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23 May, 2007

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

Dear Sir/Madam,

**Re: Inquiry into the operation and effectiveness of Patient Assisted Travel Schemes (PATS)**

We appreciate the opportunity to tender this submission to the Senate Inquiry into the *operation and effectiveness of Patient Assisted Travel Schemes (PATS)*. This submission has been compiled by the Social Work Department, Princess Margaret Hospital for Children (PMH). PMH is the tertiary centre in Western Australia for Child and Adolescent Health Services. As you would appreciate, Western Australia is geographically vast, and PATS services are crucial to our clientele.

In the past there was a nominated PATS officer located within the hospital to manage PATS enquiries and bookings. Over time by default this role has now being picked up within the Social Work Department and our staff spend an excessive amount of time advocating, negotiating, making bookings and resourcing families in regards to PATS.

The PMH Social Work Department is often involved in the role of advocate for families in their interaction with their local PATS office. We are aware through this experience that there are significant inconsistencies across the state between the many PATS jurisdictions, as well as nationally. This results in an inequity across families who access this resource.

One of the major contributing factors to this inconsistency seems to be related to the ambiguity present in the guidelines and the associated opportunity for diverse interpretations between the numerous PATS offices.

In this advocacy role, we have too frequently encountered narrow interpretations and rigid applications of these guidelines. In liaison with the relevant PATS officer, we have at times faced a challenge in negotiating reasonable flexibility or consideration of individual circumstances. This is further compounded by the non-existence of a central body that provides arbitration when there are differences of opinions between PATS clerks and consumers/health professionals.

Our clinical experience informs us that PATS is a crucial resource. Without this financial support, many rural families would experience great difficulty in accessing adequate health care for their children, which would negatively impact on health outcomes. We view this opportunity to contribute to this Senate Inquiry as valuable in providing some input into the future development of this program.

Yours Faithfully

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**Social Work Department  
Princess Margaret Hospital, Perth Western Australia**

**Submission to Senate Community Affairs Committee  
INQUIRY INTO THE OPERATION AND EFFECTIVENESS OF PATIENT  
ASSISTED TRAVEL SCHEMES (PATS)**

- a) **the need for greater national consistency and uniformity of Patient Assisted Travel Schemes across jurisdictions, especially the procedures used to determine eligibility for travel schemes covering patients, their carers, escorts and families; the level and forms of assistance provided; and reciprocal arrangements for inter-state patients and their carers;**

As the Western Australian tertiary centre for Child and Adolescent Health Services, Princess Margaret Hospital receives patients from a large number of rural areas in Western Australia, as well as at times from other Australia states. Our primary experience related to consistency across jurisdictions is within the State. We encounter significant inconsistency across the many offices in Western Australia that deliver PATS support. This is highlighted by:

- A lack of standardization of the Specialist referral and claim application forms.
- Significant differences across the jurisdictions in the interpretation of the existing PATS guidelines.
- A lack of a central body to provide arbitration when there is a dispute in the application of the PATS guidelines. Currently, such disputes are responded to by the local PATS officer, or their direct supervisor. Our experience is that such resolution is not always processed in a transparent or judicious manner. We have on occasion not received a response to our written correspondence regarding such matters.

Staff members of this department spend a great deal of time assisting families with their PATS claims, and must often play a strong advocate in such negotiations. Standardisation across the jurisdictions regarding procedures and guideline application would improve this service delivery. It would also reduce the inequity in the provision of assistance provided to rural families across the State and nation, currently influenced by local idiosyncrasies.

There are inconsistencies across PATS jurisdictions regarding young mothers (16 years of age and under) who accompany their sick child to Princess Margaret Hospital. Given the young age of these mothers, it is essential that they are escorted by an adult to assist them in making decisions on treatment/consent, navigating the hospital system and dealing with the stress of their child's medical situation. For risk management it is critical in some circumstances to have an adult present. Some PATS jurisdictions will fund a 'second' escort in these circumstances, and some refuse to assist.

There are also inconsistencies across jurisdictions related to children who are transferred to Perth with life-threatening conditions, and are not expected to survive. Some jurisdictions will fund two parents to attend, and some jurisdictions will only fund one escort. Given the trauma associated with the death of a child it is crucial for both parents to have an opportunity to be present at the hospital. It is during this time that doctors and health care professionals begin to work with families in prevention and minimization of long term negative emotional, psychological and other health sequelae. If early intervention with parents does not occur then it is anticipated they may present to health services later with mental health and other adjustment issues.

There are also inconsistencies across jurisdictions, and to families in the same jurisdiction, in regards to the amount of help and information extended by the PATS clerk for

- travel bookings
- accommodation bookings prior to travel,
- assistance from and to the airport/bus/train station

Some families, especially remote indigenous families with few resources, arrive at our Emergency Department unannounced, usually after hours, with no accommodation booked. The child is usually due for admission in the next day or so. If it is known they are traveling as the airfare is booked then full consideration and an appropriate response to the social circumstances is requested.

**b) The need for national minimum standards to improve flexibility for rural patient access to specialist health services throughout Australia;**

The inconsistency of interpretation of, and adherence to the current PATS guidelines across jurisdictions can result in a lack of flexibility in some rural areas. This then impacts on families' access to relevant health care services, producing inequality of access to health care and negatively impacting on health outcomes. Some examples of this need for greater flexibility include:

- A significant percentage of Aboriginal families attending this hospital are from the remote North West and Sandy desert. These families are located closer to Darwin than Perth, however they are sent to Perth for specialist medical care. In many occasions, it would be more convenient for the patient to be sent to Darwin, when medically appropriate. They often have family supports in Darwin, and feel more comfortable as this area is more familiar to them. A standardised scheme may allow for this consideration of the individual family's best interest.
- The existing limitation of up-to six-months of ongoing treatment to access the PATS system, with the expectation that families must relocate after this period of time. This significant length of stay in Perth for treatment may be medically necessary for oncology patients, and children needing organ or bone marrow transplants. Families endure significant hardship during these extended stays for treatment, with parental responsibility split between home and Perth (often one parent at home, one parent in Perth). A cut-off from PATS eligibility after this six-month period and expectation a family will relocate is unreasonable and extremely harsh when these families are already enduring great hardship.
- In cases of some paediatric ENT surgery, children are required to remain in Perth for two weeks due to the risk of post-surgery bleeding. However, they are not medically required to remain an inpatient for this time. Current PATS accommodation assistance provides a minimal contribution to the real cost of temporary accommodation in Perth. Families on low income find this particularly difficult, and at times decline surgery all together, or risk an early return to home against medical advice. Due to the vastness of the Western Australian countryside, rural families in Western Australia are more significantly disadvantaged.

**c) the extent to which local and cross-border issues are compromising the effectiveness of existing Patient Assisted Travel Schemes in Australia, in terms of patient and health system outcomes;**

As previously stated, families from the North West and remote Western Australia, are often directed to Perth for specialist medical care. Increased national consistency

would make it possible for health care professionals to refer families to Perth, Adelaide or Darwin, dependent on the best interests of the family.

Oncology and dialysis patients who reside 70 – 100 km from Perth are eligible for travel assistance from PATS. There is no PATS travel support for other families in this same travel distance, who are attending this hospital three to four times a week for medical attention to other conditions. This local issue is producing an inequality in health care access.

In the case of one family, two PATS jurisdictions provide input for the two children in the family – who live at the same residence. The parents have tried to just liaise with one PATS office, but have met resistance. A standardised service would ensure families are not inconvenienced with cross-jurisdiction disputes about responsibility.

**d) the current level of utilisation of schemes and identification of mechanisms to ensure that schemes are effectively marketed to all eligible patients and monitored to inform continuous improvement;**

We are aware that many families experience difficulty navigating the PATS system, interacting with PATS clerks, getting the documentation completed and lodged. This adherence to a rigid system comes at a time when many parents are stressed and anxious about their child's ill health, and they don't have the emotional capacity to pursue time-consuming PATS application requirements. At times, we are able to play an advocacy role and assist parents with this process. But we are aware many parents choose not to utilise the PATS system as they don't have the energy.

Many families do not apply for PATS because of the time that it takes too receive reimbursement of expenditure to travel and the associated difficulty they experience with completing the paperwork. It can take up to 8 weeks for reimbursement of funds. It is uncertain if this delay in payment is related to local resource issues.

It is our experience that many rural families are not made aware of PATS prior to their travel to Perth to receive treatment. They often attend the hospital Social Work Department requesting financial assistance, and this is the first time they are informed of PATS.

- Not all GP's will advise patients of PATS and assist them to lodge an application prior to travel to Perth.
- It would seem there is a lack of information and advertising about PATS in local surgery's, child health nurses, community health centres and hospitals.
- It is frequently left to hospital Social Workers and the Welfare Assistant to organize PATS retrospectively and explain this system.
- This hospital has been requesting PATS pamphlets for over 6 months without success.

We would suggest that we only see a percentage of families who are not aware of their eligibility for PATS assistance.

**e) Variations in patient outcomes between metropolitan and rural, regional and remote patients and the extent to which improved travel and accommodation support would reduce these inequalities;**

In the current Western Australian economy, there has been a significant rise in the cost of petrol and accommodation. This has severely disadvantaged country families on low income.

- The rate of accommodation of \$35 per night per person and a standard fuel subsidy of 13 cents per kilometre has not been increased within the system,

for a considerable amount of time. Hospitals and other agencies within the Perth CDB are absorbing the increases not only for low income families receiving income support but also the working poor, creating hardship with many families unable to find the money to attend an appointment

Due to the increasing cost of commercial accommodation within central Perth this limits the options available for families. Thus they may have to resort to lower standard accommodation without ability for self catering. An improvement in the level of financial support available from PATS is more likely to ensure families regular attendance at appointments, and this would improve health outcomes.

Rural support services (psychology, counselling, self-esteem programmes, allied health etc) are limited. They also do not have the expertise to work with the specialised needs of some paediatric medical conditions. As such, rural children do not receive the same emotional and therapeutic services that are available to children in the Perth metropolitan area, and therefore are at a greater risk of experiencing problems with physical and emotional adjustment.

- It would be beneficial if there was greater flexibility within the PATS criteria, to be accessible for children requiring specialised therapeutic interventions.
- It would be beneficial if PATS could be accessed for children with specific medical conditions to attend activities/groups/camps that are run to promote adjustment and provide peer support. Eg. Diabetes camps, transition to adult care seminars.

When a child is diagnosed with chronic illnesses as (e.g. Diabetes, Cystic fibrosis, renal failure and other life threatening diseases) it is crucial that both parents are able to attend Perth to meet with the medical care team to discuss treatment details and be educated with medical care. Currently, only one escort is financially subsidized to attend this discussion and education. This marginalises some families on low incomes, particularly in cases where parents are separated or divorced. This can also mean that both parents are not adequately educated on care needs, which can be detrimental to the patient.

**f) The benefit to patients in having access to a specialist who has the support of a multidisciplinary team and the option to seek a second opinion;**

It has been noted on several occasions that if there is only one specialist in a country area, families are denied financial assistance to seek a second opinion in Perth. This means they have unequal access to medical knowledge when compared to families that reside within the metropolitan area.

As previously stated, rural support services are limited and do not always have the relevant paediatric expertise. Rural doctors do not have the same access to multidisciplinary supports, which means rural families do not receive the same level of allied health supports available to city families.

**g) The relationship between initiatives in e Health and Patient Assisted Travel Schemes;**

It would be beneficial if PATS assisted with health initiatives such as Tele Conferencing and Internet information, when there are no other options than presenting to a Perth hospital.

Parents often experience difficulty contacting PATS offices during business hours. It would be convenient if they could access and lodge applications on-line.

**h) The feasibility and desirability of extending patient assisted travel schemes to all treatments listed on the Medicare Benefits Schedule. Enhanced Primary Care items such as allied health and dental treatment and fitting of artificial limbs;**

It would be extremely beneficial to extend PATS eligibility to other services, including all allied health, audiologists, dental surgeons etc which could be inclusive when families are seeking appointments with specialists. Families would generally like to have access to a professional that is coherent and expert in their child's specific condition and intervention needs. This is not always apparent when being treated by generic country professionals.

**i) The role of charity and non-profit organisations in the provision of travel and accommodation assistance to patients.**

Often an over-reliance on charities is necessary as a stop-gap when PATS will not assist. For example, a child with heart complications was recently transferred by RFDS to Perth from Kalgoorlie. The child died a few days later. PATS refused to pay for the parents to fly back with the child's body, and would only provide payment for bus travel. This was totally inappropriate given their state of grief. Significant effort was then required by staff to arrange a charity to cover the cost of air travel. This was a unique, acute event requiring flexibility and compassion from PMH and PATS.

Whilst it is useful to have charities that can step in when the PATS criteria is limited and inflexible, this is not always possible. We also do not feel this is a responsibility that charities should be required to cover.