CHAPTER 3

PATS DESIGN AND ADMINISTRATION

> *It has been evident that since 1987 different states and territories have administered PATS in many different ways, and there has never been sufficient money in state/territory health budgets to adequately meet the demand for PATS in context of the needs and comfort of patients. One of the consequences of this lack of coordination is the 'patchwork quilt' nature of the way in which PATS is administered around the country.*[1]

3.1 While the design of PATS schemes varies in each jurisdiction, a number of issues common to all schemes emerged during the inquiry. These issues included problems with the application process, eligibility requirements including distance thresholds, patient support provisions and subsidy levels. The following provides an overview of the myriad issues that were raised in evidence and points to the difficulties faced by many people in accessing adequate medical care.

3.2 The Committee has not attempted to identify issues within each jurisdiction but rather highlight the major concerns presented by witnesses. It is clear from the evidence discussed below that the various schemes – be it through poor information, unclear and/or complex guidelines or inconsistent application – present considerable challenges for consumers and health practitioners.

The application process

3.3 When a person from a rural or remote area is diagnosed with a medical condition that requires treatment at a major centre, they may be informed that they can receive some assistance from government to help with their travel and/or accommodation costs. However, witnesses argued that at a time when the patient is dealing with a significant crisis and in great need of support, they are often faced with an inflexible and overly bureaucratic system to access financial assistance.

Complexity

3.4 The Committee received many complaints about the complexity of the forms used in some jurisdictions and the imposition that completion and authorisation of the form places on both the patient and their medical practitioner:

> Authorisation of the form is an issue with each state having varying processes and restrictions. Authorisation by a medical officer creates limitations for consumers accessing the scheme.
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> As stated by a Rural Director of Nursing "filling out PATS forms is a nightmare no matter how much training is offered. This issue would be the

1 *Submission* 27, p.2 (Cancer Voices WA).

> most time consuming factor of managing the process, as in order to assist the clients to what they are entitled to we have to frequently ring/return forms for clarification. GP and the specialist are no better at this and in fact often leave it to nursing staff".[2]

3.5 The Cancer Council Australia pointed to a study which showed that even dedicated staff directly responsible for PATS administration found the system difficult. In one jurisdiction 80 per cent of staff experienced some degree of difficulty working through the procedures.[3] A consultative study of rural doctors in 2006 by the WA Centre for Remote and Rural Health found PATS to be a major frustration for GPs.[4] This study also commented that 'doctors have reported that in some circumstances the administration of the system has contributed towards poor clinical care'.[5]

3.6 Witnesses described the application process as time-consuming, and – for already over-stretched rural GPs – time-wasting.[6] In many rural areas it is becoming increasingly difficult to secure an appointment with a GP and the need to repeatedly fill out complex paperwork places pressure on the patient and the GP. It was argued that form filling results in an unnecessary cost to Medicare as some rural GPs require a separate appointment to complete the PATS form.[7] The shortage of GPs means that in some areas there is a two week wait for a non-urgent appointment to have a travel form completed.[8]

3.7 Some PATS forms are long and complex. For example, the Southern Queensland Rural Division of General Practice noted that the Queensland form had grown from a single A5 page to five A4 pages in the last 10 years.[9]

3.8 The burden on patients is also high. In one case presented to the Committee, a patient had to undertake a round trip of 220 kms to have the PATS form filled out by their GP before taking the 1400 km round trip to Brisbane.[10] Patients may only be able to access a doctor at the local hospital and may have to wait for the doctor to become available. Palliative Care Australia provided the following case:

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2 *Submission* 45, p.3 (Australian Rural Nurses & Midwives).

3 *Submission* 109, p.8 (Cancer Council Australia).

4 WA Department of Health, *Engaging Rural Doctors Final Report 2007*, pp.11, 31.

5 WA Department of Health, *Engaging Rural Doctors Final Report 2007*, pp.11, 31.

6 For example, see *Committee Hansard*, 6.8.07, p.4 (Dr E Roos, Southern Queensland Rural Division of General Practice); *Submissions* 31, p.1 (Isolated Children's Parents' Association of NSW); 34, p.12 (Hay Shire Council); 69, p.4 (Health Consumers of Rural and Remote Australia); 103, p.3 (Queensland Rural Women's Network).

7 *Submission* 4, p.1 (Yorke Peninsula Division of General Practice).

8 *Submission* 31, p.4 (Isolated Children's Parents' Association of NSW).

9 *Submission* p.2 (Southern Queensland Rural Division of General Practice).

10 *Submission* 124, p.1 (Mrs C McLean).

> Bill lives in a remote community with a small community hospital. He needs to travel to a regional centre to receive palliative chemotherapy. In the absence of a general practitioner, patients wishing to access PATS must have the form signed by a doctor at the hospital. Bill can wait up to eight hours for a doctor to sign each PATS form. On occasion, nursing staff may authorise the form, even though this is not permitted under the PATS arrangements.[11]

3.9 In some jurisdictions both the referring GP and the specialist are required to sign the form: 'It is a very cumbersome process, with people running from general practice to hospital to specialist and back to the hospital'.[12] A witness from NSW provided the following experience:

> The IPTAAS form is supposed to be signed by the nominated consulting specialist. In our case this was originally designated as the Professor surgeon who was one of two at the apex of the gastro clinic/surgical structure at [Princess Alexandra Hospital]. Of course on any given visit to the hospital you might be under the attention of the other Professor, the surgical registrar, junior surgical registrar, oncology registrar, radiation specialist, the intern on the ward, someone else who is not the original nominee, depending on what aspect of your condition has brought you there and who is available. IPTAAS couldn't seem to understand this. I had claims returned because of it and in the end submitted claims with a drawing of the medical hierarchy of PAH – a large teaching hospital. On many visits we didn't even catch sight [of] these people, already working 18 hour days, going to marathon 12 hour surgeries straight after morning-long clinics and some IPTAAS functionary demands their personal signature on a form. I'm angry about the petty stupidity of it.[13]

3.10 For Indigenous patients, the need to carry the PATS documents and obtain signatures from treating specialists is problematic as documents are often lost or the required signatures are not obtained. If this occurs, the subsidy cannot be claimed.[14]

3.11 The frustration of form-filling is exacerbated in some jurisdictions by reapplication requirements for PATS. For example, a separate application for each specialist visit may be required.[15] For chronically ill patients this is a major impost. Palliative Care Australia provided the following case:

> Jack [teenager with terminal leukaemia] requires platelet transfusions twice per week and occasionally in emergency circumstances to control

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11 *Submission* 50, p.10 (Palliative Care Australia).

12 *Committee Hansard*, 6.8.07, p.4 (Dr E Roos, Southern Queensland Rural Division of General Practice); see also *Submission* 15, p.2 (Narrandera Local Health and Golden Cluster Health Advisory Committees).

13 *Submission* 123, p.2 (Ms N Wells).

14 *Submission* 83, p.2 (Tullawon Health Service).

15 *Submission* 31, p.1 (Isolated Children's Parents' Association of NSW).

> symptoms. The family lives in regional South Australia and platelet transfusions are administered at a tertiary hospital in Adelaide. The current PATS arrangements mean [his parents] have to complete a new application for each journey to Adelaide.[16]

3.12 Ronald McDonald House Westmead submitted this case:

> Brian, who is an eight-year-old boy from Wagga Wagga, who stayed with us for 18 months, got home for about eight months and has now relapsed with his brain tumour. This is the second time. He is on six months of radiotherapy. His mother is illiterate. She cannot fill out the forms. My staff fill out the forms for her every time. We read the letters out to her. We explain everything to her. They can go home between the radiotherapy treatments for a few nights – we call it a window of opportunity to be normal – and those forms have to be filled out when they return every time, plus they have to pay $92, which they do not have. The mother has been diagnosed with an anxiety disorder. She thinks she is going to lose Brian…The father gets casual work in Sydney. They do the best they can do and try to manage.[17]

3.13 Patients away from home for significant periods of time may also be required to make a monthly reapplication for PATS. The Leukaemia Foundation WA noted that this was an arduous task when a patient is recovering from treatment.[18] The Foundation also informed the Committee that it had now started logging on patients' records the contact hours with PATS clerks. It found that staff were spending anywhere, per patient, from two hours to six or eight hours of telephone contact.[19]

3.14 The Committee received evidence that the process for completing PATS forms is so complex in some jurisdictions that patients did not attempt to make a claim for reimbursement.[20] Carers WA stated:

> Some carers have even indicated that the process is so onerous that they just give up. Carers have indicated that they have difficulty in getting the information. There is also a lack of flexibility to allow for those occasions where people are so focused on the immediate problems that they forget or do not get round to making application before they travel for the health treatments, to then find that they cannot do it retrospectively.[21]

3.15 Often it is the families who need the assistance most who find the task of completing the form daunting.[22] The NSW Farmers Association also expressed

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16 *Submission* 50, p.11 (Palliative Care Australia).

17 *Committee Hansard* 6.7.07, p.56 (Mrs A Pearson, Ronald McDonald House Westmead).

18 *Submission* 54, p.5 (Leukaemia Foundation WA).

19 *Committee Hansard* 6.8.07, p.51 (Mrs S McKiernan, Leukaemia Foundation WA).

20 *Submission* 33, p.1 (Advisory Committee for Older People).

21 *Submission* 101, p.4 (Carers WA).

22 *Submission* 31, p.4 (Isolated Children's Parents' Association of NSW).

concern that its members were 'accepting inequitable financial burdens arising from medical treatment rather than applying for assistance due to sheer volume of paperwork they are confronted by'.[23]

3.16 There were many suggestions aimed at reducing problems with the application process. These included broadening the range of people authorised to complete forms. Dr Eduard Roos from the Southern Queensland Rural Division of General Practice argued that it would be more efficient if responsibility for filling out the PATS application form was taken out of the hands of GPs:

> To me, it would make more sense if we had a clerk, perhaps a receptionist at the medical centre, fill in the form. They could look on the computer to see whether a person has been referred to Dr Joe Bloggs, confirm that and send it off to the hospital, or they could get the specialist to confirm that the patient has seen them and then there should be a different mechanism to get the claim…I think there must be an easier way to do it. With general practice time being limited, we could change the scheme to allow either the practice nurse or one of the practice staff to do that, rather than the general practitioners.[24]

3.17 Australian Rural Nurses and Midwives (ARNM) noted that in South Australia a rural liaison nurse in a major metropolitan hospital is able to authorise the forms. ARNM went on to comment that rural and remote nurses are well placed to undertake this task, as they have a depth of knowledge of the rural situation and the patient's situation. Often a specialist or junior medical officer has no ongoing relationship with the patient and 'therefore diminished insight into the patient's social circumstances'. While the local GP may have the appropriate local knowledge, their time could be better spent than completing complex forms.[25]

3.18 The Australian Physiotherapy Association noted the special case of paediatric conditions where the child must not only access specialist medical practitioners but also may require paediatric specialists in many allied health fields, such as physiotherapy, occupational therapy and speech pathology. Currently children are required to be referred to a tertiary hospital for review by a medical consultant to enable these services to be accessed even though the medical consultant will not be providing the treatment. The Association stated that 'PATS schemes need to be opened up to include access to acknowledged allied health professional specialists'.[26]

3.19 Suggestions were also made to improve the format of the form. These ranged from allowing more than one specialist visit to be included on the form to suggestions that the form be simplified and made more easy to obtain, for example, accessed

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23 *Submission* 166, p.6 (NSW Farmers Association).

24 *Committee Hansard*, 6.8.07, p.4 (Dr E Roos, Southern Queensland Rural Division of General Practice).

25 *Submission* 45, p.3 (ARNM).

26 *Submission* 87, p.4 (Australian Physiotherapy Association).

online at doctors' surgeries and treatment centres.[27] In this regard, the Committee notes that in Tasmania forms are available online through Service Tasmania.[28]

3.20 Cancer Voices NSW supported the concept of a travel or accommodation diary which would allow patients undergoing block treatment to make just one claim for a block of treatment/travel by filling in a diary rather than having to make a separate claim for each treatment episode.[29] Cancer Voices NSW also suggested that there should be a 'streamlined national minimum standards format for claims'.[30]

Inconsistent interpretation and application

> The inconsistency of interpretation of, and adherence to the current PATS guidelines across jurisdictions can result in a lack of flexibility in some rural areas. This then impacts on families' access to relevant health care services, producing inequality of access to health care and negatively impacting on health outcomes.[31]

3.21 Once forms are completed they are checked for approval against the jurisdiction's guidelines. The approval process may be undertaken by the PATS clerk/coordinator at the local hospital or health service or be outsourced (for example, South West of Western Australia).[32]

3.22 The Committee received many comments about the lack of consistency of interpretation and application of the guidelines. The Australian Red Cross for example, commented that in Queensland arrangements varied widely among health service districts 'with processes and eligibility decisions highly dependent on local interpretations and priorities'.[33] The Australian Medical Association (AMA) Tasmania also noted that there was anecdotal evidence that decisions about funding are 'very subjective and lack consistency between hospitals and between regions in Tasmania'. This becomes a major issue for those claiming retrospectively as there is no certainty that a claim will be successful. The AMA stated:

> Peculiar decisions are made where a flight from Tasmania to the mainland will be funded (varies from $50-$150) but the cost of the trip from the airport to the Specialist Service (approx $45) may or may not be covered depending on who is assessing the claim.[34]

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27 *Submission* 12, p.4 (Cancer Voices NSW). See also, *Submission* 45, p.3 (ARNM).

28 *Committee Hansard* 23.7.07, p.2 (Mr T Sanson, Department of Health and Human Services Tasmania).

29 *Submission* 12, p.4 (Cancer Voices NSW).

30 *Submission* 12, p.2 (Cancer Voices NSW).

31 *Submission* 30, p.3 (Social Work Department – Princess Margaret Hospital).

32 *Submission* 27, p.3 (Cancer Voices WA).

33 *Submission* 82, p.2 (Australian Red Cross).

34 *Submission* 65, p.2 (AMA Tasmania).

3.23 The Committee was provided with many examples of inconsistency of provision of travel assistance. One carer stated that over the time of his wife's treatment for breast cancer decisions about PATS altered according to who was in charge at the time – some clerks were very helpful but others difficult.[35] In another instance, it appeared that the decision to provide PATS depended on whether the patient received care from a private GP or the hospital's Outpatient Clinic.[36] The Leukaemia Foundation pointed to the particular problems of service decisions in small towns:

> In small rural towns, where most of our patients come from, it could depend on how well you know the PATS clerk sometimes. If you have had a family feud with their family, you can be quite guaranteed that you will have Buckley's and none of actually getting some assistance straight up. Again because of the acute nature of people's illnesses, they do not have time to start things; it is certainly not the first thing on their mind. Backtracking to get approval is nigh on impossible and it does take a very long time.[37]

3.24 Witnesses commented that the inconsistent application of the guidelines in some areas appears to be a result of budgetary constraints. Albany Community Resource Agencies Network stated that PATS eligibility was 'prioritised on the basis of patient needs due to the limitations of funding'.[38] The Association of Independent Retirees also commented on the 'filtering' of claims at a local level to 'balance a very limited restrictive budget'. The Association cited the case of an elderly patient who needed to see a specialist some 400 kms away. The patient and her older spouse felt that they needed a second night of accommodation after their consultation to ensure they were able to do the 400 km, five hour drive safely. However, they were only eligible for one night's accommodation.[39]

3.25 WA Country Health Service commented that in WA the PATS budget is part of the hospital budget and 'we do not constrain any healthcare unit or PATS group of people by saying, "This is your budget and if you run out, you run out."…They are managing a patient service. It costs what it costs'. PATS assistance continues to be paid even if it runs over budget as 'we still have to pay everything that comes through the door, but the source of the money for that is the hospital's budget'.[40]

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35 *Submission* 27, p.2 (Cancer voices WA).

36 *Submission* p.2 (Southern Queensland Rural Division of General Practice).

37 *Committee Hansard*, 6.8.07, p.47 (Mrs S McKiernan, Leukaemia Foundation).

38 *Submission* 40, p.2 (Albany Community Resource Agencies Network).

39 *Submission* 18, p.5 (Association of Independent Retirees).

40 *Committee Hansard* 13.7.07, p.14 (Mrs C O'Farrell, WA Country Health Service).

3.26 The Ingham Health Service also submitted that inconsistencies have arisen in its area because patients have appealed to their local Member of Parliament with the result that many claims not within the guidelines were approved.[41]

3.27 There were numerous suggestions to improve the consistency of the application of guidelines. Witnesses commented that improved training of PATS clerks was required. Other witnesses suggested that a centralised agency deal with all PATS applications.[42] The Southern Queensland Rural Division of General Practice saw this as a way of curtailing the 'red-tape' involved in the application process and argued that it would allow exceptional personal circumstances to be taken into consideration.[43]

3.28 The Australian Red Cross supported the establishment of a single state or nationally consistent set of processes and information on the schemes: 'a national approach to consistency would foresee equity for all users of our service regardless of which state they reside. A state consistency would foresee equity to all residents of Queensland'.[44]

3.29 National consistency is considered in more detail in chapter 7.

Acceptance of recommendations

3.30 A further concern for patients was that once the forms had been completed and lodged, the recommendation for travel assistance may be overridden. This may occur in relation to the mode of transport or the recommendation to attend a particular specialist or treatment centre.

3.31 The most common problem cited was the PATS administrator or specialist not agreeing that air transport is medically necessary for the patient. In some instances, this means that patients have to undertake a very long bus or car journey at great distress and discomfort when they are ill. Murweh Shire Council provided the following case:

> Roy has been undergoing treatment for cancer in Brisbane which is nearly 800 km from Charleville. Despite the seriousness of his illness, the effects of his treatment and recommendations of his doctors, he has had to continually fight to be given air vouchers to get to his destination.
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> The alternative is a 14 hour one way bus ticket which would be torture for anyone undergoing this type of treatment. It is disgraceful that an Australian citizen who has worked all his life and continues to work is

41 *Submission* 93, p.2 (Ingham Health Service).

42 See for example, *Submission* 83, p.3 (Tullawon Health Service).

43 *Submission* p.2 (Southern Queensland Rural Division of General Practice).

44 *Submission* 82, p.2 (Australian Red Cross).

> made suffer the additional stress of fighting health administrators for air tickets even though they are recommended by his doctor.[45]

3.32 In another case, the request by a specialist that a woman, who had been hospitalised after suffering a miscarriage, use air transport home was overridden. The woman was instead directed to travel home by bus – a trip of 14 hours.[46]

3.33 Such practices also have a financial impact on patients. The Advisory Committee for Older People stated:

> Patients can be left even further in debt if a specialist chooses to overrule the recommendation of a GP to authorise an escort and air travel for their patient. Some specialists inform patients during their consultation that air travel is unnecessary and that an escort is not required to accompany them. In some cases specialists make this assessment after having only seen the patient once. In some instances the specialists are also completely unaware of the patient's personal circumstances or the considerable distance they have travelled from Mildura to obtain medical treatment.[47]

3.34 The overriding of a recommendation may have a flow on effect for community based services. The Sunraysia Information and Referral Service (SIRS) previously funded upfront travel costs necessary to access specialist treatment more than 100 kms from Mildura. Costs were reimbursed by the Victorian Department of Human Services through VPTAS. SIRS indicated that it had stopped this service as not all travel was being refunded by VPTAS. This was because a specialist could override the referring practitioner's direction for a patient to travel by air. SIRS stated that this has 'caused real hardship and concern to patients who have been travelling regularly for necessary treatment'.[48]

3.35 Secondly, recommendations by GPs for referral to a particular specialist or medical centre may be overruled by a PATS clerk adhering strictly to guidelines concerning referrals to the nearest specialist. For example, the Karratha Cancer Support Group in Western Australia submitted that:

> Many patients become frustrated and anxious by PATS when they are queried as to their requirement to travel. The referral from a local medical practitioner to the appropriate specialist medical appointment or clinic can be refused by a non-medical practitioner, such as a PATS administrator or manager.[49]

3.36 Murweh Shire Council also commented on the attitude of some PATS administrators stating that patients 'feel humiliated by the treatment they receive by

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45 *Submission* 52, p.2 (Murweh Shire Council).

46 *Submission* 116, p.1 (Ms D Mangili).

47 *Submission* 33, p.3 (Advisory Committee for Older People).

48 *Submission* 11, p.1 (SIRS).

49 *Submission* 13, p.1 (Karratha Cancer Support Group).

administrators. It seems to them that they are perceived as going on a holiday not the reality of being treated for very grave illnesses'.[50] Other witnesses also agreed that 'patients are not being treated as such, but [it is] assumed that everyone is trying to take advantage of the system'.[51]

3.37 The Mallee Division of General Practice complained about administrators rejecting applications on 'technical quibbles' and making decisions which 'effectively override the judgement of the referring doctor without the medical knowledge and skills which informed the original decision and without the benefit of any medical advice'. The Division concluded:

> We have evidence that some patients have been left considerably out of pocket through the decisions of those who administer patient travel assistance schemes, or who cannot afford to seek the specialist care to which they are entitled and whose health can be severely compromised as a result, to the point where life itself may be endangered.[52]

3.38 WA Country Health Service noted that it had been 'accused of being inconsistent in the application of the scheme' and, on the other hand, accused of 'not being flexible enough'. WA Country Health Service went on to comment that it 'is quite a hard balancing act' as 'really rigid application of the PATS guidelines will not take account of individual circumstances for the patient'. WA Country Health Service informed the Committee that 'we try and administer the guidelines as well as we can but still with some flexibility for individual circumstances'.[53] It was noted that the scheme's devolved decision-making assisted with identification of a patient's specific needs as well as availability of regionally based health services and facilities and prevailing local issues such as road and climatic conditions which may impact on travel.[54]

Eligibility issues

Distance threshold

3.39 In all jurisdictions the reimbursement of costs of private vehicle or public transport travel is based on meeting a distance threshold. The threshold ranges from 200 kms in the Northern Territory to 50 kms in Queensland.

3.40 Witnesses raised a number of concerns with the use of a distance threshold for determining eligibility and argued that thresholds resulted in inequity of access to health services and imposed hardship on already ill patients. Witnesses stated that

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50 *Submission* 52, p.2 (Murweh Shire Council).

51 *Submission* 116, p.1 (Ms D Mangili); see also *Submission* 142, p.2 (Mr & Ms Fahl).

52 *Submission* 51, p.2 (Mallee Division of General Practice).

53 *Committee Hansard* 13.7.07, p.4 (Ms S Eslick, WA Country Health Service).

54 *Submission* 39, p.4 (WA Government).

those living just inside the threshold were disadvantaged and thresholds did not take into account local conditions such as poor roads, lack of air transport and the availability and applicability of public transport. The AMA stated:

> The geographic issue is very interesting. Wherever you draw a boundary you have an area either side of that boundary that is a problem. In the Territory there are many remote communities that are within the 200 kilometre boundary and yet it is much more difficult and costly to attend the major city centres for treatment from those communities than from another community that is well outside the 200 kilometre boundary but has good transport links and good roads. Again, there needs to be some flexibility in the determination of whether a person is eligible to travel from the place of their usual location.[55]

3.41 The Central Australian Division of Primary Care commented on one community just inside the Northern Territory threshold:

> …which is approximately 193 km away from Alice Springs that can only be accessed via an unsealed road in poor condition, for all but 30km. For patients from this community requiring specialist services, the journey often entails a four hour journey in a crowded Troup Carrier. Patients with similar health conditions who live outside the 200 km radius (sometimes just outside this zone) are often transported by air under the PATS scheme.[56]

3.42 The Cancer Council Victoria also pointed to the of use 'map distances' which fail to take into account the ease of travel. For example, cancer patients in South Gippsland are assessed for eligibility on distance from cancer specialists in the La Trobe valley. However, the Cancer Council noted that there are no major transport routes from South Gippsland to the La Trobe valley over the intervening mountain range. All highways and public transport routes go directly to Melbourne which is a greater distance but much more accessible.[57] The Peter MacCallum Cancer Centre added that in NSW the Ambulance Guide is used for measuring the distance threshold. This is the shortest and fastest route but which may not be the most suitable route for ill people in private cars.[58]

3.43 In many regional areas public transport, either train or bus, is less than convenient for patients travelling to a large centre for treatment. The Committee received numerous examples of patients having to meet a bus or train in the early hours of the morning. For example, the bus from Ceduna to Port Augusta picks up at 7.30 pm and arrives at 12.30 am, on the return journey the bus leaves at 1.00 am from

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55 *Committee Hansard*, 5.7.07, p.25 (Dr P Beaumont, AMA).

56 *Submission* 22, p.1 (Central Australian Division of Primary Health Care Inc); see also *Committee Hansard* 5.7.07, p.14 (Dr J Thurley, NT Divisions Network).

57 *Submission* 105, p.4 (Cancer Council Victoria).

58 *Submission* 133, p.1 (Peter MacCallum Cancer Centre – Bendigo Radiotherapy Centre).

Port Augusta;[59] while patients travelling from Tennant Creek to Alice Springs are picked up by the commercial bus at 3.00 am.[60]

3.44 These times are inconvenient and add to the difficulties of patients who are ill, frail or elderly. Tullawon Health Service also submitted that sometimes bus travel can prove degrading: 'recently an elderly wheelchair bound woman travelling to Port Augusta for an eye appointment had to crawl onto the bus, in front of tourists, due to the lack of wheelchair facilities on the bus'.[61]

3.45 It was noted that in Queensland, distance is calculated from the post office in the locality of the patient's nearest hospital to the post office in the locality of the health facility to which the patient is travelling.[62] The costs of travel to that point are not covered. In some instances the distance to the 'starting' point may be in excess of 50 kilometres.[63] Ronald McDonald House Charities provided this case:

> Ipswich hospital has defined the eligibility for the PTS payment to be the distance from their location to the treating hospital in Brisbane (under 50kms), as opposed to the distance from the patient's home address (over 50kms) and their planned destination. On that basis they have refused to offer PTS to the family, when the House, in fact, had accepted that the family was covered by PTS. The discussion continues as House staff attempt to recover the fees from Ipswich Hospital.[64]

3.46 As one witness commented, 'as this scheme is for isolated patients, it is strange that the [distance from home] is not factored into the scheme'.[65]

3.47 In most jurisdictions, patients who live inside the threshold distance but who must make multiple trips over a given period of time do not receive a subsidy. Patients may need to make multiple trips because of family or employment commitments such as caring for animals on farms or the type of treatment they are receiving. For example, those using dialysis need to access treatment up to three times per week and therefore are travelling great distances over a period of time.[66]

3.48 This case provided by Anglicare Tasmania illustrates the financial impact of multiple episodes of short distance travel:

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59 *Submission* 83, p.1 (Tullawon Health Service).

60 *Submission* 160, p.4 (Anyinginyi Health Aboriginal Corporation).

61 *Submission* 83, p.1 (Tullawon Health Service).

62 See Queensland Government, *The patient travel subsidy scheme*, p.3.

63 *Committee Hansard* 22.6.07, p.26 (Mrs F Armstrong, ANF).

64 *Submission* 137, p.7 (Ronald McDonald House Charities).

65 *Submission* 124, p.2 (Mrs C McLean).

66 *Submission* 10, p.4 (Association of Independent Retirees).

> They paid for me to go to Hobart and back but otherwise we don't fit in because we're not far enough away from Burnie. It's about twenty kilometres. We go into Burnie three or four times a week. Fuel is a huge thing and the time in the car when you're tired. When we had Sue in hospital for three weeks it cost us over $2,000 just with fuel. David was coming home, it was the middle of winter, it was three trips a day. He was buying a lot of take-aways because he was too busy to do any cooking. The teacher at the school enquired about the cost and got us $200 from the Sunshine Foundation which was really nice. (Jill, caring for her two year old daughter with severe cerebral palsy)[67]

3.49 In order to lessen the adverse impact of the threshold, witnesses called for a reduction in the distance to be travelled before assistance is provided. The Rural Doctors Association considered it appropriate that a minimum threshold of 70 kms be applied as 'given that very few patients in metropolitan areas would need to travel more than 10-20 kilometres to the nearest facility where they can receive treatment'.[68]

3.50 The Country Women's Association (CWA) NSW suggested that there should be no distance threshold. Rather, that a patient contribution be imposed so that those living closest would not receive a payment or the payment would be so small as to not make it worthwhile to make a claim.[69]

3.51 Many witnesses also argued that the schemes should reflect total distance travelled within a time period rather than the distance from the treatment location.[70] This system operates in Victoria where patients who travel an average of 500 kilometres per week for at least five consecutive weeks when receiving treatment in a 'block' are eligible for the Victorian scheme.[71]

Restrictions on referrals

3.52 A frequent complaint made about the schemes was the restrictions placed on referrals. Five interrelated issues were highlighted: the suitability of the specialist; access to a multidisciplinary team; the timeliness of the appointment; patient choice and access to a second opinion.

Requirement to be referred to nearest treating specialist

3.53 At the core of concerns with referral constraints is the requirement that patients be referred to the nearest specialist to be eligible for PATS. Many witnesses

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67 *Submission* 72, p.6 (Anglicare Tasmania).

68 *Submission* 90, p.3 (Rural Doctors Association of Australia).

69 *Submission* 5, p.2 (Social Issues Committee, CWA NSW).

70 *Submission* 15, p.1 (Narrandera Local Health and Golden Cluster Health Advisory Committees).

71 *Submission* 182, p.3 (Victorian Government).

argued that this ruling may not be in the best interests of the patient as the nearest specialist may not be the most appropriate specialist:

> A further issue that has been consistently raised concerning flexibility relates to the tension between the requirement that the patient attend the nearest approved medical specialist. Thus, the eligibility requirements of the scheme can undercut clinical judgments…This is also an area of stress to rural and remote GPs who are thereby not always able to refer their patients to the best care available but only the closest.[72]

3.54 Cancer Voices WA commented that in some cases, patients dependent on PATS assistance have visited a regional or a visiting surgeon and have been operated on 'disregarding the surgeon's level of expertise in a particular type of cancer'.[73]

3.55 The Advisory Committee for Older People stated that 'the ruling that GPs must now refer patients to the nearest specialist capable of treating the condition casts doubts on the GP's competence to nominate a specialist whom they consider to be the most appropriate to provide continuity of care to their patients'.[74] It can also result in a patient having to incur greater expense if the specialist cannot deal with their problem:

> This is unfair, demeaning to the Doctors and frustrating for the patients. So now they have to make the $800.00 two day round trip to see the physician who may or may not be very experienced in a particular sub specialty and then if the physician cannot deal with it they then have to pay further cost to see the proper specialist.[75]

3.56 Cancer Voices WA cited this case:

> I complained about the delay to see an oncologist in Bunbury and was told I could not get PATS because you were not eligible if there was a visiting specialist. My GP had suggested two doctors in Perth who specialised in my type of cancer but neither visited Bunbury, so I was refused PATS even though my GP tried to insist. After 3 months of treatment in Perth it was agreed to give me PATS but not for the previous visits. I should have been allowed to see the doctor my GP suggested.[76]

3.57 Witnesses stated that where this guideline had been introduced, GPs may no longer be able to refer a patient to a specialist whom they had seen previously.[77] In one example submitted to the Committee, a patient had been under the care of a

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72 *Submission* 136, p.7 (ARRWAG).

73 *Submission* 27, p.5 (Cancer Voices WA).

74 *Submission* 33, p.2 (Advisory Committee for Older People). See also *Submission* 136, p.7 (ARRWAG).

75 *Submission* 156, p.2 (Dr S Thrussell).

76 *Submission* 27, p.5 (Cancer Voices WA).

77 *Submissions* 33, p.2 (Advisory Committee for Older People); 51, p.3 (Mallee Division of General Practice).

metropolitan specialist for 15 years. However, when a visiting specialist commenced at the local hospital for visits every six months, the patient was told that she was no longer eligible for PATS if she continued to see her existing specialist. In this instance, the patient lost continuity of the doctor/patient relationship and the ability to access specialist services without waiting six months.[78]

3.58 Some patients reported they were ineligible for PATS because the treatment they were receiving was not at the nearest hospital. This was despite the fact that the nearest hospital did not actually deliver the specific treatment required. Ms Lisa Barry from NSW provided the following case:

> He does not qualify for PATS despite living nearly in Newcastle, and not being able to get treatment anywhere in Newcastle or near him on the Central Coast, being based at San Remo. Instead, he has to travel to Sydney. He can barely walk, barely see, and is on morphine. To get to his neurosurgeon, to whom he has been referred by a neurologist here, it takes nearly three hours, then nearly that home - but he can't get PATS, because he is travelling to Prince of Wales Randwick, instead of a closer hospital. PATS is dependent on you going to the CLOSEST hospital. It's true, there is also a neurosurgery ward at Royal North Shore Hospital, though as he's only 39, they're doing a disk replacement, not a disk fusion, and that he can only get at PoW Randwick…they won't pay him a red cent, because he's not going to a hospital that would turn him into a cripple unable to work for the rest of his life, he's going to a public clinic that gives him a chance at being back in the workforce.[79]

3.59 As Dr Roos from the Southern Queensland Rural Division of General Practice framed it: 'what is the specialist that patient needs to see? Do they need to see a specialist, or a specialist for their condition?'[80] Dr Roos further noted that his referrals to specialists have regularly been queried by PATS officers because they are not the nearest specialist.

3.60 In response to concerns about referrals, WA Country Health Service commented that 'PATS clerks are not the clinicians and are not allowed to fiddle with the referral but they do have a job to make sure that the patient is eligible'. In some cases, the GP simply refers the patients to where the patient wants to go and 'when the patients turn up the eligibility cannot be met. It may be a referral to a general surgeon, we may have a general surgeon available in that hospital, and the PATS is declined'.[81] WA Country Health went on to note that GPs often come under a great deal of pressure to give into patient wishes.[82]

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78 *Submission* 18, p.6 (Association of Independent Retirees).

79 *Submission* 2, p.1 (Ms L Barry & Mr D Webster).

80 *Committee Hansard*, 6.8.07, p.3 (Dr E Roos, Southern Queensland Rural Division of General Practice).

81 *Committee Hansard* 13.7.07, p.8 (Mrs C O'Farrell, WA Country Health Service).

82 *Committee Hansard* 13.7.07, p.11 (Mr K Mills, WA Country Health Service).

Access to a multidisciplinary team

3.61 The importance of access to a multidisciplinary team for patients with chronic illnesses was emphasised in a number of submissions. The AMA explained that 'chronic illnesses are often complex and multisystem' and the best way of treating them is with a GP as the central coordinating provider and 'input' from a 'multidisciplinary team'.[83]

3.62 The Cancer Council Australia submitted that research shows better outcomes for cancer patients who receive multidisciplinary care:

> There is a growing evidence base showing the benefits to cancer patients of a multidisciplinary approach to care, built on patient-centred, coordinated treatment and support plans utilising a range of clinical and allied health professionals.[84]

3.63 Not surprisingly, evidence also indicated that as residential remoteness increases patient access to multidisciplinary care decreases.[85]

3.64 Cancer Voices WA argued that access to multidisciplinary care should not be inhibited by budgetary constraints:

> At present multi-disciplinary cancer treatment is sadly lacking in regional Western Australia. It is essential that a cancer patient's clinical needs are not compromised for the sake of the efficiency and frugality of the PATS budget.[86]

Timeliness of appointments

3.65 A number of witnesses raised the issue of timeliness not being factored into the above requirement. In rural areas there may be a visiting specialist but that specialist may only visit the area once a month or in some cases once every six months.[87] Visiting specialists are also limited in the number of patients they can see in one day. As a consequence patients may have to wait many months for an appointment to become available or find their way to another centre to access an earlier appointment.[88]

3.66 In these circumstances, a patient would not be eligible for PATS if they choose to travel to the more distant city to receive specialist treatment sooner. The Yorke Peninsula Division of General Practice noted:

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83 *Submission* 47, p.8 (AMA).

84 *Submission* 109, p.17 (Cancer Council Australia).

85 *Submission* 109, p.17 (Cancer Council Australia).

86 *Submission* 27, p.4.(Cancer Council WA).

87 *Submission* 4, p.1 (Yorke Peninsula Division of General Practice).

88 *Submission* 33, p.2 (Advisory Committee for Older People).

> An example from GPs at Coober Pedy is when a particular specialist visits Port Augusta, patients can access the PATS subsidy to assist them with trave from Coober Pedy to Port Augusta – (5 hours) but not to Adelaide, even if this specialist only consults 6 monthly in Port Augusta and daily/weekly in Adelaide. The patient may choose to go to Adelaide to be seen earlier – but this will then mean that they cannot access PATS.[89]

Patient choice

> The Australian health system is centred on the principle of patient choice, and all Australians should have the same health care choices available to them. Costs of travel and accommodation must not be a barrier to these patients seeking clinically appropriate health care.[90]

3.67 The Committee heard that the 'nearest specialist rule' meant that unlike their metropolitan counterparts, rural residents are unable to exercise choice (if they require PATS assistance) – whether that be choice of specialist or choice to seek a second opinion.[91]

Access to a second opinion

3.68 A number of witnesses felt that PATS should cover travel to obtain a second opinion. It was argued that access to a second opinion was an issue of patient choice. For example, the AMA stated that:

> The Australian health system is centred on the principle of patient choice, and all Australians should have the same health care choices available to them. Costs of travel and accommodation must not be a barrier to these patients seeking clinically appropriate health care. The patient assisted travel schemes must not restrict patient access to a second opinion.[92]

3.69 It was also seen to be an option readily available to metropolitan residents. As such, lack of financial support to seek a second opinion was seen to create further inequalities between rural and remote Australians and their urban counterparts. The Qld Rural Women's Network submitted:

> People in metropolitan areas and in major regional centres take such health services as having access to a specialist who has the support of a multidisciplinary team and the option to seek a second opinion for granted.[93]

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89 *Submission* 4, p.1 (Yorke Peninsula Division of General Practice).

90 *Submission* 47, p.8 (AMA).

91 *Submissions* 33, p.2 (Advisory Committee for Older People); see also *Committee Hansard* 22.6.07, p.26 (Mrs F Armstrong, ANF).

92 *Submission* 47, p.8 (AMA).

93 *Submission* 103, p.6 (Qld Rural Women's Network).

3.70 The Isolated Children's Parents' Association of NSW argued that the option of a second opinion was a patient's 'right':

> A patient must be given the option of requesting a second opinion. This is no reflection on the doctor's original assessment but a right of the patient.[94]

3.71 It was noted by some State Governments that travel to seek a second opinion is covered by PATS if a second opinion is recommended and a referral made by the original specialist.[95] However, the WA Government argued that while a second opinion was the right of all Australians, carrying the cost was also the patient's responsibility:

> Should a patient wish to seek a second opinion then, as for all health consumers, this is the prerogative of the patient and the patient may reasonably be expected to bear the cost associated with the exercise of this choice.[96]

Referral restrictions - conclusion

3.72 The National Rural Health Alliance (NRHA) did note that some states 'operate a flexible system' in regard to the above concerns. For example, in NSW and Victoria patients who have received ongoing care with a particular specialist are generally not required to change to a closer specialist. In some States if the nearest specialist is unable to see a patient within a 'clinically accepted timeframe' assistance may be provided to consult a specialist further away.[97]

3.73 However, on balance, the evidence indicated that the 'nearest specialist' ruling presented problems for many patients and exceptions to the ruling were inconsistent across states/territories as well as inconsistently applied. As a consequence, witnesses generally considered that schemes should allow for referral to the most appropriate specialist not the nearest specialist.[98]

3.74 The importance of getting the right specialist was captured in the CWA's comments:

> There is nothing more important to a patient than to have confidence in their specialist and treatment. This can be for any number of reasons, whether continuity of past treatment, cultural reasons, reputation or the support of a multidisciplinary team and the option to seek a second opinion.
>
> The choice of treating specialist must be made between the patient and their doctor – no government department has the right to impose this restriction, simply to save a few dollars of tax payer's money.

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94 *Submission* 31, p.5. See also *Submission* 45, p.6 (ARNM).

95 *Submission* 39, p.6 (WA Government) and *Submission* 188, p.15 (NSW Health).

96 *Submission* 39, p.6 (WA Government).

97 *Submission* 55, Attachment, p.11 (NRHA).

98 *Submission* 12, p.4 (Cancer Voices NSW).

> We stress that no country person who is unwell would travel unless they had to. The stress of travelling in unfamiliar areas, heavy traffic, confusion and the added worry of finding someone to look after other family members or properties while they are away, makes travel a very unattractive option. We only do it when we have to.[99]

Type of transport

3.75 In Western Australia, assistance with air travel is very restricted with patients having to travel more than 16 hours by road to be eligible. The Rural Doctors Association considered that for most people a one way car trip of 4-5 hours is tolerable and that for travel over this distance that air travel should be an option or at the very least heavily subsidised.[100]

Appeals processes

3.76 A number of witnesses noted that some schemes do not have an appeals or arbitration process when there is a dispute concerning the application of guidelines. Where there are complaints processes these were seen as less than ideal. In Western Australia for example, disputes are responded to by the local PATS officer or their direct supervisor with the result that 'such resolution is not always processed in a transparent or judicious manner'.[101] The AMA Tasmania commented that the complaint process in Tasmania was complicated and 'as the amounts refunded are often relatively small it would be surprising if many claimants bothered to take up this option'.[102]

3.77 The Northern Territory scheme also has an appeals process. The Northern Territory Department of Health and Community Services indicated that appeals can be made where it is believed that the circumstances on which a decision was made in terms of escorts or entitlements does not reflect the true circumstances of the event. A committee hears the case and adjudicates upon entitlements.[103]

Subsidy levels

> The level of assistance provided in no way covers the cost of accessing treatment, thus increasing the discrimination caused by geographic location. It is next to impossible to find accommodation where the funds provided by PATS covers the cost of an overnight stay and the length of stay funded by PATS is in a large number of cases not sufficient to permit recovery from the treatment received. There are examples of people being required to

99 *Submission* 5, p.3 (Social Issues Committee, CWA NSW).

100 *Submission* 90, p.4 (Rural Doctors Association of Australia).

101 *Submission* 30, p.2 (Social Work Department – Princess Margaret Hospital).

102 *Submission* 65, p.2 (AMA Tasmania).

103 *Committee Hansard* 5.7.07, p.41 (Mr P Campos, NT Department of Health and Community Services).

> catch transport in a busy regional centre whilst suffering the effects of anaesthetic and analgesia.[104]

3.78 State and Territory Governments noted in their evidence that the schemes were not intended to fully reimburse patients for their travel costs.[105] Queensland Health stated that 'the purpose of PTSS is to facilitate *equity of access* to essential specialist health care services by providing a subsidy for travel and accommodation expenses. It is not to meet the full costs of travel associated with treatment or the specific needs of particular categories of patients'.[106]

3.79 In response, witnesses contended that the current level of reimbursement is a 'denial of the reality' of the costs of travelling for health care.[107] Schemes provide a subsidy for car travel and for accommodation. Some also provide a subsidy toward ancillary costs. However, witnesses argued that the subsidies have not kept pace with the real costs of travel and accommodation.

> I am fully aware that the scheme was never intended to pay all the costs of attending a medical appointment not available locally, nor do I believe it should. However I do feel it should realistically reflect the true costs people such as myself face every time we need to attend a specialist medical appointment.[108]

3.80 The Committee was provided with many cases where the out-of-pocket costs incurred by patients were significant. For example, a recent study indicated that the out-of-pocket costs for breast cancer was $7,700.[109] In the case of the birth a premature baby while the parents were interstate the costs were reported to be $16,000.[110] Other evidence included these examples:

> ...a trip to Melbourne with two nights accommodation usually results in my being $250 to $300 out of pocket…as my only income is Disability Pension, this creates a very difficult financial situation often resulting in me being unable to access the services that I require.[111]

> A local member of the Tom Price community went to Karratha to have a trigger finger operated on, which is certainly not a serious operation. It involved a general anaesthetic, meaning that the person had to be there the day before because it is not possible to get from Tom Price to Karratha on the morning of the operation. After the operation was done there was a need

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104 *Submission* 69, p.5 (HCRRA).

105 *Submission* 39, p.1 (WA Government).

106 *Submission* 184, p.7 (Queensland Health).

107 *Submission* 65, p.2 (AMA Tasmania).

108 *Submission* 126, p.1 (Ms R Hall).

109 *Committee Hansard* 6.7.07, p.8 (Ms S Stuckey, GlaxoSmithKline).

110 *Committee Hansard* 6.7.07, p.55 (Ms J North, Ronald McDonald House Monash).

111 *Submission* 138, p.2 (Ms C O'Brien).

> to stay for another day because a general anaesthetic had been used. The result was that three days were spent in Karratha. Accommodation, which may not be available because of the resource boom, is somewhere in the vicinity of $180 to $200 a night. The cost of driving a vehicle from Tom Price to Karratha and back is $250 for fuel alone. So the total cost was about $800 to $850. The reimbursement was about $80.[112]
>
> One case that came to light yesterday was about a man who travelled from Dubbo to Sydney for treatment for a myeloma. He was in Sydney for four or five days. He had out-of-pocket expenses of $1,000 for accommodation, transport and food et cetera. He got back $166. It was okay for that gentleman because he had a private income, but if you are a pensioner on $300 or $400 a week that is a month's worth of your pension. It is just not possible for people like that to fund that sort of thing.[113]
>
> …a patient from Cootamundra had radiotherapy in Wagga Wagga, Canberra and Sydney in six weeks. His accommodation and travel expenses were $12,000 and he received only $300 back through IPTAAS.[114]

3.81 While many witnesses accepted that the scheme was not intended to cover all their costs, access to services for rural people needs to be supported, as there are no equitable services available in their local area.[115] It was also argued that the current subsidy levels were so low that patients are unable to access medical care or they choose a treatment which requires less travel.[116] Some comments included:

> …anecdotal feedback from many of our doctors is that patients choose not to be treated because they are going to be away from their communities, their family supports and their loved ones – and because of costs. They choose not to be treated. That is clearly wrong and we should not be supporting that.[117]
>
> It is likely that these considerations [travel and accommodation costs] act as obstacles to some people with epilepsy attending medical appointments, with the result that their health suffers.[118]
>
> A survey of healthcare professionals in all regional Australian hospitals that provide chemotherapy found that 65 per cent of respondents reported that travel and accommodation assistance schemes were a barrier to improving cancer care provision in isolated areas.[119]

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112 *Committee Hansard* 13.7.07, pp.66-67 (Mr K Pearson, Shire of Ashburton).

113 *Committee Hansard* 22.6.07, p.3 (Mr S Sant, RDAA).

114 *Submission* 5, p.3 (Social Issues Committee, CWA).

115 *Submission* 4, p.2 (Yorke Peninsula Division of General Practice).

116 *Submission* 90, p.3 (Rural Doctors Association of Australia); 156, p.2 (Dr S Thrussell).

117 *Committee Hansard*, 22.6.07, p.11 (Mr S Sant, RDAA).

118 *Submission* 78, p.3 (Epilepsy Foundation).

119 *Submission* 109, p.8 (Cancer Council Australia).

3.82 Similarly, the Breast Cancer Action Group NSW explained that many Breast Cancer Patients in rural and regional areas opted for mastectomy rather than the 'less invasive' lumpectomy as the latter requires travelling to a metropolitan centre for a six to seven week post-lumpectomy radiotherapy course.[120]

Motor vehicle rates

3.83 The low level of subsidy for using car transport was raised by witnesses in all jurisdictions. Rates range from 13 cents to 15 cents per kilometre. In Queensland, the rate was recently increased to 15 cents per kilometre from the 10 cents per kilometre.[121] In Western Australia the subsidy is 13 cents per kilometre and 15 cents for regular travellers (classed as travelling more than four times per year).

3.84 The WA Government submitted that its fuel subsidy is 'reviewed regularly' using 'consumption costs obtained from the Australian Greenhouse Office' and the 'Royal Automobile Club of Western Australia' as a measure.[122] The South Australian Government noted that its vehicle allowance is on the higher end of the schedule of benefits of all States and Territories (i.e. 16 cents/kilometre). However, the increasing cost of fuel is one of the most reported factors country people feel limits their right to access specialised medical services. This has been especially the case with the financial effects of the drought.[123]

3.85 NSW Health submitted that the subsidy level of 15 cents per kilometre provides a reimbursement of $15 per 100 kilometres travelled. In 2006 in light of increases in petrol prices, NSW Health 'undertook some basic calculations to ascertain petrol costs' and found that current the Transport for Health vehicle subsidy was 'adequate to cover the fuel costs'. The calculations found that the costs per 100 kilometres for fuel priced at $1.44 ranged from $8.64 for small vehicles to $14.40 for large four wheel drive vehicles.[124]

3.86 However, witnesses argued that the PATS re-imbursement does not cover the real cost of a trip as petrol costs in excess of $1.20 per litre in most areas and up to $2.50 in very remote communities.[125] Other witnesses also commented that no account is taken of the poor state of mainly dirt roads which take a huge toll on vehicles and therefore adds to the cost of motor vehicle transport.

> For those with chronic conditions that require more than 4 trips a year to a specialist to be offered a 2c increase after 4 trips is, I believe, an absolute

120 *Submission* 14, p.1 (Breast Cancer Action Group NSW).

121 *Submission* 90, p.4 (Rural Doctors Association of Australia).

122 *Submission* 39, pp 2-3 (WA Government).

123 *Submission* 165, p.12 (SA Government).

124 *Submission* 188, p.12 (NSW Health).

125 *Submissions* 74, p.9 (Kimberley Aboriginal Health Planning Forum); 97, p.5 (AMSANT); 101 p.4 (Carers WA).

> insult. Chronically ill people have no choice about how many trips they need to make to their specialist per year and 15c kms is a paltry sum.[126]

3.87 The low level of subsidy also impacts on community transport services. Western Districts Health Service stated that it asked patients for a $100 donation to transport them from Hamilton to Melbourne and back again to attend a medical appointment. However, the real cost of the service is much higher:

> If they claimed that back from the Victorian Patient Assistance Transport Scheme they would get approximately $82.60. The actual cost of running the car down would be about 40c a kilometre, which is a cost of $236 to the organisation. That does not cover volunteer costs where they might give them a meal allowance and cover their petrol to pick up the car before they collect the patient. While I know that funding of community transport is not a federal issue, it is an issue in Victoria.[127]

3.88 Many pointed to the rates listed for public officials and by the Australian Taxation Office (ATO).[128] For example, in the Northern Territory a round trip of 600 kms attracts a PATS subsidy of $90 compared to $402 using the ATO rate of 67 cents per kilometre. Witnesses supported an increase to match the ATO provisions.[129]

Accommodation rates

3.89 Accommodation subsidy rates generally range from $30 to $33 per night per approved person. Ronald McDonald House noted that these had not changed since 1987. Witnesses argued that the rates do not reflect anywhere near the true cost of accommodation in major centres. The problem is exacerbated where patients must travel to capital cities or tourist destinations. In places such as Cairns, Townsville, Darwin and Alice Springs accommodation prices in the tourist seasons rise significantly.[130] Witnesses reported that because of high accommodation costs, patients are forced to go to the Salvation Army for food vouchers.[131]

3.90 As a result of the disparity between the reimbursement and accommodation costs, many patients are forced to utilise budget accommodation such as backpacker hostels with shared facilities. This is often inadequate and inappropriate.[132] Frontier Services commented:

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126 *Submission* 126, p.1 (Ms R Hall).

127 *Committee Hansard* 6.7.07, p.42 (Mrs R Morton, Western District Health Service).

128 *Submission* 105, p.4 (Cancer Council Victoria).

129 *Submission* 12, p.2 (Cancer Voices NSW).

130 *Submission* 50, p.11 (Palliative Care Australia).

131 *Submission* 40, Attachment 1, (Albany Community Resource Agencies Network).

132 *Submission* 54, p.4 (Leukaemia Foundation WA).

> A lot of the lower budget accommodation is not necessarily that appropriate. It is backpacker accommodation and that sort of thing. In North Queensland that is your only option once you start to look for cheaper accommodation. That is not always appropriate for elderly people or even for families when they need to come in. When they have a sick child, both parents need to come in or the whole family needs to come in. A lot of our families work on properties. When there is a sick child, the whole family needs to go in and there is a loss of income.[133]

3.91 Indigenous people also face difficulties in accessing suitable accommodation.[134] This is discussed further in chapter 5.

3.92 In some cities patients may find low-cost accommodation at hospital centres or facilities such as Cancer Council accommodation units. However, these facilities are in great demand and may place restrictions on access. For example, Crawford Lodge run by the Cancer Council of Western Australia has a waiting list of four to six weeks with 45 – 60 people being turned away each month.[135] Ronald McDonald House noted that the demand for accommodation is increasing as more advanced medical technology means that children are staying alive longer and their needs are more complex.[136]

3.93 Some organisations require that patients have a carer present when using their facilities. This is an additional hardship for single patients who must use external accommodation. In some instances, the organisation will fund the gap between the external accommodation and the PATS subsidy.[137]

3.94 Other witnesses commented that patients with other needs may not be able to access the little accommodation available if it is provided by disease-specific organisations. Palliative Care Australia, for example, noted that more than half of the children referred for palliative care have a diagnosis other than cancer. In such circumstances, 'families and caregivers have little choice but to incur large debts which add to the burden of grief and bereavement'.[138]

3.95 The amount of the PATS subsidy does not cover the costs of providing accommodation in these facilities. For example, the Leukaemia Foundation provides

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133 *Committee Hansard* 6.8.07, p.26 (Mrs M Izatt, Frontier Services).

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

135 *Submission* 46, p.6 (Cancer Council Western Australia).

136 *Committee Hansard* 6.7.07, p.59 (Ms D Dagg, Ronald McDonald House Charities).

137 *Submission* 54, p.7 (Leukaemia Foundation Western Australia).

138 *Submission* 50, p.12 (Palliative Care Australia).

accommodation at the PATS rate in its facilities, with the difference between the PATS payment and true cost being covered by the Foundation.[139]

3.96 The Australian Red Cross commented on the impost on organisations of providing accommodation which attracts only a small subsidy:

> Our accommodation services currently can only operate with significant operating and capital subsidy provided by us through funds we raise from the public. Lifting subsidy rates to at least $50 per night would provide a sounder financial base from which we could operate our services into the future. CPI increases to the base rate of PTS must also be a feature to ensure ongoing sustainability of service delivery. We are currently faced with the closure of our major accommodation centre in Brisbane due to the deterioration of the building and the lack of a revenue stream capable of supporting the timely renewal of the asset.[140]

3.97 Mater Health Services also noted that the low level of subsidy often discourages private providers moving into this market and providing alternative accommodation options.[141]

3.98 The Rural Doctors Association considered that where a patient had to travel more than 5-6 hours in a day that a subsidised overnight stay should be an option for the patient. Accommodation subsidies should be on a per room basis and should be at least two thirds of the reasonable daily rates accommodation allowances set by the ATO.[142]

Subsidy of other costs

3.99 There is no or little support for meals and other expenses that are incurred. These expenses can add substantially to the cost of a journey. Ms Fiona Armstrong of the Australian Nursing Federation noted that:

> Food costs are also an issue because the types of accommodation available at low cost generally do not have facilities for self catering. People are therefore forced to buy expensive takeaway food for the duration of their trip. Then there is the additional disadvantage of the poor nutritional value associated with this.[143]

3.100 Witnesses also commented that while the full price of an airfare will generally be covered, not all jurisdictions provide patients with a subsidy for taxis/public

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139 *Submission* 54, p.7 (Leukaemia Foundation Western Australia); see also *Submission* 38, p.1 (Ronald McDonald House Westmead).

140 *Submission* 82, p.2 (Australian Red Cross).

141 *Submission* 36, p.1 (Mater Health Services).

142 *Submission* 90, p.5 (Rural Doctors Association of Australia).

143 *Committee Hansard*, 22.6.07 (Ms F Armstrong, Australian Nursing Federation).

transport costs to and from the airport.[144] NSW provides $160 for ancillary transport costs but 'if you are disabled or very sick and a daily outpatient to a Sydney Hospital, public transport is out of the question and cab fares quickly amass to well in excess of $160'.[145] In Victoria, taxi fares will be reimbursed only when the patient has no other means of transport to travel from their residence to the nearest public transport or from public transport to the nearest specialist.[146] In Western Australia, taxi vouchers may be available. Kimberley Aboriginal Health Planning Forums commented that these are made available at the discretion of the PATS clerk who may have no knowledge of the patient or their physical or social needs.[147]

Restrictions and co-payments

3.101 Some jurisdictions impose restrictions and co-payments on the claimable amount. In Queensland, for example, non-concession card holders aged more than 17 years, are required to pay the first four nights of accommodation per financial year.[148] In Western Australia, non-concession card holders pay for the first three nights of accommodation.[149]

3.102 Other restrictions include discontinuing accommodation subsidies to an escort while the patient is in hospital, for example in Western Australia. Carers WA commented 'this creates significant financial hardship, especially when taken together with the additional costs for items such as petrol, transport, meals and medications'.[150]

3.103 Aged and Community Services Australia noted that in some cases, a distance threshold is applied to access the accommodation subsidy and described this as being particularly harsh:

> Overnight accommodation is covered in all states and territories if the return journey to receive specialist treatment cannot be made in one day, but the criteria for eligibility are inordinately harsh, eg accommodation is covered if the patient needs to drive more than 650 km one way.[151]

3.104 Witnesses from Western Australia pointed to the restrictions imposed when extended periods of accommodation are required. The guidelines state that after six months a patient is considered to have changed their permanent address and should be

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144 *Submission* 90, p.4 (Rural Doctors Association of Australia).

145 *Submission* 141, p.2 (Mr D Howe).

146 Department of Human Services, *Victorian Patient Transport Assistance Scheme, Policy Document*, September 2006, p.14.

147 *Submission* 74, p.8 (Kimberley Aboriginal Health Planning Forum).

148 Queensland Government, *Patient travel subsidy scheme*, p.6.

149 See *Submission* 137, p.15 (Ronald McDonald House Charities) for a comparison of payment rates.

150 *Submission* 101, p.2 (Carers WA).

151 *Submission* 58, p.5 (Aged and Community Services Australia).

expected to relocate into permanent accommodation. When this occurs, 'PATS guidelines exclude these patients from any support to return to what they will always consider to be their home'.[152] In Victoria, accommodation subsidy can be claimed for up to 120 nights of treatment per year.

3.105 Under some schemes, patients must make a co-payment. In Victoria patients without a Concession or Health Care Card have the first $100 deducted from their travel payment each year.[153] In NSW a patient contribution of $40 or $20 (for health care/pension card holders) is deducted from the total benefits reimbursed per claim. In Western Australia a $50 patient contribution is to be made prior to travel 'unless otherwise negotiated' for non-concession card holders.[154]

3.106 NSW Health stated that the contribution towards each claim is based on:

> equity considerations and the recognition that persons living within the 100 km distance limit for assistance under Transport for Health – IPTAAS also incur travelling and accommodation expenses in accessing similar specialist medical treatment.[155]

NSW Health also noted that Area Health Service Chief Executives have discretionary powers to waive the client contribution in cases of exceptional hardship.[156]

3.107 It was argued that as the rebate per kilometre and for accommodation is so low, the deduction of a patient contribution makes it hardly worth making a claim or visiting a GP to fill out the application form.[157] For example, in the case of a patient travelling from Inverell to Armidale, a return trip of 280 kms, the refund to a non-card holder is $1.10.[158] In another case, a patient from Northern NSW living just over the 100 km threshold required daily radiotherapy treatment for breast cancer for a period of 7 weeks. Effectively she drove 7-8,000 kms in this period. As she had a 14 year old child at home she needed to return home daily. Cancer Voices NSW reported that she received nothing back for her $30 per day expenditure on fuel because of the mandatory $40 co-contribution which was levied for each trip.[159]

3.108 There were a number of comments about the use of community transport and reimbursement. The Young Community Transport Service stated that while funding

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152 *Submission* 74, p.12 (Kimberley Aboriginal Health Planning Forum).

153 *Submission* 133, p.1 (Peter MacCallum Cancer Centre – Bendigo Radiotherapy Centre).

154 *Submission* 74, p.8 (Kimberley Aboriginal Health Planning Forum).

155 *Submission* 188, p.12 (NSW Health).

156 *Submission* 188, p.12 (NSW Health).

157 *Submission* 59, p.3 (NCOSS).

158 *Submission* 17, p.1 (Inverell Breast Cancer Support Group); see also *Committee Hansard* 6.8.07 (Mrs B Moore).

159 *Submission* 91, p.1 (Cancer Voices NSW)

was received from the NSW Government, that funding was inadequate to provide transport without a cost to their clients. Services have expanded over recent years and 'due to the small level of funding we receive [from the NSW Government] we cannot afford to provide free travel regularly and it seems that clients will be even more disadvantaged now under this new ruling'.[160] Community Transport groups argued that patients should be able to claim their client contribution.

Delays in reimbursements

> …re-imbursement can take anything from four weeks to four months. For many who require fortnightly or monthly treatment this becomes an impossible financial burden.[161]

3.109 Witnesses reported lengthy delays in the processing of reimbursements which ranged from one month to more than eight months. Such delays place additional stress and financial pressure on many patients and their families at a time when they are already struggling to cope with the patient's medical condition.[162] This is particularly concerning for patients who may already be dealing with economic hardship:

> Cash flow seems to be a problem. We are dealing with people from a lower socioeconomic group and the elderly. They do not have that sort of extra money on them and they need to claim back the subsidy.[163]

3.110 Many accommodation services receive reimbursement direct from PATS. However, the delays may be significant. The Leukaemia Foundation of WA stated that it can take up to three months from time of invoice for the Foundation to receive payment. PATS reimbursement is only provided once the patient returns home. As most patients stay on average five months, the Foundation does not receive payment for eight months 'impacting upon day to day services the Leukaemia Foundation provides'.[164]

3.111 Few schemes make pre-payments and require patients to claim for expenses after they have travelled. Witnesses stated that people were missing appointments because they could not afford the up-front costs for petrol and accommodation.[165] Some accommodation services suggested that they would prefer to charge PATS directly so as to limit the financial burden on patients.[166]

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160 *Submission* 10, p.1 (Young Community Transport Service); see also *Submission* 20, p.1 (Lake Cargelligo Community Transport).

161 *Submission* 11, p.1 (Sunraysia Information & Referral Service Inc).

162 See for example, *Submissions* 33, p.1 (Advisory Committee for Older People); 69, p.5 (HCRRA); 109, p.8 (Cancer Council Australia); 166, p.7 (NSW Farmers Association).

163 *Committee Hansard* 6.8.07, p.26 (Mrs M Izatt, Frontier Services); see also *Submission* 78, p.3 (Epilepsy Foundation of Victoria).

164 *Submission* 54, p.7 (Leukaemia Foundation Western Australia).

165 *Submissions* 161, p.1 (Ms S Evans); 162, p.2 (Women's Health Tasmania)

166 *Submission* 35, p.1 (MFIA).

Conclusion

> Thirty dollars to cover a night's accommodation is denying reality. No meal subsidy for patients and carers forced to live away from home for sometimes long periods is unreasonable. This is an equity issue. If a patient cannot access a service locally and has been referred to a service in another centre or State it is the belief of our organisation that all their additional costs should be met.[167]

3.112 Illness and disability imposes a financial burden on patients. However, for patients from rural, regional and remote areas the costs of transport and accommodation can add significantly to that burden. The evidence indicated that in some instances the financial burden is such that treatment decisions and health outcomes are compromised. In some cases, patients are choosing not to receive treatment. As Mr Clive Deverall from the consumer advocacy group, Cancer Voices WA, told the Committee, the decision to refuse treatment compromised a patient's chances of survival:

> If patients, because of the frustrations in dealing with travel and accommodation, decline to have radiotherapy – as follow-up to their surgery or their chemotherapy, or sometimes even preoperative radiotherapy which is to try to reduce the bulk of a tumour before they undergo surgery – then these patients obviously prejudice their survival by not having that radiotherapy. There is evidence from previous national inquiries, particularly in the context of breast cancer, which endorses that scenario with patients: because of the frustrations of dealing with travel and accommodation and other social issues, they are not following up with radiotherapy.[168]

167 *Submission* 65, p.2 (AMA Tasmania).

168 *Committee Hansard*, 13.7.07, p.23 (Mr C Deverall, Cancer Voices WA).