CHAPTER 5

SPECIAL NEEDS GROUPS

5.1 During the inquiry the needs of a number of patient groups in rural, regional or remote areas with specific issues regarding patient assisted travel were highlighted in evidence. In addition to their geographic isolation from medical services, these patient groups experienced issues specific to their circumstances or health condition that were seen to impact on their capacity to access health services.

Aboriginal and Torres Strait Islanders

5.2 Issues regarding access to health services for Indigenous peoples in rural and remote areas were repeatedly raised with the Committee. A significant proportion of the Aboriginal and Torres Strait Islander population live outside the major urban centres and approximately 26 per cent of Indigenous peoples live in remote or very remote areas.[1] Indigenous peoples are also less likely to have access to a motor vehicle and more likely to report having difficulty getting to places needed than non-Indigenous people.[2] The Department of Health and Ageing noted:

> The comparatively greater number of Aboriginal and Torres Strait Islander peoples living outside the major urban centres, and especially in remote areas, means that they are significantly affected by the geographic distribution and availability of health services. The necessity to travel considerable distances to attend health facilities is a contributing factor to the ability to obtain timely health care.[3]

5.3 It was also recognised that health and other social outcomes are generally poorer for Indigenous people. For example the Northern Territory Government stated:

> Indigenous people compared with non-Indigenous people in the NT have higher disease and injury rates, a shorter life expectancy and poor health outcomes. For example, the burden of disease attributable to cardiovascular disease, acute respiratory infections, diabetes and neonatal disorders is greater in Indigenous people than non-Indigenous people in the NT. The causes for this burden of disease include physical and social determinants, such as poor physical environment; sanitation and hygiene; food supply, nutrition and activity; education, parenting and social and emotional wellbeing.[4]

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[1] AIHW, *Australia's Health 2006*, AIHW cat.no. 73 AUS, p.222.

[2] ABS & AIHW, *The Health and Welfare of Australia's Aboriginal & Torres Strait Islander People*s, 4704.0, 2005, p.183.

[3] *Submission* 157, p.9 (Department of Health and Ageing).

[4] *Submission* 164, p.4 (NT Government).

5.4 In this context, patient travel schemes were seen as an important mechanism to address Indigenous disadvantage. The Northern Territory Government stated:

> A large number of people, predominantly Indigenous people, in the NT are disadvantaged from a health perspective by the geographic location of their residence or their socio economic status or both. It is important that PATS is an effective tool in moderating this level of disadvantage.[5]

5.5 Repeatedly, the Committee heard witnesses describe the challenges facing Indigenous patients from rural and remote areas using patient travel schemes to access health services in metropolitan centres. Ms Monica Lawrence, a nurse working with cardiac patients from remote Indigenous communities, noted that for many patients 'it is a series of firsts—they have never left their communities or their families previously…never boarded a plane or slept in a hospital bed, let alone been admitted to a major metropolitan teaching hospital'.[6]

5.6 Concerns were raised that patient travel schemes were not adequately addressing the needs of rural and remote Indigenous patients. For example the National Rural Health Alliance noted:

> There is ample evidence that the schemes generally fail for many rural and remote Aboriginal and Torres Strait Islander health consumers. They fail from the perspectives of cultural safety, service quality including 'customer service', and in providing effective, efficient health care delivery.[7]

Cultural safety

5.7 The Northern Territory Government noted it was important to consider the policy implications of cultural factors for Indigenous patients.

> The majority of patients that access PATS in the NT are Indigenous and are from culturally and linguistically diverse backgrounds. Further, in many Indigenous communities, English is the second or third language spoken. This creates a challenging experience for a patient to understand their medical condition, contextualise this, and attend a medical service away from the community where the patient lives. Indigenous patients that are required to be away from home for extended periods often feel disconnected from their homeland and suffer general anxiety regarding new experiences. It is not unusual for an Indigenous patient to have never travelled on an aircraft prior to a patient travel episode and to have limited exposure to the life style of people that live in urban communities. The policy implications of this are that PATS must provide appropriate support to Indigenous patients, in particular, to understand their medical condition and to be supported appropriately with their travel.[8]

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[5] *Submission* 164, p.6 (NT Government).

[6] *Committee Hansard*, 6.7.07, p.20 (Ms M Lawrence).

[7] *Submission* 55, p.6 (National Rural Health Alliance).

[8] *Submission* 164, p.5 (NT Government).

5.8 This sensitivity to cultural issues was described by several witnesses as 'cultural safety'. Mr David Lines of the Katherine West Health Board stated cultural safety 'for Aboriginal people means being able to experience health services and information in a way that they can understand and feel comfortable with and secure in'. He continued, emphasising the impact that dislocation from community had on Aboriginal peoples' sense of self and place:

> When remote Aboriginal people travel into hospital systems when they become unwell, not only is there a separation from community, family and culture but there is a separation from place and that person's identity. When removed from their community there is a sense that they are being stripped of who they are. They are left physically and emotionally unprotected and vulnerable. Most of this is brought about by language barriers that they experience. Most people from remote Aboriginal communities speak basic English as a second or third language. When they enter into hospital systems and talk with doctors, nurses and specialists who use medical jargon and a high level of English language, there is a lot of room for things to become confusing for them and misinterpreted.[9]

5.9 Dr Peter Beaumont of the Australian Medical Association (AMA) told the Committee that community-based informed consent should be facilitated for Indigenous patients from rural and remote communities:

> …it is not generally known, I think, that it is common in Aboriginal communities for Aboriginal persons to not consent themselves to forms of treatment. The consent is usually given by a community group. So if people have to attend distant places for investigations and then make a consideration of whether they will consent freely in a proper, informed manner to moving forward with management that may be very invasive, they almost always will need to consult with the people that are near to them in the community. They are not used to – and nor should we require them – giving their own consent without utilising the facilities of the community that they have used in the past. [10]

5.10 This was echoed by the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT), who argued that cultural safety issues – including informed consent – need to be at 'the forefront in the design and implementation of health care systems for Aboriginal communities'. AMSANT stated:

> Making an informed decision requires access to all necessary information. In relation to Aboriginal patients it may also include additional considerations, such as the need for the patient to fulfill cultural obligations and responsibilities. For example, traditionally, the patient may be required to involve their families in making decisions about their health, and get

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[9] *Committee Hansard*, 5.7.07, p.61 (Mr D Lines, Katherine West Health Board).

[10] *Committee Hansard*, 5.7.07, p.25 (Dr P Beaumont, AMA).

> their consent, particularly in respect of surgery or other significant medical procedures.[11]

5.11 Dr Pam McGrath highlighted the 'different spiritual view' of many Indigenous patients in relation to 'death, dying and healing'. In line with other witnesses she noted that Indigenous patients can have different concepts of informed consent and in the context of medical decisions there is often 'community based consent'. Dr McGrath argued for the recognition of cultural issues in health care:

> healthcare professionals who are caring for Indigenous people have to factor in that…cultural issues, especially if somebody is in the dying trajectory, are as important as…clinical issues.[12]

5.12 The Northern Territory Government submission also raised the issue of the cultural need for Indigenous palliative patients to 'return to country' to die, noting it was well recognised that 'there can be a significant and far reaching cultural and psychological effect on the individual and patient's community when a patient is not returned to country to die'.[13]

5.13 In some jurisdictions, the guidelines do not support Indigenous people to return to country for family or ceremonial reasons if they are away from their communities for medical reasons. Dr David Thurley of the Northern Territory Divisions Network commented:

> I believe that if they are sent down for extended treatment and they then want to come home PATS will not cover that…I think that it should. Being away from family, friends and your own home environment when you are sick is even more stressful. It is very unreasonable, especially for some of these people who have to go down south for six weeks or six months. To not allow them to come home for a visit is almost inhumane.[14]

Communication

5.14 Communication issues were frequently mentioned in relation to Indigenous patients from rural and remote areas. As raised in witness evidence cited above, language was identified as a major barrier in negotiating the PATS systems. Dr Thurley noted that for many people in the Indigenous communities that his organisation dealt with 'English is their second, third or fourth language'. This means they cannot access the available PATS information and are unable to understand their rights in the PATS system.[15]

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[11] *Submission* 97, pp. 2-3 (AMSANT).

[12] *Committee Hansard*, 6.8.07, p.18 (Dr P McGrath).

[13] *Submission* 164, pp.5-6 (NT Government).

[14] *Committee Hansard*, 5.7.07, p.18 (Dr D Thurley, Northern Territory Divisions Network).

[15] *Committee Hansard*, 5.7.07, p.14 (Dr D Thurley, Northern Territory Divisions Network).

5.15 The Kimberly Aboriginal Health Planning Forum recommended that interpreter services be made readily available to all clients whose first language is not English. They argued that in many instances Indigenous patients' level of understanding is overlooked by health practitioners: 'false assumptions are made about their level of comprehension – a source of distress for the patient as well as potentially jeopardizing their quality of care'.[16]

5.16 AMSANT identified a lack of adequate cross-cultural training for non-Indigenous health staff. They noted that 'there remains a huge gap in cross-cultural understanding amongst mainstream staff resulting in confusion, misunderstanding and, ultimately, poor outcomes in patient care and additional costs to the health system'. They also argued that it should not be expected that Indigenous patients will understand the 'rules' of patient travel, even if they have experienced PATS journeys previously. These rules should be explained 'every time someone is travelling'.[17]

5.17 The difficulty that many Indigenous people have in communicating their needs and concerns in relation to PATS and the health system more broadly was also noted by witnesses. Mr Lines commented:

> Aboriginal people within hospital systems usually lack the power to have a voice regarding their health concerns or their needs. Any issues must be addressed through often unsympathetic non-Aboriginal ways. Aboriginal people do not relate to or identify with paper trails to make complaints… Aboriginal people usually will not sit down and fill out complaint forms. Hence, during the inquiry into patient travel there were only two complaints. When we were out in the region consulting with Aboriginal people in communities in open meetings, there were numerous complaints from Aboriginal people.[18]

Escorts

> Escorts is a particularly cumbersome and inequitable situation across the schemes. The needs of Indigenous people, for example are not met in the current configuration of the scheme, particularly where long term hospitalisation is necessary.[19]

5.18 For Indigenous people, the need to travel for medical treatment can be particularly fraught, and many are fearful and distressed at the prospect of leaving their communities. The Committee received evidence that without an escort Indigenous people chose not to travel:

> Basically they had committee members and members of the community saying that they were just not going to travel any more. They have had so

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[16] *Submission* 74, p.5 (Kimberley Aboriginal Health Planning Forum).

[17] *Submission* 97, pp.3-4 (AMSANT).

[18] *Committee Hansard*, 5.7.07, p.62 (Mr D Lines, Katherine West Health Board).

[19] *Submission* 45, p.4 (Australian Rural Nurses and Midwives).

> many experiences of people who are very physiologically old, if not chronologically old, frail, blind in one eye, do not speak English, all sorts of things, who have ended up getting sent on their own because they were deemed not suitable for an escort by a distant PATS clerk who had nothing to do with them really. It is a terrible experience.[20]

5.19 The Wurli Wurlinjang Health Service similarly reported that the lack of recognition of escorts for cultural reasons 'has resulted in many clients…refusing to travel for essential medical care'.[21]

5.20 A number of submissions noted the inflexible rules in relation to escorts, especially in relation to long-term patients. The Aboriginal Health Council of SA argued there should be 'opportunities for escorts to change over if the stay is medium or long-term and when the escort is required to return to their Communities for family, cultural or work related obligations'.[22] The Kimberley Aboriginal Health Planning Forum stated:

> In many instances, the escort / carer simply requests a break, with a period of time back in their community while another family member temporarily assumes the role. There is no allowance in the guidelines for this situation, with approval being at the discretion of the WACHS Regional Director. This poses an unnecessary administrative burden on the system, and with the lack of assurance of relief, provides a disincentive for escorts to travel in the first instance.[23]

5.21 In a similar vein, the Australian Rural Nurses and Midwives (ARNM) cited the case of Northern Territory Indigenous children requiring high level burns treatment. They must travel to Adelaide as there is not a burns unit in the Northern Territory. The ARNM stated that 'the social and cultural isolation of these patients is profound and exacerbated during long term hospitalisation', yet there is no provision for additional escorts or the 'interchange' of escorts over this extended period.[24]

5.22 The importance of ensuring Indigenous patients have appropriate escorts was seen as a significant part of cultural safety. Concerns were raised that the various PATS guidelines regarding escort eligibility were not adequately fulfilling this role. While the PATS guidelines go some way to providing support, they fall short of what is needed to ensure cultural safety. For example the Patient Assisted Travel Scheme Guidelines in Western Australia provide for escorts on other than clinical grounds but note this is restricted:

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[20] *Committee Hansard* 13.7.07, p.85 (Dr C Nelson, Kimberley Aboriginal Medical Services Council).

[21] *Submission* 29, p.1 (Wurli Wurlinjang Health Service).

[22] *Submission* 76, p.3 (Aboriginal Health Council of SA); see also *Submission* 45, p.4 (Australian Rural Nurses and Midwives).

[23] *Submission* 74, p.5 (Kimberley Aboriginal Health Planning Forum).

[24] *Submission* 45, p.4 (ARNA).

> If the referring medical practitioner specifies that an escort is required for a reason other than a medical reason (for example, social reasons) then eligibility for the escort must be determined by a suitable, clinical health service employee...In determining eligibility for an escort, the age, general health, language barriers, remoteness of residence, exposure to life skills and resources available are to be taken into consideration.
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> Aboriginality and remoteness of residency are not automatic grounds for escort approval. Options such as teleconference or videoconference with a family member, or utilising support services available in Perth should be considered.[25]

5.23 The Kimberley Aboriginal Health Planning Forum argued that it is not appropriate that the decision regarding an escort rests with a hospital or health administrator, who is unlikely to have any first-hand knowledge of the patient and their circumstances.

> Decisions regarding a patient's need for an escort, as well as the choice/ suitability of the escort, are most appropriately made by the regular health care provider(s) in conjunction with patient and family…This applies to all patients needing to travel to a distant site for health care, but has particular importance for Aboriginal clients living in remote communities.[26]

5.24 AMSANT noted that Aboriginal patients often require assistance in dealing with the 'mainstream health system' and 'negotiating travel and accommodation arrangements in regional and large mainstream centres'. AMSANT explained that limited English, unfamiliarity with urban environments and physical frailty all warranted escort approval: 'In such cases there may be the need for an escort, usually from their community and often a close family member, to assist the patient'.[27]

5.25 The Health Consumers Council fervently argued for greater support for Indigenous patients:

> By any measure, Aboriginal people are deeply disadvantaged in health care in this country and we should be making every effort, through every avenue, to ensure that that health care is optimal. If perhaps that means that PATS has to pay for some family members then let’s pay for it. Let’s do it for 10 years. Let’s make the investment and then critically evaluate it and see if it has made some contribution to improving the health care of Aboriginal people.[28]

5.26 In a similar vein, the AMA noted it is important not only that people have a medical escort but also that they have an escort from their own cultural background

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[25] Department of Health, *Patient Assisted Travel Scheme (PATS): 2004 Policy Guidelines*, p.17.

[26] *Submission* 74, p.4 (Kimberley Aboriginal Health Planning Forum).

[27] *Submission* 97, p.3 (AMSANT).

[28] *Committee Hansard*, 13.7.07, p.33 (Ms M Kosky, Health Consumers Council).

who perhaps can ensure that informed consent is provided.[29] The AMA recommended that 'escorts should be permitted for any indigenous patient who is from, or who originates from a remote rural community irrespective of age, English language skills or medical condition'.[30] They reported that the current escort restrictions provide a disincentive to seek treatment:

> Discussion with AMA doctors working in rural areas with a high proportion of indigenous patients have noted that the restriction on more than one escort impacts on the willingness of patients to undergo treatment. The AMA is aware of cases of indigenous patients refusing elective travel to large centres unless a relative or friend accompanies them. Usually PATS will not pay for a person to accompany them unless they are a minor or have a specific medical need for an escort.[31]

5.27 AMSANT suggested that PATS guidelines should be altered so that escorts be offered to: all patients who are being evacuated acutely; all women who are going to 'sit down' awaiting the birth of a child; and all patients who don't have English as their first language.[32]

5.28 Nganampa Health Council, which administers its own PATS, has developed internal guidelines for patient escorts.

> The people we have determined are entitled to an escort are first-time antenates, children under the age of 14, medical emergencies and elderly patients with language barriers. We have a lot of people who fit within those categories. Last year we had 650 escorts, so effectively for every two patients who came in one escort would also come in. It is a high cost for us. As we pay for the transport and accommodation of a patient, we obviously also pay for the transport and accommodation of an escort. If our medical staff had their way, we would expand our policy to allow more escorts. I know, for example, they would like to have an escort for every time there was an antenate who came in, but we do not allow that for funding reasons.[33]

5.29 During hearings it was suggested that Aboriginal health services staff could play a greater role in escorting travelling patients. It was considered that someone clinically involved with the patient may be better able to understand and explain specialist health care to the patient and their community.[34]

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[29] *Committee Hansard* 5.7.07, p.25 (Dr P Beaumont, AMA).

[30] *Submission* 47, p.6 (AMA).

[31] *Submission* 47, p.6 (AMA).

[32] *Submission* 97, p.3 (AMSANT).

[33] *Committee Hansard*, 5.7.07, p.75 (Mr D Busuttil, Nganampa Health Council).

[34] *Committee Hansard* 13.7.07, p.40 (Mr B Charlie, Health Consumers Council).

Transport infrastructure

5.30 The lack of transport options for remote indigenous communities, particularly air transport since Aboriginal Air Services closed in 2006, was a concern raised in a number of submissions. With no air service, patients now have no option but to travel long distances by 'bush bus' or troop carrier to receive treatment, which may be unsuitable for their medical condition. For example the Board of Ampilatwatja Health Centre Aboriginal Corporation noted that 'the people of Walungurru (Kintore) no longer have access to a twice weekly air charter service to Alice Springs…[t]he alternative mode of transport, currently offered under PATS, is a 'bush bus' over largely unsealed roads, a journey that can take up to 8 hours'.[35]

5.31 The Nganampa Health Council noted this lack of air transport was acting as a disincentive to people seeking medical treatment. They commented:

> Since the closure of PY Air, our statistics show a reduction in the number of patients and escorts travelling. Our medical staff are concerned that this fall is caused by the reduction in transportation options, and may mean that patients in need of specialist medical care are not receiving the appropriate treatment.[36]

5.32 The Katherine West Health Board highlighted a number of issues for Indigenous people accessing PATS including 'the lack of appropriate regional transport infrastructure – for air or for buses – a lack of contemporary communication systems at airports; a lack of resources, including funding, to ensure appropriate and safe transport of remote patients; and a lack of priority in the system for Aboriginal liaison officers, interpreters, cultural brokers and Aboriginal clinicians'.[37]

5.33 The Kimberley Aboriginal Health Planning Forum noted that barriers to patient travel existed in 'not just a lack of availability of public transport for patients travelling from remote communities, but also the lack of convenient timetabling of the transport that does exist'.

> For example, women returning to areas such as the Fitzroy Valley or Halls Creek region with a newborn baby following delivery in Broome or Derby Hospital, board the bus late in the evening and arrive at their destination in the middle of the night (Fitzroy) or in the very early hours of the morning (Halls Creek), with no guarantee of being collected off the bus on arrival. This is a source of much distress, both for the travellers and for the health providers knowingly sending them on their way.[38]

5.34 Mr Simon Stafford of AMSANT recommended a flexible approach to providing Indigenous patients in remote communities with transport:

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[35] *Submission* 81, p.2 (Board of Ampilatwatja Health Centre Aboriginal Corporation).

[36] *Submission* 95, p.6 (Nganampa Health Council).

[37] *Committee Hansard*, 5.7.07, p.62 (Mr S Heffernan, Katherine West Health Board).

[38] *Submission* 74, p. 17 (Kimberly Aboriginal Health Planning Forum).

> Consideration should be given to subsidising public transportation, for example some of the bush bus services that exist. Clinics should be allocated funding to cover the cost of the trip. If they set up an efficient system that is cheaper than PATS, they should organise it. Planes should be used if they are cheaper and give an improved health outcome.[39]

Accommodation

5.35 Aboriginal patients often face difficulties accessing accommodation in major centres and where facilities do exist there may be long waiting lists. Aboriginal Hostels Limited (AHL) (owned by the Commonwealth Government) provides a national network of hostels that makes affordable, temporary accommodation and meals available for Aboriginal and Torres Strait Islander people, particularly where there are no other suitable accommodation options. In 2005–06 AHL operated 49 hostels and funded another 71 community hostels providing almost 3,000 beds. One of the target areas of AHL is accommodation and care for patients and families who must leave their remote communities to access medical treatment.[40]

5.36 Problems with accommodation for Indigenous patients were reported in evidence. Ms Michelle Doyle stated:

> …If we have, say, two people or maybe three people in Sid Ross [Aboriginal Hostel], we might also have three RFDS [Royal Flying Doctor Service] evacs. They come into the hospital and they have to be discharged. Where do you put them? We do not have a bed. The hospital then says, 'We're not keeping them.' Where do they go? They usually end up on the street. We try the best we can and most of ours get accommodated but the ones who do not will either end up on the street, in the creek or at the camps, which again is setting them up to fail. If you set them up to fail, they will fail.[41]

5.37 Mr Brian Charlie of the Health Consumers Council reported that:

> When talking to Aboriginal Hostels Ltd about availability of accommodation and about what they can do to secure further accommodation, I find that they are booked out three months in advance with PATS in most cases. Because of the influx of patients they now have a policy about how long a patient can stay so that they can accommodate other patients. There is no room for long-term patients to stay within those facilities…[42]

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[39] *Committee Hansard*, 5.7.07, p.60 (Mr S Stafford, AMSANT).

[40] Aboriginal Hostels Limited, *Annual Report 2005-2006*, p.1.

[41] *Committee Hansard*, 5.7.07, p.32 (Ms M Doyle, Ngaanyatjarra Health Service).

[42] *Committee Hansard*, 13.7.07, p.34 (Mr B Charlie, Health Consumers Council).

Continuity of care

5.38 The problems with continuity of care for Indigenous patients were highlighted by the disappearance and subsequent death of an elderly patient from Daguragu being transferred from Katherine Hospital to Kalkaringi in August 2006.

> In August 2006 an old man living at Daguragu Community (9kms from Kalkaringi Community) was acutely unwell and attended the Katherine West Health Board Clinic at Kalkaringi. He was treated and subsequently evacuated by the Northern Territory Air Medical Service to Katherine Hospital. He recovered from his illness in hospital and his transport back to Kalkaringi was arranged by the Katherine Hospital Patient Travel Office.
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> The old man was transferred via an Aboriginal Air Charter flight from Katherine to Kalkaringi. He was notified as being missing to the police three days later and a search was instigated. The search was called off after a further three days. The deceased body of the old man was found seven days after he had gone missing, some 800 metres from the Kalkaringi airstrip.[43]

5.39 In the subsequent review initiated by the Katherine West Health Board and Department of Health and Community Services, a number of key factors were identified as contributing to the death of the patient. These included the lack of an escort; the lack of well documented systems to ensure the safe completion of episodes of patient travel; ad hoc systems of communication between the patient travel system and the regional health service and the delay in the realisation of, and response to, the disappearance of the patient.[44]

5.40 While there was the comprehensive review of the circumstances of the incident, the Committee heard evidence that concerns still existed. Ms Roslyn Frith of the Katherine West Health Board stated:

> It is 2007. When are we going to be treated as equal to everybody else? We want the system to work for us, just like it works for anybody in the big cities. But it does not. It has been revealed that it is going to be made better, but only two weeks ago the same thing occurred – a patient was left and no arrangements were made for her to be picked up and taken to where she was supposed to go. We have to look hard at the system.[45]

5.41 The Committee was also very troubled to hear of similar incidents where Indigenous patients suffered through a lack of communication and/or continuity of care in their travel assistance. Dr Carmel Nelson, Medical Director of the Kimberley Aboriginal Medical Services Council described another situation:

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[43] *Submission* 3, p.5 (Katherine West Health Board).

[44] *Submission* 3, p.5 (Katherine West Health Board).

[45] *Committee Hansard*, 5.7.07, p.64 (Ms R Frith, Katherine West Health Board).

> In the Katjungka, because it is one of those places that had the extreme end of PATS disasters, we have accumulated a gigantic list of absolute disasters, including somebody ending up completely blind. He returned from Perth but no-one knew he was being discharged. He had ocular antibiotic medication that he was instructed to take, but he did not understand the instructions. He lost the medication on the way home. He ended up getting stuck in Halls Creek, but nobody knew that he was there so nobody knew to be looking out for him. He ended up with a very severe infection in the eye and lost the eye.[46]

5.42 Ms Janice Hillenbrand for Sir Charles Gairdner Hospital described a similar occurrence:

> I have an example of an Indigenous chap who came from the bush. It was set up that he would fly down and when he got to the airport he said, 'What do I do now?' Nothing was explained to him so that he understood it. He came on his own with no-one to support him; hence at the airport he disappeared for six weeks…They finally found him in a park. He had renal failure, he had an ulcer on his spine and he had pneumonia…He was then brought to hospital, put into rehab for a long time and he is now a quadriplegic through that.[47]

5.43 One issue arising from the incident of the man who died in Kalkaringi was that a 'grey area' of responsibility for Indigenous patients travelling existed between the hospital and the local health organisation or community.[48] In a number of submissions the importance of communication, continuity of care and liaison between organisations was highlighted as crucial to patient safety.

5.44 Ngaanyatjarra Health Service noted their patient travel service emphasised continuity of care. Ms Doyle stated that 'we own them [patients] from the minute they get on the plane to the minute they get off the plane to the minute they have their appointment and go back'.[49] Mr Simon Stafford of AMSANT stated:

> Resources need to be provided in order for travelling patients to be given detailed explanations of the arrangements to avoid problems. We have heard about people being left on the side of the road with a bus coming through. You end up at the bus station but no-one has told you that you have actually then got to get a taxi to the hospital and things like that. It has to be detailed. Resources need to be provided for comprehensive programs for liaison officers for all travelling patients, especially for the interstate

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[46] *Committee Hansard*, 13.7.07, p.87 (Dr C Nelson, Kimberley Aboriginal Medical Services Council).

[47] *Committee Hansard*, 13.7.07, p.58 (Ms J Hillenbrand, Sir Charles Gairdner Hospital).

[48] *Submission* 3, p.29 (Katherine West Health Board).

[49] *Committee Hansard*, 5.7.07, p.35 (Ms M Doyle, Ngaanyatjarra Health Service).

> trips. It is quite frightening for people to move out of community, let alone to move into a different state.[50]

5.45 The NT Government reported that there were 'practical issues' that need to be worked through in respect of continuity of care for Indigenous patients. There were differing degrees of control which health services had over the care of patients.[51] Dr Lucy Firth of the NT Department of Health and Community Services noted:

> …these people are free citizens; they are not under our custody. They have been under our care while they have been sick, but the fact that they are being sent back typically means that they are now fairly well…We cannot stop people getting off the bus 20 kilometres either side of where they are supposed to go, and we certainly cannot arrange for Greyhound not to proceed until they are sure that someone has been picked up beside the road at quarter to four in the morning. We cannot tell Qantas that they cannot continue. The practical issues are going to take quite a lot of working through. Except for the ideal, we have not bedded them down.[52]

5.46 Mr Peter Campos of the NT Department of Health and Community Services noted:

> We are working with Katherine West and the rest of the communities, whether we run the health service or it is run by the community controlled sector, to make sure that there is a very clear line of contact for the person leaving their community, receiving care and returning, particularly if they are vulnerable. [I]n those instances where a patient's abilities are compromised, we have all got a responsibility to make sure that the person is in safe hands all the way through.[53]

No Shows

5.47 The costs, inefficiencies and health risks of Indigenous patients not attending health appointments were highlighted. Not attending medical appointments was recognised as compromising patient care and health outcomes, sometimes endangering the lives of patients. There were also long-term consequences for patients as they could be pushed down waiting lists for necessary specialist treatment.[54] The Anyinginyi Health Aboriginal Corporation provided a case study:

> A few years ago a woman in a remote Central Australian community was identified with a lump in her breast. She was offered a specialist consultation on a couple of occasions but did not show for those

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[50] *Committee Hansard*, 5.7.07, p.59 (Mr S Stafford, AMSANT).

[51] *Committee Hansard*, 5.6.07, p.57 (Mr P Campos, Department of Health and Community Services).

[52] *Committee Hansard*, 5.6.07, p.57 (Dr L Firth, Department of Health and Community Services).

[53] *Committee Hansard*, 5.6.07, p.42 (Mr P Campos, Department of Health and Community Services).

[54] *Committee Hansard*, 5.7.07, p. 2 (Ms M Doyle, Ngaanyatjarra Health Service).

> appointments. It was reported that she had a fear of flying but no alternative was considered. She died prematurely, the death becoming a coroner's case. More cultural sensitivity and awareness in the management of specialist care for this woman would most likely have resulted in a different outcome.[55]

5.48 The cancellation of urgent medical appointments and procedures was also linked to the lack of transport and accommodation facilities for Indigenous patient in rural and remote areas.[56] The financial burdens of missed transport arrangements and medical appointments to the health system were also raised. Mr David Lines of the Katherine West Health Board noted that:

> Often patient travel clerks get very frustrated when there are no shows. It costs a fair bit of money and a fair bit of time goes into organising and coordinating appointments, planes and buses et cetera. There are also a lot of cultural reasons – things happening within the community – that prevent them from going to their appointment. They can have a very serious illness but if something goes wrong culturally in that community they are obligated to address that as a priority before going into town for a health appointment…[57]

5.49 Cultural safety and informed consent were seen as crucial to reducing 'no shows' for Indigenous patients by several witnesses. AMSANT commented:

> When an Aboriginal person makes that decision it is often done collectively – for instance, the family may be involved. We need to realise that is part of doing health business, rather than just turning up and saying, 'Here you are. This is what is going to happen. If you don't want it, don’t take it.' Often people think, 'I am not going to take it. I don’t understand it.'[58]

5.50 AMSANT argued that more focus on cultural safety and ensuring that Indigenous patents had the opportunity to exercise informed consent would reduce the number of 'no shows'.

> This might require extra trips to travel back to their homeland before returning for treatment. Doing so would obviously involve additional expense, however, in the long-run it would be more cost-effective because there would be less 'no shows' and less 'absconding' and 'non-compliance'. It would also have benefits in terms of better health outcomes through improved 'compliance' with treatment. Patients who do not attend appointments are usually not rejecting the treatment, they are simply responding to inadequate processes that offer them only a 'take-it-or-leave-

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[55] *Submission* 160, p.5 (Anyinginyi Health Aboriginal Corporation).

[56] *Submission* 29, p. 2 (Wurli Wurlinjang Health Service).

[57] *Committee Hansard*, 5.7.07, p.70 (Mr D Lines, Katherine West Health Board).

[58] *Committee Hansard* 5.7.07, p.70 (Mr S Stafford, AMSANT).

> it' option while denying them control over decision-making about their own health.[59]

Liaison

5.51 Increased patient liaison and better communication between healthcare personnel and organisations was seen as crucial to ensure continuity of care for Indigenous patients and to reduce 'no shows'. AMSANT highlighted the role of liaison officers in meeting and assisting Indigenous patients to avoid 'patients getting lost in the system or giving up'. Ms Anne Butler of the Barambah Regional Medical Service argued for a better referral and communication system between health services for country clients. She noted:

> It is a big ask for a sick individual and Country Health organisations to arrange and organise people to receive the health care they need and are entitled to. The referring health organisation also needs to be informed of ongoing treatment and future appointments as the health organisations are the ones that will arrange and inform the clients of their next visit to specialist services.[60]

5.52 The Anyinginyi Health Aboriginal Corporation stated that 'frequent occasions of miscommunications resulting in people failing to keep appointments or manage travel arrangements'.

> Communications and coordination between Alice Springs Hospital and Tennant Creek Hospital and with NGO's is very poor. Dates and times of departure and arrival are often wrong or not included in instructions. A similar situation often occurs with inter-hospital transfers further complicating the situation and resulting in compromised or no care being provided.[61]

5.53 The Committee was impressed by the results of a pilot Remote Area Liaison Nurse service for Indigenous cardiac patients in Northern Territory and its potential for benefits in other Indigenous health areas. During a six month period over 2004-2005, 21 patients out of 48 scheduled for cardiac surgery at a major metropolitan tertiary care were 'no shows'. These 'no shows' risked the patient's safety and the health care system lost the opportunity to use that operating time for another patient, disadvantaging both the system and the potential surgical patient.

5.54 The pilot Remote Area Liaison Nurse position established links with communities, Aboriginal health workers and key care providers and explored gaps in the cardiac care process. The pilot included 'mentoring in community to support the appropriate pre-admission and assessment interventions including patient/community education, informed consent and medication management' and 'improved

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[59] *Submission* 97, p.3 (AMSANT).

[60] *Submission* 100, p.1 (Barambah Regional Medical Service).

[61] *Submission* 160, p.3 (Anyinginyi Health Aboriginal Corporation).

opportunities to negotiate patients' choice of appropriate carer/escort depending on the nature of the surgery'.[62]

5.55 A number of positive outcomes were achieved ensuring additional patient safety, reducing travel costs and the incidence of unnecessary travel including zero 'no shows' in the first half of 2007. The researcher, Ms Monica Lawrence, indicated the pilot model could also be used for Indigenous patients accessing other specialty services such as oncology care, renal dialysis, ophthalmology and neonatal care.[63] She emphasised the importance of continuity of care and liaison between health organisations:

> …we should try to get all the key care providers involved from the remote area health clinic, PATS, the metropolitan teaching hospital, and the community – a primary to tertiary back to primary healthcare transfer of knowledge. If we can facilitate that, then we are bound to continue with those good outcomes.[64]

5.56 The pilot model is now being developed into a sub-acute 20 bed Indigenous step up/step down services through the *Pathways Home* program.[65]

5.57 In Western Australia, a newly established 'Meet and Assist' program provides information and support to Indigenous and non-Indigenous patients arriving Perth from remote locations. The program is intended to ensure that patients are 'directly assisted to present at scheduled appointments and…that post-treatment protocols are communicated to patients in a linguistically, and culturally, appropriate manner'.[66] Ms Christine O'Farrell of the Western Australian Country Health Service explained:

> The percentage of these difficult patients is actually quite small, but in fact they take up the largest amount of time. The biggest resource is the social work and packaging, arranging travel, scheduling appointments and so on for those people. Of course the costs are high, but they are the people who are in most need of the escorts. The reason we have put this meet-and-assist service into our Perth centre is to try to coordinate the arrangements and provide a really experienced, competent, on-the-job all the time, very responsive, flexible service to try to help people both at the regional level and also in the metropolitan area make things work for that particular group of patients.[67]

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[62] *Submission* 98, pp.2-3 (Ms M Lawrence).

[63] *Submission* 98, pp.2-3 (Ms M Lawrence).

[64] *Committee Hansard*, 6.7.07, p.21 (Ms M Lawrence).

[65] *Submission* 98. Additional Information, 16.9.07 (Ms M Lawrence).

[66] *Submission* 39, p.5 (WA Government).

[67] *Committee Hansard*, 13.7.07, p.4 (Ms C O'Farrell, WACHS).

A separate program for Indigenous Australians?

5.58 Witnesses supported the need for additional assistance to Indigenous patients from rural and remote areas. For example Aged & Community Services Australia argued that '…it is appropriate that additional assistance be given to Indigenous people in remote communities, such as reduction in the required distance for travel when there is no public transport, and 'topping-up' of assistance payments when they have no resources to add to the subsidy received'.[68]

5.59 During the hearing in Alice Springs the issue of a separate patient travel scheme for Aboriginal and Torres Strait Islander peoples, in order to provide a more culturally appropriate service, was raised. Examples were given of where community controlled health organisations had 'cashed-out' or more directly administered patient travel funding for their community. The Katherine West Health Board noted:

> There are different circumstances for Aboriginal people. The separate system means that people who know about those circumstances have to be in charge, not people who want the best for Aboriginal people but who cannot see the issue.[69]

5.60 The possibility of reducing the administrative burden of PATS on community clinics was also raised. Mr Simon Stafford of AMSANT stated they had 'doctors who end up doing two hours a day filling out PATS forms…not an effective use of doctor time'.[70] Urapuntja Health Service indicated they would look at a 'cashed-out' system for their community as they saw administrative benefits.

> I would have thought that there would be an advantage in simplifying the whole system so that everybody was cashed out for PATS travel. It would reduce the load on us in filling out forms all the time and I am sure it would reduce the load on the hospital.[71]

5.61 However it was also noted that the Katherine West Health Board had accepted a cashed-out system but had handed it back. They commented:

> …if we were going to accept a cashed-out system, we would have to be very sure that we had adequate controls and mechanisms in place and appropriate funding so that it did not become a cost-shifting exercise three or four years later when the funding for it will not keep up with the need.[72]

5.62 Cost-shifting was also seen as a risk. It was noted that clinics should not need to use their primary healthcare funding to provide transport for patients with medical

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[68] *Submission* 58, p.6 (Aged and Community Services Australia).

[69] *Committee Hansard*, 5.7.07, p.67 (Mr S Heffernan, Katherine West Health Board).

[70] *Committee Hansard*, 5.7.07, p.61 (Mr S Stafford, AMSANT).

[71] *Committee Hansard*, 5.7.07, p.63 (Mr R Blackburn, Urapuntja Health Service).

[72] *Committee Hansard*, 5.7.07, p.67 (Mr S Heffernan, Katherine West Health Board).

needs. The Nganampa Health Council, which has 'cashed out' their PATS, reported funding problems:

> Ours is cashed out from the South Australian government – and that does cause us problems. Obviously, if extra patients come in, we do not get any extra funding. If the price of a bus ticket rises – three years ago they were $35 and now they are $90 – we do not get any extra funding. That effectively adds extra pressure on our other programs.
>
> We note with interest that the South Australian government submission to this inquiry shows that since 2003-04 their expenditure has increased by 36 per cent on the PATS program. It is worth noting that we have not got one cent of that increase because we have cashed ours out.
>
> With regard to finances, in the 2005-06 financial year we spent $640,000 on PATS. The funding we got from the state government was only $500,000. That was a deficit of $140,000. If you look at it over the past decade, our deficit in this program is over $1 million. It is easily our most underfunded area and our most problematic area. It has been suggested to us in the past that maybe we should look to charge our patients when they come in. I read in the paper recently that the latest census shows that the median weekly income for people on our lands is $219 a week, so I do not see that as a realistic option.[73]

5.63 Some attempts have been made by State and Territory governments to tailor their patient travel schemes to better assist Indigenous patients. Several jurisdictions have specific programs to assist Indigenous people from rural and remote areas who need to travel to access specialist health care.

> For Indigenous patients in the NT and SA, for example, travel and accommodation are arranged in advance by specific units, and at the hospital to which the patient is referred there are Aboriginal Liaison Officers who can help with paperwork, if necessary, and may pass on the relevant forms to the administrator of the scheme. In NSW, Aboriginal health organisations may transport eligible Indigenous patients to specialist appointments in major centres, and can claim travel and accommodation assistance directly on behalf of their clients. Such initiatives are to be applauded and should be adopted by all states and territories, along with promotions to enhance program and eligibility awareness.[74]

5.64 In South Australia, the Aboriginal Step Down Service is a transport and support service for Aboriginal people from rural, remote areas and interstate who come to Adelaide to access specialist medical services within the hospital settings. Transport is provided from the Adelaide airport, bus stations and train terminals to booked accommodation and medical appointments for patients and approved escorts from country and interstate areas.[75]

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[73] *Committee Hansard*, 5.7.07, p.75 (Mr D Busuttil, Nganampa Health Council).

[74] *Submission* 58, p.6 (Aged and Community Services Australia).

[75] *Submission* 76, p.9 (Aboriginal Heath Council of SA).

5.65 The Victorian Government is piloting a modified version of VPTAS to suit the particular needs of the Koori community.

> The social work departments of four Victorian hospitals have been provided with grants of $5,000, specifically to be used for Koori patients who meet the VPTAS guidelines and are attending the hospital for treatment. Claim details are recorded and assessed by social work staff and eligible Koori applicants are provided up front payment for their travel home from the hospital, with travel to the hospital being arranged via the patient's local Aboriginal Cooperative.[76]

Conclusion

> Our vision for the future is health outcomes and health services for Aboriginal and Torres Strait Islander peoples equal to that of the general Australian community.[77]

5.66 The Committee was extremely troubled to hear that health access issues are particularly pronounced for Indigenous Australians. The relatively high rate of Indigenous peoples living in remote communities away from health services, their poorer health status and barriers to obtaining culturally sensitive health care mean that improving Indigenous access to health services must take priority.

5.67 The Committee notes that State and Territory Governments have recognised the barriers facing Indigenous patients and have sought to implement improvements to travel schemes. However, the Committee considers that further improvements are required including improving availability of escorts, enhancing access to appropriate accommodation, improving links with Indigenous communities and Aboriginal health workers and improving co-ordination of transport and health services. This will ensure that Indigenous people are able to travel to specialist medical centres knowing that they will be supported by an appropriate person, have their travel and accommodation arrangements in place and return to their communities in a similar way with a discharge plan including appropriate medications and ongoing patient monitoring. The Committee considers that improved patient travel assistance for Indigenous patients will not only improve their health outcomes but also provide benefits for the health care system by decreasing the number of 'no shows' and re-admittances.

5.68 As already stated, the Committee was impressed by a number of programs currently in place which have been successful in improving access by Indigenous patients. These included the pilot Remote Area Liaison Nurse service in South Australia, the 'Meet and Assist' program in Western Australia and the work of a number of Aboriginal Health Services which emphasise continuity of care. The

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[76] *Submission* 182, p.10 (Victorian Government).

[77] Commonwealth Department of Health and Ageing, http://www.health.gov.au/internet/wcms/publishing.nsf/Content/Indigenous+Health-1lp (accessed 17.9.07).

Committee believes that governments should examine these programs and develop their own services in a similar way to improve access across Australia.

5.69 A recommendation to address this is included in chapter 7.

Ante-natal care

5.70 Associate Professor of Midwifery Sue Kildea of Charles Darwin University stated that reproductive health outcomes for women living in remote areas of Australia are poor by national standards with families from these areas experiencing 'higher rates of maternal and perinatal mortality and morbidity'. She noted this has 'significant immediate and long-term costs to the community and the health care system'.

> Increasingly over the last 40 years, women living in remote areas of Australia have been relocated from their homes to birth in larger hospitals and larger communities. Many remote areas across Australia no longer have the infrastructure, staff or insurance cover to support on-site birthing…In many instances women are required to travel long distances for the birth of their babies and this is causing financial hardship and social disruption. Typically, pregnant women will leave their homes between 36-38 weeks gestation to await birth, usually alone. The facilities in these settings vary but are often very simple…Most women do not have the capacity to take their children with them…Partners, if they want to attend the birth also have to give up work to go and sit in the regional centre.[78]

5.71 Associate Professor Kildea argued that given the research showing the benefits of the 'constant presence of a supportive birth companion' to women during childbirth, all women should have an escort of their choice paid for by the PATS system.[79]

5.72 As noted in chapter 2, the availability of obstetrics services in rural and remote areas has declined. In many areas pregnant women and their families have to relocate for an extended period prior to the birth. This required expectant mothers to seek accommodation for extended periods and illustrated the need for PATS to be flexible.[80] Dr Peter Beaumont of the Australian Medical Association stated:

> We have decided in Australia that it is safer for mothers and new born babies to travel to large centres where they can receive safer health care than they can in their homes or communities. We do not have the means in Australia to have flying squads and other such groups of people going out and assisting women in labour or new born babies even in big cities. In a situation where the model of care is decided on aggregating these people into major hospitals, we should be facilitating that by refunding them.[81]

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[78] *Submission* 147, pp.1-2 (Assoc. Prof. S Kildea).

[79] *Submission* 147, p.3 (Assoc. Prof. S Kildea).

[80] *Committee Hansard*, 22.6.07, p.2 (Mr G Gregory, NRHA).

[81] *Committee Hansard*, 5.7.07, p.25 (Dr P Beaumont, AMA).

5.73 However the Rural Doctors Association of Australia argued that the focus should be on providing services close to rural and remote communities. A paper provided with their submission noted '…that small rural maternity units have obstetric outcomes which are at least as good as those in large metropolitan hospitals, even allowing for the transfer of high risk patients to tertiary centres'.[82] Mr Steve Sant proposed:

> We need to fix that workforce problem and not put in place a solution which, as I said, is second-rate around moving mothers 400, 500, 600 kilometres to a different centre…for us the main issue is workforce in relation to obstetricians and obstetrics and gynaecology. We must improve the workforce. We must train more GP obstetricians. We must reopen those units that have closed in the last 10 years so that mums and families can access those services in their local communities.[83]

5.74 In relation to escorts, Ronald McDonald Charities noted that there was 'inconsistent decision-making when it comes to ante-natal & post-natal patients and their partners'. They continued:

> Some branches of the Travel Scheme cover partners, some don't. There is also inconsistent interpretation of when cover ends that is, either when the mother is discharged from hospital or the birth of the baby.[84]

5.75 The problems for expectant women living in remote areas were perhaps best illustrated by the situation of women living on Christmas and Cocos Islands.[85] Because of the remoteness of their location and the lack of facilities, expectant mothers on the Islands are required to fly to Perth four weeks prior to the birth and stay for another two weeks after. While escorts were allowed, other children were not provided with airfares. Because of fears and concerns regarding the stress of travel and accommodation in Perth, some women were travelling to other countries to give birth.

> Island women want to be empowered in the birth process. They want to be able to give birth where they choose and not to be disadvantaged financially and emotionally because they live in a remote location.[86]

5.76 One solution suggested was the provision to families of a one-off pre-payment of PATS funding for the birth of children 'calculated based on a percentage of the real

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[82] Rural Doctors Association of Australia, *Preventative Healthcare and Strengthening Australia's Social and Economic Framework*, January 2005, p.14.

[83] *Committee Hansard*, 22.6.07, p.5 (Mr S Sant, Rural Doctors Association of Australia).

[84] *Submission* 137, p.7 (Ronald McDonald Charities).

[85] PATS for Christmas and Cocos Island is administered by the Commonwealth Department of Transport and Regional Services.

[86] *Submission* 70, p.11 (CA Thompson & Associates).

and current costs of travelling and relocation'. This would assist with the costs of food and accommodation.[87]

Older people

5.77 In 2005, the House of Representatives Committee on Health and Ageing in its inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years noted the difficulties for the elderly in relation to patient transport. They commented:

> Health-related transport is one area where door to door service would be ideal. Early discharge, attendance as outpatients, day treatment at doctors' surgeries mean that older people must travel more frequently for health care, often under circumstances when they require support while travelling. Older people in small rural towns may have to travel some distance for health services they often depend on the dwindling availability of volunteer transport and drivers – which makes keeping healthy even more difficult.[88]

5.78 These comments were repeated in a number of submissions to the inquiry. The National Aged Care Alliance argued that 'the quality of older people's health is inextricably linked to their capacity to get transport to health services'.[89] Aged and Community Services Australia noted that early discharge from hospitals, attendance at outpatients and day treatment at doctors' surgeries means that older people must travel more frequently for health care, often under circumstances where they require support while travelling.[90] They continued:

> As the population ages, more people from rural and remote areas will require assessment and/or treatment at distant primary health and specialist facilities (especially given the loss of many local health services, and the move towards reduced length of stay which, for older people, is associated with increased episodes of care). Travel assistance schemes will become even more important in reducing barriers to accessing health care.[91]

Dementia

5.79 A growing number of older patients with dementia were seen as an important group requiring special assistance. The National Aged Care Alliance noted 'a massive explosion in the incidence of dementia…200,000 people have now been diagnosed with dementia, and that number is increasing at the rate of 50,000 to 70,000 a year'.[92]

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[87] *Submission* 70, p.10 (CA Thompson & Associates).

[88] House of Representative Standing Committee on Health and Ageing, *Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*, March 2005. pp.56-57.

[89] *Submission* 32, p.3 (National Aged Care Alliance).

[90] *Submission* 58, p.6 (Aged & Community Services Australia).

[91] *Submission* 58, p.3 (Aged & Community Services Australia).

[92] *Committee Hansard*, 6.7.07, p.10 (Dr P Ford, National Aged Care Alliance).

They described some of the challenges facing older patients with dementia and their carers.

> The length of time waiting for either the public or community transport often adds to the confusion of the person with dementia. This group of people are commonly considered to be unsuited as passengers in public or community transport and in taxis…They are considered to be unfit to drive from an early stage of the disease. Many people with dementia are cared for by ageing family members who may themselves have difficulty accessing transport. However, they require a range of health services frequently, whether living in the community or in residential care. The increased prevalence of dementia and lack of access to health care as a result of a lack of transport services will be likely to result in premature access to long term residential care and emergency care in hospital costs.[93]

Public transport

5.80 Several submissions noted that in rural and remote areas public transport infrastructure is minimal. The National Aged Care Alliance identified the lack of public transport options as resulting in responsibility of transporting older people falling to 'family, friends and volunteers' or alternatively 'overworked health and aged care staff'. The National Aged Care Alliance stated:

> If an older person does not live close to a public transport route, and is not able to drive or be driven to a route, public transport becomes inaccessible for them. The condition of footpaths and walkways, and fall hazards such as uneven pavers and tree roots, can restrict access even for ambulatory older people. Access is further limited for those using aids such as walking frames, and for people with poor continence.
>
> While older passengers are likely to pay reduced fares for public transport, the cost can be prohibitive when many trips are required (eg. to travel to a number of health services over a period of time that is not covered by a single fare). If an older person goes to their doctor, then needs to go for tests or x-rays, and needs to return to the General Practitioner, the cost of fares as well as accessibility and time can be prohibitive.[94]

5.81 Aged and Community Services Australia also noted that in general under most patient travel schemes 'taxis to and from airports are not covered when public transport is available, leaving aged and infirm patients to negotiate public transport links and timetables'. They proposed schemes should be amended to cover these costs and lack of ease to health services is 'recognised as a disincentive to patient attendance at essential health care, especially for aged patients'.[95]

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[93] *Submission* 32, p.6 (National Aged Care Alliance).

[94] *Submission* 32, p.9 (National Aged Care Alliance).

[95] *Submission* 58, p.5 (Aged & Community Services Australia).

Patients with chronic illnesses

5.82 In November 2005 the Australian Health Ministers' Conference (AHMC) endorsed a national strategic policy approach to manage and improve chronic disease prevention and care in the Australian population. The *National Chronic Disease Strategy* noted that despite 'Patient Assistance Transport Schemes to help rural and remote area residents access specialist services…greater support is needed for people who need to travel to obtain treatment, as well as their families and carers…' It stated that '[f]urther innovation and more collaborative solutions to access problems must be found to ensure that all people in need of chronic disease prevention and care have timely access to appropriate services, irrespective of where they live in Australia'. [96]

5.83 Patients with chronic illnesses in rural and remote areas often face additional burdens due to the prolonged nature of their conditions, not reflected in patient assisted travel schemes. Witnesses frequently commented on the cost of frequent travel. For example Breast Cancer Network of Australia (BCNA) argued that the distance eligibility guidelines in many jurisdictions did not take into account 'women who travel significant distances for radiotherapy over the course of five to six weeks but who are not eligible for assistance because their daily travel falls short of the minimum distance required'. Instead it would be fairer if patient travel assistance schemes 'could take into account an average distance travelled per week for a minimum number of weeks'.[97]

5.84 Some State governments have schemes which are more appropriate for the needs of patients with chronic disease who need to travel. In Western Australia the petrol subsidy provided rises from 13c/km to 15c/km for patients who need to travel frequently. In Victoria patients are eligible for assistance if they are travelling an average of 500 kilometres per week for five consecutive weeks or more for block treatment (see further chapter 3). Patients with chronic disease also raised the lack of eligibility for clinical trials under PATS. Access to clinical trials is discussed in chapter 7.

Kidney patients

5.85 Chronic kidney disease patients require dialysis treatments, usually three times per week, carried out in hospitals or satellite community units. Because of the nature and frequency of treatment people with chronic kidney disease have a particular burden in relation to their travel and accommodation requirements.

5.86 The issue of eligibility for live organ donors under patient travel schemes was raised by Kidney Health Australia. Live organ donors are particularly important because of an inadequate supply of deceased organs for transplantation. Kidney

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[96] National Health Priority Action Council (NHPAC) (2006), *National Chronic Disease Strategy*, Department of Health and Ageing, Canberra, p.32.

[97] *Committee Hansard*, 6.7.07, p.26 (Dr Wei Leng Kwok, Breast Cancer Network Australia).

Health Australia noted that 'living donors often receive no compensation for their travel, accommodation, medical costs or loss of income'.[98] They stated:

> Following the first year after a kidney transplant, there can be a saving of $60,000 to $70,000 per year to the health system. This should indicate to the health system planners and policy makers, that it would be a cost effective strategy to support people who are willing to donate their kidney by completely subsidising their transport and accommodation for this procedure.[99]

5.87 Kidney Health Australia also noted that while Country Health in Western Australia had addressed the issue with a specific policy there were practical problems for patients and live organ donors living in different states jurisdictions. They recommended that live organ donors and the carers 'should be considered patients for the purpose of the PATS and their travel costs and accommodation that enable a live kidney donation should be completely covered by all patient assisted travel schemes, irrespective of the state in which they live, and the state in which the recipient lives'.[100]

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[98] *Submission* 68, p.9 (Kidney Health Australia).

[99] *Submission* 68, p.3 (Kidney Health Australia).

[100] *Submission* 68, p. 5 (Kidney Health Australia).