



# Submission to the Parliamentary Inquiry into the Patient Assisted Travel Scheme (PATs) in Western Australia

Carers WA

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## Introduction

Carers WA is the peak body representing people who provide ongoing care to a family member or friend with ongoing care needs due to disability or chronic illness, including age-related disability and mental illness. The Australian Bureau of Statistics<sup>1</sup> has estimated that there are more than 250,000 people in a caring role in Western Australia although academic researchers have argued that this is an undercount and there are more likely to be upwards of 307,000 people in Western Australia in a caring role.<sup>2</sup>

Current policy and practice with regard to the Patient Assisted Travel Scheme (PATs) is in contradiction to the Carers Recognition Act (2004), which requires the Department of Health to comply with the Carers Charter.<sup>3</sup>

### WA Carers Charter

1. Carers must be treated with respect and dignity.
2. The role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers.
3. The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.

In order to comply, it is necessary that the Department of Health has in place measures to identify, recognise and include carers. Expanding the eligibility of carers to access further assistance would significantly benefit this vulnerable population and would bring the Department of Health's operations in line within its requirements under current legislation.

### The Level of Funding Applied to the Transport and Accommodation Subsidies

The value of subsidies under the current system, such as fuel vouchers and accommodation, is less than that of the actual costs of travel. Additional and hidden costs, such as parking, are currently not covered under the Scheme, leaving many families under significant financial stress whilst travelling to support their loved one.

Families and friends are often called upon to help meet the gap that exists between the current PATs subsidy and the actual accommodation and transport costs incurred by the individual. Given that treatment can take place over a number of

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<sup>1</sup> ABS. 2012. *Survey of Disability, Ageing and Carers*. Canberra.

<sup>2</sup> Edwards, B., Gray, M.C., Baxter, J. and Hunter, B.H. 2009. *The Tyranny of Distance? Carers in Regional and Remote Areas of Australia*. Commonwealth of Australia and Carers Australia, Canberra.

<sup>3</sup> Government of Western Australia. 2004. *Carers Recognition Act*.  
[http://www.austlii.edu.au/au/legis/wa/consol\\_act/cra2004197/](http://www.austlii.edu.au/au/legis/wa/consol_act/cra2004197/)

months or years, this places significant financial stress on families in remote and rural areas of WA. Carers are significantly over represented amongst low income households and are therefore in a vulnerable position.

### **Eligibility for PATS Funding**

The needs of family members assisting the patient need to be better recognised

The needs of the carer are not recognised as legitimate reasons why, for example, overnight stays may be required for journeys that carers take when supporting the person they care for. Similarly the needs of carers are not recognised when determining the required mode of transport to and from specialist services. As mentioned above, this is in contradiction to the Carers Recognition Act 2004.

Certain medical related services are not considered eligible

People in need of kidney transplants, for example, are not supported to travel to Perth to attend compulsory information sessions. Without attendance, the person is unable to gain a transplant. We argue that both the individual and their family member if required, should be able to access PATS to attend compulsory information sessions.

Referrals to allied health professionals such as speech pathology, physiotherapy, podiatry, audiology, dentistry and clinical psychology are not currently accepted under the Scheme. Without these services the quality of life of families, and their ability to obtain equitable socioeconomic outcomes as compared to their counterparts residing closer to specialist services, is limited due to reduced health outcomes.

### **The Administration Process**

The eight week timeframe that currently exists to lodge PATS applications is impractical. The rotating rosters of many referring doctors who practice in regional and remote Western Australia is commonly ten weeks. As a result, it is often impossible for many families to obtain a signature from their referring doctor within the required time frame. This is a particular issue for retrospective applications and those relating to emergency transfers. In addition, carers are time poor due to an increase in caring duties and under considerable stress when their loved one is required to utilise specialist services. As a result the ability of carers to obtain and manage documentation during this period is limited.

Processing times of claims are also a significant issue for carers with some carers reporting an eight week wait period for reimbursement. This is a significant length of time for those carers who are under financial stress. Extended wait and hold times when making phone contact with PATS Offices is also a common issue and carers have reported that they have been unable to wait for their call to be answered.

Feedback from carers reveals inconsistencies in relation to the degree of support a family is considered eligible to receive depending on the PATS Officer involved.

### **Whether there is Consideration of Exceptional Circumstances**

Currently, a road trip must be greater than 16 hours before families are eligible to access flights through the Scheme. This is particularly difficult for families and individuals experiencing ill health. The extended time away from family also means that alternative care requirements must be found for children or other people requiring care back at home which can be even more difficult when the family car is no longer available<sup>4</sup>.

Access to non-medical (though health related) specialist appointments, such as hospital engineering, is currently only permitted where such appointments coincide with a medical appointment. This is a significant issue for many carers, particularly those caring for a loved one with a physical disability. Obtaining appointments with specialists is difficult under normal circumstances. A requirement to bundle such appointments together is therefore impractical. Additional assistance to coordinate appointments is required as well as flexibility when this cannot be achieved and separate trips are required.

### **Any Incidental Matter**

Currently accommodation services available to those travelling from regional and remote areas are often inadequate. Carers note a shortage of supply of beds. Similarly those beds that are allocated are at times inappropriate, for example lacking disability access. Carers note difficulties in gaining accommodation to stay at the same facility as the person they care for or near their treatment centre. It is important for families and friends who are supporting individuals accessing specialised treatment or services to be close by their loved one. This is to enable the carer to undertake their caring role by, for example, monitoring the individual's health and wellbeing, and also to allow them to provide much needed emotional support.

There are currently inconsistencies that relate to the processes and procedures of the current PATS Policy when compared to other health policies such as Consent to Treatment, Enduring Power of Guardianship, Advance Health Directives, National Safety and Quality Health Service Standards and the Carers Recognition Act. In addition, the current PATS Policy is inconsistent with current health related reforms such as those taking place within the mental health sector. These reforms, for example, dictate increased access to quality services and supports for all Australians, as well as the assurance of patient physical wellbeing. Without providing families with access to subsidies for travel to see required health and mental health

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<sup>4</sup> 2012, Carers WA, *Carers of Family and Friends in Country WA*, pge 3. [www.carerswa.asn.au](http://www.carerswa.asn.au)

specialists, the delivery of these recommendations may be limited, impeding the intended outcomes of both state and federal governments.

### **Our evidence base**

Carers WA have compiled the following report based on issues lodged with us by family members and friends in a caring role for a person with disability, by health related staff and by advocates within the health sector. The report has been compiled in consultation with the Aboriginal Health Council of Western Australia and we thank them and the carers, advocates and staff working within the health sector who have generously shared their stories.

The report describes examples of problems and, where possible provides recommendations that could improve the operation and equity of the current system.

Carers WA 2014 Report into the Patient Assisted Travel Scheme (PATS) in WA Current Issues and Recommendations for Change		
ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<p>Accommodation Subsidy</p> <ul style="list-style-type: none"> <li>Requirement stay overnight</li> </ul>	<p>Carer circumstances such as, for example, a medical condition and/or aspects of the caring role may limit the ability of the carer and patient to safely make a return journey in one day.</p> <p>Example 1. A patient with Multiple Sclerosis was travelling to Perth from Bakers Hill for specialist appointments and required assistance from their carer. The carer applied for the accommodation subsidy as she has a fused spine, which results in her being unable to sit or drive for extended periods of time. The carer was therefore unable to do a return trip in one day.</p> <p>The accommodation subsidy was refused and as a result the carer sought funding through the MS Society which paid for their accommodation costs.</p> <p>Many carers do not have the networks, or the resources to obtain funding through differing means.</p> <p>Example 2. Patient had travelled from Kalgoorlie to Perth. PATS paid for the patient. The carer however was required to pay for their own accommodation which was in the same location as the patient. When the carer contacted the PATS Office to discuss this, the person they spoke to was unable to clarify the reasoning behind this ruling.</p>	<p>Carers circumstances including medical conditions and/or aspects of the caring role be recognised as legitimate reasons for requiring overnight stays.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Eligibility to access accommodation subsidy for patients living 70-100 km from Perth GPO</li> </ul>	<p>Example.</p> <p>A patient receiving chemotherapy, and living in Toodyay, 87km from CBD, required the assistance of a carer when undergoing treatment, as they were unable to drive themselves to and from treatment and was too unwell post treatment to travel. As a result they required overnight accommodation. The pair were unable to access the accommodation subsidy and as a result obtained funding from a private organisation to assist with accommodation costs.</p>	<p>Review of the eligibility criteria to access the accommodation subsidy, to allow for impacts of treatments that results in the patient and carers need for overnight stays.</p>
<p>Financial Remuneration</p> <ul style="list-style-type: none"> <li>Processing Time</li> <li>Claimable Items</li> </ul>	<p>Carers commonly endure significant financial hardship. For this reason any out of pocket expenses and delays in receiving funds are likely to add considerable strain to their already existing financial stress.</p> <p>Example.</p> <p>A lady travelled from Albany to Sir Charles Gairdner Hospital for Breast Screening. Receipts were handed to the PATS Officer in Albany 3 working days after the appointment. A refund was received 8 weeks later.</p> <p>This is not an isolated incident. Carers inform us that reimbursement times are often 4-6 weeks.</p> <p>In many cases carers are not provided with receipts for genuine costs. There are many instances in which for example retail staff do not routinely offer receipts, like when purchasing fuel. If carers do not know that an item is claimable prior to travel, and as a result do not ask for a receipt, they are not</p>	<p>Guarantee that claims will be processed within two weeks.</p> <p>Increase staff available to process claims to ensure that refunds are processed within a two week timeframe.</p> <p>Amend the 'My Travelling Booklet' to include pictorial displays of what receipts need to be kept in order to claim, or develop a similar complementary pamphlet that is</p>

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<ul style="list-style-type: none"> <li>Claimable items cont.</li> </ul>	<p>able to be reimbursed for a genuine cost that they have incurred. Many families are unaware of what receipts they need to retain and why. They are therefore unable to gain reimbursement for numerous items that they would otherwise be able to claim.</p>	<p>similarly available in all Aboriginal languages.</p> <p>Aboriginal Liaison Officers be placed in each PATS Office. The provision of Aboriginal Liaison Officer in each PATS Office may be beneficial as they could provide information in both oral and written form. Utilising oral information provision is in keeping with traditional practice. Other tasks could include help filling in forms, as well as be a safe person to talk to and ask questions etc. These proposed Officers could visit with communities and Aboriginal Medical Services to provide information as well as pamphlets/booklets to community on a periodic basis to ensure that families are informed of requirements prior to travel as may be needed to prepare for emergency situations. This may also act to promote the uptake of the Scheme by Aboriginal communities which could result in increased health outcomes.</p>
<ul style="list-style-type: none"> <li>Cab Charges</li> </ul>	<p>Inconsistencies exist in relation to who is eligible for a cab charge. Aboriginal Liaison Officers report irregularities with the provision of</p>	<p>PATS Policy be reviewed to ensure that cab charge are eligible for genuine travel costs</p>

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<ul style="list-style-type: none"> <li>Value of fuel vouchers</li> <li>Parking Costs</li> </ul>	<p>cab charges eg some PATS Officers may accept cab charge from accommodation to the Drs appointment, whereas other do not.</p> <p>There are also instances where carers may need to travel via transport separately from the patient. We have been informed that families are being provided with four cab charges, which is not enough for families who have to make numerous trips to and from appointments.</p> <p>For example. A growing child requires the re-engineering of a wheelchair. The child may be transported by ambulance to the appropriate facility. The carer, however, is required to make their own way to the facility.</p> <p>The value of fuel vouchers does not reflect the true costs associated with long distance travel.</p> <p>The costs of parking at hospitals can be significant for carers who are staying lengthy periods at hospitals and treatment centres, particularly where treatment is for a number of days.</p>	<p>to and from accommodation and specialist services</p> <p>Review PATS Policy to ensure that carers who are required to travel separately from the patient are eligible to receive cab charges.</p> <p>Review of the value of fuel vouchers being offered through PATS to ensure that it is reflective of the true costs of fuel.</p> <p>Ensure that increases in the value of fuel vouchers is reviewed every six months and are reflective of changes in the fuel market rather than for example the Consumer Price Index.</p> <p>Review the PATS Policy to ensure that parking costs associated with travelling to specialist services are eligible for reimbursement under</p>

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<ul style="list-style-type: none"> <li>• Parking Costs cont.</li> <li>• Carers not being aware of and having difficulty covering hidden costs associated with accommodation</li> <li>• Lack of disposable income</li> </ul>	<p>Carers are commonly not notified of hidden costs related to their visit prior to their attendance at accommodation centres. As a result families/kin/carers fund hidden costs which add to the financial stress already experienced by many due to the increased costs of living that result from being away from home. Related hidden costs include carer accommodation, parking costs and bond/key deposits, toiletries and food.</p> <p>The provision of staff such as Aboriginal Liaison Officers within PATS Officers may be beneficial. Duties could include the provision of information including what receipts to obtain and keep, help fill in forms, and be a safe person to talk to and ask questions etc. The development of these roles may also improve the communities understanding of the program and may act to promote uptake of the program by Aboriginal communities which could increasing health outcomes.</p> <p>The cost of Bond Keys at accommodation facilities is approximately \$40 per room. For many families this is a significant amount of money to find at short notice, especially when other travel expenses are being incurred.</p> <p>Many families choose not to access treatment due to the additional costs associated with travel, like the gap in accommodation and food costs.</p>	<p>the Scheme.</p> <p>PATS Booklet to be reviewed to enable the inclusion of hidden costs associated with travel.</p> <p>Eligibility of accommodation costs to be reviewed to include carer accommodation costs.</p> <p>Aboriginal Liaison Officers be placed in each PATS Office</p> <p>Staff and hospitals and Aboriginal Medical Services within local communities provide PATS Booklet/Pamphlets and training to communities.</p> <p>Review the costed amount and/or need for bond keys/deposits required when accessing accommodation facilities.</p> <p>The government to explore the extent to which low or fixed income is a barrier to accessing health</p>

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<ul style="list-style-type: none"> <li>Lack of disposable income cont.</li> </ul>	<p>This is due to many families lacking the disposable income to cover both the costs that are reimbursed by the program at the time of travel, as well as the additional costs involved with travel. Families for example are required to pay for accommodation costs whilst continuing to pay rent and other costs at home.</p>	<p>services.</p>
<p>Retrospective Applications</p> <ul style="list-style-type: none"> <li>Time frame - 8 weeks to submit a retrospective application</li> <li>Difficulties obtaining signature from referring medical professional retrospectively</li> </ul>	<p>The eight week timeframe in which to lodge claims is often impractical.</p> <p>Research and anecdotal evidence shows that carers are often extremely time poor and juggle multiple tasks including their caring roles. Filling in paperwork, including filling in forms, particularly at a time when their loved one may be considerably unwell, and requiring higher care needs, is an additional task that carers often state is left for a later date or forgotten due to competing tasks. Concentration levels are also impeded, due to the ongoing stress that arises due to their caring role, which also contributes to a reduction in likelihood that such tasks will be completed during times of stress.</p> <p>Many have noted difficulties obtaining signatures retrospectively from referring Drs or medical professionals. As mentioned above, this was a significant issue for those living in rural and remote Western Australia where Drs and medical professionals are often provided via a rotating roster which can be</p>	<p>Carers WA request a review of this policy and request that the timeframe be lengthened to at least 6 months or dropped.</p> <p>Changes to guidelines to allow senior nursing or allied health staff, Aboriginal Liaison Officers, and Aboriginal Health Workers or other treating medical persons to sign the PATS forms retrospectively.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<p>Difficulties obtaining signature from referring medical professional retrospectively cont.</p> <ul style="list-style-type: none"> <li>Original paperwork required to accompany PATS form when submitting retrospective applications</li> <li>Lost referrals/electronic referrals</li> </ul>	<p>as long as ten weeks (NOTE: this is longer than the eight week period allowed for retrospective applications). In cases where these professionals are the referring health professional, it is highly problematic to gain a signature from the referee within the eight week timeframe. This is a considerable inequity for those living in rural and remote Western Australia.</p> <p>We have been informed by carers that a paper copy of the referral is required in order to complete retrospective applications. This is problematic in retrospective cases, as the provision of original paperwork is not possible as the original referral has already been given to the treating practitioner.</p> <p>This is further complicated as many GP Practices are forwarding referrals electronically, or on behalf of the patient to the treating consultant, to reduce the incidence of lost specialist referrals.</p>	<p>PATS Officers to assist the claimant to obtain copies of original paperwork.</p> <p>Electronic referrals sent directly from the GP/medical specialist to the PATS Office.</p> <p>Review of the policy requiring the provision of a referral in retrospective cases.</p> <p>Utilise Medicare receipts or other forms of proof to verify appointment attendance to enable the PATS claim to be processed.</p>
<p>Administrative difficulties (PATS Office)</p> <ul style="list-style-type: none"> <li>Extended waiting/holding times on phone calls</li> </ul>	<p>Callers report lengthy waiting periods when calling PATS Offices with some reporting wait times of up to 45 minutes. We have been told that excessive waiting periods result in callers choosing to end the call rather than wait in order to avoid high call charges.</p> <p>People phoning PATS Offices from</p>	<p>Increase staff levels in PATS Offices to reduce wait times.</p> <p>A call back service be provided by all PATS Offices.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Extended waiting/holding times on phone calls cont.</li> </ul>	remote and regional Western Australia may often be calling from a mobile phone. In many cases carers living in regional and remote Western Australia may not have a landline and rather utilise a mobile phone. Other carers may be away from home and unable to use a landline and therefore may similarly rely on the use of a mobile phone.	
<ul style="list-style-type: none"> <li>Issues identifying type of PATS application form to use</li> </ul>	Example. Patient given incorrect form from PATS Officer resulting in delay in receiving payment. A lady travelling from Albany to Sir Charles Gardner Hospital for an appointment at breast clinic attended her local PATS Office to obtain forms. She was provided with the wrong form. As a result she was required to resubmit forms to her treating Dr and then reapply for a claim through PATS. As a result it took the patient 8 weeks to complete her application, and a total of 14 weeks to receive payment.	Additional training of PATS staff in relation to the use of each type of PATS form.
<p>Training of GPs in the services eligible under PATS</p> <ul style="list-style-type: none"> <li>Increased awareness of eligibility criteria of the program</li> </ul>	Example. An 8 year old girl living in the Albany region required oral surgery for an impacted tooth. The family believed that any health related treatment which required substantial travel would be covered under PATS. Their local GP signed the appropriate PATS form. The family were later notified by PATS staff that dentistry was not covered under the Scheme.	<p>Improve awareness of the eligibility requirements of the program.</p> <p>Ensure that GPs are trained in relation to what items are covered under the Scheme.</p>
<ul style="list-style-type: none"> <li>PATS Officers not being aware of cultural protocols</li> </ul>	Many Aboriginal people from regional and remote Western Australia are hesitant to attend PATS Offices due to a lack of confidence that they will receive a	<p>All PATS Officers be supported to attend Cultural Safety Training.</p> <p>Aboriginal Liaison</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>PATS Officers not being aware of cultural protocols cont.</li> </ul>	culturally safe response.	Officers be placed in each PATS.
<p>Administrative difficulties; unexpected travel/ primary transfer (clinical/medical)</p> <ul style="list-style-type: none"> <li>Treating Dr not available to sign PATS forms</li> <li>Inability for forms to be signed retrospectively due to Dr rotations</li> </ul>	<p>Many have noted difficulties obtaining signatures retrospectively from referring Drs or medical professionals. As mentioned above, this was a significant issue for those living in rural and remote Western Australia where Drs and medical professionals are often provided via a rotating roster which can be as long as ten weeks (NOTE: this is longer than the eight week period allowed for retrospective applications). In cases where these professionals are the referring health professional, it is highly problematic to gain a signature from the referee within the eight week timeframe. This is a considerable inequity for those living in rural and remote Western Australia.</p> <p>Example. A patient was transferred from a remote area via Kalgoorlie to Perth with the Royal Flying Doctors Service (RFDS) in an emergency. The family carer was unable to travel with the patient on the plane (which is normal practice). The family was unable to have the referring Dr sign the PATS form as the Dr was addressing the patient's acute medical condition. The PATS Office was closed and as a result the carer made their own way to Perth at their own expense. The carer was unable to</p>	<p>Changes to guidelines to allow senior nursing or allied health staff, Aboriginal Liaison Officers, and Aboriginal Health Workers or other treating medical persons to sign the PATS forms retrospectively.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Inability for forms to be signed retrospectively due to Dr rotations cont.</li> </ul>	<p>have the PATS form retrospectively signed as the Dr was a locum and as such was unable to claim for reimbursement of costs.</p> <p>Carers WA would like clarification as to who can sign the PATS form for a retrospective application in the event that for example the referring Dr is a locum, and no longer available.</p>	
<p>Administrative difficulties;</p> <ul style="list-style-type: none"> <li>Air travel bookings</li> <li>Difficulty obtaining travel via air</li> </ul>	<p>The requirement of the PATS policy of at least 24 hour notice for flight cancellations is often not practical as flight bookings are often made on the same day as travel. In addition, air travel booked by the PATS Officer is often booked at times that are not suitable for both the patient and the carer. At times discharge plans change within 24 hours of the flight time, and as a result carers are unable to meet this requirement.</p> <p>Staff from Albany PATS Office pressuring applicants to utilise bus or private car, rather than air travel. Applicants report that they have to 'jump through hoops' to access air travel. This can be particularly problematic if the carer or patient is unwell or has a physical disability or is frail aged.</p> <p>For example, the requirement to travel the 6 hour bus trip from Albany to East Perth can cause continence issues for some as disability access toilets are only available at the place of Departure and Arrival.</p>	<p>Review of the 24 hour cancellation requirement of the PATS policy.</p> <p>Review of the 16 hour requirement for road travel to be eligible to access travel by air.</p> <p>Staff training in the provision of air travel in exceptional circumstances.</p>

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<ul style="list-style-type: none"> <li>Difficulty obtaining travel by air cont.</li> </ul>	<p>A requirement of 16 hours travelling time by road is excessive for many healthy people, and can be a significant risk to those that are forced to travel for health reasons, who may be tired, stressed, unwell and/or are frail.</p>	<p>Undertake a consultation process to review the 16 hour requirement in order to establish what is a safe distance that carers, and the people they care for, can travel by road.</p>
<p>Administrative difficulties;</p> <ul style="list-style-type: none"> <li>Language difficulties</li> </ul>	<p>Many Aboriginal families from regional and remote Western Australia choose not to come to Perth for treatment due to a negative perception associated with doing so. We have been notified that because of the history of people travelling to Perth when extremely unwell, and not returning, it is viewed by many in remote communities to be 'the place you go to die'. Many people as a result choose to stay at home rather than risk dying away from home. By providing information in local languages people's understanding of the program may improve. By similarly including in relevant PATS materials/resources, information about activities required once people return home, this may result in an improved understanding and recognition that the provision of the program intends to result in people returning 'to country'.</p> <p>There are many reasons why patients may be unable to complete their own paperwork. Such situations result in the carer being required to undertake such tasks on the patient's behalf. Reasons may, for example, include</p>	<p>PATS pamphlets be made available in major languages in accordance with the WA Language Services Policy 2008 (WA Health Language Services Policy 2011).</p> <p>PATS pamphlets be made available in WA local Aboriginal languages as is the case with the 'My Travelling Booklet'.</p> <p>Update the 'My Travelling Booklet' to include information regarding the trip home, including what receipts people need to keep in order to claim upon their return.</p> <p>Aboriginal Liaison Officers be placed in each PATS Office.</p> <p>PATS Officers to provide assistance to fill in the form where a language barrier or literacy skills require such.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Language difficulties cont.</li> <li>Patients unable to complete own paperwork</li> <li>Original paperwork – patient's responsibility</li> <li>Accessibility to PATS forms</li> </ul>	<p>poor literacy levels, English as a second language, the patient's medical condition, and a physical and/or psychological impairment. Regardless of the reason, carers must be assisted in aiding the patient to fill in the PATS forms and when filling out the forms themselves to ensure that the patient and/or carer has equitable access to PATS.</p> <p>There are many instances where a patient is unable to obtain or manage paperwork, and thus a carer is required to do so. For example, if a patient is transferred in an emergency for the treatment of a cardiac event, they are unable to ensure they have PATS forms and original documentation. In addition, a carer of an individual with a cognitive and/or physical disability which impacts an individual's ability to write and/or communicate will also require a carer to fill in this paperwork. It is necessary therefore to ensure that provisions are made to ensure that carers are provided with the paperwork and information they require to complete the application on the patient's behalf</p> <p>Many families if they have not been provided with a form when initially involved with a medical professional have not attempted to gain the form a second time resulting in eligible families not accessing the Scheme.</p> <p>Situations in which families have not been provided with PATS forms have included for example emergency situations and a lack of knowledge by on duty staff as to where the forms are located.</p>	<p>Procedures be developed to ensure that where a patient is unable to obtain relevant documentation and/or forms, but with consent (where consent is possible) carers are provided with the paperwork and provided with the information required to complete the application on the patient's behalf.</p> <p>Increase the accessibility and availability of PATS forms through placement in the waiting rooms of GPs, hospitals and nursing posts.</p> <p>This would make PATS forms easily accessible and also trigger health professionals to commence the application process by</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Accessibility to PATS forms cont.</li> </ul>	<p>Example 1. A family in Narrogin were to attend the plastics clinic at Princess Margaret Hospital. The family requested a PATS form outside of office hours. Nursing staff were unable to find a form and as a result the family did not access PATS. This resulted in the family paying for four trips to Perth within three weeks.</p> <p>Example 2. A patient was transferred 'from Country' outside of Kalgoorlie to Perth. The patient was unable to complete the PATS form. His mother who lived in Perth was unable to access a PATS form. As a result the patient was unable to access PATS.</p>	<p>signing them.</p>
<p>Primary Evacuation</p> <ul style="list-style-type: none"> <li>Referring staff unable to sign relevant documentation in emergency situations</li> <li>Patient is unable to give consent and therefore carer or next of kin is required.</li> </ul>	<p>During emergency situations, for example, where people require primary evacuation via the RFDS, the treating medical officer does not have enough time to sign the PATS form. This results in families funding their own travel costs. It would be beneficial in such circumstances that other staff such as allied health professionals eg Social Worker or Aboriginal Health Worker were able to sign and help fill in the PATS form after a referral has already been gained from treating medical professional.</p> <p>The current PATS policy does not provide for a family member or legal guardian to accompany an adult patient that has been evacuated via primary evacuation. This is in direct contradiction to the Treatment to Consent Policy, as well as Enduring Power of Guardianship and Advance Health</p>	<p>Changes to guidelines to allow senior nursing or allied health staff, Aboriginal Liaison Officers, and Aboriginal Health Workers or other treating medical persons to sign the PATS forms retrospectively.</p> <p>The PATS Policy be modified to ensure it is consistent with other Policies including Consent to Treatment, Enduring Power of Guardianship, Advanced Health Directives, National</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>• Patient is unable to give consent and therefore carer or next of kin is required cont.</li> <li>• Application to be submitted to the Regional Director for permission to receive accommodation and/or travel assistance for an escort</li> <li>• Accessing Regional Director</li> </ul>	<p>Directives. This also goes against the new Draft Clinical Deterioration Policy, and the new National Safety and Quality Health Service Standards</p> <p>The current PATS Policy does not include as standard practice the assessment of escorts to receive accommodation or travel assistance in emergency transfers. Rather, such applications require approval by the Regional Director.</p> <p>At present the direction within the PATS Policy in relation to providing an escort during the transfer of a patient by IHPT/PE is ambiguous. Carers must be provided with assistance to travel where they hold Enduring Power of Guardianship and/or are required to provide consent to treat. To be practicable this approval, which is currently provided by the Regional Director, must take place within a timely manner that is not onerous to enable for swift travel times. For example, currently the family is required to fund their own travel to attend to the patient who has a critical condition after a serious car accident and is unable to travel with the patient.</p> <p>The PATS Policy states that there are circumstances in which a carer may be eligible for accommodation and travel costs, and that these must be approved by the Regional Director.</p> <p>Carers WA have concerns regarding the difficulties carers may face when attempting to gain approvals by the Regional Director such as:</p>	<p>Safety and Quality Health Services Standards and the Carers Recognition Act.</p> <p>The PATS Policy be modified to ensure it is consistent with other Policies including Consent to Treatment, Enduring Power of Guardianship, Advanced Health Directives, National Safety and Quality Health Service Standards and the Carers Recognition Act.</p> <p>Review the process to approve accommodation and travel expenses to enable immediate approvals in relation to emergency situations.</p> <p>PATS Offices to be available after hours to enable access in cases of emergency such as emergency transfer and that staff who are able to approve applications be rostered for after hours contact.</p> <p>Changes to guidelines to allow, treating Dr, senior nursing or allied health staff, Aboriginal Liaison Officers, and Aboriginal Health Workers or other treating medical</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Accessing Regional Director cont.</li> </ul>	<ul style="list-style-type: none"> <li>Who is expected to refer the carer to the Regional Director?</li> <li>Is such direction embedded within procedures?</li> <li>Where is the Regional Director located in comparison to regional and remote carers ie in the major regional centres?</li> <li>The ease with which carers would be able to meet with the Regional Director?</li> <li>Is the Regional Director available after hours?</li> <li>How long does the approval process take?</li> <li>What provisions are available in emergency situations?</li> </ul>	<p>persons to sign the PATS form. The carer can then be assisted to travel immediately on following plane.</p>
<p>Eligibility issue:</p> <ul style="list-style-type: none"> <li>Calculation of distances</li> </ul>	<p>Carers have been rejected access to PATS as their trip is calculated 'as the crow flies' to the Central Business District (CBD) rather than by travel distance to their treatment centre. This practice appears to be in contradiction to the PATS Policy which states that the distance is calculated to the treatment centre.</p> <p>Example. Carer/patient denied assistance when travelling from Toodyay to Fremantle hospital as the distance was measured from the Toodyay GPO to the Perth GPO in a straight line (a distance of 87km), not by road or from home to Fremantle (a distance of 112km). This family makes the trip every 4<sup>th</sup> day for chemotherapy.</p>	<p>Ensure that distances are measured by distance travelled by road not 'as the crow flies'.</p> <p>Ensure PATS staff are sufficiently trained and are aware of the policies in relation to calculation of distance.</p> <p>PATS Office staff be able to make decisions at a local level regarding individual cases that may require revision from the policy.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>• Calculation of distance cont.</li> <li>• Permanent Resident eligibility</li> </ul>	<p>Carers WA would like clarification as to how distance is calculated ie as the crow flies or via travel distance.</p> <p>Example. A family member has moved to the country for a temporary period to care for a loved one. Whilst the carer is caring for the loved one, the individual requires assistance to attend a specialist appointment in Perth.</p> <ul style="list-style-type: none"> <li>- Is the carer eligible to access support through the PATS scheme for travel and accommodation costs?</li> <li>- Similarly if a person becomes unwell and is rushed to Perth, once discharged, is a carer located in Perth able to access the Scheme in order to return with the patient, who now needs ongoing care?</li> </ul> <p>Carers WA would like clarification as the eligibility of carers to gain access to PATS when not a permanent resident where, for example, the person receiving care resides.</p>	<p>Review of the PATS Policy to ensure that carers who do not permanently reside in the location of the person they care for are able to access PATS to enable them to undertake their caring role.</p>
<ul style="list-style-type: none"> <li>• Difficulties verifying address for transient population</li> </ul>	<p>The Permanent Residency requirement is problematic for some sectors of the State's Aboriginal community. Individuals who genuinely reside within remote or regional Western Australia, within the Western Australia Country Health Service Region, who - consistent with cultural practice - are transient, have no fixed address, are homeless and/or are staying with family are denied access to health services through the PATS</p>	<p>Enable the use of school and/or work records to be used to verify the historic and/or current (periodic) residency status within the WA Country Health Service (WACHS) region.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Difficulties verifying address for transient population cont.</li> <li>Timeframe in which one is eligible for support through PATS</li> </ul>	<p>program. In such cases, people do not have the documentation required to verify their eligibility.</p> <p>Many people are required to travel to Perth for treatment for extended periods of time due to a lack of facilities closer to home. At present the PATS program only covers accommodation costs for people for a period of six months.</p> <p>Many people require treatment in Perth for up to 2 years due to a lack of facilities closer to home. This is particularly true for those receiving for example dialysis treatment. Removing their eligibility to access PATS support for accommodation and travel costs is significant for such a population. It is important to note that many of these people do not know in advance how long they will be away from home for.</p> <p>Such issues are further complicated for the families involved due to the housing shortage, and high cost of housing in the Perth metropolitan area, when compared to country areas. Carers WA are concerned with regard to the ability of such families to support their accommodation needs whilst residing in Perth for the extended period. Carers WA would like to clarify whether referrals are made to Departments and/or agencies to assist such families to access supports to aide them in their search for suitable housing, and whether if this is undertaken, that families requiring such long term stays are identified and referred to</p>	<p>Ensure that procedures are in place whereby PATS staff refer patients and carers to other Departments and/or agencies in order to assist them to access supports in their search for suitable accommodation.</p> <p>Review the PATS Policy to allow for exceptional circumstances to be an eligible reason to lengthen the amount of time one is able to access accommodation subsidies.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>• Essential Information Sessions</li> </ul>	<p>such agencies with significant time for them to arrange alternate accommodation.</p> <p>Example. A family in Port Hedland required treatment by dialysis for chronic renal disease. Currently the waiting list for the machines located in the town is approximately two years. As a result the patient and family are required to relocate and reside in Perth for a period of two years. The waiting period has been reported to Carers WA by carers in the local area.</p> <p>Patients are often required to attend information sessions as part of the eligibility to gain specialist medical services. For example, renal transplant patients and their carers are required to attend a compulsory information session in the Perth metropolitan area prior to being able to register on the waiting list for a kidney donation. This information session forms part of the assessment of eligibility for a kidney transplant.</p> <p>Carers WA have been notified of patients who have been unable to access PATS to enable them to travel to Perth to undertake this training. In effect this means that only those rural and remote patients who can afford to travel the long distances to Perth with their carers are able to gain access to a lifesaving kidney transplant. This is a significant inequity that Carers WA request be immediately reviewed.</p> <p>Carers WA would also like clarification as to what is defined as a non-medical specialist</p>	<p>Review the PATS Policy to enable essential information sessions to be covered under the PATS.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Essential information sessions cont.</li> <li>Non-medical specialist appointment coinciding with medical specialist appointment</li> <li>Bundling of appointments – non medical specialist and medical specialist</li> </ul>	<p>service?</p> <p>There are circumstances that rural and remote patients require assistance to travel and stay in Perth to gain essential specialist services that do not coincide with a medical specialist appointment. Such an example is of a young boy who due to a growth spurt requires the provision of a new specially fitted wheelchair. To obtain this he and his carer need to travel to Perth to obtain specialist services. Such hospital engineering is an essential requirement to meet for example the young boys health, participation and accessibility needs and may take several days to complete. The provision of services such as this are essential though non-medical in nature.</p> <p>Are there provisions within the Scheme to cover travel and accommodation related to services that do not coincide with a medical specialist appointment though are essential to the functioning of an individual?</p> <p>Many carers have difficulties 'bundling' appointments together. Gaining access to appointments with specialists generally can be difficult and have prolonged waiting periods. The ability of carers and/or patients to have appointments coincide is extremely difficult, and impossible in many cases. The expectation that people are able to do so is therefore impractical.</p>	<p>Review the PATS Policy to enable essential non-medical specialist related appointments to be covered under the PATS.</p> <p>Review the PATS Policy to enable extenuating circumstances to be a legitimate reason why singular appointments are necessary.</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Bundling of appointments – non medical specialist and medical specialist cont.</li> </ul>	<p>In addition, many carers themselves have extenuating circumstances that impact their ability to attend numerous appointments on a given day with the person they care for. These may include for example their own health condition and/or are determined by factors related to the person receiving care. For example, a father of a 16 year old boy who has cerebral palsy, if required to attend several appointments in a given day would need to lift his son, who may be nearing the size of an adult, from the car into a wheelchair numerous times throughout the day. This would be additional stress on the father's body, on top of the stress that he may already experience on a daily basis as a result of his caring role. Such expectations could adversely impact the carer's own health.</p> <p>Carer assessment as to their ability to 'bundle' several appointments together should be undertaken.</p> <p>In addition, a carer's own obligations eg child care, family and work, may make it difficult to have a prolonged trip away from home rather than two short ones. The physical, emotional and psychological health of the carer can also impact the ability of the carer to 'bundle' appointments together.</p>	<p>The PATS Policy be modified to ensure it is consistent with the Carers Recognition Act.</p>
<ul style="list-style-type: none"> <li>Limited services covered under PATS</li> <li>Other medical eg Dentist, Clinical Psychologist, Psychiatry</li> </ul>	<p>The Patient Assisted Travel Scheme (PATS): A guide for Patients and Carers states "Most specialist medical services covered by Medicare are eligible under PATS. However, referrals to other health professionals, for</p>	<p>Review the PATS Policy to enable allied health such as podiatry and audiology, mental health services and dentistry to be covered under PATS and to ensure that the</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Other medical eg Dentist, Clinical, Psychologist, Psychiatry cont.</li> </ul>	<p>example allied health (speech pathology, physiotherapy, podiatry, clinical psychology, occupational therapy, audiology, and pathology), dentists and nursing professionals, are not covered by PATS."</p> <p>Carers WA have been notified that in remote communities where communities are small and interconnected, people experiencing mental health issues are reluctant and choose not to utilise psychological services that are offered locally, nor utilise buildings which are commonly known to offer psychological services as doing so would breach the privacy of the individual. In addition, these services are often provided by someone who is from within the community or is well connected in the community and staff often may therefore know an individual's personal network which poses a risk to their sense of safety when utilising a service.</p> <p>Carers are impacted as the person they care for is not able to access services anonymously within their local community and cannot afford to travel elsewhere to access services where their privacy is not at risk by the act of entering and/or utilising a service.</p> <p>Carers WA would like clarification of why psychological services are not included as eligible services within the Scheme, despite being on the Medicare Benefits Scheme.</p> <p>The inclusion of for example dentistry, podiatry and audiology within the PATS would bring the program in line with best practice</p>	<p>Policy is consistent with Models of Care as well as national and state health and mental health strategies and plans.</p> <p>Work with the Mental Health Commission to review policy to ensure people living in regional and remote areas have both access and choice in regards to mental health treatment as is outlined as best practice under the state Mental Health Strategic Plan 'Mental Health 2020: making it personal and everybody's business'.</p> <p>Work with the Mental Health Commission to ensure that the Policy is consistent the Recommendations arising as a result of the Stokes Review of the Admission or Referral to and the Discharge and Transfer Practices of Public Mental Health Facilities/Services in Western Australia in which Recommendation 2.7 states: "All mental health clinicians must ensure that the physical wellbeing (including dental) of all patients under their care are regularly assessed and treated by appropriate specialists clinicians (e.g. podiatrist, diabetes</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Other medical eg Dentist, Clinical Psychologist, Psychiatry cont</li> </ul>	<p>providing essential care and preventative measures outlined within Models of Care such as the Diabetes Model of Care, and the Cardiac Model of Care. This would go some way to prevent long term health consequences of not obtaining essential services that impact the functioning of individuals and their families, which would in turn positively impact long term health and socioeconomic outcomes.</p> <p>Carers WA would like clarification of why an essential health services such as dentistry is not included as eligible services within the Scheme, despite being on the Medicare Benefits Scheme.</p>	<p>educator). This is a key performance indicator that requires monitoring for compliance."</p> <p>Review the PATS Policy to ensure it is consistent with The Roadmap of National Mental Health Reform 2012-2022' to which all states are signatories Priority 5 of which 'Improve access to high quality services and supports, page 13. The Vision of which includes the promotion of 'good mental health, and social and emotional wellbeing among <u>all</u> Australians' (page 6).</p> <p>In addition, such provision would also go some ways to enabling the provision of Key Principle 5 of the State Mental Health Strategy 'Mental Health 2020: making it personal and everybody's business' "Mental health programs and services are state wide, based on contemporary best practice, easily accessed and delivered in a timely and collaboratively." Pg 4.</p>
<ul style="list-style-type: none"> <li>Access to suitable accommodation</li> </ul>	<p>Carers are often not given the choice of accommodation that suits their own needs and the needs of the person they are caring for. This includes circumstances in which disability access is required as well as location to treatment.</p>	<p>A review of accommodation available to regional travellers, such as for example Aboriginal hostels, to ensure that availability meets demand and that these</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Access to suitable accommodation</li> </ul>	<p>Example 1 A new dialysis patient, who is also a carer for her daughter who has a disability, was unable to access accommodation for her and her daughter in Perth. As a result the patient held off having dialysis because of this issue. The Aboriginal Health Nurse involved was told that the Aboriginal hostels in Perth were full and don't accommodate other family members.</p> <p>Example 2 Accommodation booked for the patient and carer by the Albany PATS Office. Accommodation location and facilities was not appropriate as the patient needed disability access. The accommodation did not have such facilities. Feedback received stated that the booking of the accommodation was restricted by monetary value, rather than the needs of the patient and the carer. We have been informed that this is a common issue in relation to bookings by the Albany PATS Office.</p>	<p>facilities are disability friendly.</p> <p>Ensure that carers are able to stay in the same facility as the patient (when the patient is not in hospital) and that facilities are located within close proximity to major primary health facilities.</p> <p>Ensure that carers are able to gain access to accommodation facilities when travelling to regional centres to support and continue to care for the person requiring care.</p> <p>Eligibility of accommodation costs to be reviewed to include carer accommodation costs.</p>
<ul style="list-style-type: none"> <li>Lack of access to PATS when arrive in Perth without prebooking</li> </ul>	<p>Carers needing to pay additional costs for their accommodation when accompanying the patient to hospital. Carers WA are notified of a common occurrence where families/kin/carers are sleeping in bushes in parks by the city because they do not have access or cannot afford to pay for accommodation costs.</p>	<p>The provision of specially trained hospital staff, that can assist the families/kin/carers gain accommodation via PATS once they arrive in Perth, where pre arrangement has not been possible.</p> <p>Hospital staff be trained as part of their Carers Recognition Act requirement to assess whether a carers</p>

ISSUE	EXPLANATION/EXAMPLE	RECOMMENDATION
<ul style="list-style-type: none"> <li>Lack of access to PATS when arrive in Perth without prebooking cont.</li> </ul>		<p>accommodation needs are met.</p>
<ul style="list-style-type: none"> <li>Review of the complaints and review process and reassessment of eligibility</li> </ul>	<p>Once turned down, many carers may not have the energy or confidence to initiate an appeals process or exception ruling. Many applicants are also likely to be unaware of their rights to do so.</p> <p>For many families in remote communities, engagement with government Offices may be tenuous. Similarly, filling in forms may pose a significant barrier for many who may have poor literary skills or limited experience in doing so. In such cases people are considerably less likely to assert their needs after having an unsuccessful application. Rather they will choose to not have treatment, or attempt to find the resources and means through their own personal and familial networks despite their potential to successfully meet requirements.</p>	<p>Ensure that procedures include the notification of applicants that an appeals process is available.</p> <p>Access to complaints and review process be made available in other languages (in accordance with the WA Languages Services Policy 2008).</p> <p>Request that provision is made for suitably trained PATS Officers to be able to refer more complex cases through to the Regional Director, rather than them only being able to do so after it has been requested by the applicant, who may not know their rights.</p>