AUSTRALIAN MEDICAL ASSOCIATION



WESTERN AUSTRALIA

12 May 2014

Ms Lauren Mesiti Committee Clerk - Standing Committee on Public Administration Legislative Council Parliament House Perth WA 6000



Dear Ms Mesiti

INQUIRY INTO THE PATIENT ASSISTED TRAVEL SCHEME

I am writing to you in reference to the Standing Committee on Public Administration Inquiry into the Patient Assisted Travel Scheme (PATS).

The Association is pleased to enclose its submission to the Inquiry. The AMA (WA) submission focuses on feedback received from medical practitioners on their and their patients' experiences in using the PATS.

Following broad consultation with WA medical practitioners, the Association has identified a broad range of concerns relating to the PATS as it currently operates. Those medical practitioners who communicated their issues to the AMA (WA) represented regional general practice and specialty medicine and specialists based in the metropolitan area who provide medical care to patients from rural, regional and remote areas of WA.

There is a clear and widely held view that PATS has frequently failed patients in regional WA and numerous examples were cited to support these claims. I sincerely hope that the Inquiry will fully investigate and comprehensively respond to the issues raised by WA medical practitioners.

Please contact me if you wish to further discuss the AMA (WA)'s Inquiry submission.

Yours sincerely

DR RICHARD CHOON

PRESIDENT



AUSTRALIAN MEDICAL ASSOCIATION (WA) SUBMISSION TO THE PARLIAMENTARY INQUIRY INTO THE PATIENT ASSISTED TRAVEL SCHEME

The Australian Medical Association (WA) consulted with its members to ascertain the views of WA medical practitioners as to the adequacy of PATS' delivery of assistance to regional residents' in their access to medical care. A number of responses were received from members who expressed a range of concerns relating to the PATS system as it currently operates. Those medical practitioners who communicated their issues to the AMA (WA) represented regional general practice and specialty medicine and specialists based in the metropolitan area who provide medical care to patients from rural, regional and remote areas of WA.

There is a clear and widely held view that PATS has frequently failed patients in regional WA and numerous examples were cited to support these claims.

Lack of Flexibility

Lack of flexibility to allow for clinical judgement by the patient's treating GP or specialist was often cited as a serious flaw of PATS. Whilst it seems reasonable on face value that PATS provides for travel to the nearest specialist, problems arise when this is rigidly applied by PATS administrators without any application of clinical judgement or common sense. For instance, for Narrogin patients, PATS may be refused for a trip to Perth on the grounds that Bunbury is a few kilometres closer. This ignores the reality of transport links and the patient's options for accommodation.

Rural doctors cited immense and continued frustration at having to attempt to convince PATS to pay for a trip when there is a specialist service available locally, but is not accessible soon enough or does not have the required specialist expertise.

Whilst it is often the case that if a doctor represents the patient, he or she is able to secure access to PATS, the process of doing so is time consuming and frustrating.

Several doctors cited issues around the inflexibility of one specific regional PATS office. In many cases, patients have a long to endure before being able to see a specialist practising out of Merredin and in these cases, many patients would be better off if they were able to travel to Perth to access the appropriate specialty treatment. However, it appears that the regional office is not receptive to the clinical judgement of the local doctors.

Conversely, the Hedland regional co-ordinator was praised for demonstrating a willingness to make the system work for patients. It appears that applications at that office are processed in a timely manner and appropriate feedback is given to patients and doctors. Exceptional circumstances are able to be communicated directly by the doctor and consideration is given to each case on its clinical merit.

It is recommended that consideration be given to the human cost experienced by different regional patients when accessing medical care outside of their home towns. These experiences will be very personal and should be given due consideration.

Gap Charges and Visiting Specialists

PATS may be denied for travel where there is a visiting specialist to the region. However, there may be significant out of pocket gap charges for the patient to see the visiting specialist, which in many cases, the patient cannot afford. Doctors have recommended that, if there is no free public outpatient service in the required medical specialty, the patient should be permitted to access PATS to travel to a location that does offer this.

Cumbersome Administrative Processes

Doctors have described the administrative process of PATS as cumbersome and bureaucratic. They have questioned why every form, irrespective of medical specialty, requires an explanation as to why PATS is deemed necessary. An example of this being entirely unnecessary is in the case of a neurosurgery for a Narrogin patient where it is well-known that Narrogin does not have a neurosurgery service.

Doctors are concerned that patients who need the PATS support are not claiming it due to the administrative hassles they are presented with.

Doctors have recommended that, due to some patients presenting to metropolitan specialists being unaware of the PATS processes, provision be made to allow for retrospective PATS cover in permissible circumstances and that forms be made available in Specialist rooms.

A suggested improvement was to have one PATS form for the whole of the State so that doctors do not have to read the entire document every time a form is presented in order to ascertain how to complete each different version.

Concern has been expressed at the occurrence of PATS staff administrative members refusing specific claims for specialist care that is only available in Perth on the basis that they have confused the nature of the specialty (e.g. paediatric surgeon / paediatric urologist with a paediatrician) and have determined that the (incorrect) specialist care is available closer to the patient's home.

It was reported that the administration of PATS is, in many cases, slow, uncaring and unhelpful with rural patients being not only disadvantaged but also discriminated against. A level of verbal abuse of patients from PATS staff was reported to have occurred within some PATS offices.

Accommodation

There is a need for access to more accommodation that is suitable for families that is close to the tertiary medical centres. This would necessitate a significant increase in the current subsidies.

Indigenous patients find the PATS processes daunting and complex. They often do not have credit cards and cannot book accommodation in Perth. Many are short of cash and are therefore unable to pay up front. Consideration is needed for these patients.

In the Central Eastern Wheatbelt, PATS will not pay for overnight stay for colonoscopy patients and patients are often unable to return home the same day from Northam where they access the treatment. This means that the patient is required to take a support person with them. In many cases, the patient would be able to travel to Perth and stay with relatives, but PATS will not provide for this.

It appears that some patients have experienced delays in treatment due to their being unable to access suitable accommodation.

Travel

Many rural patients have difficulty accessing public transport and it was recommended that a greater use of taxi vouchers is required. Travel to appointments from accommodation for patients in Perth can take a considerable amount of time when using public transport and is difficult for those patients who are unfamiliar with the geography of Perth – and particularly those with mobility issues, small children or poor literacy.

It was suggested that more ambulatory care officers were needed to co-ordinate appointments across services. Much money appears to be wasted because the task of patients' liaising, negotiating and co-ordinating appointments is too time consuming and difficult. Patients make multiple trips for things that could have been addressed in a single visit.

Doctors reported that arranging urgent PATS travel has become increasingly more challenging due to the requirement for stricter application of the rules by PATS clerical staff. These applications are frequently initially rejected, but can often be resolved once the doctor has presented a case to administrators. However, the administrators have, at times, been very difficult to contact resulting in delays in urgent referrals for treatment. It is recommended that negotiations for urgent patient transfers should be more timely.

There was concern raised at the transport problems experienced by Tom Price patients travelling to Karratha for specialist medical services. Issues occur in relation to the logistics of this travel which often requires travel via Perth or Hedland. It was highlighted that PATS is reticent to cover many of the patients affected by these logistical instances.

One doctor referred to a recent experience where a patient was referred to travel from Perth to the Royal Adelaide hospital in order to receive medical treatment that was not available in Perth. It is recommended that, in specified circumstances, interstate travel should be covered under the PATS provisions.

There is a significant issue with urgent travel (e.g. an orthopaedic review for a complicated acute fracture). Because PATS doesn't process urgently to accommodate this, the patient pays then claims back. However, sometimes PATS decide that, because there is a visiting specialist in a defined period of time, it wasn't necessary for the patient to go to a location further away (i.e. they make a clinical decision about urgency and refuse to pay). After numerous letters back and forth, the local doctor has eventually succeeded in getting the refund – but at great cost in time, effort and distress to the patient.

Transport and accommodation subsidies are not reviewed regularly. Petrol prices have increased substantially, but the subsidy has remained the same for many years.

An RFDS doctor has reported that patients living east of Kalgoorlie and south of the transcontinental railway line receive a very inequitable service from PATS that is administered from Kalgoorlie Hospital. The doctor cited anecdotal evidence from patients who have been retrieved by RFDS from the Nullarbor and have been admitted to Kalgoorlie regional hospital. When their episode of hospital care has been completed, they have been subsequently discharged from hospital, given \$50 and told to "find your own way home". The doctor has tried to get these patients more equitable access to PATS, but has been told nothing more will be done. This is despite their being no road, rail or air services to the Nullarbor.

Esperance Hospital has been reported as providing a very poor PATS service for any problems arising out of business hours. This occasionally causes very inappropriate referrals to RFDS services or leaves relatives of seriously ill patients that RFDS may transport stranded in Esperance, or seriously inconvenienced and out of pocket.

Telehealth

It is evident that telehealth is an option that is often preferred by the patients and local doctors. However, it has not reached its potential because many sub-speciality clinics remain unavailable for telehealth consultations.

Telemedicine requires the Department of Health to provide a financial structure for GPs or regional medical practitioners to have an incentive to be involved in the country, linked to regional nurses and the information structure back to Perth where funding to run the telemedicine clinic is also clearly needed and to be provided to the hospital divisions.

Promoting telehealth services for many specialties can minimise cost and revolutionise service delivery.

Waiting Times

If there is a visiting service in a regional area, a patient may not be able to access PATS. Whilst this appears reasonable, the issue of waiting times needs to be considered in context. In Geraldton for instance, the waiting time to see a dermatologist is nearly one year. However, in Perth it is 2 months. Clearly, the visiting service is not always able to provide timely patient care – however doctors have criticised the PATS system for assuming that it is.

Misuse of PATS

There was concern raised that in some areas of regional WA (Exmouth was one example cited) there is a tendency for new arrivals in popular tourist towns to have a high expectancy for frequent and full access to PATS subsidies. Exmouth has a high number of itinerant residents and holiday makers who are moving slowly around Australia. These people may stop in the area for just a few months and register their move officially. They access PATS with no checks on how long they have been residing in the town and associated circumstances. This was highlighted as an area for potential review of those accessing PATS.

Consistency of Care and Patient Management

A constant source of frustration with PATS amongst doctors is the 'nearest specialist' requirement which requires patients to often change specialists in the middle of a course of treatment. This is seen by clinicians as being inappropriate in many cases and a serious failing of PATS.

Aboriginal Patients

There were many concerns raised in relation to the application of PATS to Aboriginal patients from regional WA. These patients are often let down by a system which does not recognise their nuanced circumstances. For example, when an Aboriginal woman from a remote community is required to attend KEMH for a complicated pregnancy, she is often scared, has never travelled away from her community and has English as a second language. If she is not allowed an appropriate escort, subsidised by PATS, it is very likely that she will abscond and head home.

Obstetric Patients

Obstetric patients were commonly identified as being of particular concern, notably those who are not fit for delivery in rural settings due to risk factors. These patients are denied PATS support for their spouse or support person to travel with them. This creates a situation where a woman has to

deliver without their spouse or support person and in many cases, the patient makes the choice to stay in their nearest town and deliver locally without the specialist staff available to manage complications. As well as the stress and risk this causes to the woman, it also places considerable pressure on the local clinical staff.

Doctors are concerned that PATS treats regional pregnant women poorly and is at odds with safe and reasonable maternity care. In uncomplicated pregnancies, PATS only subsidises transport and accommodation costs from 38 weeks gestation. This inhibits women from travelling from some regional and remote settings until 38 weeks. Term is 37 weeks. Western Australian Country Health Service (WACHS) data show that 4% of women who are pregnant at 37 weeks, and who are awaiting on onset of spontaneous labour will do so within the next week. Transport out can mean an extremely uncomfortable (and potentially dangerous) drive in labour from an outer Wheatbelt town, or RFDS transfer from a remote Kimberley community. It is a stressful exercise for all concerned. One specialist who responded to the AMA (WA)'s call for input into the Inquiry recommended that women should routinely be encouraged to be near the place they will be delivering by at least 37 weeks, and routinely subsidised by PATS for doing so.

PATS generally only subsidises for 2 weeks' accommodation. This is at odds with evidence based pregnancy care which is defer induction of labour until 41 weeks gestation in uncomplicated pregnancies. If women leave home at 37 weeks, they are potentially looking at 4 weeks 'sit down' time if they don't labour spontaneously by 41 weeks or have an indication for delivery before then. Two weeks is inadequate even by the current rules which support accommodation from 38 weeks. The additional financial burden of unsubsidised accommodation can be a pressure point on obstetricians to agree to induction of labour when it is not clinically indicated. Women are now routinely discharged from maternity care units in the metro area and most regional centres within 48 hours of birth. 48 hours post birth is not an ideal time to be travelling long distances back to a home base. Women should sensibly be supported to stay in accommodation close to their site of birth for at least 5 days to minimise the risk of either them or their babies having to seek help for a complication of childbirth in a remote setting. This also promotes breastfeeding from the ongoing support of home visiting midwives from the birth unit.

Unless 'medically indicated', no assistance by way of travel subsidy or accommodation assistance is offered for women to have a support person with her during her sit down time away from home. This is stressful for any woman, but particularly for women from remote communities who are frightened of travel to the foreign environment of larger regional centres or the metropolitan area to await birth. An additional anxiety for Aboriginal women in particular, but not exclusively, is the lack of any appreciation in the current system of the stress of leaving young children behind in potentially dangerous and vulnerable situations.

Current PATS rules only allow subsidies to be paid when women travel to the nearest public maternity care site appropriate to the woman's level of pregnancy risk. Whilst it might be wise to limit the subsidy to that which would be paid for a woman to attend the nearest appropriate public maternity care site, it seems very unfair that women don't qualify for any subsidy when they choose to travel not to the nearest maternity site, but to the nearest one where the woman can have the support of her family or friends who may assist with accommodation and care for accompanying children. This is particularly pertinent in that very few rural maternity care centres have safe, affordable and readily accessible accommodation for women awaiting childbirth, let alone accommodation that is suitable for families.

Accommodation subsidies are token at best for women who don't have the option of staying with family. Even caravan park fees long ago outstripped the subsidies offered.

It has been further recommended that better services are required for regional obstetric patients including visiting specialist obstetricians, more support for the local GP obstetricians who are available and adequate support for women who have to move away from home to deliver.

Patients Requiring Hyperbaric Oxygen Therapy

Rural patients requiring hyperbaric oxygen therapy (HBOT) for an extended period before and after complex head and neck surgery / ENT or maxilla-facial surgery on the background of prior radiotherapy induced tissue damage in the operative field were also highlighted as being failed by PATS. Typically, these patients require 20-30 sessions of HBOT (4-6 weeks) prior to surgery, followed immediately by a further 10 sessions. Currently, there is no PATS funding available to such patients — except by obtaining an 'Exceptional Ruling' which is a time-consuming and tedious process for both the doctor and the patient. Alternatively, the patient may be kept (unnecessarily) in hospital as an inpatient — clearly a waste of resources.

Bariatric Surgery

Bariatric Surgery was another discipline associated with PATS access problems. Perth Specialists performing sleeve gastrectomies advised that these procedures require a consultation with dietician and psychologist, then a further consultation with the specialist if the patient chooses to proceed with the surgery. A face-to-face post-operative appointment is required six months after surgery. There are currently no facilities for video-conferencing for follow-up appointments. However, it has been highlighted that the North-West PATS co-ordinator has determined that these post-operative patients can see the visiting surgeon so that PATS does not have to pay for them to travel to Perth. This means that any choice for patients to see their Perth surgeon and choice for the referring GP has been removed.

PATS has ceased allowance for gastric band patients attending Perth for follow-up. PATS administrators have stated that doctors in rural areas can perform band fills, but there have been a number of Australian and International studies stating that weight loss following gastric banding is not only about band fills, but requires long term care provided by an experienced multi-disciplinary team. Doctors have advised PATS that allowing patients to come for surgery but not follow-up will result in inadequate weight loss. To date they have received no response from PATS.

Dental Services

Doctors have recommended that consideration needs to be given to eligibility for PATS remuneration for patients accessing dental services. Many patients have poor oral health and a high incidence of rheumatic heart disease. Access to a dentistry service is difficult enough for these patients – even more so without access to PATS assistance.

Children with Diabetes

A Perth-based specialist in this field highlighted that, for serious conditions such as newly diagnosed Type 1 Diabetes in childhood, where it is recommended that both carers are present for education about management, PATS should cover both parents.

In addition, it has proved to be very frustrating when clinicians are trying to mount a business case for the provision of local specialist services and there is a disconnect between the PATS budget and local health. An example is a recent request from the Esperance community to recommence a visiting PMH clinic for children with diabetes. There was a critical number of patients, so the cost of the multidisciplinary visiting service was much less than the PATS cost of each patient and parent attending Perth. The business case was put together, but was rejected because the money pot for PATS is different to the one that would pay for the visiting service. In the end, the local community

has raised money to support the commencement of the service in the first year. This is a concerning situation and not efficient for health or health delivery or patients.

Maxillo-Facial Treatment

There appears to be an issue with patients requiring this maxillo-facial treatment at RPH accessing PATS. Patients are advised that they are ineligible for PATS when accessing this treatment as it is considered by PATS administrators to be semi-elective or dental. It is recommended that these cases be reviewed in relation to PATS eligibility as a matter of some urgency.

Oncology and Haematology

Lack of accommodation for regional patients is expected to be a serious issue for Oncology and Haematology at Fiona Stanley Hospital (FSH). PATS and Royalties for Regions funding should be considered as possible contributors to answering how regional patients will access, with their families, appropriate care in Perth from 2015. The AMA (WA) requests urgent consideration be given to this matter and can provide further information as to the nature and ramifications of this shortfall.

Further, there are concerns for Oncology and Haematology patients from Carnarvon who are unable to access flights to Geraldton which, for many, is their preferred site for treatment. This situation appears to be unreasonable for patients who therefore cannot be seen in Geraldton, but are not covered by PATS for flights to Perth.

Royal Perth Hospital country oncology clinics have, at times, been unable to meet the demands for oncology regional services at the regional site and have had to have patients sent to RPH (40 in 2013). The ad-hoc care of regional services linked to tertiary metropolitan sites has led to RPH (which is closing) providing the only five regional sites (Geraldton, Northam, Kalgoorlie, Esperance and Albany) with oncology services. There is presently no ongoing contract to have these services continue into FSH and the North Metropolitan Health Service (NMHS) provides no onsite regional oncology service. Improvement of PATS is therefore linked to the ability of the metropolitan hospitals to provide care, and for oncology, the willingness of NMHS to share the burden. At present, FSH will acquire in oncology a very unbalanced large regional commitment to provide outreach services which in Geraldton requires additional workforce.

MRI, EEG and Cardiology

It is recommended that there needs to be analysis applied to the reasons for regional patients travelling to Perth to ascertain whether there is a significant number travelling for MRI, EEG and Cardiology (for example). If it is evident that this is the case (and it appears that it would be), it may be more appropriate for DoH to facilitate these investigations taking place in larger towns such as Geraldton, Kalgoorlie and Albany. For example, Geraldton private radiology providers can perform an MRI brain investigation for approximately \$400 and ECHOs can be performed by technicians using portable machines with results interpreted by Perth consultants. This would likely be a more convenient and cost-effective option for regional people.

Palliative Care

The WACHS program in palliative care is reported to be a very successful initiative. It demonstrates the value in bringing the specialist to the patient. Once a month, a consultant palliative care physician goes to Moora, Northam, Merredin or Narrogin. The specialist sees country hospital inpatients, outpatients and undertakes visits to patients on their farms. Many of these patients are too sick to travel, regardless of any subsidy provided. For example, one quadriplegic patient is ventilator-dependent and has received excellent care in his farmhouse for the past 4 years. This

would therefore suggest that increasing the number of doctor visits to the country may sometimes be more helpful than increasing the number of patient visits to Perth.

Conclusion

The comments included in the AMA (WA) submission reflect concerns of WA doctors and their patients who have participated actively in the PATS system over many years within a variety of contexts, medical specialities and geographic locations. The AMA (WA) thanks those members who responded to the Association's call for comment and trusts that the Inquiry will fully investigate and respond comprehensively to the issues raised.

Christine Kane – Executive Officer 12 May 2014