



**Submission in response to the Standing Committee on Public
Administration Inquiry into the Patient Assisted Travel Scheme**

May 2014

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1. Background to EDAC:

The Ethnic Disability Advocacy Centre (EDAC) is a Western Australian not-for-profit community-based organisation that advocates for the rights and interests of people with disabilities from culturally and linguistically diverse backgrounds (CaLD), their families, carers and communities. EDAC provides individual and systemic advocacy to migrants and refugees with disability living in Western Australia. EDAC represents Western Australia as a member of the National Ethnic Disability Alliance (NEDA) and is funded by the Department of Social Services (DSS) and the Disability Services Commission (DSC).

EDAC vigorously supports the promotion and protection of the rights of CaLD people with disability in order that they reach their full potential as active participants in the community. EDAC, as a peak voice of advocacy for CaLD people with disability and their carers, note that people with disability generally face barriers to social participation; access to employment, technology, social activity and economic wellbeing. However people from non-English speaking backgrounds with a disability are a vulnerable, high risk group and are prone to 'triple discrimination'. They are discriminated against due to their ethnicity and disability in mainstream society, and their disability within their own cultural community due to negative cultural perceptions of disability.

EDAC appreciates the opportunity to provide a submission in response to the Standing Committee on Public Administration Inquiry into the Patient Assisted Travel Scheme regarding issues facing CaLD people with disability and their carers in remote and regional WA.

In this submission, EDAC will focus on four significant areas in the terms of reference: the eligibility criteria for PATS funding, PATS level of funding applicable to transport and accommodation, notable gaps in the administration of PATS and the need to consider exceptional circumstances for some patients.

For more information on EDAC's advocacy services and projects, please visit our website at: www.edac.org.au

2. The Eligibility Criteria for PATS Funding:

The purpose of the Patient Assisted Travel Scheme (PATS) is to subsidise costs associated with travel and accommodation for eligible permanent country residents, and their approved escorts, who are required to travel a long distance to access certain categories of specialist medical services (including Telehealth). A person with disability or medical condition will most likely require a carer or companion to help with travel and accommodation. However, PATS have often dismissed requests for the assistance of an escort even when clearly recommended by the referring doctor.

Case Study 1:

A patient with dementia had to fly to Perth for Specialist treatment. This person did not have capacity to remember the reason for travel to Perth or arrange transportation to and from the specialist appointment. This person was denied funding for a carer to provide support. As a consequence of this, the patient missed the specialist appointment.

Case Study 2:

A patient application for an escort to accompany her to Perth was rejected because she was capable of walking and driving prior to her surgery. The patient was required to stay in Perth for three months following extensive surgery on her right ankle. The patient had her foot in plaster for 4 ½ weeks and was not allowed to put any pressure on it for 6 weeks. During this time the patient had difficulty driving to and from regular appointments with her specialist. She also could not afford to pay for taxis. In such a situation, the patient's application for an escort should have been approved taking into account her exceptional circumstances following surgery.

People accessing Mental Health and Allied Health services are not eligible to claim for expenses as these are not covered under the PATS scheme. This greatly disadvantages low income earners and those on Centrelink payments. As a result many people in this income bracket, regardless of need, have no choice but to forgo specialist medical services. The consequences of not accessing specialist services when needed are that the health of that person is likely to deteriorate with possible adverse outcomes. This is of particular concern for people of CaLD or Indigenous background living in regional WA.

3. PATS level of funding applicable to transport and accommodation in Regional WA:

The scheme has not factored the real cost of contemporary transport and accommodation and the extent the PATS supports patients. Reimbursement for accommodation is capped at \$60.00 per night for any person travelling alone, and \$75.00 when travelling with an approved escort. Patients have raised concern about the low rate of reimbursement when being escorted by a non-family member as it is usually assumed by PATS that they will share a room. The amount of reimbursement offered by PATS is inadequate compared to the market price for accommodation in Perth or regional centres of WA. In many cases, patients and their carers cannot afford to pay the gap. Additionally, the reimbursement PATS provides for travel expenses is insufficient when compared to the actual costs of travel.

Case Study 3:

Recently a cheap and user friendly accommodation outlet familiar to most of the people in the Kimberley and Pilbara was closed unexpectedly in Perth. People already in transit were unaware of this and as a consequence were left stranded in the city. Alternative accommodation was not an option for them due to the higher costs involved and the amount allocated by the PATS scheme.

Case Study 4:

Patients can currently claim a fuel subsidy of 16 cents per kilometre which has not been increased for a considerable number of years. An average motor vehicle using 9.5 litres per 100km would burn \$160.00 of fuel on a return trip between Carnarvon and Geraldton at the current rate of \$1.74 per litre. According to the RAC the cheapest vehicle cost \$ 0.7865 per kilometre to run. The current low fuel reimbursement rate disadvantages patients that are on

Centrelink benefits and that, due to their illness and/or disability, need to regularly attend Specialist appointments in either Geraldton or Perth.

While PATS subsidises the costs of travel and accommodation, they do not include other basic needs, such as meals. A family, who may have to make many trips due to multiple members having medical conditions, and on Centrelink benefits, may not be able to afford to meet the additional costs.

Case Study 5:

The only choice a family from the Kimberley had was to stay with extended family in the Perth metro area as they were unable to afford the cost of commercial accommodation. As a consequence this created added expenses and impost on the host family.

4. Notable Gaps in PATS's Administration Process:

EDAC is concerned that information on the PATS Scheme is only available in English on the *WACHS* web site. This marginalizes patients from NESB or CaLD background when trying to understand the complexities of the scheme, and what their entitlements are. Information on the PATS Scheme should be made available in languages that represent the diversity of the community in the regional WA. Information on the appeal process is also not offered in any language other than English. Therefore, this lack of accessibility of information for CaLD people with disability and their carers impacts on our clients.

Several of our clients have raised concerns with regard to the administrative approval process. There does not appear to be capacity to expedite the decision-making process for those patients who require urgent specialist attention. As a consequence the patient may miss an appointment in Perth or in a regional centre as it can take up to 10 working days for an application to be approved. EDAC has had to provide advocacy support to a number of clients to ensure approval was expedited and travel bookings promptly arranged. However, such an advocacy service does not operate in all regions of WA. There is also the concern that there is a lack of logistical coordination in PATS scheme. A person who is unfamiliar with their destination or has English as a second language may not be able to find the location of their specialist appointment or accommodation. In such a situation PATS should make an arrangement for a support person to be available.

5. The Need to Consider Exceptional Circumstances for Some Patients

EDAC is concerned that little consideration is given to the exceptional circumstances for certain patients given their personal, social and financial situations.

Case Study 6:

One of our clients advised that she underwent chemotherapy in Perth over a period of 8 weeks following a diagnosis for breast cancer. On the recommendation of her specialist, the client sought PATS assistance to return home to be with her young family for a brief period half way through her treatment. Her request for PATS assistance was declined and she was not provided with any information on her right to appeal the decision.

There does not appear to be any discretionary consideration given to the distance and time taken to travel to attend specialist appointments. At present funding is only available for accommodation if the patient travels for more than 16 hours. However, for a patient travelling from Carnarvon to Geraldton the road trip is between 10 – 12 hours depending on mode of transport. This patient is not eligible to receive payment for accommodation costs, even though he/she may have to stay overnight in order to attend a morning appointment,

6. Conclusion

In conclusion, we note with concern that there is a gap between the real cost of transport and accommodation and the extent that PATS supports patients. The scheme is not flexible enough to provide adequate support to patients living in regional and remote Western Australia. EDAC supports access to a health care system that does not ignore or discriminate against any Western Australian resident because of where they live. PATS should be funded at a level that takes into account the actual costs to families, and have regard to a safety net for frequent users of specialist services. Therefore a structural review of the scheme is necessary to support patients and people with disability.

7. Recommendations

- That the scope of services eligible under the Scheme be expanded to include people accessing mental health and allied health services.
- PATS should arrange for support or assistance to be available for vulnerable people who are travelling without an escort. This may include the organising and paying in advance accommodation and travel expenses.
- PATS should accept the recommendations of medical professionals regarding need for accompanying support persons.
- The application and appeals process is inaccessible to patients and carers from CaLD backgrounds. All necessary documents should be provided in accessible formats and interpreters and translators should be available when needed.