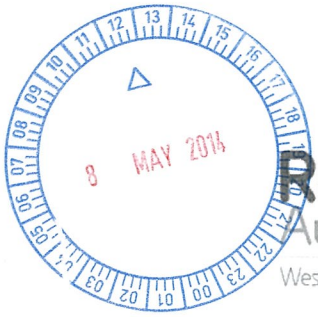
Government of Western Australia
Department of Health
WA Country Health Service



RHD Australia
Western Australia

WA Rheumatic Heart Disease (RHD) Register and Control Program Submission to the Standing Committee on Public Administration Inquiry into the Patient Assisted Travel Scheme (PATS).

Background

The Western Australia Rheumatic Heart Disease (WA RHD) Register and Control Program was established in 2009 as part of the Rheumatic Fever Strategy to tackle Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) in Australia. The Commonwealth Department of Health and Ageing (DoHA) partnered with the government of Western Australia (WA) to establish and maintain a coordinated WA ARF/RHD register and control program (the Program). In 2013 an agreement was signed between the Commonwealth and the WA government to continue the program until 30 June 2016.

The objectives of the program are to:

- implement and expand/maintain a dedicated state wide patient register and recall system for ARF and RHD;
- improve clinical care including improved delivery of and adherence to secondary prophylaxis antibiotics;
- provide education and training for health care providers, individuals, families and communities; and
- collect and provide data for national monitoring and reporting of ARF and RHD and measuring program effectiveness in the detection and management of ARF and RHD.

The WA RHD Register has over 600 patients consented to the register of which greater than 90% live in remote WA and 98% are Aboriginal. The feedback the program has received from patients and families with ARF/RHD and health care providers is that the PATS system does not deliver adequate assistance to Aboriginal clients living in remote WA. The issues relate to unmet cultural needs and support for socially and economically disadvantaged patients travelling to access specialist medical care.

ARF/RHD

ARF is an illness caused by an immunological reaction to a bacterial infection from a type of group A streptococcus (GAS). This causes an inflammatory response that can affect joints, brain, skin and the heart. ARF commonly occurs in children aged 5 – 14 years and they are often unwell requiring hospitalisation. If they develop cardiac (heart) symptoms during this phase of their illness, transfer to specialist paediatric cardiology services at Princess Margaret Hospital (PMH) for observation and possible surgery is required. RHD is the lasting damage caused by ARF. The damage to the heart is specifically to the mitral and/or aortic valves and can lead to multiple heart and circulation problems and early death. The medical management of RHD consists of regular cardiology review and can be as frequent as three monthly depending on the severity of the disease. Moderate or severe disease often requires surgical intervention, which will require lengthy stays in Perth, away from family and community. The more episodes of ARF a young person is exposed to the more likely they are to develop RHD resulting in permanent valve damage.

ARF and RHD are rare in Australia due to improved socioeconomic and environmental conditions. However, Aboriginal and Torres Strait Islander communities in Australia have the highest rates in the world. It is estimated that Aboriginal and Torres Strait Islander people are up to eight times more likely than other groups to be hospitalised for ARF and RHD and nearly 20 times as likely to die (ARF/RHD Writing Group 2012).

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The Parliamentary Inquiry into PATS TOR:

1. How adequately PATS delivers assistance to regional people accessing specialist medical care including:

a. Level of funding applied to the transport and accommodation subsides provided;
b. Eligibility for PATS funding;
c. The administration process;
d. Whether there is consideration for exceptional circumstances and
2. Any incidental matter

1. How adequately PATS delivers assistance to regional people accessing specialist medical care

The PATS system does not adequately deliver assistance to Aboriginal clients living in remote WA. The issues relate to unmet cultural needs and support for socially and economically disadvantaged patients travelling to access specialist medical care. The issues will be outlined below with a case study as an example.

a. **Level of funding applied to the transport and accommodation subsides provided**

The level of funding applied to the transport and accommodation subsides provided for PATS is inadequate because it does not have sufficient flexibility to provide a culturally safe environment for patients with ARF and RHD.

Children with ARF and RHD obtain specialist care from Princess Margaret Hospital (PMH) and the current PATS provision is for one care-giver to travel with a child. These children can be hospitalized for up to ten weeks depending on their condition. During this time decisions need to be made by the care-giver and consent for procedures are required. If the appointed care giver gives permission for a procedure that is not successful and the child deteriorates or dies, cultural blame can be apportioned to the care giver who gave permission for the procedure.

In Aboriginal communities, particularly in the Kimberley, the responsibility for raising a child is conducted by more than just the biological parents or appointed guardian. There are cultural relationship bonds that are not clearly defined in Western culture and these cultural bonds have responsibilities that are equally as important as the biological parent or appointed guardian. When major decisions are required about the child's future other community members needs to be part of the decision making and this makes the decision more culturally appropriate. The current PATS system does not allow for other significant decision makers to be present during hospitalization of the child.

Accommodation

There is inadequate accommodation for appointed care givers travelling to Perth with a sick child. PMH does not have adequate sleeping facilities for care givers and this results in them sleeping in Jason recliner chairs for up to eight weeks leading to sleep deprivation and compounding the stressful situation of a hopitalised sick child thousands of kilometers from home.

It is not uncommon for family or community members to make the journey to Perth at their own expense, to further support the patient. Affordable and culturally appropriate accommodation is both limited and often some distance away. This in turn leads to difficulties for the group getting back to the community and can result in homelessness in Perth. The group that paid their own way to Perth in order to provide cultural support to the patient invariably is unable to negotiate the system to work out how they can get access to pension payments and other funding sources to afford return home.

A major reason for family and community being with the sick child or adult is to provide cultural support to the patient and should they die away from home they can still be surrounded by kinsmen from their country who can perform the necessary required ceremonies.

b. Eligibility for PATS funding

Allowing other significant decision makers present during the hospitalization of a child assists the primary care giver to comprehend what is taking place. Hospitals are foreign environments and the language associated with illness is difficult for a lay person to understand. The enormity of what is taking place particularly for the parent or the appointed guardian may interfere with comprehension of what is being medically described. For an Aboriginal person to be immersed into a hospital

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environment is a disempowering situation so they may not feel in a position to question what is going on. Allowing other family or community members to accompany the child and the parent allows for better comprehension particularly in relation to the care of the child once they leave hospital.

When a child has had heart surgery for RHD their condition is considered severe and they require secondary prophylaxis treatment until they are at least aged 40 or for life for some people. There have been many situations where this message has not been comprehended by the attendant carer who is often isolated and overwhelmed. They leave hospital with the impression that because the child has had surgery the situation has resolved.

c. The administration process

The experiences reported by patients accessing health care are that the system does not take into account social, economic and cultural needs of the patient.
The majority of patients with ARF and RHD living in remote WA are Aboriginal people (98%). To access specialist care for patients with ARF and RHD requires travel from a remote community to the regional centre, then a flight to Perth, followed by travel to accommodation in Perth and then travel from the accommodation to the hospital appointment. The journey for many patients and families with ARF and RHD equates to a foreign environment where the process to get from one mode of transport to another are not easily negotiated. It is the equivalent to travel overseas without a guidebook in your language. This has been identified as a reason for patients with severe RHD not willing to have follow-up investigations. Should their condition deteriorate to the point of requiring surgery, they are frightened to embark on this foreign journey and some cases refuse follow up care and surgery as a result.

d. Whether there is consideration for exceptional circumstances

Aboriginal people living in remote WA make up a small proportion of the population and have some unique cultural needs that can be better met by the PATS system. As previously stated in this submission, of the 600 patients consented to the WA RHD register 98% are Aboriginal.
Some exceptional circumstances:

- A single care giver travelling with an Aboriginal child or adult is considered culturally unsafe. There needs to be flexibility in the system to support having multiple care givers travelling with an Aboriginal child or adult who needs to be hospitalized. There also needs to be flexibility in allowing interchangeable care givers because there are also cultural and family obligations for the designated care givers particularly if it is a long hospitalization. For example if the care givers have health problems or have children back in the community who require attention.
- Support is required to assist Aboriginal people from remote communities to navigate the system and the administration process. English may not be the main language spoken at home and comprehension of English and jargon associated with the process may be limited.
- Given the economic and social disadvantage of Aboriginal people there needs to be provision of accommodation, food and cooking facilities for careers whilst accompanying patients.

2. Any incidental matter

Case study:

A four year old child living in a remote community 200km from Broome was diagnosed with ARF and admitted to Broome hospital. During hospitalisation in Broome Hospital the patient's condition deteriorated necessitating aeromedical transfer to PMH in Perth for specialised treatment.
Socially the child was being looked after by the mother's family. When the child was admitted to hospital an aunt accompanied the child to Broome and because there was only one care giver allowed to travel with the child to Perth the same aunt was nominated to accompany the child.
While in Perth the child continued to deteriorate and became unstable. Decisions needed to be made about the treatment plan and consent was required from the aunt to perform surgery on the child.

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The consequences of performing surgery and not performing surgery were explained to the aunt. The aunt was not the sole carer of the child in the community and did not want sole responsibility; however she was unable to contact all the other cultural care givers and family of the child back in the community. The aunt stated that she was frightened of having to make a decision in case there was negative outcome and she would be blamed for the decision.
The aunt describes being too frightened to talk to the staff because she had difficulty in comprehending everything that was being explained to her.
The aunt also described her time while in hospital with the child and having to sleep on a Jason recliner because there was not a bed available for her. She was unable to sleep well and was stressed, worried and sleep deprived which was not conducive to making decisions. There was also the issue of finding food and meals that were affordable for her.
The aunt was given instructions for the after care of the child but has no comprehension of what was discussed, because at that time she was concerned about how they were going to get home again. She had not travelled to Perth before and was nervous about the steps required to get a taxi from the hospital and then the process of getting on the plane.
In discussing her experience with the WA RHD team she stated that she never wants to repeat that experience again because it was a traumatic experience that could have been alleviated if there were other family or community members that accompanied her and if there was someone who could of explained how they were to get home.
A PATS system that recognises that Aboriginal families from remote WA are rarely if never nuclear, would have provision for more than one family/community member to travel with a sick child to a metropolitan centre. Two carers would be able to provide support for one another, are more likely to be confident to ask questions and better comprehend health information provided or together articulate that they do not understand. A local governance approach where the ACCHS CEO and WACHS RD for example are required to approve additional carers following advice from clinicians should be considered.

Conclusion

The importance of culture and country are very important for Aboriginal patients. Being removed from country has significant psychological consequences for patients and this affects their decisions to pursue treatment that has the potential to improve their quality of life. The decisions made about the medical care of a child need to be made by more than the biological parents or the designated care-giver in order to ensure cultural safety. If the decision made by the designated care giver has negative consequences then the community may blame them for that decision.
Consideration should be made in PATS policy review for ensuring cultural safety by making provisions for additional family / community members to assist the patients' journey for rural and remote patients.
Thank you for your consideration of this submission,

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