

Health Consumer's Council Submission to PATS Review

The Health Consumers' Council WA (the Council) is an independent community based organisation advocating for the consumer voice in health policy, planning, research and service delivery. The Council advocates on behalf of consumers to government, doctors, other health professionals, hospitals and the wider health system. Recognised as the peak body representing the health consumer, the Council provides a state wide service.

The Patient Assistance Travel Scheme (PATS) provides some cost relief for some health consumers outside the metropolitan area. This subsidy scheme has limited application to the diversity of needs across the state especially regarding access to Dentists, Speech pathologists, Physiotherapists, Podiatrists, Clinical psychologists and the capacity to assist with the seeking of second opinions.

The size and low population density of Western Australia makes a scheme such as PATS essential to be able to provide access to services which are not economically or regularly able to be provided in regional areas. There are areas where the scheme is working well, largely through the personal dedication of individuals to serve their community. The service needs and should be process rather than personality driven, and the needs and servicing of individuals should be independent of the area or type of health need being examined.

The scheme needs to meet a greater degree of the real cost of travel and accommodation for health care, and the assessment and eligibility for patient escorts. The arrangement of PATS needs to take into account the high likelihood that a patient's stay may be extended once they have received a diagnosis and treatment plan whilst in Perth.

Many consumers find themselves in Perth facing a more complex procedure than they anticipated and this, coupled with challenges in navigating the broader health system, leads to anxiety and confusion. As a result, patients are often left stranded when this occurs. Further to this, patients who are required to stay longer than six months in Perth, have their PATS assistance discontinued after six months. This is a significant and ongoing issue for dialysis patients, including currently over twenty Aboriginal consumers.

The Council provides an advocacy service to assist patients to lodge a complaint with health service providers in Western Australia. Our advocates receive approximately five hundred new inquiries each year from consumers across WA. Our advocates provide advice, and support to raise complaint with a service; support to make a complaint to the Health & Disability Services Complaints Office; to Registration Boards and to the State Administrative Tribunal. We also host a monthly legal clinic with Medical Negligence lawyers as many consumers have legal queries about their complaint about which we ourselves cannot provide advice.

In the past 3 months we have experienced an increase in the number of PATS related concerns. The Council has heard a number of claims by consumers that PATS officers have directed treatment and overridden the wishes of specialist doctors.

In a recent example, a consumer who required orthopaedic surgery and had been waiting for almost 2 years, was offered surgery due to a cancellation. He had already attended 2 appointments with his specialist in Perth for which he received PATS payments. After accepting the surgery the PATS officer contacted the orthopaedic specialist and the consumer was then advised the surgery was now cancelled and he could see a visiting orthopaedic specialist in his home town. He was also advised by PATS that he would have to return to his GP to obtain a referral to the visiting specialist and restart the entire process again after already waiting almost 2 years. The consumer's knee had chronically

deteriorated and was greatly affecting his quality of life. The anxiety caused by having to re-start the consultative process for treatment was significant and would no doubt affect his recovery and overall trust of the health system.

This is not the only incident where PATS officers are overriding the advice or wishes of specialists. In another example, PATS arrangement to return a patient to their home were made with a hostel manager without the patient's consent and against the wishes of the treating Specialist. When the patient returned to their remote home, they were immediately admitted to their regional hospital for five days with pneumonia.

The Health Consumers' Council has an Aboriginal Advocacy Program which meets with Aboriginal consumers around the state to listen to Aboriginal people's experiences and views about accessing health services. We facilitate outcomes and solutions using our non-statutory individual advocacy to support Aboriginal consumers experiencing a problem with a health service. We regularly host community forums where consumers identify any issues, concerns or ideas they have about services they use or need. Challenges relating to local access of health services and then co-ordinating PATS and specialist services, accommodation and issues related to family and carer travel have been frequently raised by regional Aboriginal consumers.

Western Australia is a huge state and many regional and remote consumers find the speed and impersonal nature of Perth daunting and frightening. We recognise that poor attendance at appointments for consumers transported via PATS can be frustrating, but the overwhelming nature of cultural and geographical dislocation is often not given adequate consideration. All kinds of things can get in the way of a patient making an appointment - from accommodation shortages to getting lost and afraid to ask for directions. Being away from family, friends and everything familiar can be very daunting, and not just for Aboriginal consumers. Being away from 'Country' is extremely difficult for many Aboriginal people – where *Country* is both home and a source of belonging, identity and spirituality. The health administrators find it difficult to understand or recognise that it can be especially important to be on Country for births and deaths, but also during any kind of sickness.

The WACHS Country Health Connect service for Aboriginal country patients in Perth alleviates these problems for some patients, however the service does not meet the demand, including not operating after-hours and on weekends. The establishment of new Aboriginal Liaison Officers and the state-wide coordinating roles are very positive developments towards better realising and meeting Aboriginal patient's needs and their journey through different services. However, these service need more formal links with the PATS service.

The Council has provided advocacy to country patients who have been flown to Perth in emergency situations. We often get calls to assist stranded Outpatients who, after seeing a doctor or getting test results, have had to stay longer than originally planned, but cannot as their accommodation has been fully booked. While these can sometimes be considered as side issues to treating a patient's physical needs – they can undermine the patient's ability to access health care and can greatly affect their mental wellbeing. We see the need to keep families in better contact with patients when they are away from home, and as a crucial support for the patient. There have also been instances where carers have flown to Perth in emergency situations and then been unable to return home, as carer support may not be guaranteed.

The Council has received many reports of consumers returning home which, after a plane and bus ride, can sometimes be in the middle of the night, and with family and/or carers unaware of, or

logistically unable to be there to meet and comfort them. There can be significant emotional and health concerns for patients left 'stranded' in a remote location without support, and perhaps under the influence of strong pain relief medication.

The transition and information exchange back to regional Western Australia is frequently a difficulty. Remote Patients have sometimes been referred through several health services, which can include their remote clinic, regional Aboriginal Medical Service and/or regional hospital as part of their referral process to Perth. We are also concerned that the metropolitan hospital discharging the patient is not always aware of this.

The Council is concerned that the discharge summary does not always make it to the clinic that will provide the follow up treatment. We provided support to a consumer whose test results, which could have warned her General Practitioner that she was experiencing the early stages of Cancer, were never sent home from the treating metropolitan hospital. She sought our assistance after receiving a terminal diagnosis. We recommend reviewing the process that determines to whom discharge information is sent and how confirmation it has been received is communicated.

Not enough is known about existing Aboriginal or Culturally and Linguistically Diverse interpreting services by mainstream health services, especially in the metropolitan region. There is not enough awareness that Aboriginal people may need an Interpreter, and may speak three or several languages and are uncomfortable and lack confidence with English.

We speak to a lot of patients and families who have no idea what is happening to them in hospital. This undermines their ability to provide informed consent to medical treatment, their ability to comply with instructions while in hospital and their ability to follow medication regimes safely when they go home. We also still find some patients presenting without any paperwork or knowledge of when and where their appointments are and we still come across stranded patients without accommodation and have facilitated outcomes for a number of consumers.

While the Council is happy to provide a service in exceptional circumstances, these problems are common and systemic and need to be resolved through greater co-ordination between the regional and metropolitan health (and support including accommodation) service providers. PATS is the link between these services and needs to have a better defined and more accountable role in this process.

"Our Uncle was sent to Perth as an Outpatient to see a Specialist. The Pats clerk only booked for the original appointment but the Specialist said he really needed to stay longer for more tests and he ended up on the streets, and in the parks – and no-one was there to help him - no-one even asked."

The Council believes Aboriginal patient's needs would be better identified if Aboriginal Medical Services (AMS) administer PATS assistance for their clients, including assessing whether a person needs an Interpreter or an escort. In areas that don't have an AMS we recommend the most local service to where the patient will return taking a bigger role in monitoring the patient's progress in Perth. There is clear empirical evidence to show that the prognosis and re-presentation of Aboriginal consumers from areas where there is not an effective AMS. This should provide the impetus for further expansion of the role in meeting culturally secure, safe and effective services.

The Council believes that improvements need to be made in better identification of the need for a patient escort, carer and/or Interpreter to be arranged for appointments in Perth. The formalisation

of these arrangements and strengthening of these partnerships can only benefit the emotional and medical prognosis for the patient. These people also provide an essential role in informing the patient, who may be so unwell as to make self-management a significant challenge, of who to contact if plans change and they are required to stay longer in Perth.

We believe that many of the above issues need to be thoroughly identified in the PATS referral process, before a patient has left home to ensure patient safety.

Finally, there are ongoing issues regarding the boundaries to which PATS applies. As the metropolitan area grows, outer areas of Perth will be likely withdrawn from PATS benefits. Medicare Local research indicates that many consumers in outer suburbs in the eastern and southern corridors have significantly higher co-morbidities and wait much longer before seeking help. If cost is, as identified, a major inhibitor to those seeking assistance, then the removal of PATS is counter-productive and will lead to greater system costs in the future.

The Council believes that the PATS review should consider the implications for these outer metropolitan consumers and make recommendations that do not disenfranchise or penalise these consumers.

The Council would be happy to meet with the committee to clarify or add to the submission which we have provided.

Yours sincerely,

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Health Consumers' Council of Western Australia Inc.

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