth. This request was rejected by my PATS clerk as I was deemed well enough to look after myself. This meant that I had to stay in Perth alone for up to seven weeks at a time without the support of my husband and children while having chemotherapy. PATS would not even cover accommodation for my husband for one weekend in the whole seven weeks I was in Perth.

At a time when I was struggling emotionally with my cancer diagnosis being isolated from my family for such a long time made the whole experience even more difficult."

The existing PATS need to be modified to reflect the needs of individuals affected by different health conditions. Presently PATS in WA provides a blanket scheme (one-size-fits-all) for people living in rural areas who must travel to the city for adequate health care. The scheme does not differentiate between a person involved in a motor vehicle accident in the Pilbara and a person with lung cancer in the Eastern Goldfields.

Treatment regimens for people affected by cancer vary enormously dependant on the type and stage of the cancer e.g. some people need radiation treatment for 2 hours a day for 6 weeks, some people need surgery and hospitalisation for 1 week; some people need chemotherapy 1 day a week for 13 weeks, others need a combination of the above. The practical implications of accessing cancer treatments, for rural patients, set them apart from the majority of people living with an acute or chronic health problem.

The behavioural science and psycho-social literature suggests a diagnosis of cancer frequently leads to clinical anxiety and depression. Unlike other chronic diseases the National Health and Medical Research Council has published specific clinical practice guidelines to assist clinicians in the psycho-social care for cancer

patients. Rural cancer patients are required to leave their usual family, social and community networks to access life saving health care. The need for country cancer patients to have the support and care of their loved ones is essential when commuting back and forth for treatment. Due to unique distances and geography this issue is of great significance for WA patients.

The current PATS guidelines in WA state that patients are only eligible to have a carer or escort accompany them in instances where the patient is under the age of 18, the patient requires constant assistance due to medical reasons, or if there is the need for an interpreter. Therefore, in cases where patients are required to stay in Perth for a number of weeks for cancer treatment they must do so without the support and assistance of a partner or relative. Not only is this extremely isolating for patients who are unaccustomed to the city but also emotionally difficult when confronted with dealing with their illness and treatment alone.

In addition, if a patient has been approved a carer, yet is hospitalised during their treatment, the carer will not receive an accommodation allowance during this time. PATS will only cover the night before hospitalisation and following discharge of the patient.

The need for clarity about approval for carer travel and accommodation support is even greater when considering Aboriginal patients who must travel to Perth for treatment. Currently there is nothing specific in the WA PATS guidelines about the special needs or cultural sensitivities required for this group of people. Feedback from local sources indicates inconsistencies where sometimes a carer or escort is approved and sometimes not. Similarly there are reports where sometimes Aboriginal patients are met at the airport or station by a funded transport service or given taxi vouchers and sometimes not.

A major concern for both consumers and PATS clerks is the inconsistencies with the interpretation of the guidelines and discrepancies in the administration of the scheme within and across states. Anecdotal consumer feedback suggested particular PATS clerks make special allowances for certain individuals. For example there have even been instances whereby the same PATS clerk has authorised a payment to a patient which was previously rejected for another person, despite having identical circumstances.

Some PATS clerks acknowledge being more lenient towards oncology patients whereas others always abide by the guidelines. Other PATS clerks felt the guidelines were complicated and confusing making it very difficult to have a clear understanding of the exact subsidies allowed, which increases the inconsistencies.

"My PATS clerk would not allow me to have a carer while I was in Perth for treatment, yet I met another patient at Crawford Lodge who was allowed her husband with her the whole time but there was no medical reason for it"

2.0) LEVELS AND FORMS OF ASSISTANCE

- **RECOMMENDATION:** Review PATS eligibility criteria for zone allowances and petrol subsidies with increased allowances and flexibility.
- **RECOMMENDATION:** Review PATS guidelines and criteria to address the current inequities between healthcare card holders and non-healthcare card holders in rural areas.
- **RECOMMENDATION:** Increase PATS allowances for accommodation, travel distances and petrol to reflect the current economic environment.

Patients who live within 70 – 100 kms of their closest treatment centre, who qualify for PATS assistance, only receive a flat subsidy of \$20.00 per return trip, without the allowance of overnight accommodation. With increasing petrol prices, the allowance would not even cover the cost of petrol for one trip.

In some instances, cancer patients are required to have daily treatment sessions for up to six or seven weeks. This would mean the patient would need to drive back and forth in one day over the course of this time period, which would be extremely exhausting and demanding especially if they had adverse reactions each time. Unfortunately PATS will not cover the accommodation for such patients as they are deemed to live too close to their treatment centre.

In cases of extreme reactions to the treatment, PATS will cover only one retrospective claim for one night of accommodation and the patient is required to provide evidence of its necessity with a letter supplied by the specialist as well as any other necessary documents.

In addition, the allowances of the scheme are notably worse for patients with private health insurance or those without a health care card. The financial burden of cancer on any family is significant whether you qualify for a health care card or not. Discussions with country cancer patients who have private health insurance suggests the annual cost for gaps in service can be as much as \$20,000. This financial burden is amplified when often there is a loss of one income for several months at a time.

Healthcare card holders and pensioners receive fully subsidised accommodation, are not required to pay a personal contribution and can receive petrol vouchers if necessary.

Currently, patients who do not qualify for a healthcare card are required to pay for their first three night's accommodation. They are required to pay this for their first four trips and then if further trips are necessary, they will be covered for the remainder of the treatment year to the value of \$35.00 per night. However, the first \$50.00 of this cost, for the first four trips, is not claimable.

The reimbursement that non-healthcare card holders receive from PATS covers a small fraction of the total expenses incurred when travelling to Perth for treatment. The petrol subsidy for non-healthcare card holders is offered at a rate of 13c/km. After the first four trips to Perth the petrol subsidy then increases to 15c/km. In comparison, healthcare card holders are automatically reimbursed at 15c/km.

There is ample feedback from cancer care health professionals and patients that loss of income and gap costs associated with cancer result in a significant financial burden for non-healthcare card holder cancer patients in rural Western Australia.

The travel subsidy does not reflect current petrol prices, with patients only being reimbursed 13c/km, which increases to 15c/km after four trips. This rate was awarded in 2001/02 after three years of lobbying Government yet it still needs to be increased substantially to realistically assist patients financially.

In addition, the accommodation subsidy also needs to be reviewed. Patients are required to pay the first three (3) nights accommodation before PATS will cover subsequent nights at a rate of \$35.00. There are limited accommodation facilities that offer the subsidised rate and they tend to have long waiting lists. Therefore patients find they are required to pay higher accommodation rates per night until they are able to secure accommodation at facilities like The Cancer Council Crawford Lodge. For example, the waiting list at Crawford Lodge is four to six weeks with the number being turned away in any one month at 45 – 60 people.

Due to the unavailability of treatment options in their region, country patients find this cost financially disabling, particularly when they also need to pay for meals, medications, petrol and other incidentals while in Perth. This situation equates to patients effectively maintaining the cost of their own home as well as the burden of travel and accommodation in Perth. This is especially difficult for those who are struggling financially and do not quite qualify for a health care card but certainly do not have readily available funds to cover such expenses.

Taking into account our vast state, under the present scheme, patients can apply for air travel if their journey is longer than 16 hours one way by road, or they have a medical condition whereby air travel is essential; which would only be in exceptional circumstances. This aspect of the guidelines needs to be urgently reviewed, especially for cancer patients; as such a distance is certainly difficult and distressing for patients who are unwell or elderly. Even a distance of six to eight hours is not appropriate for a cancer patient travelling on their own. In 2005/06 9,401 patients (18%) were granted air travel compared to 38,072 who travelled by private vehicle (74%). Considering over half of all PATS patients (56%) were from regions with distances greater than five hours driving time this equates to a large percentage of people expected to travel for a day or more when they are not at optimum health, especially if they have been diagnosed with cancer.

3.0) NATIONAL MINIMUM STANDARDS TO IMPROVE FLEXIBILITY FOR RURAL PATIENTS ACCESS TO SPECIALIST HEALTH SERVICES

- **RECOMMENDATION:** Establish national standards for PATS administration and evaluation.
- **RECOMMENDATION:** Establish a national minimum data set to ensure future benchmarking for PATS administration and evaluation.

In WA in 2005/06 there were a total of 51,089 patients who utilised PATS. The system currently used to administer the Scheme in WA does not have capacity to identify such critical information as the reason or disease/condition that requires a rural patient to access the scheme.

To ensure the PATS system can be effectively monitored and improved, a minimum data set needs to be identified and data collected. This can then be analysed to help determine the use and measurement of service standards of the scheme. This process should be planned at a national level so that meaningful benchmarking may be undertaken.

Under PATS, patients are required to be treated by a specialist at their closest treatment centre. This guideline however does not consider the level of expertise of the specialist, especially in operating on or treating different types of cancers.

Patients should expect to be treated by a specialist who is an expert in their type of cancer, even if it is at greater expense to the PATS system. Every patient should have the right to request the best health care and access to a multidisciplinary team that will ensure optimum individual treatment.

4.0) THE CURRENT LEVELS OF UTILISATION OF SCHEMES AND IDENTIFICATION OF MECHANISMS TO ENSURE SCHEMES ARE EFFECTIVELY MARKETED TO ALL ELIGIBLE PATIENTS AND MONITORED TO INFORM CONTINUOUS IMPROVEMENT

- **RECOMMENDATION:** State and Commonwealth governments should raise awareness and provide improved information to the public about PATS.

Feedback from consumers and health professionals is that there is an overall lack of information available to consumers about PATS entitlements. There is a need for a nationally consistent program to raise awareness and provide specific information about the Scheme.