

The Senate

Standing Committee on
Community Affairs

Highway to health: better access for
rural, regional and remote patients

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RECOMMENDATIONS

Recommendation 1

7.105 That the next Australian Health Care Agreement recognise the fundamental importance of patient assisted travel schemes and include:

- a clear commitment to improvement of services;
- a clear allocation of funding for the schemes;
- a clear articulation of the services and supports that people using transport schemes can access; and
- a commitment to regular monitoring of access and service provision.

Recommendation 2

7.110 That as a matter of urgency, the Australian Health Ministers' Advisory Council establish a taskforce comprised of government, consumer and practitioner representatives to develop a set of national standards for patient assisted travel schemes that ensure equity of access to medical services for people living in rural, regional and remote Australia.

7.111 That, in establishing national standards, the taskforce:

- identify relevant legislative, geographic, demographic and health service variables of the States and Territories impacting on access;
- identify barriers to access including costs of travel and accommodation, restrictions on escort eligibility and access to transport;
- assess the impact of co-payments;
- identify mechanisms to improve access for patients travelling between jurisdictions;
- identify, as a matter of priority, core, minimum standards that are relevant to all jurisdictions particularly in relation to eligibility criteria and subsidy levels; and
- give consideration to the development of optimal, outcomes-based standards that support consistent, quality outcomes for consumers, whilst enabling different State/Territory approaches that are responsive to local need.

7.112 Development of the national standards should include (but not be limited by) consideration of the following areas:

- patient escorts including approval for:
 - psycho-social support;

- approval for more than one caregiver to accompany a child; and
- approval for a caregiver to accompany a pregnant woman.
- eligibility:
 - identify a means other than the distance threshold to determine eligibility that takes into account a broader range of factors such as public transport access and road conditions; and
 - referral on the basis of the nearest appropriate specialists where an appointment can be secured within a clinically acceptable timeframe.
- appeals processes.

Recommendation 3

7.114 That the taskforce report to the Australian Health Ministers' Advisory Council expeditiously so that national standards can be formulated and instituted within twelve months of tabling of the Committee's report.

Recommendation 4

7.116 That the taskforce develop a performance monitoring framework, which enables ongoing assessment of State/Territory travel schemes against the national standards and relevant goals set out in the (revised) *Healthy Horizons* Framework, and facilitates continuous quality improvement.

Recommendation 5

7.117 That the Australian Health Ministers' Advisory Council establish a mechanism to monitor performance, identify areas for improvement and review the standards as required.

Recommendation 6

7.119 That the taskforce review existing administrative arrangements to make them less complex, including development of a simplified generic application form; consideration of an on-line application process; and revision of the authorisation processes.

Recommendation 7

7.123 That the Australian Health Ministers' Advisory Council determine transport and accommodation subsidy rates that better reflect a reasonable proportion of actual travel costs and encourage people to access treatment early.

Recommendation 8

7.124 That the taskforce identify appropriate mechanisms against which to review subsidy levels on a regular basis to keep pace with changes in living costs.

Recommendation 9

7.125 That all States and Territories adopt a pre-payment system, whether by vouchers, tickets or advance bookings, for patients experiencing financial difficulty with the initial outlay.

Recommendation 10

7.126 That the Commonwealth Government initiate negotiations with the private health insurance sector to encourage insurers to offer products that include transport and accommodation assistance.

Recommendation 11

7.127 That State and Territory Governments develop memoranda of understanding that underpin clear, workable reciprocal arrangements for cross-border travel.

Recommendation 12

7.129 That State and Territory Governments expand travel schemes to cover items on the Medical Benefits Schedule – Enhanced Primary Care and live organ donor transplants (with assistance to the donor and recipient) and access to clinical trials.

Recommendation 13

7.131 That the taskforce develop a marketing and communication strategy that targets consumers and health practitioners. Consideration should be given to the role of the Divisions of General Practice in educating GPs about the scheme.

Recommendation 14

7.133 That appropriate, on-site (or nearby) accommodation facilities be incorporated into the planning and design of new hospitals/treatment centres.

Recommendation 15

7.134 That State and Territory Governments work proactively with charities and not-for-profit organisations to provide affordable patient accommodation and services. This should include:

- developing administrative arrangements that facilitate organisations' access to PATS funding;
- establishing memoranda of understanding with charitable organisations, which set out commitments to quality service delivery; and
- developing partnerships with the non-government sector to provide suitable patient accommodation.

Recommendation 16

7.138 That State and Territory Governments, in consultation with Indigenous representatives and Indigenous Health Services, identify and adopt best practice standards and develop programs to improve Indigenous patients' access to medical services by:

- ensuring continuity of care for Indigenous patients by establishing liaison services and improving coordination in, and between, remote communities and treatment centres;
- accommodating the cultural and language needs of Indigenous patients from remote communities, particularly in respect to the provision of escorts and translators; and
- expanding access to appropriate accommodation services.

7.139 In establishing these best practice standards and programs government and Indigenous representatives should:

- identify and build on existing examples of good practice by health services in Indigenous communities and State and Territory programs; and
- establish clear governance and administrative arrangements for the delivery of programs, including consideration of the most appropriate bodies to provide day-to-day administration of services (for example, a government body or community-managed Aboriginal and Torres Strait Islander health services).

CHAPTER 1

INTRODUCTION

Terms of Reference

1.1 On 28 March 2007 the Senate, on the motion of Senator Adams, referred the following matter to the Community Affairs Committee for inquiry and report by 20 September 2007:

The operation and effectiveness of Patient Assisted Travel Schemes including:

- (a) the need for greater national consistency and uniformity of Patient Assisted Travel Schemes across jurisdictions, especially the procedures used to determine eligibility for travel schemes covering patients, their carers, escorts and families; the level and forms of assistance provided; and reciprocal arrangements for inter-state patients and their carers;
- (b) the need for national minimum standards to improve flexibility for rural patient access to specialist health services throughout Australia;
- (c) the extent to which local and cross-border issues are compromising the effectiveness of existing Patient Assisted Travel Schemes in Australia, in terms of patient and health system outcomes;
- (d) the current level of utilisation of schemes and identification of mechanisms to ensure that schemes are effectively marketed to all eligible patients and monitored to inform continuous improvement;
- (e) variations in patient outcomes between metropolitan and rural, regional and remote patients and the extent to which improved travel and accommodation support would reduce these inequalities;
- (f) the benefit to patients in having access to a specialist who has the support of a multidisciplinary team and the option to seek a second opinion;
- (g) the relationship between initiatives in e Health and Patient Assisted Travel Schemes;
- (h) the feasibility and desirability of extending patient assisted travel schemes to all treatments listed on the Medicare Benefits Schedule – Enhanced Primary Care items such as allied health and dental treatment and fitting of artificial limbs; and
- (i) the role of charity and non-profit organisations in the provision of travel and accommodation assistance to patients.

Conduct of the inquiry

1.2 The inquiry was advertised in *The Australian*, several regional papers and through the Internet. The Committee invited submissions from Commonwealth, State and Territory Governments, Patient Assisted Travel Scheme (PATS) coordinators and other interested organisations and individuals.

1.3 The Committee received 190 public and four confidential submissions. All State and Territory Governments and the Commonwealth Government provided submissions. A list of individuals and organisations that made public submissions to the inquiry together with other information authorised for publication is at Appendix 1.

1.4 The Committee held six days of public hearings in Canberra, Alice Springs, Melbourne, Perth, Launceston and Brisbane. While in Alice Springs, the Committee undertook discussions and inspections at the Alice Springs Base Hospital, Central Australian Aboriginal Congress, and the Western Desert Dialysis Unit. Witnesses who gave evidence at the hearings are listed in Appendix 2.

Background to the inquiry

The Broader Context – Australia's health care system

1.5 Australia has a complex health care system with all levels of government playing a role in the funding and/or provision of health services. The system is financed by a mix of public (government) and private (individuals, private health insurers, injury compensation bodies) funds.

1.6 In 2003-04 an estimated total of \$78.6 billion (9.7 per cent as a proportion of Gross Domestic Product) was spent on health as follows:

- Commonwealth Government – estimated \$35.7b (45.5 per cent);
- State/Territory and Local Governments – estimated \$17.7b (22.6 per cent); and
- Private sector – estimated \$25.1b (32 per cent).¹

Commonwealth Government

1.7 The Commonwealth Government plays a principal role in the provision of universal access to medical, pharmaceutical and hospital services through the Medicare arrangements. This includes the Medicare Benefits Schedule (MBS), the Pharmaceutical Benefits Scheme (PBS) and the Australian Health Care Agreements (AHCAs).

1 AIHW, *Health Expenditure Australia 2003-04*, September 2005, pp.18-19.

1.8 Under the MBS, the Commonwealth subsidises patient costs for medical services provided on a fee-for-service basis. These services include medical consultations, surgical procedures, diagnostic services, and a range of preventative health checks and allied health services. The PBS subsidises the cost of pharmaceuticals for all Medicare-eligible people. The Government contributes to the funding of public hospitals through the AHCAs. The AHCAs are five-year bilateral agreements between the Commonwealth and the States/Territories, which set out the Commonwealth Government's financial commitment and the conditions and obligations of the States and Territories underpinning the provision of free public hospital services.² The current agreements will expire on 30 June 2008.

1.9 The Commonwealth Government is also involved in the supply and distribution of the medical workforce,³ and provides the bulk of funding for high-level residential care and health research.⁴

State, Territory and Local Governments

1.10 State and Territory Governments are principally responsible for the provision of public hospital infrastructure and services, community health services, mental health programs, patient transport and population health programs.⁵ Local Governments also contribute to the delivery of health programs.

Private sector

1.11 The private sector plays a significant role in the delivery of primary, specialist and allied health care. Services are provided by general practitioners, specialists, pharmacists, dentists and a range of other allied health professionals. In general, services are provided on a fee-for-service basis with financial assistance provided through Medicare.

1.12 Private hospitals complement the public hospital system. There are also private health insurers who offer a range of health insurance products.⁶

1.13 The non-government (not-for-profit) sector also holds an important place within Australia's health care system. Community organisations, research and educational bodies, consumer and support groups and professional bodies provide health services, which ease the 'burden' on the government sector.⁷

2 *Submission 157*, pp.5-6 (DoHA).

3 *Submission 157*, p.6 (DoHA).

4 AIHW, *Health Expenditure Australia 2003-04*, September 2005, p.2.

5 *Submission 157*, p.6 (DoHA).

6 *Submission 157*, pp.6-7 (DoHA).

7 Senate Community Affairs References Committee, *The Cancer Journey: informing choice*, June 2005, p.17.

Health care and travel assistance

Effective health care depends on access to that care, but the sheer size of Australia precludes easy physical contact between patients living in rural and remote areas and medical specialists, the majority of whom are in urban centres.⁸

1.14 While Australia has a relatively sophisticated public and private health care system, for some people geographic isolation inhibits their access to specialist health care. Out of a total population of just over 21 million,⁹ approximately 34 per cent of Australians reside in regional, rural and remote areas with limited specialist health services.¹⁰

1.15 To improve patient access all States and Territories have established a Patient Assisted Travel Scheme (PATS). The schemes provide assistance – in the form of travel and accommodation subsidies – to patients for whom specialist medical care is not locally available.

1.16 The State-based schemes replaced the Isolated Patients Travel and Accommodation Scheme (IPTAAS), which was centrally administered by the Commonwealth Government.

Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)

1.17 The Commonwealth Government established IPTAAS on 1 October 1978. The scheme provided financial assistance to persons living in rural and remote areas who had to travel long distances (more than 200 kilometres) to obtain specialist medical treatment and oral surgery.¹¹

1.18 In June 1985 a working party comprised of Commonwealth, State and Territory officials was established to review the scheme and related patient transport issues. It was agreed that responsibility for the administration of the scheme should be transferred to the States and Territories.¹² The then Minister for Health, the Hon. Neal Blewett announced that IPTAAS would be abolished from 1 January 1987 with funding provided directly to the States and Territories through special revenue (financial) assistance grants. It was stated that the Commonwealth would provide

8 *Submission 55, Attachment 1, p.6 (NRHA).*

9 ABS, *Population clock* (accessed 13 September 2007).

10 *Submission 90, p.1 (RDAA).*

11 Senate Community Affairs Committee, *Breaking the silence: a national voice for gynaecological cancers*, October 2006, p.87; see also *Submission 157, p.7 (DoHA).*

12 Mr Robert L. Chynoweth, member for Dunkley, *House of Representatives Hansard*, 7 October 1986, p.1587.

funding of \$21.8m (indexed) per year to the States and the Northern Territory.¹³ This was an increase of 26 per cent of Commonwealth benefits paid in 1985-86.¹⁴

1.19 Dr Blewett explained that IPTAAS had been the subject of criticism from a number of sources including State and Federal members of Parliament, consumer advocacy groups, individuals, social worker associations, the Commonwealth Ombudsman and the Administrative Appeals Tribunal. The principal concern was that the Commonwealth Government lacked the requisite local knowledge and delivery mechanisms to respond flexibly to the needs of different geographical communities. Dr Blewett concluded that the States and Territories would be able to administer the scheme more effectively:

[T]he Commonwealth is poorly placed to administer any scheme of this nature, having no suitable delivery and processing mechanism outside the capital cities and at best only a second-hand knowledge of available services. On the other hand, State hospital and welfare delivery networks are well established and some already provide cash advances to the needy in anticipation of IPTAAS benefits. Accordingly, the States and Territories are well placed to develop and administer more flexible and effective measures for those in need.¹⁵

1.20 The State-managed schemes became known generally as the Patient Assisted Travel Schemes (PATS), with different titles adopted across the States and Territories.

PATS funding

1.21 In 1999, the States and Territories surrendered the Financial Assistance Grants in return for the Goods and Services Tax (GST) revenue stream.¹⁶

1.22 As noted above, funding is granted to all States and Territories for the provision of free public hospital services through the AHCAs. The Department of Health and Ageing pointed out that under the AHCAs, the States and Territories must ensure that people have equal access to public hospital care regardless of their geographic location. Therefore, while funds are not specifically earmarked for patient transport, PATS is one obvious mechanism to achieve equal patient access.¹⁷

13 As noted by the Department of Health and Ageing, the transfer of the travel scheme predated self government in the ACT. *Submission 157*, p.7 (DoHA).

14 The Hon. Neal Blewett, MP, Minister for Health, 'Budget Information 1986-87', *Press release 147*, 19 August 1986 and *House of Representatives Hansard*, 17 September 1986, p.847.

15 The Hon. Neal Blewett, MP, Minister for Health, *House of Representatives Hansard*, 17 September 1986, p.847.

16 *Submission 157*, p.7 (DoHA).

17 *Submission 157*, p.16 (DoHA).

Other forms of patient travel assistance

1.23 The *Private Health Insurance Act 2007* regulates private health insurance benefits including patient travel and accommodation. Roughly half of all private health insurers provide some form of travel and accommodation cover for their members who must travel a specified minimum distance to receive health care. Benefits vary across insurers, with a basic benefit offering \$30-\$40 for travel, \$30-40 for accommodation and a limit of \$200 per person per year.¹⁸

1.24 Transport services are one of a range of services provided through the joint Commonwealth and State/Territory Government program, Home and Community Care (HACC). The HACC program supports frail elderly Australians and people with a disability and their carers to maintain independent living. Transport is provided for attendance at medical appointments along with other activities such as shopping and social outings.¹⁹

1.25 A number of not-for-profit organisations – including volunteer organisations – provide free or subsidised transport to medical appointments. Further, there are various (but limited) accommodation facilities, which house patients undergoing specialist treatment. This is discussed in chapter 6.

Current arrangements – Patient assisted travel schemes (PATS)

Case Study

The PATS system...is administered locally with States and Territories having different rules, for example: if Carly had lived in Cape York Queensland she would have had an escort paid for by the PATS system if she was an Aboriginal or Torres Strait Islander woman, not if she was a non-Indigenous Australian. In remote NSW Carly would have had to pay the bus fares up front claiming back a proportion if she was able to prove financial hardship, an escort would probably not have been approved. In the Kimberley in Western Australia a trip home could have entailed a 12 hour overnight bus trip where Carly was too frightened to sleep in case she dropped her baby. In the Northern Territory she may have had an escort paid for if the remote staff had pushed hard enough and if she had had a sympathetic medical officer to approve it; though this often depends on the PATS budget at the time and the amount of pressure being applied to decrease it.

Source: Submission 147 p.2 (Associate Professor Sue Kildea).

1.26 The health departments in each State and Territory oversee their respective schemes. As noted above, the schemes assist patients to access planned (non-emergency) clinical care that is not available locally. With a few exceptions, the schemes cover patients accessing treatment from medical specialists only; allied

18 *Submission 157*, Attachment B, p.1 (DoHA).

19 *Submission 157*, Attachment B, p.1 (DoHA).

health care is excluded. Assistance involves a contribution towards the travel and accommodation costs of the patient and, in some circumstances, the patient's escort. The schemes are expressly subsidy schemes. They are not designed to cover the full cost of transport and accommodation or other costs incurred such as meals and incidental expenses.²⁰

1.27 To be broadly eligible for travel assistance patients must be residents of the jurisdiction in which they are making an application and must not be entitled to other sources of financial assistance such as the Department of Veterans' Affairs' travel assistance or other compensation schemes.

1.28 Whilst the schemes have some basic features in common, travel assistance arrangements vary across the States and Territories with different eligibility criteria, subsidy levels, requirements for patient contributions and areas of medical care covered.

1.29 An overview of the travel schemes on a State-by-State basis is provided below, along with a brief outline of relevant demographic and geographic characteristics. A table of major features of each scheme is included.

New South Wales - demographic and geographic characteristics

1.30 The population of NSW is just over six and half million. Over 25 per cent of the population live outside of the major centres of Sydney, Newcastle and Wollongong.²¹ The percentage of Indigenous Australians residing in NSW is 2.1 per cent.²²

New South Wales – travel scheme overview

1.31 NSW retained the Commonwealth title for its travel scheme – IPTAAS – until 2006 when the scheme was integrated with other transport schemes under the program *Transport for Health*. The policy provides a framework for all non-emergency health-related transport services – including patient assisted travel. Under *Transport for Health*, the various transport services have been integrated into one multifaceted program, which is delivered through six Transport for Health units within the four NSW rural Area Health Services.²³

1.32 NSW Health noted that *Transport for Health* has the aim of improving patient access to health services by:

20 *Submission 55*, Attachment 1, p.6 (NRHA).

21 *Submission 188*, p.3 (NSW Health).

22 ABS, *2006 Census QuickStats*, www.censusdata.abs.gov.au (accessed 2 August 2007).

23 NSW Department of Health, *Transport for Health Policy 2006-2011*, August 2006, p.1; see also *Submission 188*, p.7 (NSW Health).

- responding to the health transport needs of patients in a consistent, strategic and efficient manner;
- developing and maintaining working partnerships with transport providers and stakeholders; and
- recognising the role and importance of health transport in service planning and delivery within the NSW Health system.²⁴

1.33 On 1 July 2006, two changes to the scheme took effect: the vehicle allowance was increased to fifteen cents per kilometre and the distance eligibility threshold was reduced from 200km to 100km (one way).²⁵

1.34 In 2006-7, the total budget for the *Transport for Health* program was \$15.9 million. In the previous year, just under \$8.2 million in IPTAAS benefits was paid out for 40,082 claims. The average benefit paid per claim was \$141.²⁶

Australian Capital Territory - demographic and geographic characteristics

1.35 The ACT's population is 324,034. Of this total, 323,056 reside in Canberra with the remainder in relatively close proximity to the city. Indigenous peoples comprise 1.2 percent of the ACT population.²⁷

Australian Capital Territory – travel scheme overview

1.36 The ACT operates an Interstate Patient Travel Assistance Scheme (IPTAS). All permanent ACT residents are eligible for the scheme as the ACT does not impose distance criteria. ACT residents are eligible for assistance toward travel and accommodation costs incurred irrespective of whether they hold concession cards.

1.37 In 2007-08 the ACT expects 1,800 claims for travel and accommodation assistance totalling an estimated \$625,000. A recent review of the scheme resulted in an increase in reimbursement amounts as well as putting in place mechanisms for regular review of the amounts reimbursed under the scheme.²⁸

Northern Territory - demographic and geographic characteristics

1.38 The Northern Territory's population is just under 200,000²⁹ and is widely dispersed over a vast area. The NT encompasses 17.5 per cent of Australia's total land mass. Close to 60 per cent of people in the NT live in the major urban areas of

24 *Submission* 188, p.8 (NSW Health).

25 *Submission* 188, p.11 (NSW Health).

26 *Submission* 188, pp.18-20 (NSW Health).

27 ABS, *2006 Census QuickStats*, www.censusdata.abs.gov.au (accessed 2 August 2007).

28 *Submission* 150, p.1 (ACT Government).

29 ABS, *2006 Census QuickStats*, www.censusdata.abs.gov.au (accessed 2 August 2007).

Darwin, Palmerston and Alice Springs. The remaining 40 per cent reside in regional towns, Indigenous communities and pastoral properties.³⁰

1.39 A total of 29 per cent of the NT population are Indigenous Australians, far exceeding all other States and the ACT on a percentage basis. Approximately 70 per cent of Indigenous peoples in the NT reside outside of the major urban centres, with a number living on remote communities. As a result, they have limited access to public or private health services.³¹

1.40 Overall, people that live in the NT are the youngest Australians, with a median age of 31 years compared with the national average of 37 years. The median age of Indigenous people in the NT is lower than non-Indigenous people. This is a function of a higher birth rate, having children at an earlier age and the shorter life expectancy of Indigenous people.

1.41 The NT Government noted that the NT has the highest burden of fatal disease and injury in Australia. Cardiovascular disease, mental disorders, cancers, unintentional injury and chronic respiratory disease are the principal contributing conditions. A significant proportion of the Indigenous population live with one or more chronic illnesses such as cardiovascular, diabetes, renal and respiratory diseases.³²

Northern Territory – travel scheme overview

1.42 In the NT, the scheme is known as the Patient Assistance Travel Scheme (PATS) and sits within a broader travel assistance program – the Patient Travel Scheme (PTS), which also includes Inter-hospital Transfer and Medical Evacuation. PATS is funded by the NT Government at \$6 million per year. The scheme is administered through the NT Hospital Network, which includes five public hospitals – two in central Australia and three in the top end. Each of the five hospitals has a PATS officer.

1.43 The scheme is promoted to patients through the NT Government website, posters, brochures, health boards and the patient-GP interface. The scheme is monitored through 'specific patient travel data collection and reporting'.³³

1.44 The travel scheme was last reviewed in the NT in 2004. A separate review of the staff training manual was recently completed.³⁴

30 *Submission 164*, p.3 (NT Government).

31 *Submission 164*, p.3 (NT Government).

32 *Submission 164*, p.3 (NT Government).

33 *Submission 164*, pp 2-3 & 9 (NT Government).

34 *Committee Hansard*, 5.7.07, p.48 (Dr L Firth, NT Government).

Queensland - demographic and geographic characteristics

1.45 Queensland's population is close to four million. Of this four million, 3.3 per cent are Indigenous Australians.³⁵ The south-east corner of the State and the larger regional coastal centres are densely populated with close to two-thirds of the Queensland population. In contrast, large tracts of the state are very sparsely populated.³⁶

1.46 Queensland Health identified three demographic factors that present challenges to the delivery of health care in Queensland: an ageing and growing population, a decentralised population and a diverse population. Queensland is currently experiencing the highest rate of population growth in Australia, with an expected increase from four million to 5.6 million within 20 years. It is projected that the bulk of this growth will be concentrated in the older age groups.³⁷

1.47 As with the general Queensland population, the health workforce is unevenly distributed across the state, with a concentration of workers in the south-east. Areas with a low population density struggle to attract health professionals or have sufficient 'throughput of patients' to maintain workforce skills. Queensland has the second lowest number of health professionals on a per capita basis.³⁸

1.48 Queensland Health noted that within the state's population there are significant differences in health status and life expectancy. Consistent with the country more broadly, disadvantaged population groups such as Aboriginal and Torres Strait Islander peoples and those experiencing socio-economic disadvantage have higher rates of ill-health and death.

Queensland – travel scheme overview

1.49 In Queensland, the scheme is known as the Patient Travel Subsidy Scheme (PTSS). It is broadly administered by Queensland Health with the day-to-day running of the scheme undertaken by public hospitals.

1.50 Queensland Health recently reviewed the scheme and, as a result, is making the following changes:

- redesigning and streamlining the application forms;
- updating PTSS brochures and information sheets;
- reworking the administration guidelines to improve consistency of interpretation; and

35 ABS, *2006 Census QuickStats*, www.censusdata.abs.gov.au (accessed 2 August 2007).

36 *Submission* 184, p.2 (Queensland Health).

37 *Submission* 184, p.2 (Queensland Health).

38 *Submission* 184, p.3 (Queensland Health).

-
- raising the mileage subsidy from 10 cents to 15 cents per kilometre (already implemented).³⁹

South Australia - demographic and geographic characteristics

1.51 South Australia's population is just over 1.5 million with some 429,000 living in rural areas. Of this number, 1.7 per cent are Indigenous Australians.⁴⁰

1.52 The SA Government pointed to the remoteness of many communities and the large number of small towns in South Australia. This presents significant challenges. The general lack of resident country specialists creates a high reliance on access to transport to the city for specialist medical services. On any given day there are about 550 country inpatients in metropolitan hospitals receiving treatment and care.⁴¹

South Australia – travel scheme overview

1.53 In broad terms, PATS in South Australia provides for treatment by the nearest registered specialist for patients residing more than 100kms from the treatment centre.

1.54 In some communities different models of administration have been applied to enable better management and support, particularly for remote communities. An example is the Nganampa Health Council, an Aboriginal Community Controlled Organisation located in the APY Lands, where people travel both to the Northern Territory and to Adelaide or other South Australian regional centres depending on their health needs and cultural linkages. To facilitate service delivery, funding from PATS has been cashed out to Nganampa Health Council to enable them to manage their own PATS service for their clients.

1.55 At the time of transfer of the IPTAAS scheme from the Commonwealth Government to the States and Territories, SA's PATS funding in 1987-88 was \$1.8 million. For 2006-07, it is projected that actual expenditure on PATS will be around \$6.95 million for an estimated 41,600 claims. The average cost per claim is estimated at \$167.06.

1.56 In 2006 PATS was included in a review under the *Patient Journey Initiative*. In response, the SA Government has announced the establishment of an overarching support program – the *Transport and Patient Support Program*.

1.57 A key component of this program is enhanced transport support, which includes a Health Bus Network. The key elements of the proposed Health Bus Network are:

39 *Submission* 184, pp.3-4 (Queensland Health).

40 ABS, *2006 Census QuickStats*, www.censusdata.abs.gov.au (accessed 2 August 2007).

41 *Submission* 165, p.4 (SA Government).

- a door-to-door service incorporating expanded Community Passenger Networks and a significant number of identified contracted Health Bus routes;
- a nominal vehicle allowance proposed for those choosing to take a private vehicle;
- additional air travel (Medical Specialist Services Only if approved) and provision for special circumstances;
- assistance for the metropolitan component of the journey could be enhanced by two new patient support programs, a 'Meet & Assist' service and the provision of two 'Transit Lounges' through NGO's; and
- support for accommodation costs will remain only for specialist medical services.

To complement the transport system, additional patient support could be provided in partnership with Non Government Organisations (NGO's). A trial of the Health Bus Network will be implemented in one country region and pending a satisfactory evaluation, will be rolled out across country SA.⁴²

Tasmania - demographic and geographic characteristics

1.58 The total population of Tasmania is approximately 489,000 with 16,900 (3.5 per cent) Indigenous Australians.⁴³

1.59 As Tasmania has a relatively low population, a range of specialist services are not available intrastate. In the 2005-06 financial year, roughly \$1.6 million was spent on interstate travel with only \$800,000 spent on intrastate travel.⁴⁴

Tasmania – travel scheme overview

1.60 The Acute Health Services Group in the Department of Health and Human Services (DHHS) funds the Patient Travel Assistance Scheme (PTAS) in Tasmania. Financial assistance is provided for both intra- and inter-state travel to access eligible specialist services.⁴⁵

1.61 The three major hospitals in the state each have a PTAS travel coordinator, who assess patient eligibility and, in the case of interstate travel, assist with transport and accommodation bookings.⁴⁶ The PTAS Review Committee – comprised of the

42 *Submission* 165, pp.7-8 (SA Government).

43 ABS, *Population Distribution, Aboriginal and Torres Strait Islander Australians* 2006, Cat. No. 4705.0, p.5.

44 *Committee Hansard*, 23.7.07, p.4 (Dr P Renshaw, Launceston General Hospital).

45 *Submission* 183, p.3 (Tasmanian Government).

46 DHHS, 'Patient Travel Assistance Scheme (PTAS)', interstate and intrastate information sheets, www.dhhs.tas.gov.au/services (accessed 14 August 2007).

PTAS travel coordinators and medical authorisers – is responsible for reviewing and monitoring the travel scheme as well as serving as an appeals mechanism.⁴⁷

Victoria - demographic and geographic characteristics

1.62 Victoria has close to five million residents. Victoria has a relatively low number of Indigenous residents – 0.6 per cent Victoria's population.

Victoria – travel scheme overview

1.63 In Victoria, the travel scheme is known as the Victorian Patient Transport Assistance Scheme (VPTAS). In the last five years, the number of recipients of VPTAS payments has increased by 64 per cent, with VPTAS real expenditure (above CPI increases) increasing by an average of 8.7 per cent per annum. Projected VPTAS expenditure for the 2006-2007 financial year is nearly \$6 million. In 2005-06, approximately 34,000 VPTAS claims were paid to nearly 12,000 recipients.⁴⁸

1.64 In 2001 changes to VPTAS were introduced:

- car travel subsidy increased from 11 to 13 cents per kilometre, with reviews recommended every two years, based on local operating costs as determined by the Royal Automobile Club Victoria (the rate was subsequently lifted to 14 cents);
- the patient and escort travel contribution was abolished for concession cardholders;
- the patient and escort travel contribution for non-concession cardholders was reduced to a maximum of \$100 in a treatment year; and
- accommodation assistance was made available for the first night for patients and escorts.⁴⁹

1.65 Reviews of VPTAS policy and guidelines were conducted in 2001, 2004 and 2006. A review of VPTAS claims processing was also undertaken in 2006 leading to increased administrative efficiency and consistency.⁵⁰

1.66 The Victorian Government stated that VPTAS plays an important role in assisting equitable access to specialist medical services for those most in need by reducing the cost of travelling to appointments. However, it stated that it is 'also working to improve patient access to the right care in the best setting, as close to home as possible'.⁵¹

47 *Submission* 183, p.4 (Tasmanian Government).

48 *Submission* 182, pp.2,5 (Victorian Government).

49 *Submission* 182, p.8 (Victorian Government).

50 *Submission* 182, p.6 (Victorian Government).

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

Western Australia - demographic and geographic characteristics

1.67 Western Australia has a population of just under two million. Three per cent of the population are Indigenous Australians.⁵² The WA Government explained that:

The WA Country Health Service (WACHS) is the single biggest Area Health Service in Western Australia, and the largest country health system in Australia. It services an area of some 2.55 million square kilometres with a combined regional population of 454,000 people (almost a quarter of the State's population), including 44,900 Aboriginal people (around 10% of the State's total rural population).⁵³

WA – travel scheme overview

1.68 The WA Government stated that PATS 'provides a safety net to enable patients to gain access to the nearest appropriate medical specialist'. In the 12 months ending 31 March 2006, the scheme assisted a total of 51,089 trips at a cost of \$13.9 million. The majority of trips were made by private vehicle; however the largest item of expenditure was for air fares – over \$6.4 million. Some \$2.7 million was paid for accommodation costs. Over 41,000 trips were made to Perth with a small number interstate (275).⁵⁴

1.69 The WA Government indicated that the scheme is reviewed regularly and improvements made to administrative practices on an on-going basis, subject to budget constraints. Following reviews in 2002 and 2005, the scheme was amended to:

- provide a safety net for patients who regularly travel between 70-100 km (one way) to access specialist medical services;
- improve awareness of the scheme among health professionals and potential recipients;
- provide assistance to patients in advance of travel for the booking and payment of transport and accommodation, and for the purchase of fuel; and
- increase the subsidy rate for frequent travellers (those with chronic conditions) and for group travel from remote communities.⁵⁵

52 ABS, *2006 Census QuickStats*, www.censusdata.abs.gov.au (accessed 2 August 2007).

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

54 *Submission 39*, p.2 (WA Government).

55 *Submission 39*, p.3 (WA Government).

Table 1.1: Summary of PATS in Australia

	Eligibility requirements	Nearest specialist	Travel assistance	Accommodation assistance	Patient contributions	Escorts
NSW	<p>Patient must:</p> <ul style="list-style-type: none"> - be a permanent resident of NSW or Norfolk Island; - reside more than 100 km (one way) from nearest treating specialist; - referred by medical practitioner to specialist, by optometrist, by dental practitioner to specialist for oral surgery or orthodontics for cleft lip and palate 	<p>Referred to nearest specialist; includes nearest appropriate interstate specialist; exceptions made in certain circumstances. Referrals initiated by nearest specialist for a 2nd opinion or referral to another specialist also accepted; interstate referral if treatment not available in NSW</p>	<p>Assistance provided for rail or bus at economy rates</p> <p>Fuel subsidy of 15c/km for private car or hire car</p> <p>Air travel available if valid medical reason put forward by GP or treating specialist and prior approval received</p> <p>Partial reimbursement of relevant taxi and public transport cost</p>	<p>Payable if:</p> <ul style="list-style-type: none"> - referring practitioner certifies in-transit accommodation required for medical need; - transport schedules require overnight stay; - treatment as outpatient. <p>Commercial: \$33 per night (single); or \$46 per night (double)</p> <p>Private: \$30 per week after 1st week for pensioners or Health Care Card holders</p>	<p>\$40 (\$20 for pensioner or Health Care Card holders) personal contribution deducted from the total benefits paid per claim</p>	<p>Medical practitioner or treating specialist certifies that escort medically necessary to accompany patient and/or remain during treatment; or patient under age of 17 years</p>
Qld	<p>Patient must:</p> <ul style="list-style-type: none"> - be a permanent resident; - service being sought not within 50 kms of nearest public hospital; - referred by medical practitioner, in remote areas by a remote area nurse, by dental services or by an ophthalmologist 	<p>Referred to closest service of its type; some exceptions including travel to a more distant service if support of family and friends available</p>	<p>Assistance provided at the cost of the least expensive form of public transport from the town of local hospital to the transport terminal of the town the patient is travelling to</p> <p>Fuel subsidy of 15c/km for private car calculated from post office nearest to local hospitals to post office nearest to medical facility being attended</p>	<p>Available for minimum period required to be away for medical reasons; one nights accommodation if travelling more than 600 kms or 8 hours</p> <p>Commercial: \$30 per night per person for concession card holders</p> <p>Private: \$10 per night per person for concession card holders</p> <p>Non-concession card holders pay first 4 nights each financial year</p>	<p>Nil</p>	<p>If hospital medical officer decides it is medically necessary or patient under 17 years of age</p>

	Eligibility requirements	Nearest specialist	Travel assistance	Accommodation assistance	Patient contributions	Escorts
Vic	<p>Patient must:</p> <ul style="list-style-type: none"> - be a permanent resident in a DHS designated rural region or reside on Mornington Peninsula; - travel more than 100 km (one way) from place of residence or travel an average of 500 kms per week in a block of at least 5 weeks; - have a current referral by GP to the nearest approved medical specialist; by optometrist; by dental practitioner to nearest oral surgeon, orthodontist for cleft lip and palate; by breast screening service; by approved rural and remote area nurse; by psychologist to nearest psychiatrist 	<p>Referred to nearest approved specialist; includes specialists visiting rural and remote areas</p> <p>Nearest specialist can be bypassed if referring practitioner decides treatment is urgent</p>	<p>Assistance provided for most direct means of public transport at economy or concession rate</p> <p>Fuel subsidy of 14c/km for private car</p> <p>Air travel available if living more than 350 kms (one way) from nearest approved specialist</p> <p>Taxi fares reimbursed only when no other means of transport to travel from residence to nearest public transport or from public transport to nearest specialist</p>	<p>Payable if specialist states that it is necessary to be accommodated close to or at treatment location</p> <p>Commercial: Up to \$30 per night each for patient and escort (if approved) for a maximum of 120 nights in a treatment year</p> <p>Private: Not eligible</p>	<p>First \$100 deducted from travel each treatment year for non-concession card holders</p>	<p>Referring practitioner and treating specialist state escort appropriate and responsible for patient's needs; or patient under 18 years of age</p>
ACT	<p>Patient must:</p> <ul style="list-style-type: none"> - be a permanent resident - referred by medical practitioner; by optometrist to ophthalmologist; by dental practitioner to specialist for surgery or orthodontics for cleft lip and palate 	<p>Referred to nearest treating specialist; exemptions where specialist service not available at nearest specialist including urgency of referral; referral from specialist to more distant specialist</p>	<p>Coach or rail cost of return economy ticket</p> <p>Fuel subsidy of 16c/km (from 1 July 2007)</p> <p>Air fares if certified by specialist</p>	<p>Commercial: \$35 per night</p> <p>Private: \$10 per night</p>	<p>Nil</p>	<p>Referring medical practitioner or treating specialist certifies escort necessary based primarily on medical or medically related need or patient under 17 years of age</p>

Eligibility requirements	Nearest specialist	Travel assistance	Accommodation assistance	Patient contributions	Escorts
<p>WA</p> <p>Patient must</p> <ul style="list-style-type: none"> - be permanent resident; - travel more than 100 km (one way) from the nearest treating specialist - travel more than 70kms (one way) to access treatment for a chronic medical condition 	<p>Referred to nearest specialist</p> <p>Referral to another specialist only if regional service is unable to make appointment in a clinically acceptable time frame</p>	<p>Assistance provided at economy rate for bus or train</p> <p>Air travel only if required by medical condition or journey by road over 16 hrs</p> <p>Fuel subsidy of 13c/km for private car or 15/km for frequent travellers (more than 4 times per year)</p> <p>May be eligible for fuel voucher, taxi voucher or shuttle bus tickets</p>	<p>Available if forward and return journeys cannot be completed in 1 day; for stop-over if travelling by car more than 750 kms (one way); transport schedules do not permit return on day of discharge</p> <p>Commercial: Up to \$35 per night.</p> <p>Private: \$10 per night</p> <p>Max of \$140 per week if patient enters into domestic rental agreement</p> <p>Non-concession card holders pay first 3 nights accommodation</p>	<p>Non-concession card holders pay first \$50 for a maximum of 4 trips in 12 month period</p>	<p>Referring practitioner specifies escort required for physical well-being of patient or well-being of patient due to an effect of treatment to be received; or patient under 18 years</p>
<p>Tas</p> <p>Patient must:</p> <ul style="list-style-type: none"> - be a permanent resident - live more than 75 km (one way) by shortest practical route to access nearest appropriate specialist - resident of King Island and Furneaux Islands and have to leave island to access eligible specialist medical service - referred by medical specialist, oral/maxillofacial surgeon or rural GP 	<p>Referred to nearest specialist; interstate referrals only if treatment not available in Tasmania</p>	<p>Assistance provided at economy bus travel from patient's residence</p> <p>Fuel subsidy of 13c/km for private car</p> <p>Air fare for King & Furneaux Island residents or for travel interstate</p>	<p>Commercial: up to \$30 per night for each approved person</p> <p>Private: not applicable</p> <p>Non-concession card holders pay first 2 nights</p>	<p>Card holders: \$15 per trip; maximum contribution \$120 per fiscal year</p> <p>Non card holders: \$75 per trip; maximum contribution \$300 per fiscal year</p>	<p>If referring specialist certifies escort necessary to provide active assistance while travelling or for specific medical reasons relating to treatment or patient aged under 18 years</p>

Eligibility requirements	Nearest specialist	Travel assistance	Accommodation assistance	Patient contributions	Escorts
<p>SA</p> <p>Patient must:</p> <ul style="list-style-type: none"> - be a permanent resident of a rural region - travel more than 100 km (one way) to nearest medical specialist 	<p>Referred to nearest registered specialist; travel to interstate allowed through referring teaching hospital if treatment not available in SA</p>	<p>Assistance provided at economy rate for bus/ferry/train</p> <p>Fuel subsidy of 16c/km for private car</p> <p>Air travel only where medically endorsed</p>	<p>Commercial: up to \$30 per night for patient and approved escort</p> <p>No reimbursement on 1st night for non-concession card holders</p> <p>Private: Not applicable</p>	<p>Patient contribution of \$30 deducted from total travel benefits: means tested exemption for genuine hardship</p>	<p>Need for escort medically endorsed or person under 17 years</p>
<p>NT</p> <p>Patient must:</p> <ul style="list-style-type: none"> - be a permanent resident - live more than 200 km from nearest specialist service or interstate service if service not available in NT; exceptions for dialysis patients and aged and disabled patients 	<p>Referred to closest resident or visiting eligible service or nearest appropriate interstate specialist if service not available in NT</p>	<p>Assistance provided at the cost of an economy return bus trip from the bus depot closest to the patient's residence</p> <p>Air for Alice Springs/Darwin and interstate or medically necessary or no alternate means of transport</p> <p>Fuel subsidy of 15c/km for private car</p>	<p>Available if forward and return journey cannot be completed in one day, for follow-up treatment, or travel schedules do not permit immediate return</p> <p>Commercial: Up to \$30 per night per person</p> <p>Private: \$10 per night per person</p>	<p>Nil</p>	<p>If necessary to assist with patient care and support services at place of treatment cannot provide adequate assistance or patient under 16 years; mentally or physically disabled</p>

Source: *Submissions 150*, (ACT Government); 164 (NT Government); 182 (Victorian Government); 183 (Tasmanian Government); 188 (NSW Health) and guides to patient assisted travel schemes published by each jurisdiction.

The call to improve the operation of Patient Assisted Travel Schemes

1.70 The lack of uniformity across jurisdictions and, consequently, the perceived lack of consumer equity form the basis of criticism of PATS. Along with this, concerns have been expressed in relation to cross-jurisdictional portability, subsidy levels, community awareness of the schemes and the scope of treatments covered under the schemes.

1.71 The need to improve the operation and effectiveness of PATS has been identified in several parliamentary and non-government reports.

Parliamentary inquiries

1.72 Three recent Senate inquiries have produced recommendations to comprehensively improve the operation of the travel schemes:⁵⁶ the inquiry into public hospital funding (2000), the inquiry into services and treatment options for persons with cancer (2005), and the inquiry into gynaecological cancer in Australia (2006). The most recent inquiry report – *Breaking the Silence: a national voice for gynaecological cancers* – recommended that:

[T]he Council of Australian Governments, as a matter of urgency, improve the current patient travel assistance arrangements in order to:

- establish equity and standardisation of benefits;
- ensure portability of benefits across jurisdictions; and
- increase the level benefits to better reflect the real costs of travel and accommodation.⁵⁷

1.73 This echoes an earlier House of Representatives Committee report, which recommended that:

the Department of Health and Aged Care work with state and territory governments to review patient assistance travel schemes, particularly in relation to eligibility criteria, escorts, return travel, cross-border issues, pre-

56 In addition, two inquiry reports include recommendations that aim to improve travel assistance for specific consumer groups. The Senate Community Affairs Committee recommended that 'the importance of access to appropriate transport and Patient Assisted Travel Schemes for people with disabilities be reflected in the terms of the next CSTDA', *Funding and operation of the Commonwealth State/Territory Disability Agreement*, February 2007, p.98. The (former) Senate Community Affairs References Committee recommended that: 'the Commonwealth Government work with State governments to assist Aboriginal and Torres Strait Islander women who have to give birth outside their communities by funding an accompanying family member, with funding provided through their patient transfer assistance schemes.', *Rocking the Cradle – A Report into Childbirth Procedures*, December 1999, p.15.

57 Senate Community Affairs Committee, *Breaking the silence: a national voice for gynaecological cancers*, October 2006, p.100.

payment and access to allied health, dental and other non-medical services.⁵⁸

1.74 Despite these appeals for reform, the Commonwealth Government has declined to take action on the basis that the schemes are the responsibility of the States and Territories. For example, the Government's response to the recommendation from the gynaecological cancer inquiry (cited above) calling for COAG to improve the schemes stated:

Implementation of this recommendation is the responsibility of the state and territory governments. On 1 January 1987, responsibility for the provision of the Isolated Patient Travel and Accommodation Assistance Scheme (IPTAAS) - with funding - was transferred from the Commonwealth Government to the states and territories.

States and territories are best placed to develop and administer flexible and effective measures for those in need, having regard to their own distribution of specialist services and the specific needs of their rural population.⁵⁹

Other reports

1.75 The call to reform the travel schemes was also highlighted in the 2003 Radiation Oncology Jurisdictional Implementation Group (ROJIG) report.⁶⁰ The intergovernmental ROJIG was established by the Commonwealth and State/Territory Health Ministers to respond to a 2002 radiation oncology inquiry (the Baume inquiry) and provide advice on measures for improvement. The ROJIG final report was endorsed on 28 November 2003 at the Australian Health Ministers' Conference (AHMC) in Sydney. Alongside four other actions the Health Ministers agreed to:

State and territory strategies to raise awareness of Patient Travel Assistance Schemes that are available to radiotherapy patients and consideration of a range of principles produced by ROJIG, which will help patients to access those schemes.⁶¹

1.76 In 2003, a report on cancer care was jointly prepared by the Clinical Oncological Society of Australia, the Cancer Council of Australia and the National

58 House of Representatives Standing Committee on Primary Industries and Regional Services, *Time Running Out: Shaping Regional Australia's Future*, February 2000, p.326.

59 The Commonwealth Government, *Response to the Committee's Report - Breaking the Silence: a national voice for gynaecological cancers*, February 2007, http://www.aph.gov.au/Senate/committee/clac_ctte/gynaecological_cancer/gov-resp.pdf (accessed 15 May 2007).

60 Radiation Oncology Jurisdictional Implementation Group Final Report, September 2003.

61 Australian Health Ministers' Conference Joint Communique, 'Australian Health Ministers Announce Radiotherapy Plans', *Press release*, 28 November 2003.

Cancer Control Initiative.⁶² It recommended that a national review of access issues be undertaken, 'including an investigation into problems with travel'.⁶³

1.77 Similarly, the National Rural Health Alliance (NRHA) has called for a review of all State and Territory schemes with a view to achieving consistency across jurisdictions. Additionally, the NRHA has made a number of recommendations to improve or remedy other problems within the schemes.⁶⁴

Outline of the report

1.78 The Committee received much evidence identifying problems in the schemes with many witnesses providing examples of their personal experiences. The Committee has used these to identify a number of issues common to all the schemes rather than assessing the schemes on a State-by-State basis. In this way, the Committee has been able to highlight the areas where major improvements can be made and to make recommendations which it considers will improve access to medical service for the many Australians living outside metropolitan areas.

1.79 Chapter 2 of the report provides a brief overview of health service delivery in regional, rural and remote Australia. Chapter 3 addresses the impact of the design and administration of PATS across all jurisdictions while chapter 4 discusses the provision of escorts and cross-border issues. Chapter 5 discusses the impact of PATS on particular groups including Indigenous Australians. Chapter 6 examines the role of charities and non-government organisations and the means of improving and integrating services. The Committee's discussion on reforming PATS, conclusions and recommendations are contained in chapter 7.

Acknowledgements

1.80 While in Alice Springs the Committee undertook an number of inspections and would like to thank Ms Maxine Chaseling, Branch Manager, Mrs Deanna Habib and Mr Matthew Strangeways from the Central Australian Aboriginal Congress; Ms Vicki Taylor, General Manager, and staff of the Alice Springs Base Hospital; Ms Sarah Brown of the Western Desert Dialysis Unit; Ms Sabina Knight, Senior Lecturer, Nursing and Remote Health Practice and Mr Tristan Ray from CAYLUS.

1.81 The Committee also expresses its appreciation to the individuals and organisations that made submissions to the Committee or gave evidence to the inquiry

62 Clinical Oncological Society of Australia, Cancer Council Australia and the National Cancer Control Initiative, *Optimising Cancer Care in Australia*, February 2003.

63 Clinical Oncological Society of Australia, Cancer Council Australia and the National Cancer Control Initiative, *Optimising Cancer Care in Australia*, February 2003, p.xvii.

64 *Submission 55*, Attachment 1, (NRHA).

CHAPTER 2

HEALTH SERVICE DELIVERY: REGIONAL, RURAL AND REMOTE AUSTRALIA

2.1 It was clear from the evidence received that the operation and effectiveness of the travel schemes can only be understood within the broader context of health service delivery in rural and remote Australia. A number of supply and demand issues were presented to the Committee, which impact on the efficacy of the current travel schemes and present future challenges for health service delivery in rural and remote areas.

Regional, rural, remote: demography

2.2 There are three principal systems for defining non-metropolitan areas (areas with less than 100,000 inhabitants) in Australia: the Australian Standard Geographical Classification (ASGC), which defines an area's 'urbanness/ruralness'; the Accessibility/Remoteness Index of Australia (ARIA), which defines an area's level of accessibility to goods and services; and the Rural, Remote and Metropolitan Areas (RRMA) classification.¹

2.3 The ASGC system was established by the Australian Bureau of Statistics. Sections of the States and Territories are classified as follows:

- Major Urban: urban areas with a population of 100,000 and over
- Other Urban: urban areas with a population of 1000 to 99,999
- Bounded rural locality: rural areas with a population of 200 to 999
- Rural balance: the remainder of the states and territories
- Migratory: areas composed of offshore, shipping, and migratory collection districts.²

2.4 The ARIA system was developed by the National Key Centre for Social Applications of Geographical Information Systems (GISCA) at the University of Adelaide. It has been summarised as follows:

Highly accessible: locations with relatively unrestricted accessibility to a wide range of goods, services and opportunities for social interaction.

Accessible: locations with some restrictions of some goods, services and opportunities for social interaction.

Moderately accessible: locations with significantly restricted accessibility of goods, services and opportunities for social interaction.

1 Hugo, G., 'Australia's Changing Non-metropolitan population', in Wilkinson, D. & Blue, I. (eds.) *The New Rural Health*, Oxford University Press, Melbourne, 2002, p.13.

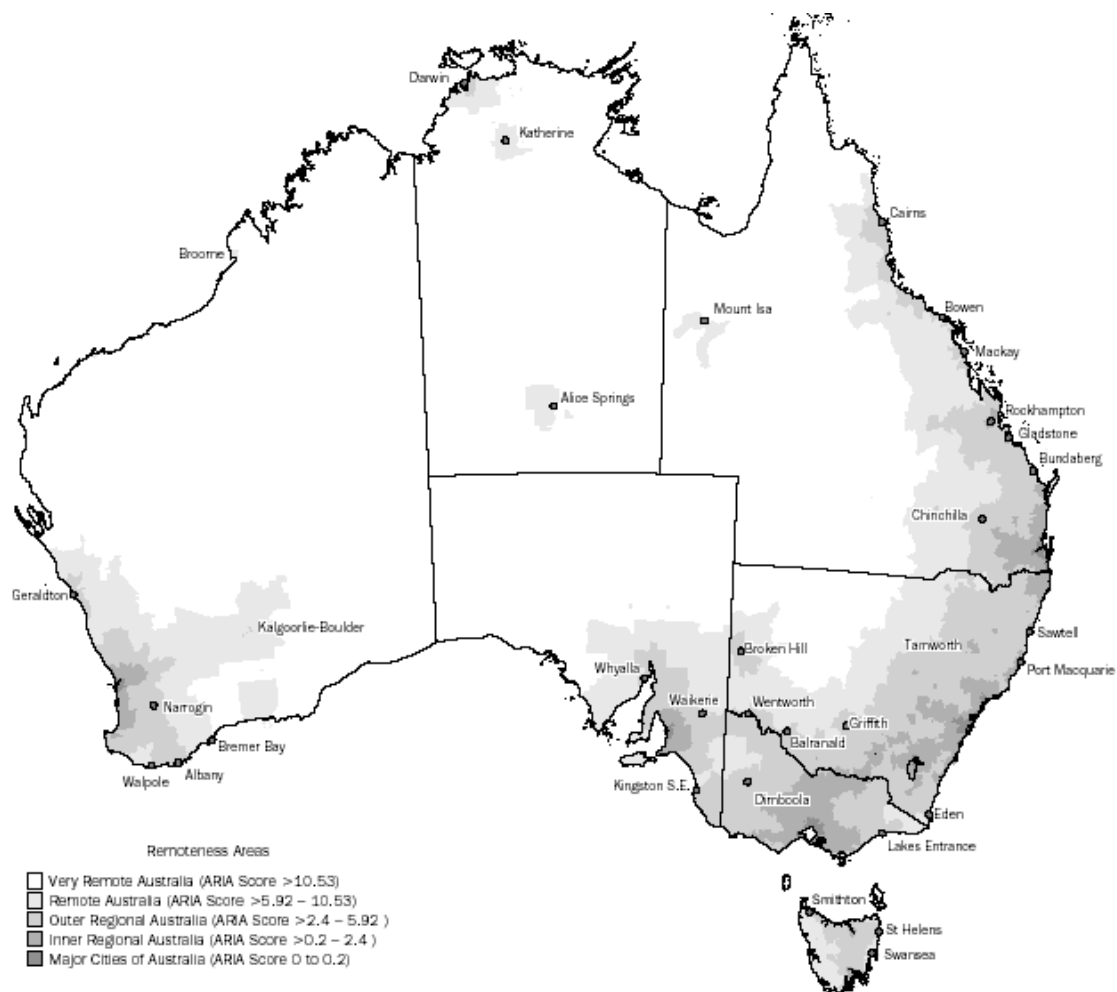
2 Hugo, G., 'Australia's Changing Non-metropolitan population', in Wilkinson, D. & Blue, I. (eds.) *The New Rural Health*, Oxford University Press, Melbourne, 2002, p.13.

Remote: locations with very restricted accessibility of goods, services and opportunities for social interaction.

Very remote: locations with very little accessibility of goods, services and opportunities for social interaction.³

2.5 The following discussion draws extensively on publications by the Australian Institute of Health and Welfare (AIHW), which uses the ASGC categories of Major Cities, Inner Regional, Outer Regional, Remote and Very Remote. The following map shows these classifications.

Figure 2.1: Australian Remoteness Areas



Source: <http://www.abs.gov.au> [accessed 31.8.07]

2.6 The regions outside Major Cities encompass an extremely diverse area ranging from coastal or inland areas within commuting distance of Major Cities to the sparsely populated, hot and dry outback. Many areas outside Major Cities, predominantly on the coast, attract older people in retirement. A significant proportion

3 Hugo, G., 'Australia's Changing Non-metropolitan population', in Wilkinson, D. & Blue, I. (eds.) *The New Rural Health*, Oxford University Press, Melbourne, 2002, p.14.

of the occupations in regional and remote areas (for example mining, transport, forestry, commercial fishing and farming) entail higher levels of risk than other occupations. One in ten people in the non-metropolitan workforce is engaged in agriculture.

2.7 In Australia, two-thirds of the total population live in Major Cities, with 21 per cent, 11 per cent, 2 per cent and 1 per cent living in Inner Regional, Outer Regional, Remote and Very Remote areas respectively. The Indigenous population of Major Cities is only 1 per cent (representing 30 per cent of the total Indigenous population), increasing to 2 per cent and 5 per cent in Inner and Outer Regional areas (43 per cent of the total Indigenous population), 12 per cent in Remote areas and 45 per cent in Very Remote areas (27 per cent of the total Indigenous population).⁴

2.8 Males outnumber females in almost all age groups in the more remote areas. This is largely influenced by the non-Indigenous population. The number of Indigenous males in each area is similar to the number of females.

2.9 Remote area populations tend to have proportionally more children and working age males, and fewer elderly people than other areas. Regional areas have proportionally lower numbers of people aged 25-44 years, higher numbers of people aged 45-74 years and similar or slightly lower numbers of people older than 75 years than other areas. In regional areas, children make up a higher proportion than in Major Cities, but lower than in remote areas.⁵

Measures of health status in rural and remote areas

2.10 People in rural and remote areas generally do worse than other Australians on a range of health status measures. There are higher mortality rates, poorer dental health and higher levels of mental health concerns. This is likely to be a result of a mix of behavioural, socioeconomic factors and poorer access to health services.

2.11 The following is a brief overview of the findings of the AIHW's 2005 report *Rural, regional and remote health – Indicators of health* which includes measures of both health status and the determinants of health.⁶

2.12 The AIHW reported the following indicators of rural and remote health status:

- Chronic disease: overall there was no significant difference between the prevalence of self reported chronic diseases in regional areas and Major Cities;

4 AIHW, *Australia's Health 2006*, p.240.

5 AIHW, 2003. *Rural, regional and remote health: a study on mortality*. AIHW cat. no. PHE 45. Canberra: AIHW (Rural Health Series no. 2), p.5.

6 AIHW, 2005, *Rural, regional and remote health – Indicators of health*. AIHW Cat. No. PHE 59. Canberra: AIHW (Rural Health Series no. 5).

- Injury: people in regional areas were 1.2 times more likely to self-report a recent injury and more likely to self-report a long-term condition due to injury;
- Mental health: depression was more prevalent in regional areas;
- Dental health: children had more decayed, missing or filled teeth in regional/remote areas;
- Communicable diseases: the rates of communicable disease notification tend to increase with remoteness;
- Birthweight: very low birthweight babies were more prevalent compared to Major Cities;
- Disability: disability was more prevalent compared to Major Cities;
- Reduced activity because of illness: the average number of days of reduced activity because of illness was greater in regional areas than in Major Cities;
- Life expectancy: life expectancy was highest in Major Cities and lowest in Very Remote areas likely due to the much lower Indigenous life expectancy;
- Overall mortality: compared with their counterparts in Major Cities males and females from regional and especially remote areas had higher rates of death and death rates rose with increasing remoteness – this is about 3,300 additional deaths annually;
- Perinatal mortality: compared with their counterparts in Major Cities rates of foetal and neonatal death were higher in regional and especially remote areas which is at least partly a reflection of Indigenous population distribution; and
- Causes of death: the leading causes of the higher death rates experienced in regional and remote areas are mainly circulatory diseases (42 per cent of the excess deaths) and injury (24 per cent) with respiratory disease and cancers contributing about 10 per cent of the 'excess' deaths each.⁷

2.13 The AIHW also noted that rural and regional areas had poorer determinants of health including less access to fluoridated water (only 30-40 per cent of those in regional and Remote areas, and 25 per cent of those in Very Remote areas have access to fluoridated water). Other determinants highlighted by the AIHW included:

- higher unemployment rates in regional and remote areas compared to Major Cities;
- lower after-tax household incomes in regional areas;
- the main sources of employment are agriculture, forestry, fishing and mining with less employment in manufacturing;

7 AIHW, 2005, *Rural, regional and remote health – Indicators of health*. AIHW Cat. No. PHE 59. Canberra: AIHW (Rural Health Series no. 5), pp.8-12.

- the three indexes of relative socioeconomic disadvantage (economic resources, and education and occupation) outcomes were better in Major Cities than in regional and remote areas;
- birth rates were higher for women in regional and remote areas than for those in Major Cities, and increased with increasing remoteness;
- homicide death rates were substantially higher in Remote and Very Remote areas (although the actual numbers of deaths were relatively small);
- there is more household crowding in Very Remote areas;
- food prices increased with remoteness – food prices in Very Remote areas were between 14 per cent and 19 per cent higher than in the Australian capital cities;
- fuel prices also increased with remoteness; and
- the cost of housing decreased with remoteness.

2.14 People in regional areas are more likely to smoke and more likely to engage in risky alcohol consumption. Illicit drug use is more prevalent in regional areas. The situation in remote areas is unclear. People in regional areas are more likely to be sedentary and more likely to be overweight.⁸

2.15 The AIHW noted that people who live away from Major Cities and for whom access to health services is restricted may be disadvantaged because of different access to:

- preventive services such as immunisation and information allowing healthy life choices;
- health management and monitoring;
- specialist surgery and medical care;
- emergency care, for example ambulance;
- rehabilitation services after medical or surgical intervention; and
- aged care services.⁹

2.16 Evidence received by the Committee also emphasised the variation of health outcomes in regional and remote Australia.¹⁰

8 AIHW, 2005, *Rural, regional and remote health – Indicators of health*. AIHW Cat. No. PHE 59. Canberra: AIHW (Rural Health Series no. 5), pp.12-19.

9 AIHW, 2003. *Rural, regional and remote health: a study on mortality*. AIHW cat. no. PHE 45. Canberra: AIHW (Rural Health Series no. 2), pp.3-4.

10 See for example, *Submission 55*, p.2 (NRHA) and *Submission 47*, p.5 (AMA).

2.17 The Australian Rural and Remote Workforce Agencies Group (ARRWAG) cited the following statement from J. Dade-Smith in *Australia's Rural and Remote Health. A social justice perspective*:

Australians living in rural areas have unique health concerns that relate directly to their living conditions, social isolation, socioeconomic disadvantage and distance from health services. They have death rates that are double the urban rate due to injury, triple due to road accidents and double due to falls in the aged. Hospital admission rates due to diabetes are four times the urban admission rate. Yet rural people have lower access to health care compared with their metropolitan counterparts because of distance, time factors, costs and transport availability.¹¹

2.18 Focusing specifically on breast cancer, a study commissioned by the pharmaceutical company GlaxoSmithKline revealed that the higher mortality rate of rural and remote women with breast cancer was due, in part, to 'later diagnosis and less access to cancer screening and treatment services in regional areas'.¹² Other witnesses also noted that rural women are significantly more likely to undergo mastectomy rather than breast-conserving therapy unlike urban women. It was argued that rural women were less likely to travel to have breast-conserving surgery at an urban treatment centre for adjuvant therapy.¹³

2.19 The Cancer Council Australia also pointed to poor outcomes for cancer patients in rural and remote areas:

There is growing epidemiological evidence that cancer mortality rates increase significantly in step with geographic isolation. A study published in the *Medical Journal of Australia* in 2004 showed that people with cancer in regional NSW were 35% more likely to die within five years of diagnosis than patients in cities. Mortality rates increased with remoteness. For some cancers, remote patients were up to 300% more likely to die within five years of diagnosis.

A study published by COSA [Clinical Oncological Society of Australia] in 2006 and editorialised in the *Medical Journal of Australia* mapped the provision of rural/remote oncology services across Australia. The study was the first national analysis to statistically demonstrate what has long been assumed: that access to essential cancer care in all disciplines decreases nationwide as communities became more isolated.¹⁴

2.20 There is also evidence on differences in the rate at which people from major cities, regional and remote areas were admitted to hospital for a range of surgical procedures in 2002–03. For example, rates of coronary artery bypass graft and

11 *Submission* 136, p.2 (ARRWAG).

12 *Submission* 60, p.3 (GlaxoSmithKline).

13 *Submission* 136, p.8 (ARRWAG).

14 *Submission* 109, p.11 (Cancer Council Australia).

coronary angioplasty were lower among people from regional and especially remote areas (and at odds with the pattern of death rates due to coronary heart disease). Compared with residents of Major Cities, rates of:

- diagnostic gastrointestinal endoscopy and myringotomy were also lower for residents of regional and especially remote areas;
- appendectomy and lens insertion were higher for residents of regional and remote areas; and
- cholecystectomy, hip replacement, revision of hip replacement, knee replacement, hysterectomy, tonsillectomy and arthroscopic procedures were typically higher for residents of regional areas and lower for residents of remote areas.¹⁵

2.21 The Australian Medical Association (AMA) concluded that:

A driving factor behind these poorer health outcomes is the difficulty people in regional and remote areas face in accessing specialist and primary health care. Isolation and lack of services make it complicated for these patients to receive preventive services and manage chronic diseases. Consumers needing to travel long distances to access services can face considerable disruption and personal financial cost.¹⁶

Access to services

2.22 Limited access to health services is a significant issue for people living in rural and remote Australia. An inadequate supply of hospital and other health services and workforce shortages in these areas were identified as key factors.

Supply of hospital services

2.23 The provision of hospitals and hospital beds are concentrated in Major Cities and regional areas. Some 22 per cent of public hospitals (but only 4.8 per cent of the available beds) are located in remote and very remote areas (compared with 6 per cent of the population).¹⁷ Most hospitals in remote areas are public hospitals. However, hospitals are less likely to be accredited in regional and remote areas.

2.24 Most smaller rural hospitals are not equipped to provide the full range of specialised services and people must be transferred to larger regional or metropolitan centres. Some smaller hospitals operate as Multi-purpose Services (MPSs) and provide a range of services such as emergency triage, hospital care and aged and community care.

15 AIHW, 2005, *Rural, regional and remote health – Indicators of health*. AIHW Cat. No. PHE 59. Canberra: AIHW (Rural Health Series no. 5), pp.19-20.

16 *Submission 47*, p.5 (AMA).

17 *Submission 157*, pp.10-11 (DoHA).

Workforce shortages

2.25 The supply of health workers in regional areas has long been an issue. The AIHW reported that the supply of health workers declines with remoteness. Table 2.1 shows the number of employed medical practitioners in 2003 by type of practitioner and remoteness area.

Table 2.1: Employed medical practitioners, by type of practitioner and remoteness areas

	Major Cities	Inner Regional	Outer Regional	Remote	Very Remote	Total ^[a]
Type of medical practitioner						
Clinicians	39,389	7,074	2,948	468	212	51,819
Primary care practitioners	15,132	3,901	1,740	301	152	21,919
Hospital non-specialists	4,561	659	359	69	42	5,915
Specialists	14,580	2,164	665	79	15	18,093
Specialists-in-training	5,116	350	185	20	3	5,892
Non-clinicians	3,621	372	205	30	18	4,388
Total	43,010	7,446	3,154	498	230	56,207
No. per 100,000 population	326	179	155	154	130	283
Percentage female	32.6	27.4	30.3	31.5	35.0	31.9
Average age (years)	45.7	46.8	45.1	44.7	43.4	45.9
Average hours worked per week	44.2	44.8	46.2	47.8	50.0	44.4

^[a] Includes 1,870 medical practitioners who did not provide information on the location of their main job.

Source: Australian Institute of Health and Welfare, *Australia's Health 2006*, p.325.

2.26 The AIHW noted that to some extent, the decrease in supply of medical practitioners was countered by patterns of average hours worked by medical practitioners which increased from 44.2 hours per week in Major Cities to 50.0 hours per week in Very Remote areas. The AIHW also noted that, consistent with the placement of the large teaching hospitals near population centres, Major Cities and Inner Regional areas together accounted for 84.3 per cent of specialists and 92.8 per cent of specialists in training.

2.27 ARRWAG commented on access to primary health care providers, particularly GPs and noted that in 1998 the Australian Medical Workforce Advisory Committee (AMWAC) estimated the shortage to be in the region of 1240 GPs. Four years later, in 2002, the AMA commissioned a report from Access Economics which

estimated that there was a shortage of between 700 and 800 full time equivalent GPs in rural and remote areas.¹⁸

2.28 The nursing workforce is more evenly distributed across regions than medical practitioners, and shows a smaller variation in number per 100,000 population. Nurses in regional and remote Australia are older than in Major Cities and tended to work longer hours per week in Remote and Very Remote areas. Table 2.2 show employed registered and enrolled nurses in 2003.

Table 2.2: Employed registered and enrolled nurses, by remoteness areas of main job, 2003

	Major Cities	Inner Regional	Outer Regional	Remote	Very Remote	Total ^[a]
Number	147,670	48,440	22,719	3,870	1,936	236,645
No. per 100, 000	1,120	1,167	1,115	1,193	1,095	1,191
Percentage female	91.2	90.9	93.9	93.3	89.7	91.4
Percentage registered	83.3	75.0	71.5	73.4	79.1	79.9
Average age (years)	42.5	44.2	44.3	44.2	44.3	43.1
Average hours worked per week	32.8	31.7	32.3	34.1	37.8	32.5

^[a] Includes 12,009 nurses who did not provide information on the location of their main job.

Source: Australian Institute of Health and Welfare, *Australia's Health 2006*, p.327.

2.29 The distribution of dentists in Major Cities is more than three times that in Remote and Very Remote areas with the rate dropping from 57.6 to 18.1 per 100,000 population.¹⁹

2.30 The Rural Doctors Association of Australia (RDAA) also commented on the discrepancy between the levels of ill health that people in rural and remote areas and the health dollars spent in those areas:

Even though rural and remote Australia has a more aged and a 'sicker' population there is less spent on their health needs compared to their city counterparts. Medicare figures provided by the Department of Health and Ageing also show that if you lived in a capital city that the average general practitioner benefit paid per capita was \$195 but if you lived in a remote area of Australia that this figure falls to \$120...Many specialist services are also not available or viable in rural areas either because of workforce shortages, low concentrations of patients or because they require the facilities of a large hospital.²⁰

18 *Submission 136*, p.3 (ARRWAG).

19 AIHW, 2006, *Australia's Health 2006*, AIHW Cat. No. AUS73, Canberra: AIHW, p.328.

20 *Submission 90*, p.2 (RDAA); see also *Submission 47*, p.4 (AMA).

2.31 While the analysis of rural services and workforce gives an indication of the general limits to access, there are differences between jurisdictions and within regions. The Australian Rural Nurses and Midwives (ARNM) explained:

There are considerable differences between states with regard to the geographical spread of services. Remoteness factor cannot only be measured by geographical location or distance; regional health services for example are in much greater numbers in rural New South Wales, Victoria and Queensland as opposed to Western Australia and South Australia. As such specialist services in these states are only available in the capital cities.²¹

Diminishing services in regional, rural and remote areas

2.32 Many witnesses noted that there has been a continuing diminution of services in rural and remote areas with a decline in GP numbers and a downgrading of hospital services. The Country Women's Association of NSW stated that:

With the down-grading of country and regional hospitals it is now necessary for patients to travel greater distances. In the past it was not unusual for specialists to regularly visit country and regional hospitals which meant that patients were able to access locally many of the services for which they now need to travel vast distances.²²

2.33 The Shire of Sandstone provided an example of the decrease in access to general practitioners:

In Mount Magnet the situation has become quite dire, in that, from having a full-time general practitioner a couple of years ago, the town of 700 people is now serviced once a month by a visiting medical practitioner from Geraldton who sees between 60 and 70 clients for one day a month. The nursing posts have gone down from four nurses to one. It is a town which is experiencing significant social and health problems in terms of drug and alcohol abuse, which of course precedes child abuse.²³

2.34 The Australian Nurses Federation (ANF) raised concerns about access to obstetric services:

Access to health care also means access to services to assist with normal life events, such as maternity and birthing services; the ANF is very concerned that people in rural and remote Australia are being denied access to birthing services with over 130 birthing services in country areas closed in the last decade.²⁴

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

22 *Submission 5*, p.2 (Social Issues Committee – Country Women's Association of NSW).

23 *Committee Hansard*, 13.7.07, p.67 (Mr W Atkinson, Shire of Sandstone).

24 *Submission 96*, p.2 (ANF).

2.35 The RDAA also commented that half of the obstetric services had closed in the last 10 years which meant 'that many GP obstetricians and obstetrician gynaecologists who want to provide services are unable to provide those services in their community'.²⁵

2.36 ARRWAG also reported a reduction in services being offered by GPs:

...there has been a decline in the proportion of GPs providing procedural services – down from 24% in 2002 to 21.5% in 2005. Rural GPs have traditionally been more likely to undertake procedures than their urban counterparts because of a lack of specialists in rural and remote areas. A decline in GPs undertaking this work may be a major factor in people living in rural and remote areas having to travel to visit a medical specialist in addition to an on-going decline in proceduralist GPs.²⁶

2.37 WA Country Health Services indicated that workforce issues were impacting on the delivery of services to the extent that a regional 'hub and spoke' model had been introduced in an attempt to maintain service delivery levels:

Obstetric services are becoming harder to deliver. Anaesthetic services are harder to deliver. General surgeons are in scarce supply; they threw away the mould and they are not making generalist positions. Procedural trained GPs that are willing to go out into the bush, which are the backbone of our country hospital system, are not being made any more. I would contend, that is just going to be the way the rural health service delivery is going to be. That is why we have introduced a regional hub-and-spoke model because it is the only way we think that you can try and maintain at least some services in a region in the face of those workforce difficulties.²⁷

2.38 However, witnesses commented that the hub and spoke model does not always take into account the transport problems of the area. The Shire of Ashburton WA stated:

The issues are: hub and spoke does not work because there is no spoke in the sense that there is no public transport; there is no commercial link or integration of any type whatsoever between any town in the Pilbara at the air level; there is absolutely no land service of a commercial public nature; and, all interaction is through private travel. We are talking about extremely long distances and times. Most one way distances are 400 to 500 kilometres or more. This puts great pressure on patients because, the way the system works, carers do not get a great deal of support through the PATS system. Also, the road systems, the distances travelled, the safety risks from animals on the road, the sheer heat and such types of things mean that it is a test for

25 *Committee Hansard*, 22.6.07, p.5 (Mr S Sant, RDAA).

26 *Submission* 136, p.5 (ARRWAG).

27 *Committee Hansard*, 13.7.07, p.15 (Mrs C O'Farrell, WA Country Health Service).

an able-bodied, healthy person, let alone someone who is suffering an illness.²⁸

2.39 The Department of Health and Ageing (DoHA) cited two reasons for the centralisation of services. Firstly, evidence shows that sufficient patient 'throughput' is required to achieve 'safe and appropriate clinical outcomes'. To put it simply, specialists need the opportunity to practice. Secondly, advances in medical technology have resulted in the development of sophisticated procedures and (often highly expensive) medical equipment. Due to the cost and degree of specialisation, treatments are restricted to a few health centres:

Because of the needs for cost effective utilisation of expensive equipment and/or to achieve and maintain clinical competence in complex and costly procedures, it may be feasible to have only a limited number of health-care establishments, such as hospitals, providing certain specialised health services.²⁹

2.40 Haematology services in Western Australia are an example of centralised services:

Throughout regional Western Australia there are extremely limited haematology services available. There is limited low level care available in Bunbury and in Albany. These treatment areas provide only simple administration of chemotherapy. They are not resourced for admissions of an un-well immunised compromised patient.

No haematology patient diagnosed within regional WA would be able to avoid multiple trips to Perth as is evidenced by the following list of diagnostics and treatment that are not available elsewhere:

- all haematologist appointments.
- scanning and radiology appointments.
- any nuclear medicine scans.
- chemotherapy regimes – either preformed as inpatient or outpatient.
- admission to treat neutropenia infections post chemotherapy.
- access to specialised physio; dietetics; rehabilitation and psychological health professionals.³⁰

2.41 While there may be sound reasons for centralisation, the lack of services places greater pressure on rural GPs to provide more specialised services and manage more highly complex cases:

Clearly, if patients do not have access to specialist care in their community and they do not have access to, say, the Alfred or Prince of Wales hospital,

28 *Committee Hansard*, 13.7.07, p.66 (Mr K Pearson, Shire of Ashburton).

29 AIHW cited in *Submission 157*, p. 12 (DoHA); see also *Submission 136*, p.7 (ARRWAG).

30 *Submission 54*, p.3 (Leukaemia Foundation WA).

those patients end up being managed by the GP in their community often without being able to get support from their specialist colleagues. There are some money issues involved, but it is broader than that. There are training issues as well. I think that we really have to make it attractive for GPs to train in procedural specialties, that is, anaesthetics, obstetrics.³¹

ARRWAG also concurred that work intensity was a problem with attracting and retaining rural GPs.³²

An increasing demand for PATS

2.42 Witnesses argued that the demand for PATS will continue to increase over time as services in regional, rural and remote areas continue to decline, the population ages and other issues such as more sophisticated and more expensive medical technologies are introduced.

Future pressures on PATS

2.43 DoHA identified 'future pressures' that could impact on patient transport, with more patients needing to travel to receive treatment:

- increased health needs of the ageing population;
- increase in the number of patients with chronic conditions and, consequently, complex health needs;
- advances in medical technology:
 - patient expectations of treatment available to them grows as treatment becomes more effective and previously untreatable conditions become treatable;
 - highly specialised and expensive equipment is provided in limited hospitals/specialist centres requiring patients to travel for treatment; and
- possible rationalisation of hospital and health services by State and Territory governments.³³

2.44 State and Territory Governments concurred with the majority of DoHA's observations,³⁴ with the impact of the drought also identified as increasing demand. The Victorian Government commented that the lack of access to Commonwealth-funded medical and allied health services was also contributing to demand pressures, while South Australia argued that 'the level of growth [in demand for PATS] is

31 *Committee Hansard*, 22.6.07, p.6 (Mr S Sant, RDAA).

32 *Submission* 136, pp.3-4 (ARRWAG).

33 *Submission* 157, pp.15-16 (Department of Health and Ageing).

34 *Submissions* 150, p.1 (ACT Government); 164. p.8 (NT Government); 165, p.6 (SA Government); 182, p.2 (Victorian Government); 184, p.2 (Queensland Health).

causing increasing pressure on SA resources while the Australian Government contribution has grown more slowly'.³⁵

2.45 The Rural Doctors Association of Australia similarly noted that the ageing population will impact on demand:

Chronic disease (conditions likely to persist for at least six months) constitutes about 80% of the burden of disease in Australia today, a figure which will rise with demographic ageing.³⁶

2.46 At the same time, the ageing population is impacting on the medical workforce with more than 50 per cent of the GP workforce in rural and remote Australia aged over 45 years.³⁷ As demographic ageing continues, there will be a relatively smaller pool of professionals to attract to rural and remote areas.³⁸

A changed operating environment

2.47 Witnesses argued that PATS as it was envisioned in the 1980s is no longer sustainable. The environment in which PATS operates has changed significantly. As discussed above, people in regional, rural and remote areas have poorer health status than other Australians; there are significant workforce shortages which are exacerbated by the need to centralise services due to cost and technology imperatives; and ageing is impacting on both the general population and the medical professional population. The WA Country Health Service commented:

The difficulty I think for us is that we are losing ground. We have had quite a lot of success in recent years but we are losing ground with that strategy at the moment because the workforce shortages that we forecast five years ago are now with us and they are getting worse. So we have lots of vacancies, we have lots of services where the skills mix is skewed and out of plumb; we have lots of services that are completely failed and we have some that are so fragile they work some days and not on others. The Pilbara region is absolutely in tremendous difficulty at the moment with fragile services. We have enormous numbers of overseas trained doctors who are not familiar with the Western Australian system and who have varying skills mix, so our services have never been so challenged.³⁹

2.48 The WA Country Health Service went on to comment that to try and operate PATS in the same old way, 'where the services that would ordinarily be available

35 *Submissions* 182, p.5 (Victorian Government); 165, p.2 (SA Government).

36 *Submission* 90, Additional information, 26.6.07 (RDAA).

37 *Submission* 136, p.5 (ARRWAG).

38 *Committee Hansard*, 22.6.07, p.6 (Mr G Gregory, NRHA).

39 *Committee Hansard*, 13.7.07, p.15 (Mrs C O'Farrell, WA Country Health Service).

locally are sometimes there and sometimes not, is starting to create some more tension'.⁴⁰

2.49 The South Australian Government also commented on the changes in health care delivery since the introduction of patient assisted travel schemes:

The schemes started from a base where they focused on access to medical specialist services. Health care delivery has changed over the last 20 years and it is critical that PATS look towards expanding to include access to primary and allied health care services. The cost implications of expanding need to be considered and the Australian Government needs to provide its fair share of funding support.⁴¹

2.50 In addition, the schemes have not evolved as advances in treatments and care have evolved. A case in point is the treatment of cancer where access to a multidisciplinary team increases survival rates and decreases adverse outcomes. The NRHA stated that:

Complete cancer care often includes care coordination and planning between medical, surgical and other cancer care specialists, specialist investigative procedures, surgery, radiation therapy and chemotherapy, with a range of frequencies and intensities, and monitoring requirements. This is necessary for some conditions, in order to match a subsequent therapy with the patient's response to an earlier treatment. Often, acute side-effects are debilitating for the patient. A secure home-like environment, whilst experiencing unpleasant side effects of some treatments away from home, with support from relevant carer/s, will assist treatment compliance and maximise benefit. The failure of the schemes to genuinely cover essential care for many cancer patients probably contributes to poorer survival rates in cancer among people in rural and remote areas.⁴²

2.51 Other examples include access to coordinated treatment and support for chronic conditions such as epilepsy, kidney disease and Parkinson's disease where access to a range of allied health services can decrease the adverse impact of the disease through physiotherapy, specialised nursing care and occupational therapy.

2.52 At the same time, witnesses commented that it was short-sighted for governments not to provide adequate access to health services as in the long-term costs incurred were greater through health complications and economic loss and could, in fact, undermine other health initiatives.

2.53 The RDAA argued that there was a 'compelling case' for increasing the level of benefits because country people are 'just not getting the access that they used to get'. Not providing good transport assistance schemes is a false economy as the likely

40 *Committee Hansard*, 13.7.07, p.15 (Mrs C O'Farrell, WA Country Health Service).

41 *Submission* 165, p.15 (SA Government).

42 *Submission* 55, p.6 (NRHA).

outcome will be additional health system costs being incurred in both Federal and State funded areas. This is due to late treatment of conditions and increased costs to the community associated with an increased burden of illness and even avoidable and premature death.

In the long run, one would think, one would achieve better outcomes. But it would be a lot less expensive for the Commonwealth in the long run...if we were able to assist people to access preventive care and screening in antenatal care and so on, thus saving money on acute healthcare in the long run.⁴³

2.54 The RDAA also noted that other initiatives could be undermined by the lack of patient transport. For example, the Commonwealth Bowel Cancer Screening Program – which enables people in any part of the country to be screened – is not coordinated with follow-on care. People in rural and remote areas with a positive test result still face enormous access issues in securing further tests and treatment. RDAA research showed that following a positive screening test a rural patient may have to wait six months or more to get a colonoscopy which is 'a disaster for those people'.⁴⁴

2.55 Dr Eduard Roos of the Southern Queensland Rural Division of General Practice concluded that 'prevention is better than cure' and told the Committee that:

...there is a cost saving if we can get the patient to see the specialist sooner rather than later. So for us it is very important to make sure that our patients can access the services.⁴⁵

2.56 However, NSW Health argued that other factors such as 'access to carers for children' and 'potential loss of income' impact on people's decisions about how, when and if to travel to receive health care, as well as the adequacy of the travel schemes. As such, NSW Health concluded:

[I]t would be extremely difficult to draw solid connections between improved travel and accommodation support and clinical outcomes for patients given the number of variables that affect a patient's clinical outcomes.⁴⁶

Conclusion

2.57 The health outcomes of people living in rural, regional and remote communities are poorer than those in major cities in Australia. As discussed above,

43 *Committee Hansard*, 22.6.07, p.16 (Ms S Stratigos, RDAA); see also *Submission 157*, Answers to questions on notice, p.2 (DoHA) for information on research on the cost effectiveness of early and appropriate intervention.

44 *Committee Hansard*, 22.6.07, p.5 (Ms S Stratigos, RDAA).

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

46 *Submission 188*, p.23 (NSW Health); see also *Submission 183*, p.6 (Tasmanian Government).

the reasons for this are multifaceted and include a range of socioeconomic and behavioural factors.

2.58 It is evident that rural, regional and remote communities are facing considerable disadvantage in accessing services that those in major cities take for granted. While the Committee acknowledges that many factors contribute to decisions to travel (or not to) for treatment, the schemes that have been put in place to assist with access should not themselves form a barrier to that access.

2.59 The Committee considers that, although there are considerable challenges in providing services to a dispersed population, it is imperative that access to services be improved. The failure to do so means health priorities are undermined; costs to government may increase in the long term and most importantly, the health status of those living in rural, regional and remote communities will not be improved.

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.

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:

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

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

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

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

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

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.

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

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

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 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

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:

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

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

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

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:

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 travel 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

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.

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

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

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-imburement 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:

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

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

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

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

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-imburement 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

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).

CHAPTER 4

PATIENT SUPPORT AND CROSS BORDER ISSUES

Patient support

...I would not see a carer as being a luxury; I would see it as a baseline for negotiating really quite a challenging experience. Most people within the metropolitan area have their carer up there, so it seems fairly discriminatory that we do not provide that and that we do not see that as a baseline for people who come from outside the metropolitan area and who may not have had any familiarity with our freeways and our shopping centres and all of those issues. Then of course there are the other issues of dealing with treatment, with diagnosis; you really do need a carer there...If people do not have a carer there – they are very lonely, they are very isolated, they are in a very alien environment – they spend an enormous amount of money in ringing long distance to get something of that support.¹

4.1 An issue raised in all jurisdictions was PATS funding of an escort for patients needing to travel for specialist medical care. All jurisdictions allow an escort for children. For other patients, most jurisdictions (NSW, Queensland, South Australia, Western Australia and the ACT) require the referring GP or specialist to certify that an escort is necessary for medical reasons. In Tasmania an escort is allowed if they are necessary to provide active assistance while travelling or for medical reasons; in the Northern Territory an escort is allowed if they are necessary to assist with patient care and the support services at the place of treatment cannot provide adequate assistance; and in Victoria an escort is allowed if the referring GP or the specialist states that an escort is necessary.

4.2 Witnesses argued that the rules concerning escorts, particularly those in jurisdictions which preclude escorts on grounds other than medical reasons, ignore the very important contribution that escorts make to patient care and well-being. The contribution includes assisting the patient with the practical problems of travelling to a busy, unfamiliar metropolitan area, attending a hospital or specialist appointment and finding accommodation. Even if the patient is familiar with where they are going, their medical condition may make it difficult to access public transport and/or their treatment may leave them debilitated.² The Great Southern GP Network commented:

The major concern we have at the GP network is patients being discharged from the Perth hospitals and sent home unaccompanied by plane often with no support person...There is a real need for the PATS scheme to provide a

1 *Committee Hansard* 6.8.07, p.16 (Dr P McGrath).

2 See for example, *Submissions* 22, p.2 (Central Australian Division of Primary Health Care Inc); 69, p.5 (HCRRA).

liaison person who can provide additional care and support to patients travelling alone.³

4.3 The assistance of an escort for older patients was highlighted, particularly in the light of hospital admission and discharge practices.⁴ The needs of older people are discussed further in chapter 5.

4.4 In addition to assistance with the practical problems of travel, witnesses argued strongly that escorts provide significant psychosocial support for patients which is crucial to positive health outcomes:

The need for psychosocial and practical support during the time of cancer diagnosis and treatment is a crucial factor affecting an individual's psychological well-being. Patients who must travel long distances to obtain treatment are often faced with the difficult decision to forgo the emotional support of family whilst in the city due to the high costs of travel and accommodation. Lack of this access to this support is a significant risk factor associated with the development of co morbid anxiety and depression.⁵

4.5 Young people are particularly vulnerable. Those over the age limit for automatic allocation of an escort may find it difficult to cope with the treatment regime and being away from friends and family. The Cancer Council of Australia commented:

Particularly in young people, we are seeing more frequently a need to have psychosocial support to get through the often intensive chemotherapy treatment regimes which have multiple side effects that cause extensive distress. Being able to have someone close by to support them through that, as well as having a multidisciplinary team, is absolutely imperative.⁶

4.6 The needs of other groups of patients were also discussed in evidence. Patients with severe psychological conditions and distress find it difficult to travel without an escort.⁷ In the case of patients who must be away from home for long periods because of treatment needs, the lack of an escort can impact severely and increase isolation and loneliness. Indigenous people find it particularly difficult to be isolated their communities for extended periods of time. The needs of Indigenous people are discussed in chapter 5.

4.7 Palliative Care Australia pointed to the special needs of those diagnosed with a terminal illness which it made it a necessity for the presence of an escort:

3 *Submission 9*, p.1 (Great Southern GP Network).

4 *Submission 58*, pp.5-6 (Aged and Community Services Australia).

5 *Submission 85*, p.1 (Psyco-oncology Collaborative of the Cancer & Palliative Care Network WA); see also *Submission 101*, p.2 (Carers WA).

6 *Committee Hansard 6.7.07*, p.38 (Ms K Thompson, Cancer Council of Australia).

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

The diagnosis of a terminal illness is a time of extraordinary stress. Requiring a patient receiving treatment to travel without a funded escort is inappropriate, particularly in a palliative situation, where patients experience extreme frailty. PATS arrangements should, as a matter of course, cover the cost of an escort for patients receiving palliative care and include provision for two escorts, particularly in cases of children.⁸

4.8 Another issue raised was the limited options for patients and/or their escort to access assistance to return home for a period of time during an extended treatment regime. This is especially significant when having to relocate for long periods of radiotherapy and for pregnant women who may have to relocate four weeks prior to birthing.⁹

4.9 The Australian Nursing Federation (ANF) argued that the current arrangements around escorts are not patient focused and very few people find that they are eligible for an escort. The schemes do not consider individual patient needs such as the severity of individual conditions, the urgency associated with the episode of care required or the length of time for treatment.¹⁰

Women and children

4.10 With the closing of many rural obstetric facilities, women are now required to travel to a larger centre to await the birth of their child. If they cannot travel to a centre where they have family members, they may have to stay some weeks in a town with no support. Witnesses commented that this increased expectant mothers' anxiety and distress. Mater Health Services commented:

In this day and age, when we are promoting two parents being involved in the process of pregnancy and parenting and family, to be removed from your partner at this critical time is quite devastating for some women, and they do not cope all that well. In fact, I have got a number of examples where women will refuse to stay and want to go home, even to the point of putting themselves and the baby at risk because they do not want to stay without some support from a partner or a mother or a family member.¹¹

4.11 Maningrida Community Health Centre argued that escorts should be provided for all women having a baby because of the improved outcomes that derive from appropriate support. While this is the case for all women, support is particularly important for Indigenous mothers:

Improved emotional and psychological coping with the birthing process and fewer interventions have been demonstrated by the presence of a support

8 *Committee Hansard* 22.6.07, p.23 (Ms F Couchman, Palliative Care Australia)

9 *Submission* 45, p.4 (Australian Rural Nurses and Midwives); see also *Committee Hansard* 5.7.07, p.30 (Ms M Doyle, Ngaanyatjarra Health Service).

10 *Committee Hansard* 22.6.07, p.26 (Ms F Armstrong, ANF).

11 *Committee Hansard* 6.8.07, p.31 (Ms J Petty, Mater Health Services Brisbane).

person. Such evidence is derived from the mainstream, so one would imagine that that benefit would be magnified when the patient group are women from traditionally-based Aboriginal communities, many of whom barely speak English. The young age of many Aboriginal mothers, combined with limited knowledge and experience of Western systems/hospitals makes for a particularly disempowering experience.¹²

4.12 Associate Professor Sue Kildea provided the following case where the inflexible application of guidelines resulted in a young, first time Indigenous mother being unable to be accompanied by an escort although she was only 16 years of age.

Carly turned 16 years old a week ago. For most Australian women this would be a time of celebration. For Carly the timing could not have been worse. Carly was due to have her first baby and for this she was being flown into Darwin, the regional centre. Being her first baby she was frightened. She wanted to stay in her community to have her baby but was told she had to go. She wanted her grandmother to come with her, after all her grandmother had been a traditional midwife and had been preparing Carly for this event for months. But the rules of the PATS system meant that Carly was now too old to have a paid escort come with her for her journey. At 38 weeks of pregnancy she would have to wait in Darwin by herself until her baby came. Feeling lonely, surrounded by an unfamiliar environment, people and food Carly was miserable. If her 16th birthday had been a week later she would have had a relative travel with her, be by her side for the birth of her baby and stay to assist her with breastfeeding, travelling back with her when it was time to go home.¹³

4.13 In all jurisdictions escorts are available for children. However, witnesses noted that this was generally restricted to one escort per child. More often than not, the mother travels with the child which places an enormous burden on the mother to be the sole person accompanying the child through the treatment and beyond. Most families wish to be together when a child is seriously ill but must pay for the other parent to travel to the treatment centre. This imposes a further financial burden on the family at a stressful time. Mater Health Services provided the following example:

A patient from a regional area of Queensland, pregnant with twins, is required to stay in Brisbane from 24 weeks gestation until the birth of her babies who have cardiac abnormalities. She is refused a paid escort on the basis that she is an adult and can look after herself. The family do not have the necessary funds to pay for the escort so the patient is sent on her own. The patient developed complications during her time in Brisbane, and despite written communication from specialists at the Mater, was still refused eligibility for an escort. Upon the birth of the twins who required cardiac surgery and follow-up after discharge, the hospital would only

12 *Submission* 163, p.1 (Maningrida Community Health Centre).

13 *Submission* 147, p.2 (Ass Professor S Kildea).

provide one escort, even though the PTS guidelines state that each child is entitled to an escort. This placed more financial burden on this family.¹⁴

4.14 There is also a special need for both parents to be present when a child is admitted to a hospital and is not expected to live. Princess Margaret Hospital, Perth, commented that 'from our point of view, certainly where a child's death is imminent, that is a crucial event that both parents need to be there for'. However, PATS approval is not always given for a second parent to be present.¹⁵

4.15 Where children have a chronic condition such as diabetes or cystic fibrosis the presence of both parents provides the opportunity for them to receive education on how to care for their child:

In this world of growing social complexity, quite often we are dealing with blended families and separated parents, so you cannot always rely on one parent being educated and then going home to the biological father of the child and educating him. So sometimes having the flexibility to get the second parent down is crucial for us.¹⁶

4.16 Princess Margaret Hospital, Perth also pointed to the problem of young mothers (16 years of age or under) who accompany a sick child to the hospital. The Hospital argued that given the young age of these mothers, it is essential that they are escorted by an adult to assist them in making decisions on treatment/consent, navigating the hospital system and dealing with the stress of their child's medical situation. For risk management it is critical in some circumstances to have an adult present. The Hospital has found that some PATS jurisdictions will fund a 'second' escort in these circumstances, and some refuse to assist.¹⁷

Inconsistencies in the application of escort guidelines

4.17 Witnesses commented on inconsistencies of application of guidelines in relation to escorts. Examples were given of some patients being allowed an escort while others with similar needs were not. This was often very distressing for the patient without the escort.¹⁸

4.18 One matter raised was the withdrawal of financial support for the escort in some jurisdictions when the patient is admitted to hospital. This was viewed as being particularly harsh as 'the costs to the carer (and patient) do not cease just because the

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

15 *Committee Hansard*, 13.7.07, p.48 (Ms J Mace, Princess Margaret Hospital for Children).

16 *Committee Hansard*, 13.7.07, pp.48-49 (Ms J Mace, Princess Margaret Hospital for Children).

17 *Submission 30*, p.2 (Social Work Department – Princess Margaret Hospital); see also *Committee Hansard* 13.7.07, pp.48-49 (Ms J Mace, Princess Margerat Hospital).

18 *Committee Hansard* 22.6.07, p.24 (Ms J Bevan, Kidney Health Australia); 6.7.07, p.31 (Ms K Thompson, Cancer Council of Australia); 6.8.07, pp.4-5 (Dr E Roos, Southern Queensland Rural Division of General Practice).

patient is admitted to hospital, thereby adding to the financial impact and additional costs'.¹⁹

4.19 The ANF also raised the issue of the rules regarding financial assistance if an escort is only required for travel home. In some jurisdictions, the escort's full journey is not subsidised:

Other issues include the lack of reimbursement for escorts to assist patients to travel prior to surgery. If people require an escort to travel home with them, the escort is required to pay for their travel away from the community because only the return part of the journey is covered.²⁰

4.20 There was also extensive evidence on refusal to fund escorts even though the application may be within the guidelines. Witnesses argued that it is for the doctor to make a decision in the best interests of the patient and it should not be for someone who is not clinically trained to override that decision because of budgetary or other concerns. ARRWAG commented:

A doctor makes a decision in the best interests of the patient on what they seem to be contributing to their health care, but sometimes there is someone else who has a budget in mind and there are constraints around a program. So that is their prime focus rather than the actual care of the patient. I think that is a very difficult position to put someone in – someone who is not clinically trained, and I know they are not, to override a clinical decision.²¹

4.21 Examples of decisions being changed by another medical practitioner were also provided. In these instances the emotional and financial implications can be severe. The Mallee Division of General Practice provided this case:

The patient was admitted to hospital and the specialist disagreed that an escort was required. Two days later the patient was sent home via ambulance and his wife, who was 78, was left in Melbourne with no way of getting home. Because the specialist said that it was not a requirement, she was stranded and stuck. That is not an isolated situation. It really needs to be addressed.²²

Improving access to escorts

4.22 Witnesses called for greater flexibility in the provision of escorts and recognition of the benefits to patient care that an escort can provide. In some particular instances, such as young first-time mothers and patients receiving palliative care, it was considered that the provision of an escort be mandatory.

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

20 *Committee Hansard* 22.6.07, p.26 (Ms F Armstrong, ANF).

21 *Committee Hansard* 6.7.07, p.73 (Dr K Webber, ARRWAG).

22 *Committee Hansard* 6.7.07, p.45 (Mrs M Withers, Mallee Division of General Practice).

4.23 In response, the Western Australian Government commented that while extending travel and accommodation support for escorts may assist in improved health outcomes for patients who may benefit from the presence of such a person due to psychosocial reasons, 'the effective cost of such an initiative would be extremely high'.²³

4.24 WA Country Health also commented on the need to ensure that the escort who travels with a patient is able to provide assistance and are not themselves in need of support:

...our experience is that quite often escorts who come down with a patient are not always the best option for that patient. The escorts themselves are often not familiar with the city and do not know their way around hospitals, so they are not really able to help the patient navigate through the hospital system when they are down here. We are told anecdotally that sometimes they do not stay with the patient and can be hard to find when the patient is ready to return home. Often, the escorts themselves are in need of support when they are down here, so it is an additional burden for our health services rather than a support for the patient.

...in our experience, it is sometimes difficult to find escorts who are more competent than the patient and who are not equally as intimidated by the whole thing as the patient. In some cases they can be of little value to the patient.²⁴

4.25 As a consequence of these concerns, Western Australia has established a 'meet and assist' service for patients travelling to Perth for treatment and needing assistance when they arrive. WA Country Health concluded:

It is better, in our experience, to be very exquisite about packaging the journey and making sure there are no breaks and vulnerabilities – that everything is really well lined up and the person is cared for, met and assisted all the way through – than it is to simply say, 'An escort will do the job' and have two people who get lost and do not make connections. That is our philosophy.²⁵

4.26 The Northern Territory Government responded that there was a great deal of subjectivity in who makes the decisions and how assessments are made about escorts. To overcome these difficulties, some rules had been established but problems still exist:

We have established some rules there. They are still fairly light. A lot of the escort discussion is about the clinician's assessment of the individual and their need for support when they go to another location. A lot is left to their discretion. One of the problems is that we probably need to be a bit more prescriptive as to what will qualify and what will not. There is a lot of

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

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

25 *Committee Hansard 13.7.07*, p.4 (Mrs C O'Farrell, WA Country Health Services).

discretion in it. I have some clinicians who give everybody an escort, and I have others who engage with the process a lot more interactively. There are probably others who take a much more hardnosed position on it. There is a lot of variability in there at the moment.²⁶

4.27 Queensland Health argued that the introduction of automatic approval for escorts for patients on the basis of their diagnosis would introduce inequity of access as other categories of patients who may have similar health needs could argue that their exclusion is inequitable and lobby for similar access.²⁷

4.28 The South Australia Government stated that it recognised the importance of emotional support to assist in achieving good health outcomes. South Australian PATS 'provides assistance to carers who provide support in terms of physical care of the patient as well as support for travel and accommodation for an additional escort to act as an interpreter if needed to assist the patient/family to understand treatment'. Two carers are available where a child requiring medical care is under 17 years of age if the child is seriously ill or both parents are required to make decisions on treatment options. The Government indicated that, from available PATS data, approximately 55 per cent of all claims have an approved escort/s.

4.29 In addition, South Australia has developed a Patient Liaison Nurse network through the Patient Journey Initiative to support country patients and their carers. The Patient Liaison Nurse will be a central point of contact within health units to assist in the transition of care for individuals from country South Australia needing to access health services locally, regionally and within Adelaide.²⁸

Conclusion

4.30 The evidence strongly supports the benefits to patients of having support and assistance when they travel for treatment. The Committee considers that patient assisted travel schemes should recognise these benefits through more flexible guidelines in relation to escorts.

Cross-border issues

4.31 Witnesses raised five concerns in relation to cross-jurisdictional travel: variations in subsidy rates and processes; limited cross-state arrangements; determining eligibility for transient residential status; lack of patient choice; and the inability to claim PATS if treatment is required while travelling interstate.

26 *Committee Hansard* 5.7.07, p.52 (Mr P Campos, DHCS).

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

28 *Submission* 165, pp.11-12 (SA Government).

Differences across the States and Territories

People are travelling and being subsidised in different ways as they arrive in different major centres. The emphasis on the discrepancy is more that it is not fair to Australians to have people being funded at different levels through a scheme which is basically a Commonwealth scheme but delivered in state and territory parts.²⁹

4.32 Witnesses commented that differences across the States and Territories leads to frustration for patients and administrative difficulties for staff. There are differences in the guidelines for escorts, the level of subsidy for travel and accommodation and the ability to access closer, but interstate, treatment centres. The Cancer Council cited this example in relation to access to escorts:

We are treating three young men for subtissue sarcomas – one is from South Australia, one is from Victoria and one is from New South Wales. They have all been signed off as being eligible for different levels of support through the individuals PATS programs. It has been incredibly distressful for one of the young men – who is 19 years old – who cannot understand why he could not get approval for an escort to come with him while he undergoes treatment. So there are very strong inconsistencies regarding the eligibility for specific kinds of support.³⁰

4.33 The Cancer Council also stated that dealing with the administrative processes of different jurisdictions was 'challenging'.³¹

4.34 The Leukaemia Foundation cited difficulties dealing with different schemes:

You are already aware of the issues of the different schemes crossing borders and what the conditions are. For instance...in New South Wales, for every trip they make up here, they have to pay the first two nights; in Queensland, it is the first four nights annually – so there is a variance there...

Then, of course, there is the issue of obtaining approvals. Their process is that the patient has to get up here, and we have to get forms signed by the treating specialist so that we can then fax them down and get approval from their governing district; whereas in Queensland it can be all done by the local hospital or GP prior to travel...

Then there is the issue of how long the treatment is going to be, getting the escort approved and the various ways that reviews are done. I have a patient from Darwin at the moment whose application was approved for two months, and now they are asking for a letter from the treating specialist asking how much longer it will be and what treatment is going on before they will extend it past the two months. New South Wales varies on decisions – sometimes they will approve it for the full period and other

29 *Committee Hansard*, 5.7.07, p.22 (Dr P Beaumont, AMA).

30 *Committee Hansard* 6.7.07, p.31 (Ms K Thompson, Cancer Council of Australia).

31 *Committee Hansard* 6.7.07, p.31 (Ms K Thompson, Cancer Council of Australia).

times they will ask for reviews, and that review will depend on who is in the chair at the time.³²

Interstate arrangements

4.35 When patients access interstate facilities, it is not only the differences in the schemes but also the lack of coordination of services and arrangements that cause difficulties. The South Australian Government noted that there were no PATS reciprocal arrangements for interstate patients and their carers at the national/cross border levels for travel and accommodation assistance. Where arrangements are made, they are ad hoc solutions such as individual negotiations between the sending and receiving hospitals on any transfer costs or through charitable organisations providing some financial support where people require it. The only current agreement between States and Territories is for the reimbursement for costs incurred for admitted patient services for residents of another state. The charging arrangement for these cross border admitted patient services is set out under the 2003-08 Australian Health Care Agreement.³³

4.36 The Northern Territory Government provided information on how admitted patient arrangements are utilised. As there are limited services to treat cranial injuries, major spinal injuries and major burns in the NT, patients may be evacuated to Adelaide, Sydney, Melbourne, Brisbane or Perth. About 3,081 people from the Northern Territory are cared for interstate, with the Territory paying \$25 million in 2005-06 to State Governments.³⁴ Patients from the APY lands and the Western Desert access services in Alice Springs, principally for dialysis. The Northern Territory Government indicated that it is developing a memorandum of understanding with Western Australia on how to enhance access for Kimberley patients to Royal Darwin Hospital, which is closer to them than Perth, to receive care.³⁵

4.37 While these arrangements are in place for hospital admissions, the transport and accommodation arrangements remain problematic. The Ngaanyatjarra Health Service commented on moving patients from Western Australia to Alice Springs and then to Adelaide:

It is really hard when we bring people here [to Alice Springs from WA communities] for an appointment and then they are referred to Adelaide. Who pays? Northern Territory consider they are WA patients, WA consider that it is the Territory referring them, so they are Territory patients. They are stuck in the middle here and it is like a fight.

32 *Committee Hansard* 6.8.07, p.50 (Mr R Bolton-Wood, Leukaemia Foundation).

33 *Submission* 165, pp.10-11 (South Australian Government).

34 *Committee Hansard* 5.7.07, p. 50 (Mr P Campos, DHCS).

35 *Committee Hansard* 5.7.07, p.51 (Mr P Campos, DHCS).

...It usually gets resolved with a lot of phone calls and a lot of arguments and somebody gives in. It is never resolved nicely, it is just that somebody gives in.³⁶

4.38 A further issue with the lack of coordination of arrangements was raised by the Tasmanian Government. Where patients have to travel interstate for specialist services, the timing of travel was not recognised:

[T]here appears to be little effort on the part of major mainland specialist centres to allow for the increased travel requirements of Tasmanian patients. For example, Melbourne specialist centres appear to assume that the travel requirements of Tasmanian patients are no more onerous than those of patients living in the outer Melbourne suburbs. As a result, these centres make little attempt to modify arrangements for further treatment to take this into account.

Compounding this issue is the reluctance of some specialist units in Melbourne to hand care back to suitably qualified Tasmanian specialists for maintenance therapy, which places additional travel requirements on affected patients.³⁷

4.39 The Tasmanian Government went on to argue that metropolitan specialist centres should 'critically evaluate clinical pathways' to better cater for interstate patients.³⁸

Patient choice and interstate treatment

4.40 Witnesses were particularly concerned that the PATS guidelines often do not allow for choice of interstate treatment centre. As most PATS guidelines restrict travel to the nearest specialist or treatment centre within the State, patients cannot generally nominate a different city in which to receive treatment. In a case provided to the Committee, a patient from Wentworth NSW did not receive PATS to attend Adelaide (400 km) for treatment for Sleep Apnoea but could if she attended a clinic in Sydney (1200 km).³⁹

4.41 Where jurisdictions assist patients who seek treatment across a border, the 'nearest service' guideline generally applies.⁴⁰

4.42 Often patients prefer a different treatment centre as they may have family or friends to offer support:

36 *Committee Hansard* 5.7.07, p.33 (Ms M Doyle, Ngaanyatjarra Health Service).

37 *Submission* 183, p.5 (Tasmanian Government).

38 *Submission* 183, p.6 (Tasmanian Government).

39 *Submission* 111, p.1 (Mrs K Collinson).

40 *Submission* 165, p.10 (SA Government).

There are also across-border issues for people living on the Victoria/South Australia border at places such as Dartmoor or Mount Gambier. For example, someone in Dartmoor chose to go to Adelaide for treatment because they had family and a support network there, but they were not eligible for VIPTAS because Melbourne is closer, meaning that they were not travelling to the nearest treatment centre.⁴¹

4.43 The importance of support was emphasised by Dr Peter Beaumont from the AMA. He noted that 'there are many situations where the social and family issues are of such a significant nature that it is important that the people responsible for administering the scheme need to be able to take that into account'.⁴²

4.44 Bosom Buddies also raised the issue of new radiation unit in Darwin and the requirement for Northern Territory patients to go there rather than southern states where they have family support. This is also an issue of patient-choice in terms of accessing the best treatment centre.⁴³

PATS and interstate travellers

4.45 A concern raised in several submissions was that patients are not eligible for PATS if they require treatment while travelling interstate. A number of cases of premature birth while parents were interstate were cited. The babies required hospitalisation for several months but the parents received no support and as a result faced severe financial difficulties.⁴⁴

4.46 The problem of residency is particularly difficult for Indigenous people. The Nganampa Health Council explained:

Our patients are highly transient. They could have family in the Northern Territory, Western Australia or South Australia, and they may live in each of those three areas at various times. We state that our PATS is only for people who are on the APY lands at that time. I understand that in the Northern Territory there is a requirement for a patient to have been a resident of the Northern Territory for, I think, couple of months before they become entitled to PATS. An issue arises, if we have booked an appointment for one of our patients and they have since moved to the Northern Territory and have been there for a couple of weeks, of who is going to pay to get that patient to the appointment. They are no longer on the APY lands, so we would say they are no longer our patient. The Northern Territory government would say: 'They are not actually a resident of the Northern Territory; they have not been here long enough. We are not

41 *Committee Hansard* 6.7.07, p.52 (Ms R Morton, Western District Health Services); see also *Committee Hansard* 6.7.07, p.71 (Dr K Webber, ARRWAG).

42 *Committee Hansard* 5.7.07, p.24 (Dr P Beaumont, AMA).

43 *Committee Hansard* 5.7.07, p.5 (Mrs L Locke, Bosom Buddies).

44 *Submission* 148, p.3 (The Royal Women's Hospital).

going to pay for it.' To be honest, I guess we do not have an answer to that. Those situations are generally dealt with on a case-by-case basis.⁴⁵

4.47 The Victorian Government explained that assistance is not provided to visitors or Victorians who are visiting other areas (intra and inter-state) for work or holidays on the basis that travel insurance or Work Cover are the appropriate mechanisms for assistance in these circumstances. However, the Victorian Government did note that there is a review process to cater for Victorians while travelling:

This process allows that if a patient who is travelling would normally be eligible for VPTAS assistance when at their usual place of residence in Victoria, VPTAS would pay the equivalent of travel from the patient's home to the nearest appropriate treatment location.⁴⁶

4.48 The NT Government commented that there were issues for it to meet the demands of patients from neighbouring States while maintaining health services for its residents. To provide the level of access that is sometimes demanded would require capital investment that is beyond the NT. As a result, the NT has limited some cross border activities and encouraged jurisdictions to refer patients to hospitals in their respective jurisdiction.⁴⁷

Conclusion

4.49 While there was evidence that some patients seeking medical care in another jurisdiction had received PATS assistance, on balance, there appears to be difficulties for patients crossing borders for medical care. The differences in the schemes create administrative difficulties for patients, health service staff and for organisations trying to assist patients in times of crisis. The Cancer Council Australia concluded that:

Evidence shows that cross-border complications and inconsistencies are contributing to poor usage of the schemes and to patients making decisions about their treatment that lead to inferior outcomes.⁴⁸

4.50 Witnesses called for greater coordination. The Country Women's Association NSW argued that the anomalies created by different criteria and administrative arrangements between states be reviewed, and recommended that this be addressed by a national minimum standard.⁴⁹ Other witnesses considered that as it is not uncommon for patients to cross borders for treatment, the Commonwealth should administer PATS to ensure that equitable access to assistance.⁵⁰

45 *Committee Hansard* 5.7.07, p.78 (Mr D Busuttil, Nganampa Health Council).

46 *Submission* 182, p.5 (Victorian Government).

47 *Submission* 164, pp.7-8 (NT Government).

48 *Submission* 109, p.15 (Cancer Council Australia).

49 *Submission* 5, p.5 (CWA NSW).

50 See for example, *Submission* 12, p.3 (Cancer Voices NSW).

4.51 The Committee considers that there is a great deal of scope to improve coordination of cross-border arrangements. In this regard, the Committee considers that greater coordination in relation to administrative arrangements will provide benefits to both patients and health service staff through decreased paperwork and complexity of procedures.

4.52 Patients should be provided the option to access interstate services if these are the closest or provide the most appropriate care. There should also be flexibility in the schemes to allow patients to access facilities where they may have family or friends able to provide support – in the long-term this may provide cost savings for jurisdictions as there is significant evidence that support assists patient well-being.

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

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 Peoples*, 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

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

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

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

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:

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.

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

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

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:

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

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.

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:

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

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

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 patients 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-

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

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

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

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

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 Health 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

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-11p> (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

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

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

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

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

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

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

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

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

CHAPTER 6

IMPROVING AND INTEGRATING SERVICES

The role of charities and not-for-profit organisations

The role of charities that provide the accommodation and other assistance has increased and whilst there is a so called travel allowance it does not cover many issues that families face.¹

6.1 Charities and community organisations play a significant role in providing services to patients who must travel for health care. These services include travel assistance, accommodation and general assistance to patients and their families. Some organisations are disease-specific, for example the Leukaemia Foundation and the Cancer Councils, while others assist any patient in need. An Access Economics report commissioned by The Cancer Council NSW found that at least \$2.5 million was spent on providing accommodation to people with cancer by non-profit organisations in NSW in 2005.² The South Australian Government acknowledged the major role non-profit organisations play in supporting country patients:

Without this support country patients would find it more difficult to cope with the dislocation and disconnection from the support of family and friends.

Without the accommodation services provided by support organisations, such as the Cancer Society and the Red Cross, the effectiveness of the SA PATS would be significantly curtailed.³

6.2 One of the best known medical assistance charities is Ronald McDonald House. There are 12 Ronald McDonald Houses across Australia which accommodates seriously ill children and its activities demonstrate the broad range of assistance that is provided to families.

6.3 Ronald McDonald House Westmead accommodates families from rural NSW, the Northern Territory, Western Australia, Queensland, ACT and overseas as Westmead Children's Hospital offers specialised treatments such as liver transplants. For NSW patients, IPTAAS covers half the cost for each night of accommodation and fundraising is undertaken to cover the other half of the accommodation cost and to cover items which a family may not be able to afford:

We provide clothing, breakfast cereals, milk, bread and other food items to the families, to reduce their day to day living costs...Many mothers live here all week with a child with cancer while father works at home. They

1 *Submission* 38, p.3 (Ronald McDonald House – Westmead).

2 *Submission* 56, p.7 (Cancer Voices Australia).

3 *Submission* 165, p.14 (SA Government).

need to have that emotional support on the weekends from their partners that we cannot offer. We provide petrol money on an ad hoc basis (only because a family donates for this and it runs out quickly) to families who want to have the emotional support of a partner –average cost for a father to visit Sydney on a weekend is \$100.

Many of the cars are not roadworthy, usually not reliable for long distance travel, bald tyres, no registration – all costs to the families. This is for the families who have a car.

If the family has to use public transport it becomes a nightmare for them. We take them to the train or bus station (we have an arrangement with Greyhound where they can travel free of charge) with luggage and wheelchairs, sometimes one suitcase is for the medication and healthcare needs. They somehow manage to travel with sick children to their home town. I know in some cases, particularly for remote indigenous families they opt not to bring their child for treatment because the difficulties seem insurmountable.⁴

6.4 Accommodation and assistance is also provided by many other organisations. The following provides just a very small number of examples of the accommodation services that non-government organisations supply:

- the Leukaemia Foundation of Western Australia provides 14 self-contained units in Perth;
- Australian Red Cross operates 28 accommodation centres throughout Queensland with 1300 clients per month and managed by volunteers;⁵ and
- the Australian Heart Lung Transport Association provides a house next to St Vincent's Hospital for up to three families.⁶

6.5 Charities also subsidise travel costs or provide transport and drivers. For example, the Cancer Council NSW provides two cars, driven by volunteers, to transport cancers patients from Foster/Tuncurry and Taree for treatment. The Cancer Council NSW also provides reimbursement for volunteers who drive cancer patients from Gloucester to Taree for treatment – a distance of 84 kms each way.⁷ The Cancer Council Tasmania has launched a volunteer-based cancer patient transport system – transport 2 treatment. Many Red Cross branches provide volunteers to assist patients to attend appointments.

6.6 It is not just large organisations which provide assistance. Many examples of the work of small community organisations were provided to the Committee. The Country Women's Association explained the work of one:

4 *Submission 38*, p.2 (Ronald McDonald House – Westmead).

5 *Submission 82*, p.1 (Australian Red Cross).

6 *Submission 122*, p.2 (Mr P Hughes).

7 *Submission 12*, p.5 (Cancer Voices NSW).

In one instance we know of a small country town where the Cancer Patient Assist Society paid between \$1200 and \$1500 per month for patients travel assistance and \$52,000 annually for accommodation. It is not unusual in some rural communities where such organisations are the only means of transport. There is no public transport, families are not living together intergenerationally and if a partner or family friend cannot drive the patient to treatment a voluntary organisation is usually approached for help. That provider of transport and/or accommodation in such cases whether an individual, family or organisation should still be eligible to receive the subsidy.⁸

6.7 Community transport services also provide an invaluable service. For example, Orbost Regional Health Volunteer Transport uses a small band of retired volunteers to provide long distance transport service. The trip to Melbourne takes between 4 ½ and 5 ½ hours one way and can be affected by the health needs of the client being transported, traffic conditions and location of appointment and/or accommodation.⁹ Organisations also noted that volunteers are ageing leading to a decrease in the number of drivers.¹⁰

6.8 Assistance is not restricted to travel and accommodation. The Breast Cancer Association of Queensland indicated that it had provided funding for a 23 year old single mother of three children under school age to access child care so that she could attend chemotherapy and radiation therapy and also have some respite. In another case, the Association provided funding for a patient's car registration to allow her to visit the breast cancer nurse.¹¹

6.9 Hospitals also play a significant role in providing financial support to patients. The Mater Hospital for example, provides funds through the Mater Foundation and through donations provided to the Social Work Department. The Social Work Department also relies on community organisations to support patients when they are away from home.¹²

6.10 Witnesses commented that demand for the services provided by charities and not-for-profit organisations is growing. The Leukaemia Foundation provided this overview of its activities in the financial year 2005-06:

Free transport to 4070 families with 17,598 trips for treatment, covering almost 700,000km in 31 vehicles. This service is provided with generous support from 266 volunteer drivers who committed 24,814 hours to this service for blood cancer patients and their carers/escorts.

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

9 *Submission 49*, p.2 (Let's Get Connect Gippsland East Transport Connections).

10 *Submission 69*, p.9 (Health Consumers of Rural and Remote Australia).

11 *Submission 44*, p.2 (Queensland Breast Cancer Association).

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

Free accommodation to 105 families each night in Leukaemia Foundation accommodation and up to approximately 40 families per night in commercial accommodation. Our accommodation service assisted 1149 families with 43,135 nights of accommodation in 05/06 with an average length of stay of 8 months.

1,357 families were supported with practical assistance valued at almost \$400,000 in 05/06. This includes fuel and taxi vouchers to enable patients to access treatment as well as other assistance as needed e.g. food vouchers.

Demand for and usage of our transport and accommodation services increases each year. Demand is expected to increase more rapidly as the Australian population ages and with population drift to coastal and hinterland areas beyond suburbia.¹³

6.11 In part, this growing demand is due to the range of services that are provided, their expertise in the areas of accommodation and welfare support and the lack of expansion of government services in this area. Ronald McDonald House Charities also commented that hospital practices such as early discharge mean that services are coming under pressure as 'children are likely to need intensive follow-up, and need to stay in close proximity to Hospital'. Children who survive serious illness may also be more dependent on specialised equipment, which they need to learn how to use following discharge.¹⁴

6.12 The NSW Farmers Association noted that charities and non-profit organisations play an important role in light of the 'negligible financial assistance available for accommodation under IPTASS'.¹⁵ Ronald McDonald House Charities also stressed the benefits of their services stating that 'Ronald McDonald Houses can be seen as providing outsourced hospital beds, yet the cost burden has shifted to the Charity'.¹⁶

6.13 Increasing demand is placing a greater burden on organisation to fund their activities. Inadequate subsidy levels for accommodation and slow reimbursement means that organisations face cash flow pressures and the continual need to fund raise. Ronald McDonald House Charities commented:

Funding and cash flow are major issues for houses. They cannot afford to have delays in funding for lengthy periods.¹⁷

6.14 Charities and not-for-profit organisations commented that improved support would make a significant difference to the services that they provide.¹⁸ Ronald McDonald House stated:

13 *Submission* 89, p.5 (Leukaemia Foundation).

14 *Submission* 137, p.3 (Ronald McDonald House Charities).

15 *Submission* 166, p.11 (NSW Farmers Association).

16 *Submission* 137, p.3 (Ronald McDonald House Charities).

17 *Committee Hansard* 6.7.07, p.54 (Ms D Dagg, Ronald McDonald House Charities).

For example, if that cost were to go up by a small \$10, that would have a big impact on families. They could claim that little bit more to help them out. A small \$10 increase per year would mean about \$100,000 extra per house. This was an example for our house, given the number of rooms that we have. That funding is important and vital in keeping our operation open for the families that need our house. Many would have stayed in various places – wards, cars and things – before we came along.¹⁹

6.15 Witnesses also argued that the provision of government funding for charities to expand their services would be an efficient way of providing services in the face on significant unmet need and increasing demand. Cancer Voices Australia commented that charities and non-government organisations are well placed to increase their role: they have the systems, they have the personnel and they have the trust and respect of cancer patients. Cancer Voices suggested that the Commonwealth 'through one off capital grants for accommodation close to treatment centres could 'fill the void'. The centres would be managed and run by the charities.²⁰

6.16 NCOSS also considered that there is potential for an expanded role of not-for-profit community transport providers. Many of the community transport providers specialise in the provision of non emergency health related transport to health facilities, and utilise drivers who have some expertise in meeting the support needs of people who require this form of transport. NCOSS argued that in some cases there could be opportunities for individuals to use the IPTAAS scheme to cover community transport related costs, or for community transport providers to deal directly with IPTAAS administrators in order to save clients from having to deal with intensive paperwork or high upfront costs. NCOSS concluded:

...NGO community transport and neighbour aid providers currently face overwhelming demand for services – any proposal to expand the work of the community transport industry would require careful consultation with providers, and adequate resources to cover the costs of operations, administration and vehicles.²¹

Conclusion

6.17 The Committee was overwhelmed by the range and level of services provided by charities and not-for-profit organisation to patients in all jurisdictions. The Committee considers that it is clear that without the provision of services by charities and not-for-profit organisations, government patient assisted travel schemes would be significantly compromised.

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

19 *Committee Hansard 6.7.07*, p.57 (Ms N Boyd, Ronald McDonald House Charities).

20 *Submission 56*, p.7 (Cancer Voices Australia).

21 *Submission 59*, p.5 (NCOSS).

6.18 However, the Committee was concerned that charities and not-for-profit organisations face both administrative problems and delays in reimbursements of travel and accommodation subsidies.

6.19 The Committee acknowledges that some governments have recognised the service capability and expertise of charities and not-for-profit organisation and work with them to improve services. However, the Committee considers that the role of these organisations could be expanded through partnerships with government to meet the shortfall in services. The Committee believes that not only would patients benefit but also health services.

6.20 The Committee's recommendations in relation to charities and not-for-profit organisations are included in chapter 7.

Improving communication

Awareness, marketing and promotion

6.21 Where the issue was raised, the Committee almost uniformly received evidence that there was little community awareness of patient travel schemes and that the marketing and promotion of schemes was insufficient.²² The Australian Rural and Remote Workforce Agencies Group cited a 2005 study *General Practice Hospital Integration: Issues in Rural and Remote Australia* which found that there were significant gaps in public knowledge of the schemes. The study found:

Many patients involved in this study did not receive practical non-clinical information to assist in the transition of care from the rural to the metropolitan environment. While some hospital staff reported that they provided this type of information through leaflets and through websites, a number of hospitals reported that they were aware that they did not inform their rural patients enough. Patients described the stress of not having appropriate information adding to an already stressful period in their life.²³

6.22 While a number of witnesses claimed that awareness of PATS was limited, others suggested that GPs were generally aware of the schemes but were reluctant to promote it. Dr Eduard Roos from the Southern Queensland Division of Rural General Practice suggested this was because of the administrative burden:

There is a wide awareness of the scheme. Doctors do not like paperwork – we get so many requests and forms to fill in – and sometimes they are quite happy not to promote to patients that this is available.²⁴

22 See for example, *Submissions* 5, 7, 18, 26, 29, 31, 40, 43, 46, 47, 49, 53, 73, 87, 89, 96, 103, 104, 107, 108, 115, 141, 166, 173.

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

24 *Committee Hansard*, 6.8.07, p.6 (Dr E Roos, Southern Queensland Rural Division of General Practice).

6.23 Dr Pam McGrath from Central Queensland University told the Committee that her research revealed reluctance by public hospitals to promote the schemes because of budgetary pressures. Consequently the schemes were not being appropriately accessed by those in need. Her research indicated that strategies are required to increase public knowledge of these schemes.²⁵ Dr McGrath stated:

[T]he data in the questionnaires from the travel clerks and superintendents who were giving us feedback said: 'We can't advertise this. We are having trouble coping with it as it is. If we go advertising it, we are going to be inundated.' They were their exact words, written on the form. I would say from my data—and that is all I can speak about—that there is strong evidence, firstly, that it is not well publicised and, secondly, that there is an investment in it not being publicised, because if they did then they would really need the funding, and they are only just coping with the demand as it is.²⁶

6.24 This assessment was supported by the Country Women's Association of Australia which stated:

The present marketing has some problems. There is reluctance to encourage patients to use the scheme and one of the reasons is that the money apparently comes out of the hospital budgets and the doctors may not offer the scheme unless they are asked. The GPs surgery has a poster on display but advice is not always given by doctors or staff probably because the form to be filled in by the doctor requires extra time...²⁷

6.25 The National Rural Health Alliance commented that there was a 'perverse incentive because, if the jurisdiction running the scheme does not have enough money for the whole year or for the whole quarter, they are not going to be very keen to promote it'. They suggested 'that more professionals should be encouraging patients to apply and it may be that the application can be...assessed by an agency which is not encumbered by having limited funds'.²⁸

6.26 The Denmark Health Service commented in the same vein, that hospitals administering the scheme 'don't want to actively market the scheme...as this will attract more submissions, and put the hospital budget at risk'. GPs were also 'particularly poor in advising clients about PATS and eligibility for PATS, despite information being given to them'. They also noted that the scheme will need to be adequately funded if active marketing occurs.²⁹

25 *Submission 73*, p.4 (International Program of Psychosocial Health Research, Central Queensland University).

26 *Committee Hansard*, 6.8.07, p. 23 (Dr P McGrath, Central Queensland University).

27 *Submission 104*, p.3 (Country Women's Association of Australia).

28 *Committee Hansard* 22.6.07, p.22 (Mr G Gregory, National Rural Health Alliance).

29 *Submission 43*, p.2 (Denmark Health Service).

6.27 The Association of Independent Retirees (AIR) noted that the issue of marketing and promotion of PATS received the greatest response from their members. AIR members reported it was 'generally poorly done' and that most patients were unaware of the scheme and were not informed about it by their GP. They observed that there was a need for consistent and effective marketing of the scheme to and by all rural GP's who refer patients to distant specialists.³⁰ The Isolated Children's Parents' Association of NSW recommended 'application forms need to be readily available at doctors' surgeries' and that medical receptionists and secretaries need to be educated about the scheme and be able to help patients complete the form.³¹

6.28 The Australian Medical Association acknowledged that 'a patient's access to PATS is largely dependant on their local GP knowing about the scheme' and their eligibility. The AMA called for more promoting the schemes through the publication of forms, posters, and booklets and distributed widely to all health care practitioners.³²

Conclusion

6.29 Given the extent of the evidence concerning the marketing of PATS it is clear that the promotion of PATS could be improved. GPs have an important role in ensuring their patients are aware of PATS if they may be eligible. The Committee was particularly concerned that, because of budgetary considerations or additional administrative burdens, health organisations and their personnel were not offering information about PATS to eligible patients. While a publicity campaign may assist public awareness regarding the existence of schemes to patients, it may not address the structural 'perverse incentives' raised by the National Rural Health Alliance. This should be a consideration in Commonwealth, State and Territory discussions regarding PATS.

Other related health initiatives

E-health

6.30 E-health (or telehealth) refers to healthcare services delivered or supported by electronic processes and communication. E-health can enhance clinical networks and access to timely consultations for patients and health professionals. The Commonwealth, State and Territory governments have invested in e-health and its use, particularly as a diagnostic and teaching tool, is increasing. For example, the Commonwealth Broadband for Health Program provides broadband Internet access to GPs, Aboriginal Community Controlled Health Services (ACCHS), and community pharmacies. In the longer term, e-health is seen as 'taking health care to the patient'

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

31 *Submission* 31, p.6 (Isolated Children's Parents' Association of NSW).

32 *Submission* 47, p.4 (Australian Medical Association).

and as having the potential to reduce the need for patients to seek medical care in distant locations.³³

6.31 NSW Health has utilised telehealth for some time. It commenced operations in 1996 with 12 pilot projects connecting 16 sites and now has a network to over 257 facilities, which supports 35 clinical services. Telehealth connects patients, carers and health care providers, improving access to quality public health care, particularly in rural and remote parts of NSW. NSW Health stated that telehealth has been used to support a range of assessment and treatment programs and may reduce the need to travel to large towns or cities to receive treatment.³⁴

6.32 The South Australian Government noted there 'are opportunities to expand the use of e Health for people living in rural and remote areas without compromising the delivery of safe services'. However they also raised the issue of restrictions on practitioners claiming for client consultations under the Medicare Benefits Schedule.

There is the potential to reduce the need for patients to travel, particularly for follow-up consultations and post surgery reviews. SA is currently exploring ways to use e Health to improve the transfer of care between high acuity health services in Adelaide and local health care providers in country SA. It is already being employed successfully with video-conference link-ups between the Adelaide Based Rural & Remote Mental Health Service, mental health workers and consumers.

One of the impediments to fully developing e Health is the restrictions on practitioners claiming for client consultations under the Medicare Benefits Schedule. The provision of these IT services to support consulting diagnostic services and client support needs to include voice and image over the internet protocol in addition to telemedicine and satellite access. SA strongly argues that the Australian Government should support this initiative for rural residents.³⁵

6.33 This issue was also raised by Queensland Health which encouraged the Commonwealth to urgently consider developing a schedule of MSB payments for use with telehealth consultations for both the specialist service and the referring service.

There is currently no capacity for specialists (other than psychiatrists) to charge MBS for consultations undertaken through Telehealth. This limitation restricts the potential of Telehealth to offer a wider range of specialist consultations to those living in rural and remote communities. The lack of an MBS payment for the referring service ie general practitioner further limits the use of Telehealth in rural and remote communities as shown by the MBS payment for telepsychiatry consultations where only specialist service is covered.³⁶

33 *Submission 157*, p.18 (Department of Health and Ageing).

34 *Submission 188*, p.6 (NSW Health).

35 *Submission 165*, pp.13-14 (South Australian Government).

36 *Submission 184*, p.8 (Queensland Health).

6.34 A number of submissions noted that to be effective e-health or telehealth would need to be adequately resourced with equipment, training and marketing to patients and GPs.³⁷ The Let's GET Connected Gippsland East Transport Project identified e-health as 'one of the most under utilised tools available to rural communities'. They continued:

Whilst many health agencies and clinics have the technology to provide these services there appears to be a lack of willingness on behalf of specialists and hospitals to utilise these services in order to avoid long distance and often unnecessary travel by the public. It has also been suggested that one of the barriers is how the Medicare benefit is claimed and shared as part of case management.³⁸

6.35 The potential for e-health to upskill the primary care workforce was noted by Palliative Care Australia and that 'creating linkages through e-health initiatives such as videoconferencing between local general practitioners and appropriate specialist expertise has the potential to enhance the care provided to patients'. Palliative Care Australia concluded that 'it is appropriate that models of service provision move away from fact-to-face consultation, as long as the care received is of equal quality'.³⁹

6.36 The Australian Medical Association considered 'that technology, such as video conferencing, has the capacity to allow patients to access medical services that would otherwise be unavailable' but called for e-health solutions to only be 'delivered with another medical professional, usually the patient's GP, present with the patient'. They also noted that there must continue to be mechanisms through which rural and remote patients can access face-to-face care when required.⁴⁰

6.37 The lack of communications infrastructure in Australia was acknowledged as inhibiting the utilisation of e-health. For example Mr Steve Sant of Rural Doctors Association of Australia stated:

We think that there are huge opportunities in Telehealth. They are yet to be realised. The recent announcements around increasing broadband access is a good start, but we would need 100 megabits per second to make Telehealth work well in rural communities. That is what you need to have –advanced Telehealth consultations, advanced streaming of things like ultrasound, and that sort of thing, across a broadband network.⁴¹

6.38 Several submissions noted it would be more convenient if patients could access and lodge PATS applications electronically via a website.⁴² The ACT

37 For example see *Submission 43*, p.2 (Denmark Health Service).

38 *Submission 49*, p.4 (Let's Get Connected Gippsland East Transport Project).

39 *Committee Hansard 22.6.07*, p.24 (Ms F Couchman, Palliative Care Australia).

40 *Submission 47*, p.9 (AMA).

41 *Committee Hansard, 22.6.07*, pp.21-22 (Mr S Sant, Rural Doctors Association of Australia).

42 For example see *Submission 30*, p.5 (Princess Margaret Hospital); *Submission 43*, p.2 (Denmark Health Service).

Government stated that while there was no reason an electronic system for PATS form lodgement would not work, a 'paper based accompaniment' would need to continue because of the number of patients who do not have access to computers.⁴³

6.39 Use of e-health is a developing area in health services. While it can never replace face-to-face specialist care, it has the potential to reduce the need for some rural and remote patients to travel for access to some services. The Committee considers that the Commonwealth, State and Territory governments should continue to support and develop e-health initiatives for the benefit of rural and remote patients.

Medical Specialist Outreach Assistance Program (MSOAP)

6.40 MSOAP is a Commonwealth Government funded program that provides for the provision of outreach speciality services. MSOAP encourages medical specialists to visit rural areas by providing funding to cover some of the costs associated with delivering outreach. These include travel, accommodation and consulting room hire costs. It also makes payments to visiting specialists who provide training and professional support to local general practitioners, specialists and, in some cases, other health professionals such as allied health professionals.

6.41 The need for better coordination between MSOAP and PATS was raised in a number of submissions. AMSANT noted that MSOAP was greatly appreciated by remote communities but 'the lack of coordination between them is an endless source of frustration and an inefficient use of the very scarce resources of specialist services'.⁴⁴

6.42 Maningrida Community Health Centre stated that despite good local evidence supporting MSOAP 'in our context outreach remains fractured, disorganised and inequitable'.

A local general physician has demonstrated a 4 fold cost benefit by seeing people in their home communities over seeing the same people in Alice Springs or Darwin. This has led to an argument that PATS money should be used to support specialist out-reach. Such arguments quickly descend into state and commonwealth gridlock with little gain to the patient.⁴⁵

6.43 There were also suggestions that MSOAP should be extended to provide primary care services in rural and remote areas. The Anyinginyi Health Aboriginal Corporation noted that:

PATS services are only provided for specialist services (with some exceptions). This seems to be based upon an assumption that GP services

43 *Committee Hansard*, 22.6.07, p.39 (Ms J George, ACT Health).

44 *Submission 97*, p.4 (AMSANT).

45 *Submission 163*, p.2 (Maningrida Community Health Centre).

are readily available in rural and remote areas. The availability of a GP in a remote area is an exception rather than the rule.⁴⁶

6.44 There were also some witnesses and submissions which suggested additional funding should be able to be channelled to specialist outreach services. For example Dr John Preddy, a paediatrician in Wagga Wagga, noted:

...it is my view that the best way to deliver specialty services to rural patients, if possible, is to 'bring the Mountain to Mohamed' and bring the service to the patients. I believe this is more cost effective and is certainly very supportive to existing local services and in the development of new local services. We have established many outreach clinics locally and feedback from our patients has been extremely positive. Obviously, this will not replace the need for some patients to travel to metropolitan centres for care.⁴⁷

6.45 Mr Paul Quinlivan of Ampilatwatja Health said that in his opinion additional funding would be better used on specialist outreach services.

My experience having worked in the field for three years in Ampilatwatja and having worked in the Northern Territory in remote communities for 20 years is that if you fly in a specialist – be it a cardiologist or a physician – they go to the community and if a certain Aboriginal person is not there on that day there are always three or four other people who are there. So you are going to get very efficient productivity out of any specialist. Additionally, if you fly a physician into a remote community, you already have all the culturally appropriate processes there in terms of both clinicians and family members. So you get a highly dynamic environment going on, which you cannot reproduce, no matter how much money you invest, when you transport people from the community.⁴⁸

6.46 PATS and MSOAP are opposite sides of the same coin. One assists patients to access specialists, while the other assists specialists to access patients. The Committee considers that better coordination between the schemes and between the levels of government which administer them is necessary. Allowing rural communities some flexibility to utilise PATS funding to bring specialists to them is an option that should also be explored by Commonwealth, State and Territory governments in consultation with other stakeholders.

46 *Submission* 160, p.6 (Anyinginyi Health Aboriginal Corporation).

47 *Submission* 16, p.1 (Dr J Preddy).

48 *Committee Hansard*, 5.7.07, p.79 (Mr P Quinlivan, Ampilatwatja Health).

CHAPTER 7

REFORMING PATIENT ASSISTED TRAVEL SCHEMES

The prime consideration of the operation of the scheme should be the benefit of the person travelling to access health services. The scheme should be funded and flexible to the level that ensures that isolation and lack of access to health professionals is not the difference between sickness and wellbeing.¹

7.1 A vision of improved health outcomes for rural and remote Australians lies at the heart of this inquiry. Better access to health services is fundamental to achieving this vision. In the absence of locally-based services travel assistance to access appropriate services is vital. As such, the Patient Assisted Travel Schemes should be viewed as a necessary, 'core' health service:

Patient travel and accommodation assistance schemes cannot be seen as discretionary extra services, but as the only means by which people in more remote areas can obtain access to specialist services not available locally. Good patient accommodation and travel systems will never compensate for the absence of face-to-face services. In more remote areas these travel and accommodation schemes are essential services that need to be responsive, affordable, well-promoted and widely available.²

7.2 During the course of this inquiry it became evident that considerable changes to the travel schemes are needed. Since the inception of the former Commonwealth scheme, IPTAAS, the environment in which the scheme operates has changed. Diminishing services in rural areas have resulted in a growing need for patient travel. Along with this, we have seen an increased prevalence of chronic disease. This will continue to rise with demographic ageing. On a more positive note, advances in medical technology mean that a broader range of conditions can now be treated – and treated more effectively. Travel assistance is no longer primarily directed at one-off needs to access specialist treatment. More and more, it forms an integral service for people requiring ongoing or block treatment.

7.3 This chapter discusses some potential measures to better meet the demands of a changed environment and remedy flaws in the existing schemes. Such measures include greater national consistency, the introduction of national standards and the expansion of the travel schemes to cover a wider range of treatments. Consideration is given to funding an enhanced and expanded scheme. This chapter also outlines the Committee's conclusions and recommendations for reform.

1 *Submission 69*, p.5 (Health Consumers of Rural and Remote Australia).

2 *Submission 55*, p.2 (NRHA).

A National Approach

7.4 As discussed in chapter 1, the Commonwealth travel scheme was originally transferred to the States and Territories to enable greater flexibility and local responsiveness. Yet one of the common concerns presented to the Committee was a lack of flexibility in responding to the often complex circumstances of individual patients. It was felt that the guidelines were too rigid, the system 'overly bureaucratic' and decision-making constrained:

Most of the schemes now in place in the States are under-funded, overly bureaucratic and unfairly restrictive. The schemes appear to be process driven and centred around bureaucratic control and management rather than being patient centred and focused on ensuring that Australians living in rural and remote areas have the same access to treatment services as their city counterparts. For example, the schemes do not appear to take into account factors such as individual needs of particular patients, cultural/language issues, socio-economic status, urgency of care, choice of provider or treatment centre, need for support from family, etc.³

7.5 At the same time, a number of witnesses argued that guidelines weren't clear enough and that the rules were inconsistently interpreted and applied:

Evidence indicates that clerks in some jurisdictions use a variety of interpretations of criteria in the guidelines in their decision-making for approval for both patients and their escorts to receive assistance.⁴

7.6 In effect, PATS officers' discretionary decision-making powers were characterised as excessive, resulting in subjectively based decisions and different outcomes for different patients. For example, the Cancer Council WA reported that:

A major concern for both consumers and PATS clerks is the inconsistencies with the interpretation of the guidelines and discrepancies in the administration of the scheme within and across states. Anecdotal consumer feedback suggested particular PATS clerks make special allowances for certain individuals. For example there have even been instances whereby the same PATS clerk has authorised a payment to a patient which was previously rejected for another person, despite having identical circumstances.⁵

7.7 Along with this, disparate State eligibility criteria and subsidy levels were seen to create an inequitable system for rural and remote Australians.

3 *Submission* 90, p.2 (Rural Doctors Association of Australia), See also *Committee Hansard*, 5.7.07, p.2 (Mrs L Reilly, Bosom Buddies NT) and *Submission* 30, p.1 (Social Work Department, Princess Margaret Hospital).

4 *Submission* 109, p.14 (Cancer Council Australia). See also *Submission* 158, p.1 (Tom Price Hospital Action Group).

5 *Submission* 46, p.4 (Cancer Council WA).

7.8 The following section looks at the tension between flexibility and consistency and considers the introduction of some form of national standards to create a fairer travel assistance scheme.

National consistency and uniformity

7.9 Many witnesses were supportive of greater national consistency and uniformity, arguing that it would create a fairer system and simplify cross-border arrangements. National inconsistencies were seen to produce an inequitable service. For example, Dr Beaumont from the Australian Medical Association (AMA), told the Committee that:

People are travelling and being subsidised in different ways as they arrive in different major centres. The emphasis on the discrepancy is more that it is not fair to Australians to have people being funded at different levels through a scheme which is basically a Commonwealth scheme but delivered in state and territory parts.⁶

7.10 The NSW Farmers Association stated that it felt 'extremely concerned' by the lack of consistency in the various schemes' eligibility criteria and the administration of the schemes more broadly.⁷

7.11 Reflecting the views of a number of witnesses, the Australian Red Cross commented that consistency would be fairer for consumers:

A national approach to consistency would foresee equity for all users of our service regardless of which state they reside.⁸

7.12 Witnesses submitted that national consistency would help improve cross-border arrangements. For example, the AMA noted its support for national consistency pointing out that different entitlements created confusion with cross-border travel:

The AMA supports consistency in the application of the schemes. Currently entitlements differ between the states and questions arise over which jurisdiction is responsible in cases where patients travel across borders for assistance.⁹

7.13 Ms Cahill from ACT Health told the Committee that uniformity would help at an operational level:

[A]lmost 25 per cent of the number of patients that are admitted in ACT hospitals come from New South Wales. So from our perspective,

6 *Committee Hansard*, 5.7.07, pp 22-23 (Dr P Beaumont, AMA).

7 *Submission* 166, p.4 (NSW Farmers Association).

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

9 *Submission* 47, p.4 (AMA).

particularly from an operational perspective, it would certainly make some aspects easier if there was uniformity in how arrangements are applied.¹⁰

7.14 However some witnesses had reservations about the move towards greater national consistency and uniformity. The Australian Rural Nurses and Midwives (ARNM), for example, made the point that uniformity of criteria does not necessarily create equity of outcomes. Differences between and within jurisdictions such as fuel costs, accommodation costs, road quality and so on impact on the ease of access patients have to health services:

We would like to emphasise that it is a matter of ensuring equitable health outcomes, which is not necessarily facilitated by uniformity of criteria. Uniformity of criteria can create inequity of access (and subsequently poor health outcomes) where geographical patterns vary between states.¹¹

7.15 An obvious example is the distance threshold. A nationally standardised threshold of 100 km for example, would fail the equity test when comparing patients travelling 100 km on an unsealed road to patients travelling 100 km on sealed roads.

7.16 Similarly, the Western Australian Government submitted that:

Differing arrangements and circumstances across jurisdictions (such as fuel and accommodation costs, air fares for commercially marginal routes) suggest that the application of a uniform specified rate would not necessarily result in a more equitable system, or one which meets the diverse needs of rural health consumers.¹²

7.17 The AMA characterised equity in a way that resonated with the above observations, noting that different processes may be needed to produce equal outcomes:

Equity can be considered as being equal access to services for equal need, equal utilisation of services for equal need and equal quality of care or services for all. Central to this is the recognition that not everyone has the same level of health or capacity to deal with their health problems, and it may therefore be important to deal with people differently in order to work towards equal outcomes.¹³

7.18 While all were open to improving the schemes, State and Territory governments were cautious in their support for greater national consistency and uniformity. For example, the ACT Government stated that it would not support a national scheme if assistance currently provided to ACT residents was in any way undercut:

10 *Committee Hansard*, 22.6.07, p.40 (Ms M Cahill, ACT Health).

11 *Submission* 45, p.1 (ARNM).

12 *Submission* 39, p.3. See also *Submission* 136, p.6 (ARRWAG).

13 *Submission* 47, p.3 (AMA).

The ACT would not support a uniform national scheme under which eligibility for assistance toward costs incurred in accessing interstate medical care was reduced for residents of the ACT currently eligible for assistance under the ACT scheme.¹⁴

7.19 The NT Government expressed in-principle support for greater national consistency but emphasised its budgetary constraints in this regard.¹⁵

7.20 The Victorian Government argued that current differences across jurisdictions were a reflection of state/territory endeavours to respond to local need. Moves towards greater national consistency should not undermine these local responses:

While Victoria endorses national consistency of PATS to the extent that this improves equity of access to specialist medical treatment, this needs to be weighed against the particular circumstances and constraints within each jurisdiction. Existing discrepancies reflect jurisdictional attempts to best tailor their PATS to suit the particular geographic, demographic, socioeconomic and health service features within their jurisdictions and to meet the demand that these features create for PATS within available funding.¹⁶

7.21 The Victorian Government went on to provide an example of well-founded jurisdictional differences:

In regards to minimum distance for travel reimbursement and air travel eligibility, it is clearly appropriate that these criteria are different across certain jurisdictions, to account for differences in size of jurisdictions, settlement patterns and the locations and numbers of their specialist medical services.¹⁷

7.22 Likewise, NSW Health commented that national minimum standards for travel schemes need to be 'balanced with the recognition of the geographic, demographic and health system differences between jurisdictions'.¹⁸

7.23 While the Committee certainly appreciates the argument of local responsiveness in theory, it is not confident that all state/territory scheme differences represent a strategic and considered response to local conditions in practice. For example, the high 200 km eligibility limit imposed on Northern Territory residents makes little sense in a jurisdiction where a relatively high proportion of the population live in communities with unsealed road access, no public transport, and limited flight

14 *Submission* 150, p.1 (ACT Government).

15 *Submission* 164, p.4 (NT Government).

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

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

18 *Submission* 188, p.23 (NSW Health).

services. The 200 km limit would seem to be a product of history rather than responsive policy.¹⁹

7.24 The Victorian Government further noted that jurisdictional differences in relation to eligibility may be a reflection of legislative differences across the States and Territories. They provided the following example:

[T]he cut off age for automatic entitlement to an escort is 18 years in some jurisdictions and 17 in others. This may reflect differences across jurisdictions regarding legal rights of passage such as legal driving age.²⁰

Achieving a balance between consistency and flexibility

7.25 Based on the evidence received, it is clear that a balance between consistency and flexibility is required. Witnesses wanted a system that was fair for all consumers. Adopting a uniform approach for some aspects of the scheme was seen as a way to create a fairer system. At the same time it was recognised that other aspects of the scheme would need to be treated differently to reflect jurisdictional differences. Further, flexibility in the assessment of applications to respond to the diverse circumstances of consumers was highlighted.

7.26 Mrs O'Farrell, WA Country Health Service, pointed to the difficulties in establishing a scheme that is both flexible and consistent arguing that, to some extent, the two aims are incompatible:

We noticed when we read the submissions that there was a lot about inconsistency and a lot about flexibility. We are flexible. We have a delegated arrangement to every region to be able to flex around the guidelines for individual circumstances, and they do because we do not have a generic consumer group here. We have vast differences between regions and distinctly different groups of patients, so there does need to be a lot of flexibility and we do accommodate that. Hence, there is a perception of a lack of consistency. But I do not know how you have both. You cannot have a flexible scheme and then have it be highly consistent. So we kind of keep consistency at a broad level but have a great deal of case by case flexibility to try to match up circumstances for individual families or patients.²¹

7.27 Mr Gregory explained the National Rural Health Alliance's (NRHA) understanding of how uniformity and flexibility could both be applied to create equity, arguing that uniformity was required in some respects and discretion in others:

[E]quivalence and equity dictate that people in similar circumstances must be treated in an equivalent fashion within all jurisdictions. This is what is meant by greater uniformity when it is listed as one of the key elements of

19 The 200km limit was a feature of the former Commonwealth Scheme, IPTAAS.

20 *Submission* 182, p.4 (Victorian Government).

21 *Committee Hansard*, 13.7.07, p.5 (Mrs C O'Farrell, WA Country Health Service).

the alliance's position. Currently there are substantial differences between jurisdictions in eligibility criteria, in how the schemes are promoted, in the treatments which are deemed eligible, in the way organ transplant and transplant donors are treated, in the degree of discretion exercised by authorities in respect of the transport used, in terms of payment schedules, in terms of the treatment of carers and escorts, and in terms of appeals. These are all fundamental aspects of the right to supported travel and accommodation that should be set at a high level and should be uniform between the various jurisdictions.

Where there should not be uniformity is in respect of the aspects of the scheme determined by distance alone. Travel times and costs are significantly different in Tasmania compared with Western Australia, for example. There needs to be discretion about transport arrangements. Arbitrary standards such as 30 hours on a train or 15 hours in a car may well be detrimental to a patient's health and should be weighed against the higher cost of an airfare. In these sorts of cases evaluation on a case-by-case basis would clearly be sensible.²²

A case for national standards

The absence of national minimum standards and a national framework has, over 20 years, led to an inequitable, fragmented, and inefficiently administered collection of schemes operating in isolation within jurisdictions.²³

7.28 There was extensive support from a broad range of witnesses for the introduction of national standards as a means of creating a more equitable and efficient system.²⁴ As discussed in chapter 3, a number of witnesses felt that access to specialist services should not be compromised by state idiosyncrasies. National standards were seen as a way of gaining greater national consistency and, in turn, a fairer system.

7.29 Health Consumers of Rural and Remote Australia argued that minimum standards would form a clear point of reference for the assessment of PATS applications and would enable a flexible response:

The key to improved operation of the PATS scheme is flexibility. Because personal circumstances can present the most complex challenges for administrators, it can be difficult to assess accurately within the rules and regulations, the entitlement for people under PATS schemes. Minimum standards would act to level out the eligibility of individuals for assistance under these schemes, making the implementation of the provisions

22 *Committee Hansard*, 22.6.07, p.2 (Mr G Gregory, NRHA).

23 *Submission* 109, p.2 (Cancer Council Australia).

24 See for example, *Submissions* 12, p.1 (Cancer Voices NSW), 137, p. 11 (Ronald McDonald House Charities) and 55, p.10 (NRHA).

streamlined and hassle-free, thus improving the access to and affordability of health care services to people from rural and remote areas.²⁵

7.30 The Australian Rural and Remote Workforce Agencies Group (ARRWAG) focused on the issue of health outcomes in their support of minimum 'access' standards:

A critical question to ask is "what health outcomes should we expect from an assisted travel scheme?" In this regard, it may be important to develop minimum standards of *access* as a baseline in terms of key health services.²⁶

7.31 The Social Issues Committee of the Country Women's Association of NSW highlighted uniform eligibility criteria in their support for national standards:

We believe that this is a national issue and there should be national consistency and uniformity across all jurisdictions particularly with relation to eligibility. The level and forms of assistance provided may need to be modified depending upon the areas and availability of various forms of transport, but the eligibility should be uniform.²⁷

7.32 The Rural Doctors Association of Australia (RDAA) indicated a longstanding commitment to the introduction of national standards in calling for the establishment of a Rural Health Obligation covering health service access:

The RDAA has been for some time calling on the Federal Government to put in place a Rural Health Obligation that...establishes minimum health service standards that rural Australians can expect with regard to access to health services.²⁸

7.33 Not all witnesses were confident that national standards could easily be introduced. The WA Government, for example, argued that national uniformity would need to underlie national standards, which in turn would impact on local flexibility and responsiveness:

The success of any initiative to provide for national minimum standards would be contingent upon nationally measurable criteria. This would be difficult to achieve without consistency and uniformity of schemes cross Australia. The remoteness of Western Australia's rural population, and the transport difficulties associated with access to certain regions would need to be given consideration in terms of the development of any national standards for rural patient access to specialist health services. In particular, the logistical issues associated with the culturally appropriate transportation of small numbers of people across large distances to various treatment

25 *Submission 69*, p.6 (Health Consumers of Rural and Remote Australia).

26 *Submission 136*, p.6 (ARRWAG).

27 *Submission 5*, p.2 (Country Women's Association of NSW).

28 *Submission 90*, p.6 (RDAA).

centres requires flexibility and a strong knowledge of patient needs, local conditions, and available transport options.²⁹

7.34 NSW Health noted that the difference in service delivery between the jurisdictions has been recognised under the Council of Australian Governments (COAG) initiative *Better Health Access for Rural and Remote Australians*: 'while there is a national approach in relation to priority areas for action, actual implementation will be negotiated on a bilateral basis'. This is in recognition that a 'one size fits all' approach is not appropriate. NSW Health concluded that 'it may be appropriate to consider state-based approaches taking into consideration other initiatives to improve access to services'.³⁰

7.35 While the introduction of some form of national standards was, in the main, supported, the Committee received little evidence on the type of standards that should be developed (prescriptive or outcomes-based) or suggestions as to specific standards.

7.36 However, the peak body for cancer support and advocacy groups in NSW, Cancer Voices NSW, in their support of the introduction of 'uniform minimum standards' did highlight the following broad areas for consideration: choice of treating specialist, fuel and vehicle rebate, claim forms and process, increased level of accommodation reimbursement with regular CPI adjustments, eligibility for PATS by clinical trial participants and consistent eligibility criteria and administrative arrangements.³¹

Monitoring and reporting

There is a need for...better data collection and public reporting of scheme performance, including against carefully designed key performance criteria, that cover measures of safety, quality and efficiency. In few other areas of health care is such a simple 'gate-keeping' arrangement applied in the provision of necessary health care services.³²

7.37 Evidence provided on the issue of monitoring and reporting indicated an absence of robust performance monitoring or quality improvement frameworks across the country. The Committee notes that the States and Territories currently provide a progress report against the *Healthy Horizons* Framework to the National Rural Health Policy Sub-Committee.³³ This includes details of programs that aim to facilitate access to health services. However, this reporting is at a very broad, descriptive level and gives no indication of the success of each program.

29 *Submission* 39, p.3 (WA Government).

30 *Submission* 188, p.23 (NSW Health).

31 *Submission* 12, pp1-3 (Cancer Voices NSW). See also, *Submissions* 14 and 18.

32 *Submission* 55, p.3 (NRHA).

33 The National Rural Health Policy Sub-Committee provides advice to AHMAC on rural and remote health policy issues. The Sub-Committee is responsible for overseeing progress against the goals of the *Healthy Horizons* Framework.

7.38 In its submission the Department of Health and Ageing noted that the States and Territories are required to ensure access to public health services under the Australian Health Care Agreements (AHCAs). The Department conceded that this requirement could be better monitored:

More information is needed from the states and territories to find out how this obligation is being met. Greater accountability and the ability to measure the performance of the states and territories in ensuring access to public hospital services by people living in different regions could be considered by the Australian Government in developing the next AHCAs.³⁴

7.39 The NRHA highlighted the importance of monitoring the schemes to enable continuous quality improvement:

Whilst national minimum standards will bring improved consistency to the schemes' operation, operational monitoring, annual reporting and fair and reasonable benchmarking will promote continuous improvement. Flexible and responsive scheme arrangements, and best practice, are a reasonable expectation.³⁵

7.40 The NRHA isolated the relevant areas that could be usefully benchmarked:

Differences between States and Territories with regard to population demography, health status and health service distribution; population densities and geographic size mean that performance comparisons in terms of total allocations and per capita cost will be of limited value. However the rate of adverse events, eligibility criteria and some aspects of utilisation should be directly comparable. Benchmarking performance should be achievable on relevant measures.³⁶

7.41 The Committee notes that, as outlined in chapter 1, reviews of the travel schemes have recently been undertaken in several jurisdictions and improvements have been made as a result of these reviews. While such reviews are commendable, they form a poor proxy for the quality assurance that a well-developed, robust monitoring system can provide.

Who should administer a national approach?

7.42 While, on balance, there was considerable support for some degree of national coordination and consistency, only a handful of witnesses recommended transferring administration of the travel schemes back to the Commonwealth. The Country Women's Association of NSW, for example, highlighted the issue of cross-border travel in their recommendation that the scheme be administered at the Commonwealth level.³⁷

34 *Submission 157*, p.16 (DoHA).

35 *Submission 55*, p.10 (NRHA).

36 *Submission 55*, p.4 (NRHA).

37 *Submission 5*, p.5 (Country Women's Association of NSW).

7.43 Mr Sant from the Rural Doctors Association of Australia (RDAA) saw the Medicare system as the appropriate avenue through which to administer the scheme:

We would argue that the great bulk of services provided under the patient assistance schemes are MBS funded services, so why would you not bundle it back into the Commonwealth? For all its sins, Medicare, through its offices, can administer things quite well. You could do it fairly simply. You could have a form like the Veterans' Affairs form. I do not see any reason why this should not be addressed as part of the Australian healthcare agreements, brought back to the Commonwealth and administered through a Commonwealth program.³⁸

7.44 Similarly, the Cancer Council Australia argued that a 'robust national framework' is required and suggested this be 'administered through Medicare (e.g. funded through the Extended Safety Net)'.³⁹

Expanding PATS

7.45 There was considerable support for the expansion of PATS to cover a broader range of treatments. Many witnesses recommended that PATS include all items listed on the Medicare Benefits Schedule – Enhanced Primary Care.⁴⁰

Ante-natal and post-natal care

7.46 As discussed in chapter 5, a number of witnesses highlighted ante-natal and post-natal care as a priority area for PATS expansion. Several witnesses pointed to the closure of maternity and birthing services across the Country. For example the NRHA stated:

A specific matter of concern relates to access to maternity and birthing services for rural people. Some 130 birthing services in country areas have been closed in the last decade. This has the effects, inter alia, of increasing the travel and financial burden on rural families and may even adversely influence decisions about having children or remaining in country Australia. An extended patient assistance scheme would reduce the financial burden on those mothers and families required to relocate temporarily to close proximity of the birthing service some weeks prior to the anticipated birth.⁴¹

7.47 Ms Stratigos from RDAA recommended that inclusion of obstetric and infant care should take precedence in an expanded travel scheme:

38 *Committee Hansard*, 22.6.07, p.10 (Mr S Sant, RDAA).

39 *Submission* 109, p.2 (Cancer Council Australia).

40 See for example, *Submissions* 47, p.2 (AMA); 57, p.5 (Health Consumers' Council WA) and 136 (ARRWAG).

41 *Submission* 55, p.2 (NRHA).

I would like to say that we could begin at the beginning and there would be fairly defined parameters. We could begin this wider approach to the scheme by ensuring that assistance for pregnant women and mothers of infants of up to a year are supported with transport and accommodation to access the normal support services that mothers and babies have in urban Australia. That would be a start.⁴²

Allied health services and dental care

7.48 A major concern for those living in rural and remote areas is access to allied health services and dental care. In many jurisdictions, PATS does not cover travel to access these services. As a result, there was significant support for the extension of PATS to cover allied health services and dental care.⁴³

7.49 The Committee was particularly concerned to hear that allied health and dental care services that form an integral part of treatment – for example, oral and dental care in managing rheumatic heart disease – are not covered by the majority of schemes. As the NRHA pointed out, the travel schemes are not designed for:

whole-of-health-care necessities, such as coordinated care, for example where oral and dental health care are integral components of health enhancement, as occurs in managing heart valve damage in rheumatic heart disease.⁴⁴

7.50 The Queensland Government is an exception to this:

Queensland PTSS is the only scheme that has a provision for the use of allied health services where these are provided as an essential component of services for eg physiotherapy following orthopaedic surgery, psychological assessment in preparation for psychiatric treatment.⁴⁵

7.51 Dental care was one area of particular concern given that 'poor dental health has been shown to greatly increase systemic infections and retard return to health after illness'.⁴⁶ Poor dental health in rural, regional and remote areas is, in part, a result of the lack of fluoridation and poor access to dental services.

7.52 Many submissions noted that dental services are very restricted in rural areas and specialist dental services all but non-existent. Witnesses commented that the

42 *Committee Hansard*, 22.6.07, p.16 (Ms S Stratigos, RDAA).

43 See for example, *Submissions* 6, p.2 (Frontier Services); 1, p.1 (Miss J Andrew, Marree Health Service), 103, p.6 (Qld Rural Women's Network) and 159, p.2 (Australian General Practice Network).

44 *Submission* 55, p.3 (NRHA).

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

46 *Submission* 1, p.1 (Miss J Andrew).

problem is compounded in some rural areas because dental practices have 'closed books', forcing patients to travel further for routine and emergency dental treatment.⁴⁷

7.53 In the area around Charleville in Queensland there is currently one public dentist servicing an area of 233,020 km and a population of around 9,046 people.⁴⁸ In NSW, a survey of Country Women's Association (CWA) branches provided the following findings:

44 branches reported travelling more than 50 km to access the school dental service e.g. Bourke and district residents have to travel 400 km to a school dental service in Dubbo. Seventy branches reported travelling more than 50 km to use a private dentist and 78 reported they travel 50 km or more to use the government dental clinic.⁴⁹

7.54 The Tullawon Health Service cited the case of one of its Indigenous patients who had to attend Port Augusta for dental surgery following a tongue malignancy. Because dental work is not covered by PATS, the patient was not eligible for accommodation and had to sleep in the Accident and Emergency Department of the Port Augusta hospital.⁵⁰ In the Northern Territory, the Kakadu Health Service commented that, as there were no dental services in its region, it assisted clients to travel to attend dental services in Darwin. However, in the main this was only for emergency treatment.⁵¹

7.55 Access to other allied health services is similarly difficult and does not attract support through PATS. The Isolated Children's Parents' Association of NSW commented that families often travel many hours to access speech pathology and other services for their special needs children.⁵² Other services not covered include counselling or related services such as occupational therapy for people with epilepsy;⁵³ access to Parkinsons Disorder Clinics providing multidisciplinary support; and access to community mental health services.⁵⁴

Screening services

7.56 Of particular concern was the lack of PATS for rural women who need to travel to visit mobile breast screen programs. In NSW for example, travel to visit the

47 *Submission* 34, p.2 (Hay Shire Council).

48 *Submissions* 6, p.2 (Frontier Services); 25, p.3 (Southern Queensland Rural Division of General Practice).

49 *Submission* 59, p.5 (NCOSS).

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

51 *Submission* 94, p.2 (Kakadu Health Service).

52 *Submission* 31, p.5 (Isolated Children's Parents' Association of NSW).

53 *Submission* 78, p.2 (Epilepsy Foundation of Victoria).

54 *Submission* 127, p.1 (Child & Adolescent Mental Health Services Rural & Remote Network).

mobile service fails to attract a PATS benefit because the service is not provided in a 'designated building'.⁵⁵

7.57 In the Northern Territory, Bosom Buddies noted that there are only limited windows of opportunity for rural women to access Breast Screen services. While there is a full-time service in Darwin, screening in Alice Springs takes place in three, three-week blocks annually, Tennant Creek has one week of screening per year and there are periodic visits in Katherine and Nhulunbuy. Bosom Buddies also noted that mammogram units cannot travel off the bitumen road, so it is necessary for women to travel many hundred of kilometres on dirt roads to access screening. In some cases, this is a three day trip.⁵⁶

7.58 The CWA NSW commented that the current situation is 'bizarre' as funds are being spent on urging women to have regular breast screening but they are then denied the financial assistance to do so. Ironically, 'if they fail to be screened, develop breast cancer, then they are eligible!'⁵⁷

Primary medical care

7.59 While PATS is available for travel to specialist appointments, a number of witnesses commented on the costs of accessing general practitioner care for those in rural and remote areas. As workforce difficulties rise and single practitioners move to less remote centres, patients are increasingly faced with travelling greater distances to access primary medical care.⁵⁸

7.60 Along with this, the importance of primary care in early intervention and prevention was highlighted. With an ageing population and, correspondingly, an expected future increase in chronic disease statistics, early intervention and prevention were presented as critical.⁵⁹

Procedural and specialised services undertaken by GPs

7.61 The RDAA commented that assistance should not be restricted to specialist treatment arguing that travel assistance schemes should cover procedural and specialised services undertaken by GPs:

The requirement that assistance only be available to receive specialist treatment does not reflect the situation in rural and remote Australia where procedural general practitioners (e.g. GP surgeons, GP obstetricians, GP anaesthetists, etc) undertake much of the work that is done by their

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

56 *Submission 8*, p.4 (Bosom Buddies NT).

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

58 See for example, *Submissions 61*, p.2 (Shire of Sandstone, WA); 47, p.7 (AMA); 31, p.4 (ICPA-NSW).

59 See for example, *Submissions 47*, pp 7-8 (AMA); 90, Additional Information, p.7 (RDAA).

specialist counterparts in large centres. Subsidies should also be available to travel to see GPs who provide procedural and other 'specialised' services.⁶⁰

7.62 Similarly, Women's Health Tasmania called for PATS to include procedural services undertaken by GPs. Their focus was on terminations for women from rural and remote areas. Women's Health Tasmania pointed out that first-trimester terminations are generally performed by GPs with specialised training. However, there is a limited number of GPs trained in this area nationally and none in Tasmania specifically. Further, terminations undertaken after the first trimester, which are performed by specialists, do not attract PATS assistance unless there are 'foetal abnormalities'.⁶¹

7.63 Marie Stopes International – a sexual and reproductive health care organisation with seven centres in Australia – also raised concerns around the issue of terminations. It was noted that, in keeping with State laws, the organisation provides termination services up to nineteen weeks and six days. Ideally, however, terminations are performed at less than twelve weeks. Marie Stopes International argued that women seeking terminations should be eligible for PATS assistance – particularly as the lack of financial support sometimes led to delays in seeking terminations:

We do, however, see some women presenting at a later gestation and often this delay has been caused by the need to save up funds to pay for related travel and accommodation to our centres. These travel costs particularly impact on disadvantaged young women, teenagers and women who are sole parents.⁶²

Clinical trials

7.64 Rural patients have very little opportunity to access clinical trials. Costs of participation in clinical trials are perceived by some governments to be the responsibility of the institution conducting the trial. As a result, patients outside metropolitan areas are ineligible for PATS.⁶³ However, the Committee heard that clinical trials frequently do not cover travel-related costs. Witnesses argued strongly that rural and remote patients should be supported to take part in clinical trials (particularly publicly funded trials) as cancer patients, for example, enlisted in clinical trials have been found to have better outcomes.⁶⁴

7.65 This was echoed by the Cancer Council Australia which submitted that:

60 *Submission* 90, p.3 (RDAA).

61 *Submission* 162, p.1 (Women's Health Tasmania).

62 *Submission* 19, p.1 (Marie Stopes International); see also *Submission* 84, (Pregnancy Advisory-Centre – Central Northern Adelaide Health Service).

63 *Submission* 12, p.3 (Cancer Voices NSW).

64 *Submission* 105, p.3. (Cancer Council Victoria).

Cancer clinical trials deliver a range of benefits to participating patients. For example, patients trialling successful new modalities are at the cutting edge of new treatment technology, while patients on a trials control arm also benefit from the rigorous standards of care and monitoring applied in a trial. Patients also report a sense of heightened care quality from their experience of a trial's disciplined and structured environment.⁶⁵

7.66 Cancer Voices NSW commented that it believed that 'participation in clinical trials should be encouraged by Government, not discouraged – in both the interests of individual cancer patients and the public good'.⁶⁶

7.67 Professor Currow from Cancer Australia told the Committee that: 'There is no doubt that, if we can take into account improving access to quality clinical trials, we will have done a very substantial good'.⁶⁷ However, he did note that in a limited number of cases 'physical proximity' to the centre where the trial was being conducted would be important for the patient's safety.⁶⁸

7.68 The Department of Health and Ageing also noted the importance of clinical trials:

Patient participation in cancer clinical trials is increasingly important because of new technologies and treatments becoming available. Patient participation is being actively sought and promoted by governments and health care professionals because of the benefits to the patient irrespective of the trial outcome and to many subsequent patients. Many patients have to travel to be able to participate in trials.⁶⁹

7.69 The Committee was concerned to hear about this apparent anomaly in the various PATS eligibility guidelines. It presented yet another example of the many disadvantages that Australians living in rural and remote Australia face in accessing health care.

Other services

7.70 There is currently no consideration given to the impact on family, business or property. Frontier Services argued that property owners who are self-employed could greatly benefit by the provision of a caretaker subsidy.⁷⁰ Other witnesses noted that additional child care is required when parents travel for medical reasons.⁷¹

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

66 *Submission* 12, p.3 (Cancer Voices NSW).

67 *Committee Hansard*, 22.6.07, p.49 (Professor D Currow, Cancer Australia).

68 *Committee Hansard*, 22.6.07, p.49 (Professor D Currow, Cancer Australia).

69 *Submission* 157, p.8 (Department of Health and Ageing).

70 *Submission* 6, p.2 (Frontier Services).

71 *Submission* 154, p.3 (Ms Callabro-Rowse). See also *Submissions* 44, p.2 (The Breast Cancer Association of Qld) and 60a, p.71 (GlaxoSmithKline).

7.71 The South Australian Government recommended that the Australian Government establish a 'Living Away from Home Allowance', which families needing to travel for treatment for an 'extended period' could access.⁷²

An expanded scheme – government responses

7.72 State and Territory Governments submitted that they had, in various ways, expanded the scheme coverage in their respective states.

7.73 The SA Government reported that since 1987 it has 'relaxed' the 'medical specialist service criterion' to address some specific issues for rural residents. This includes:

- Women who deliver with the nearest General Practitioner Obstetrician in attendance
- Dental work that is part of an oncology treatment plan provided the referral is by a medical specialist
- Children who have been referred to the Women's & Children's Hospital for assessment and/or treatment by any member of the Child Protection Team.⁷³

7.74 The Western Australian Government noted that under its scheme assistance is provided for the fitting of artificial limbs and, in exceptional circumstances, for certain dental health treatments.⁷⁴ In Queensland, there is a provision for the use of allied health services where these are provided as an essential component of treatment.⁷⁵

7.75 The Victorian Government reported that it is 'continuing to work towards improving access to allied health services for rural Victorians' but it was doing this through increasing services in large regional centres and other programs.⁷⁶

7.76 NSW Health noted that oral health procedures performed under general anaesthetic are eligible for assistance and stated that there may be 'merit' in including a 'broader range of dental procedures' under the scheme.⁷⁷

Concerns about cost

7.77 Some State and Territory Governments gave in-principle support for further expansion of the schemes. However, concerns were raised about the cost. For example, NSW Health stated: 'extension of the scheme to treatments that are not

72 *Submission* 165, p.3 (SA Government).

73 *Submission* 165, p.9 (SA Government).

74 *Submission* 39, p.5 (WA Government).

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

76 *Submission* 182, p.9 (Victorian Government).

77 *Submission* 188, p.24 (NSW Health).

currently covered under the scheme would pose a considerable cost impost for the states'.⁷⁸

7.78 Similarly, the WA Government commented that extending the Scheme to all items listed on the Medicare Benefits Schedule would entail extremely high costs. Furthermore, it was argued that extension of the scheme for second opinions 'would potentially jeopardise the viability of the provision of specialist medical services in regional and remote areas, as patients may bypass their regionally based specialist or service'. The WA Government concluded that:

should the patient wishes 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.⁷⁹

7.79 While providing for allied health treatments that form part of an integrated care plan, Queensland health argued that further expansion would not be viable: 'broadening the PTSS to include access to all allied health services would impact significantly on the sustainability of the scheme'.⁸⁰

7.80 The Tasmanian Government stated: 'within the current funding arrangement, it is not possible to expand the scope of PTAS services'.⁸¹

7.81 The Northern Territory Government submitted that it 'would support a change to the business rules, such as extending the availability of PATS via the Medicare Benefits Schedule (MBS), to dental services to improve health outcomes particularly for Indigenous people'. However, it was noted that it would be difficult for the Northern Territory Government to contribute additional resources to PATS.⁸²

Funding

Funding for patient assisted travel is almost certainly insufficient at the individual patient and scheme level. Better financing and administration of the schemes could be brokered with the re-negotiation of the Australian Health Care Agreements.⁸³

7.82 The dominant perspective of witnesses was that the travel schemes were insufficiently funded across the States and Territories. Research conducted in Queensland, for example, revealed that hospital administrators thought the

78 *Submission* 188, p.24 (NSW Health).

79 *Submission* 39, p.5 (WA Government).

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

81 *Submission* 183, p.6 (Tasmanian Government).

82 *Submission* 164, p.5 (NT Government).

83 *Submission* 55, p.8 (NRHA).

Queensland travel scheme was under-funded.⁸⁴ Similarly, the NRHA stated that: 'The schemes are almost certainly under-funded at both the patient and service levels'.⁸⁵

7.83 Within this context of insufficient funding State/Territory Governments reported the increasing demand for travel assistance, which outstripped available resources. The SA Government submitted that PATS has grown on an average of 12 per cent per annum while Commonwealth funding through the AHCA's has increased by just under five per cent per annum. The SA Government argued that this level of indexation is 'inadequate' and should be redressed.⁸⁶

7.84 As discussed in chapter 3, under-funding translated into insufficient subsidy rates and, in some areas at least, a budget-focused rather than patient-focused system. Recent changes to various state schemes – the increase in Queensland's mileage subsidy from 10 cents per kilometre to 15 cents, the lowering of the distance threshold in NSW from 200 to 100 kms and the introduction of a 'safety net' in Western Australia were acknowledged by witnesses. However, the changes were seen to fall considerably short of what could be viewed as adequate.

7.85 Several witnesses argued that under-funding was compounded by the fact that funds were not specifically allocated for PATS within hospital budgets. It was explained that this put pressure on those having to manage hospital budgets. For example, Dr Pam McGrath from the International Program of Psychosocial Health Research, Central Queensland University, told the Committee that in her research:

...the data from the medical superintendent would say that their problem is the difficulty of juggling competing interests over a fund of money when they have other significant hospital expenses.⁸⁷

7.86 Dr McGrath concluded that a discrete budget item for PATS would be beneficial:

One of the strong recommendations that we have is that the money is specifically targeted for it so that you remove that sense of 'if we take it from them, we give it to them', which I think sets up a very inappropriate conflict of interest.⁸⁸

7.87 Similarly, Mrs O'Farrell, CEO of WA Country Health Service stated:

84 *Submission 73*, p.5 (International Program of Psychosocial Health Research, Central Queensland University).

85 *Submission 55*, p. 3 (NRHA). See also for example *Submissions 6*, p. 1 (Frontier Services); 65, p.1 (AMA Tasmania); and 109, p.2 (The Cancer Council Australia).

86 *Submission 165*, p.10 (SA Government).

87 *Committee Hansard*, 6.8.07, p.13 (Dr P McGrath, Central Queensland University).

88 *Committee Hansard*, 6.8.07, p.13 (Dr P McGrath, Central Queensland University). See also *Submission 189*, p.2 (Childhood Cancer Support Inc.).

This is the rub here: there is no budget for PATS. We are allocated a budget, I allocate a budget to regions, they allocate budgets to the health care units and PATS has to be paid for within that budget. It may be very helpful in the future if we could have a stand-alone line item budget for PATS based on a more generous application of the scheme and based on what PATS cost and indexed annually. We would love that. My proposition to you is that that would be a great way to go, because as long as PATS money is integrated with hospital budget money, there is no saving to a hospital if a patient has to be sent on PATS to Perth. We have to pay for PATS and pay for hospitals, so there is always a tension between PATS and the operation of budgets.⁸⁹

7.88 Other witnesses looked to the Commonwealth for additional funding. As noted earlier, witnesses identified Medicare as an appropriate avenue. The NRHA stated:

The Medicare safety net could be expanded to cover travel for eligible treatments, courses of care or diagnostic tests for rural people.⁹⁰

7.89 The NRHA identified the Department of Health and Ageing's Rural Health Strategy as another possible source:

It is recognised that the existing schemes operate at the State and Territory levels. However capacity building, benchmarking and system development to achieve a nationally consistent framework could have a Commonwealth funding co-contribution provided through the Australian Government Department of Health and Ageing's Rural Health Strategy.⁹¹

7.90 The Cancer Council Australia suggested an 'inter-jurisdictional funding pool' administered through Medicare or a 'national funding agreement involving all jurisdictions and negotiated through the Australian Health Care Agreements'.⁹²

Private health insurance

The Health Consumers' Council is of the view that private health insurance should provide financial assistance for travel and accommodation for country people.⁹³

7.91 Witnesses argued that private health insurance should offer financial assistance for treatment related travel costs.⁹⁴

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

90 *Submission 55*, p.7 (NRHA).

91 *Submission 55*, p.7 (NRHA).

92 *Submission 109*, p.2 (Cancer Council Australia).

93 *Submission 57*, p.4 (Health Consumers' Council WA).

94 See for example, *Submission 55*, p.7 (NRHA).

7.92 As discussed in chapter 1, approximately half of all private health insurers do provide some form of cover for health-related travel costs. Information provided by the Department of Health and Ageing indicates that cover varies from one insurer to the next with basic benefits offering restricted cover with limits of \$200 per person per year.⁹⁵ The Committee notes that basic cover would be insufficient for patients requiring block or ongoing treatment.

7.93 The Queensland Government argued that the Commonwealth Government should amend legislation so that all private health insurers include cover for travel costs:

The Queensland Government is calling on the Commonwealth Government to reform the private health insurance legislation to ensure patient transport costs are included in private hospital insurance products by all private health insurance companies.⁹⁶

7.94 Similarly, the ACT Government saw a 'greater role' for private health insurers in providing financial assistance for health-related travel and accommodation expenses.⁹⁷

7.95 The NRHA supported financial assistance for travel and accommodation as an insurance product but expressed concern about the transfer of cost to individuals. Mr Gregory from the NRHA, told the Committee that:

Our proposal is just that given the greater flexibility that has now recently been made available to insurance companies for the products they provide we see no reason why this should not be a new product. In other words, because the legislative change – I think it was legislated recently—has enabled private health insurance companies to cover a wider range of things, we think it might usefully cover necessary transport and accommodation. This is not our first order response because, again, it transfers the risk or the cost to private individuals.⁹⁸

7.96 Mr Sant from RDAA was also concerned about transferring the cost to individuals – particularly for financially disadvantaged individuals:

The people who can most afford private health insurance are probably those who can most afford to meet the costs of transport. It is the disadvantaged part of our community that cannot afford the private health insurance that will be doubly disadvantaged by relying on private health insurance.⁹⁹

95 *Submission 157*, Additional Information, p.1 (Department of Health and Ageing).

96 *Submission 184*, p.8 (Queensland Health).

97 *Submission 150*, p.2 (ACT Government).

98 *Committee Hansard*, 22.6.07, p.18 (Mr G Gregory, NRHA).

99 *Committee Hansard*, 22.6.07, p.18 (Mr S Sant, RDAA).

7.97 Given the above reservations, the Committee emphasises that private health insurance cover should be encouraged as a supplementary – and not alternative – source of finance. This would enable the targeting of (limited) government funds to those most in need.

A path to reform

7.98 The Patient Assisted Travel Schemes provide important – and in many cases, vital – travel support to Australians living in regional, rural and remote areas who need to access specialist medical services. A number of witnesses expressed their appreciation for the assistance available through PATS. However, it was clear from the evidence received that improvement and increased funding of the Patient Assisted Travel Schemes is urgently needed.

7.99 Reform of the travel schemes is timely. The imminent re-negotiation of the Australian Health Care Agreements (AHCAs) and the review of the *Healthy Horizons* framework provide ideal vehicles for the State, Territory and Commonwealth Governments to jointly consider patient access in a systematic and integrated way.

7.100 The Committee considers that there is ample evidence that a greater commitment to patient travel schemes will not only improve health outcomes for people living in rural, regional and remote areas but will also ease the healthcare burden in the longer term. While there were calls for increased commitment to improving services *in situ*, it is evident that there are factors which mean that this cannot be the only solution considered: the move to centralisation of services; more advanced medical technology; workforce shortages; safety and efficiency concerns; and improved patient outcomes for those accessing multidisciplinary teams means that patients will have to travel to access services.

7.101 In order to travel, patients need assistance with costs. The assistance scheme, either because of the complexity of the application process, inconsistency of provision or insufficient funding, should not in itself create a barrier or disincentive to access medical care.

7.102 The Committee welcomes the State and Territory Governments' commitment to improving outcomes for patient travel. The Committee considers it is imperative that all governments work together to produce a travel assistance approach that can meet both current and future demands. This approach will require a joint commitment to, and plan of action for, improved outcomes. The Committee believes that the AHCAs provide the appropriate mechanism through which to reform patient assisted travel schemes and, consequently, enhance rural and remote patient access to health care.

Recommendation 1

7.103 That the next Australian Health Care Agreement recognise the fundamental importance of patient assisted travel schemes and include:

- **a clear commitment to improvement of services;**
- **a clear allocation of funding for the schemes;**
- **a clear articulation of the services and supports that people using transport schemes can access; and**
- **a commitment to regular monitoring of access and service provision.**

7.104 The Committee recognises that each jurisdiction has its own geographic, demographic and health system differences and, therefore, believes that administration of the schemes should remain with the States and Territories. However, the evidence received by the Committee indicates that there is need for an overarching national framework to improve patient access to services. Greater national consistency through the introduction of national standards would add value to the travel schemes for the following reasons:

- it would facilitate development of reciprocal arrangements between States and Territories;
- it would encourage patient-focused travel assistance schemes;
- it would give greater certainty to consumers on the nature and quality of the service they can expect to receive;
- it would provide clearer guidance to PATS officers in assessing and processing claims; and
- it would promote greater equity of access to services for all Australians living in regional, rural and remote areas.

7.105 However, the Committee recognises the concerns raised about a move towards national consistency, that is, that uniformity of criteria does not necessarily lead to equity in outcomes; and that national consistency could undermine the capacity for local responsiveness and reduce flexibility.

7.106 On this basis, the Committee concurs with the view that governments should seek to achieve national consistency in the 'health outcomes' of consumers. Uniformity of criteria should only be introduced if it facilitates such a result. The Committee notes that recent trends in the development of human service standards focus on the outcome to be achieved, rather than prescribing the process taken to achieve an outcome. Such an approach recognises that there may be more than one way of achieving an outcome and enables a tailored service delivery response that accommodates jurisdictional differences. At the same time, there may be core features of a service that are relevant to all jurisdictions and national standards capturing these features will contribute to improved consumer outcomes. As a result, the Committee also supports the introduction of a subset of baseline, minimum standards.

7.107 Witnesses identified a range of technical and administrative anomalies that create barriers to patient access to health services: complex application processes, eligibility inconsistencies, inadequate patient support, inadequate appeals processes, treatment coverage, inconsistencies and insufficient review of subsidy levels. The Committee considers that the development of national standards – and a review of the schemes more broadly – provide an opportunity to address these issues.

Recommendation 2

7.108 That as a matter of urgency, the Australian Health Ministers' Advisory Council establish a taskforce comprised of government, consumer and practitioner representatives to develop a set of national standards for patient assisted travel schemes that ensure equity of access to medical services for people living in rural, regional and remote Australia.

7.109 That, in establishing national standards, the taskforce:

- **identify relevant legislative, geographic, demographic and health service variables of the States and Territories impacting on access;**
- **identify barriers to access including costs of travel and accommodation, restrictions on escort eligibility and access to transport;**
- **assess the impact of co-payments;**
- **identify mechanisms to improve access for patients travelling between jurisdictions;**
- **identify, as a matter of priority, core, minimum standards that are relevant to all jurisdictions particularly in relation to eligibility criteria and subsidy levels; and**
- **give consideration to the development of optimal, outcomes-based standards that support consistent, quality outcomes for consumers, whilst enabling different State/Territory approaches that are responsive to local need.**

7.110 Development of the national standards should include (but not be limited by) consideration of the following areas:

- **patient escorts including approval for:**
 - **psycho-social support;**
 - **approval for more than one caregiver to accompany a child; and**
 - **approval for a caregiver to accompany a pregnant woman.**
- **eligibility:**
 - **identify a means other than the distance threshold to determine eligibility that takes into account a broader range of factors such as public transport access and road conditions; and**

-
- **referral on the basis of the nearest appropriate specialists where an appointment can be secured within a clinically acceptable timeframe.**
 - **appeals processes.**

7.111 The Committee considers that the improvement of patient assisted travel schemes is vitally important and improvements should be implemented as a matter of priority.

Recommendation 3

7.112 That the taskforce report to the Australian Health Ministers' Advisory Council expeditiously so that national standards can be formulated and instituted within twelve months of tabling of the Committee's report.

7.113 The Committee notes with concern the numerous complaints regarding inconsistency in the interpretation and application of PATS guidelines. In order to meet the diverse and complex needs of applicants, it is important that PATS officers have discretionary powers. Assurance that assessments are objective, fair and patient-focussed would be assisted through a robust performance monitoring system.

Recommendation 4

7.114 That the taskforce develop a performance monitoring framework, which enables ongoing assessment of State/Territory travel schemes against the national standards and relevant goals set out in the (revised) *Healthy Horizons* Framework, and facilitates continuous quality improvement.

Recommendation 5

7.115 That the Australian Health Ministers' Advisory Council establish a mechanism to monitor performance, identify areas for improvement and review the standards as required.

7.116 On the basis of the considerable evidence submitted to the Committee on the administrative complexity of the schemes (discussed in chapter 3), the Committee strongly encourages streamlining of existing arrangements.

Recommendation 6

7.117 That the taskforce review existing administrative arrangements to make them less complex, including development of a simplified generic application form; consideration of an on-line application process; and revision of the authorisation processes.

7.118 Current subsidy levels for travel and accommodation are clearly insufficient in all States and Territories and have not kept pace with rising living costs. Once patient contributions are factored in, negligible reimbursement amounts, combined with the complexity of the application process, can provide a disincentive to apply for

assistance. In turn, the lack of adequate travel assistance can provide a disincentive to seek appropriate treatment in a timely manner.

7.119 The Committee recognises that the travel schemes are subsidy schemes and that full reimbursement would be prohibitively expensive on the public purse. However, the Committee strongly believes that the subsidy levels should better recompense people disadvantaged by their residential status and should reflect current associated costs, such as petrol and private accommodation. A more generous scheme will provide an incentive for people to seek early treatment.

7.120 At the same time, the Committee appreciates that public funds are not unlimited and for this reason believes that consideration should be given to prioritising those most disadvantaged. The Committee is particularly concerned that health card holders, the 'working poor' and asset-rich but cash poor residents are inadequately supported by the current schemes. Encouraging private health insurance take-up by those who can afford it, through inclusion of travel assistance in health insurance products, would free-up funds for those most in need.

Recommendation 7

7.121 That the Australian Health Ministers' Advisory Council determine transport and accommodation subsidy rates that better reflect a reasonable proportion of actual travel costs and encourage people to access treatment early.

Recommendation 8

7.122 That the taskforce identify appropriate mechanisms against which to review subsidy levels on a regular basis to keep pace with changes in living costs.

Recommendation 9

7.123 That all States and Territories adopt a pre-payment system, whether by vouchers, tickets or advance bookings, for patients experiencing financial difficulty with the initial outlay.

Recommendation 10

7.124 That the Commonwealth Government initiate negotiations with the private health insurance sector to encourage insurers to offer products that include transport and accommodation assistance.

Recommendation 11

7.125 That State and Territory Governments develop memoranda of understanding that underpin clear, workable reciprocal arrangements for cross-border travel.

7.126 The Committee recognises that historically, the travel schemes were designed to assist patients to access specialist services. However, in view of the broader decline of health services in rural and remote areas and the difficulties in attracting GPs and other primary health care workers to these areas, the Committee strongly believes that

the schemes should be expanded to cover all MBS items, including primary care. The Committee recognises this will have significant funding implications in the immediate term. Nevertheless, inaction in this regard will, the Committee concludes, result in enormous costs to the health system in the longer term. Expanding the schemes' coverage is consistent with the focus on health promotion and disease prevention in COAG's 2006 National Reform Agenda¹⁰⁰ and the goals of the *Healthy Horizons* Framework.

Recommendation 12

7.127 That State and Territory Governments expand travel schemes to cover items on the Medical Benefits Schedule – Enhanced Primary Care and live organ donor transplants (with assistance to the donor and recipient) and access to clinical trials.

7.128 Consumer and practitioner knowledge and understanding of the scheme was variable. If access to health services for rural and remote Australians is to be improved, better promotion of the schemes is paramount.

Recommendation 13

7.129 That the taskforce develop a marketing and communication strategy that targets consumers and health practitioners. Consideration should be given to the role of the Divisions of General Practice in educating GPs about the scheme.

7.130 The lack of appropriate, affordable accommodation for people accessing outpatient specialist care across the country was emphasised in the evidence. Accommodation in tourist centres was particularly limited. Charities play a critical role in providing suitable accommodation for the chronically ill. However, demand outstrips supply.

Recommendation 14

7.131 That appropriate, on-site (or nearby) accommodation facilities be incorporated into the planning and design of new hospitals/treatment centres.

Recommendation 15

7.132 That State and Territory Governments work proactively with charities and not-for-profit organisations to provide affordable patient accommodation and services. This should include:

- **developing administrative arrangements that facilitate organisations' access to PATS funding;**
- **establishing memoranda of understanding with charitable organisations, which set out commitments to quality service delivery; and**

100 COAG, *Council of Australian Governments Communique – 10.2.06*, (accessed 4.9.07).

- **developing partnerships with the non-government sector to provide suitable patient accommodation.**

7.133 As discussed in chapter 5, health access issues for Indigenous Australians are of particular concern to the Committee. Many Indigenous Australians live in remote areas without ready access to primary, allied or specialist health services. In addition, Indigenous peoples face considerable social and economic disadvantage leading, in part, to poorer health outcomes and a shorter life expectancy than non-Indigenous Australians. Further, cultural factors – for example, community-based consent – and language barriers bring particular challenges to health care access.

7.134 The Committee believes that improved access to health services for Aboriginal and Torres Strait Islander peoples can be achieved through programs targeted at overcoming the barriers that Indigenous patients face. The Committee considers that such programs should include a greater availability of escorts, enhanced access to appropriate accommodation, improved links with communities and Aboriginal health workers and improved coordination of transport and health services. The improvements in coordination must take place both within communities and at treatment centres and address the specific problems of Indigenous patients moving interstate for treatment.

7.135 Increased patient liaison and coordination of services is crucial to ensuring that there are arrangements in place so that Indigenous patients move from their communities to health facilities and back again in a seamless and appropriate manner. The Committee received considerable evidence that programs with a high level of coordination have been very successful in decreasing the number of 'no shows' at medical appointments, improving management of travel arrangements, improving health outcomes for Indigenous patients and ensuring cultural safety. These programs included the pilot Remote Area Liaison Nurse service in South Australia which has now been expanded to a step up/step down program in Adelaide. The Committee believes that such programs could serve as a best practice model for other jurisdictions. While these programs require intensive administrative support, the Committee considers that the benefits far outweigh the costs.

Recommendation 16

7.136 That State and Territory Governments, in consultation with Indigenous representatives and Indigenous Health Services, identify and adopt best practice standards and develop programs to improve Indigenous patients' access to medical services by:

- **ensuring continuity of care for Indigenous patients by establishing liaison services and improving coordination in, and between, remote communities and treatment centres;**
- **accommodating the cultural and language needs of Indigenous patients from remote communities, particularly in respect to the provision of escorts and translators; and**
- **expanding access to appropriate accommodation services.**

7.137 In establishing these best practice standards and programs government and Indigenous representatives should:

- **identify and build on existing examples of good practice by health services in Indigenous communities and State and Territory programs; and**
- **establish clear governance and administrative arrangements for the delivery of programs, including consideration of the most appropriate bodies to provide day-to-day administration of services (for example, a government body or community-managed Aboriginal and Torres Strait Islander health services).**

Senator Gary Humphries
Chair

September 2007

APPENDIX 1

LIST OF PUBLIC SUBMISSIONS AND TABLED DOCUMENTS AUTHORISED FOR PUBLICATION BY THE COMMITTEE

- 1 Andrew, Ms June (SA)
- 2 Barry, Ms Lisa and Webster, Mr Dean (NSW)
- 3 Katherine West Health Board (NT)
- 4 York Peninsula Division of General Practice (SA)
- 5 Social Issues Committee – Country Women's Association of NSW (NSW)
- 6 Frontier Services (QLD)
- 7 Southern Mallee Transport Connections Partnership (SMTCP) (VIC)
- 8 Bosom Buddies NT Inc (NT)
 - Supplementary information*
 - Copy of letter dated 21.6.07 concerning obstacles surrounding specialist referral tabled at hearing 5.7.07
 - Response to evidence given by NT Department of Health and Community Services at hearing 5.7.07
- 9 Great Southern GP Network (WA)
- 10 Young Community Transport Service Inc (NSW)
- 11 Sunraysia Information & Referral Service Inc (SIRS) (VIC)
- 12 Cancer Voices NSW (NSW)
- 13 Karratha Cancer Support Group (WA)
- 14 Breast Cancer Action NSW (NSW)
- 15 Narrandera Local Health & Golden Cluster Health Advisory Committees (NSW)
- 16 Preddy, Dr John S (NSW)
- 17 Inverell Breast Cancer Support Group (NSW)
- 18 Association of Independent Retirees (AIR) (ACT)
- 19 Marie Stopes International (VIC)
- 20 Lake Cargelligo Community Transport (NSW)
- 21 Moore, Ms Betty (NSW)
 - Supplementary information*
 - Additional information following hearing 6.8.07, received 12.9.07

- 22 Central Australian Division of Primary Health Care Inc (NT)
- 23 J Ravet Pty Ltd (WA)
- 24 Ethnic Community Care Links (QLD)
- 25 Southern Queensland Rural Division of General Practice (SQRDGP) (QLD)
- 26 Chronic Illness Alliance Inc (VIC)
- 27 Cancer Voices WA (WA)
- Supplementary information*
- Copy of presentation at hearing tabled at hearing 13.7.07
- 28 Parkinson's Tasmania Inc (TAS)
- 29 Wurli Wurlinjang Health Service (NT)
- 30 Social Work Department - Princess Margaret Hospital (WA)
- 31 Isolated Children's Parents' Association of NSW (ICPA-NSW) (NSW)
- 32 National Aged Care Alliance (ACT)
- 33 Advisory Committee for Older People (ACOP) (VIC)
- 34 Hay Shire Council (NSW)
- 35 MFIA (SA)
- 36 Mater Health Services (QLD)
- 37 BCNACTION Group (ACT)
- 38 Ronald McDonald House – Westmead (NSW)
- Supplementary information*
- Tabled at hearing 6.7.07
- Copy of remittance advice
 - Copies of documents relating to reimbursement from IPTAAS
- 39 Western Australian Government (WA)
- Supplementary information*
- Tabled at hearing 13.7.07
- Brochure – PATS – A Guide for Patients and their Carers
 - Copy of presentation at hearing
 - Responses to questions and additional information following the hearing received 10.8.07
- 40 Albany Community Resource Agencies Network (WA)
- 41 Bowie, Dr James (WA)
- 42 Motor Neurone Disease Association WA Inc (MNDAWA) (WA)
- 43 Denmark Health Service (WA)

-
- 44 The Breast Cancer Association of Queensland Inc (QLD)
- 45 Australian Rural Nurses & Midwives (ACT)
Supplementary information
- *An analysis of the needs of people with cancer travelling from Toowoomba and south-west Queensland to Brisbane for Radiotherapy treatment*, Hegney et al, April 2002 tabled at hearing 6.8.07
- 46 Cancer Council Western Australia (WA)
- 47 Australian Medical Association (AMA) (ACT)
- 48 NT Breast Cancer Voice (NT)
- 49 Lets GET Connected Gippsland East Transport Connections (VIC)
- 50 Palliative Care Australia (ACT)
- 51 Mallee Division of General Practice (VIC)
- 52 Murweh Shire Council (QLD)
- 53 Ronald McDonald House Monash (VIC)
Supplementary information
- Copy of a case study tabled at hearing 6.7.07
 - Additional information following hearing, received 9.7.07
- 54 Leukaemia Foundation of WA (WA)
- 55 National Rural Health Alliance (NRHA) (ACT)
- 56 Cancer Voices Australia (NSW)
- 57 Health Consumers' Council WA Inc (WA)
- 58 Aged and Community Services Australia (VIC)
- 59 Council of Social Service of New South Wales (NCOSS) (NSW)
- 60 GlaxoSmithKline Australia (VIC)
- 61 Shire of Sandstone (WA)
- 62 Bayliss, Dr Evan (WA)
- 63 Breast Cancer Network Australia (BCNA) (VIC)
Supplementary information
- *DVD Digital Storytelling Project* received 3.7.07
 - Response to questions received 3.8.07
- 64 Health & Community Services Complaints Commissioner SA (HCSCC) (SA)
- 65 AMA Tasmania (TAS)
Supplementary information
- Response to questions on notice received 3.8.07
- 66 Greater Southern Area Health Advisory Council (NSW)

- 67 Social Work Department – Sir Charles Cairdner Hospital (WA)
- 68 Kidney Health Australia (ACT)
Supplementary information
Tabled at hearing 22.6.07
- Walker, Christine & Tamlyn, Jo-Anne, *The Cost of chronic Illnesses for Rural and Regional Victorians*, Chronic Illness Alliance 2004
 - Kidney Health Australia, *The cost-effectiveness of early detection and intervention to prevent the progression of chronic kidney disease in Australia*, 2006
 - Kidney Health Australia, *The economic impact of end-stage kidney disease in Australia*, 2006
- 69 Health Consumers of Rural and Remote Australia (SA)
- 70 C A Thompson & Associates on behalf of Individuals of the Territories of Cocos & Christmas Islands (WA)
- 71 Western District Health Service (VIC)
- 72 Anglicare Tasmania (TAS)
- 73 International Program of Psycho-Social Health Research (IPP-SHR) (QLD)
- 74 Kimberley Aboriginal Health Planning Forum (WA)
- 75 Pettigrew, A/Professor Ian (VIC)
- 76 Aboriginal Health Council of SA Inc (AHCSA) (SA)
- 77 National Heart Foundation – Northern Territory Division (NT)
- 78 Epilepsy Foundation of Victoria Inc (VIC)
- 79 Northern Territory Divisions Network (NT)
- 80 Marshall, Mr Gary (NT)
- 81 Board of Ampilatwatja Health Centre Aboriginal Corporation (NT)
- 82 Australian Red Cross (QLD)
- 83 Tullawon Health Service (SA)
- 84 Pregnancy Advisory Centre – Central Northern Adelaide Health Service (SA)
- 85 Psycho-Oncology Collaborative of the Cancer & Palliative Care Network WA (WA)
- 86 Parkinson's Victoria (VIC)
- 87 Australian Physiotherapy Association (VIC)
- 88 Buswell MLA, Mr Troy (WA)
- 89 Leukaemia Foundation of Australia (QLD)
Supplementary information
- Application form and brochure tabled at hearing 6.8.07

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- 90 Rural Doctors Association of Australia (ACT)
Supplementary information
- Additional information concerning research priorities relating to better access to preventive and acute services received 26.6.07 and 27.6.07
- 91 Cancer Voices NSW (NSW) – Supplementary submission
- 92 King Island Multi-Purpose Centre Advisory Committee (TAS)
Supplementary information
- Additional information following hearing 23.7.07, received 21.8.07
- 93 Ingham Health Service (QLD)
- 94 Kakadu Health Service (NT)
- 95 Nganampa Health Council (NT)
Supplementary information
- Annual Report 2006 tabled at hearing 5.7.07
- 96 Australian Nursing Federation (ACT)
- 97 Aboriginal Medical Services Alliance of the Northern Territory (AMSANT) (NT)
- 98 Lawrence, Ms Monica (SA)
Supplementary information
- Additional information concerning cardiac care for Aboriginal people in remote areas received 11.7.07
- 99 Royal Flying Doctor Service (NSW)
- 100 Barambah Regional Medical Service (QLD)
- 101 Carers WA (WA)
Supplementary information
- Additional information tabled at public hearing 13.7.07
- 102 Urapuntja Health Service (NT)
- 103 Queensland Rural Women's Network Inc (QLD)
Supplementary information
- Additional information following hearing, received 8.8.07
- 104 Country Women's Association of Australia (TAS)
- 105 Cancer Council Victoria & Victorian Cooperative Oncology Group (VIC)
- 106 Haase MP, Mr Barry (WA)
- 107 Lee, Ms Jill (VIC)
- 108 RWM Consultancy & Djinyini, Mr Keith (NT)
- 109 Cancer Council Australia (NSW)
- 110 Ding, Mr Darryl (WA)

- 111 Collinson, Mrs Kathy (NSW)
- 112 Becroft, Mr Arthur (WA)
- 113 Ward, Mr Donald and Mrs Gloria (WA)
- 114 Jones, Mr Richard (WA)
- 115 Pica, Ms Eileen (VIC)
- 116 Mangili, Ms Doriana (WA)
- 117 Dawson, Mr Geoffrey (NSW)
- 118 Richard, Mrs Carol (NSW)
- 119 Archer, Mr Keith (WA)
- 120 Romaior, Mr Mario (QLD)
- 121 Farmer, Ms J A (WA)
- 122 Hughes, Mr Paul (NSW)
- 123 Wells, Ms Noni (NSW)
- 124 McLean, Mrs Christine (QLD)
- 125 De Bonde, Mr Brian & Ms Amanda
- 126 Hall, Ms Raelene (WA)
- 127 Child and Adolescent Mental health Services (CAMHS) Rural and Remote Network (WA)
- 128 Name withheld
- 129 O'Dwyer, Mr Kevin (WA)
- 130 Lewis, Mr Eric & Mrs Ann (WA)
- 131 Venn, Ms Pauline (VIC)
- 132 Webster, Ms Anne
- 133 Peter MacCallum Cancer Centre – Bendigo Radiotherapy Centre (VIC)
- 134 Campbell Town Health and Community Services Board (TAS)
- 135 McIvor, Mr Angus (NT)
- 136 Australian Rural & Remote Workforce Agencies Group Limited (ARRWAG) (VIC)
- Supplementary information*
- *General Practice Hospital Integration, Issues in Rural and Remote Australia – Summary of Findings & Literature Review* by tabled at hearing 6.7.07
- 137 Ronald McDonald House Charities (NSW)
- Supplementary information*
- *The impact of Ronald McDonald Houses on their Partner Children's Hospitals*, study by Monica Enand 2004 received 9.7.07

-
- 138 O'Brien, Ms Cheryl (NSW)
- 139 Robinson, Mr Edward (SA)
- 140 Payne, Ms Yvonne (WA)
- 141 Howe, Mr Don (NSW)
- 142 Fahl, Mr Peter & Ms Yvonne (WA)
- 143 Rogers, Mr Roy & Ms Dorothy (WA)
- 144 Westerman, Mr Alan (NT)
- 145 Graham, Ms Rosina (WA)
- 146 Ostigh, Ms Monica (NT)
- 147 Kildea, Associate Professor Sue (NT)
- 148 The Royal Women's Hospital (VIC)
- 149 Talaulikar, Dr Girish (ACT)
- 150 ACT Government (ACT)
Supplementary information
- Response to questions on notice relating to travel allowance received 14.7.07
- 151 Lynch, Ms Josephine (WA)
- 152 Johnston, Mr Donald & Mrs Helen (WA)
- 153 Hinze, Mr Graham ()
- 154 Calabro-Rowse, Ms Antonella (NT)
- 155 Shire of Ashburton (WA)
- 156 Thrussell, Dr Sheryl (WA)
- 157 Department of Health and Ageing (ACT)
Supplementary information
- Response to questions on notice received 20.8.07
- 158 Members of Tom Price Hospital Action Group (WA)
- 159 Australian General Practice Network (AGPN) (ACT)
- 160 Anyinginyi Health Aboriginal Corporation (NT)
- 161 Evans, Ms Sue (NT)
- 162 Women's Health Tasmania (TAS)
- 163 Maningrida Community Health Centre (NT)
- 164 Northern Territory Government (NT)
Supplementary information
- Additional information provided following the hearing 5.7.07, received 6.9.07
- 165 South Australian Government (SA)

- 166 NSW Farmers Association (NSW)
- 167 Ozanne, Mr Rob (WA)
- 168 Brotherton, Ms Grace (WA)
- 169 Smith, Ms Annette (NSW)
- 170 Fraser, Mrs Jennifer (SA)
- 171 Abell, Mr Eric & Mrs Audrey (WA)
- 172 Scardina, Ms Amy
- 173 Boyd, Mr Ray (QLD)
- 174 Drage, Mr Graham (VIC)
- 175 Currie, Ms Judith
- 176 Tink, Ms Jenny (VIC)
- 177 Stafford, Mr Simon (NT)
- 178 Robertson, Mrs Pam (VIC)
- 179 Gregory, Mr John (VIC)
- 180 Soroptimist International Cootamundra (NSW)
- 181 Lowcock, Mr Mick
- 182 Victorian Government (VIC)
- 183 Tasmanian Government (TAS)
- Supplementary information*
- Additional information provided following the hearing 23.7.07, received 30.7.07
 - Response to questions on notice received 13.8.07
- 184 Queensland Health (QLD)
- Supplementary information*
- Response to questions received 7.9.07
- 185 Kidney Health Australia's Tasmanian Consumer Participation Committee (TAS)
- Supplementary information*
- Document with comments on PATS needs tabled at hearing 23.7.07

- 186 Roden, Mr Phillip (TAS)
Supplementary information
- Document with comments on PATS needs provided at hearing 23.7.07
- 187 Aspley Lions Club Inc (QLD)
Supplementary information
Tabled at hearing 6.8.07
- Rural men's health: supplementary information
 - Lions sight project CD
 - Supplementary submission received 23.8.07
- 188 NSW Health (NSW)
- 189 Childhood Cancer Support Inc (QLD)
- 190 Elliott, Mrs Sharon (WA)

APPENDIX 2

WITNESSES WHO APPEARED BEFORE THE COMMITTEE AT PUBLIC HEARINGS

Friday, 22 June 2007

Parliament House, Canberra

Committee Members in attendance

Senator Gary Humphries (Chair)

Senator Claire Moore (Deputy Chair)

Senator Judith Adams

Senator Lyn Allison

Senator Sue Boyce

Senator Carol Brown

Senator the Hon Kay Patterson

Senator Ruth Webber

Witnesses

National Rural Health Alliance

Mr Gordon Gregory, Executive Director

Rural Doctors Association of Australia

Mr Steve Sant, Chief Executive Officer

Ms Susan Stratigos, Policy Adviser

Australian General Practice Network

Mr Steven Morris, Senior Policy Officer

Kidney Health Australia

Ms Janine Bevan, National Manager, Health Programs, Government and Consumer Relations

Mr Wayne Stuart

Mrs Claudia Stuart

Palliative Care Australia

Ms Fiona Couchman, National Policy Officer

Ms Camilla Rowland, National Program Manager

Australian Nursing Federation

Ms Fiona Armstrong, Federal Professional Officer

ACT Government

Miss Megan Cahill, Executive Director, Government Relations and Planning, ACT Health

Ms Jacinta George, Senior Manager, Health Services Planning Unit, ACT Health

Department of Health and Ageing

Mr Richard Eccles, First Assistant Secretary, Primary and Ambulatory Care Division

Ms Sharon Appleyard, Assistant Secretary, Rural Health Branch

Professor David Currow, Chief Executive Officer – Cancer Australia

Thursday, 5 July 2007

Crowne Plaza Hotel, Alice Springs

Committee Members in attendance

Senator Gary Humphries (Chair)

Senator Judith Adams

Senator Claire Moore (Deputy Chair)

Senator Sue Boyce

Witnesses

Bosom Buddies NT

Mrs Liz Locke, President

Miss Joy White, Deputy President

Mrs Leslie Reilly, Secretary

Central Australian Division of Primary Health Care

Mrs Gonam Pillay, Team Leader, Mental Health Project Office

Northern Territory Divisions Network

Dr Jim Thurley, Medical Adviser

Australian Medical Association

Dr Peter Beaumont

Ngaanyatjarra Health Service

Miss Michelle Doyle, Patient Liaison Coordinator

Northern Territory Government

Mr Peter Campos, Assistant Secretary, Acute Care

Dr Lucy Firth, Director, Systems Performance, Acute Care

Aboriginal Medical Services Alliance of the Northern Territory (AMSANT)

Mr Simon Stafford, Senior Primary Health Care, Corporate Support Officer

Katherine West Health Board

Mr Sean Heffernan, Chief Executive Officer

Mr Joseph Cox

Ms Roslyn Frith, Board Member

Mr David Lines, Assistant Community Health Manager

Mr Jack Little, Honorary Board Member

Urapuntja Health Service

Mr Robin Blackburn, Chief Executive Officer

Nganampa Health Council

Mr David Busuttill, Corporate Services Manager

Ms Eileen Moseley, Hospital Liaison Officer

Board of Ampilatwatja Health Centre Aboriginal Corporation

Mr Paul Quinlivan, Administrator

Friday, 6 July 2007

St James Court Conference Centre, Melbourne

Committee Members in attendance

Senator Gary Humphries (Chair)

Senator Sue Boyce

Senator Claire Moore (Deputy Chair)

Senator Carol Brown

Senator Judith Adams

Senator the Hon Kay Patterson

Senator Lyn Allison

Senator Ruth Webber

Witnesses**GlaxoSmithKline**

Mr Alex Gosman, Director, Government and Corporate Affairs

Ms Sarah Stuckey, Policy Manager

Dr Gerard Cudmore, Associate Medical Director

National Aged Care Alliance

Mr Ian Yates

Dr Peter Ford

Ms Monica Lawrence (*via teleconference*)**Cancer Council Australia**

Professor Ian Olver, Chief Executive Officer

Ms Kate Thompson, Senior Social Worker

Breast Cancer Network Australia

Ms Terri Smith, National Policy and Advocacy Manager

Dr Wei Leng Kwok, Senior Policy Officer

Royal Women's Hospital

Ms Marg Darcy, Program Manager

Ms Anne Marsh, Manager, Family Accommodation Services

Mallee Division of General Practice

Mrs Michelle Withers, Program Services Officer

Western District Health Service

Ms Rebecca Morton, Coordinator - South West Community Transport Program

Ronald McDonald House

Ms Diana Dagg, National House Development Manager, Charities

Ms Jennifer North, Executive Officer, Monash

Mrs Adrienne Pearson, General Manager, Westmead

Ms Nikki Boyd, House Manager, Parkville House

Australian Rural and Remote Workforce Agencies Group (ARHEN)

Dr Kim Webber, Chief Executive Officer

Council of Social Services NSW (*via teleconference*)

Dr Dinesh Wadiwel, Senior Policy Officer

Ms Eileen Pica (*via teleconference*)

Ms Liz Scott, Committee Member, Health Consumers Voice, Northern Territory

Friday, 13 July 2007

Commonwealth Offices, Perth**Committee Members in attendance**

Senator Gary Humphries (Chair)

Senator Helen Polley

Senator Claire Moore (Deputy Chair)

Senator Ruth Webber

Senator Judith Adams

Witnesses**Western Australian Government**

Ms Christine O'Farrell, Chief Executive Officer, WA Country Health Service

Mr Ken Mills, Acting Area Director Corporate and Finance

Ms Sue Eslick, Manager Health Strategies

Cancer Voices WA

Mr Clive Deverall, Chair

Cancer Council WA

Ms Belinda Bailey, Director Cancer Services

Health Consumers' Council WA

Ms Michele Kosky, Executive Director

Mr Brian Charlie, Aboriginal Programme Coordinator

Carers WA

Ms Noreen Fynn, Chief Executive Officer

Sir Charles Gairdner Hospital

Ms Annie Collet, Welfare Officer

Ms Jan Hillenbrand, Welfare Officer

Princess Margaret Hospital

Ms Jennifer Mace, Acting Head of Social Work Department

Ms Sharon Patterson, Senior Welfare Assistant

Shire of Ashburton

Mr Keith Pearson, Chief Executive Officer

Shire of Sandstone (*via teleconference*)

Mr William Atkinson, Chief Executive Officer

CA Thompson Cocos and Christmas Islands (*via teleconference*)

Ms Charlene Thompson, Social Worker

Mrs Ali Norzaini

Kimberley Aboriginal Health Planning Forum (*via teleconference*)

Dr Carmel Nelson, Medical Director

Kidney Health Australia (*Accommodation Project Presentation*)

Ms Julie Edmonds, WA Area Manager

Monday, 23 July 2007

Grand Chancellor Hotel, Launceston

Committee Members in attendance

Senator Gary Humphries (Chair)

Senator Claire Moore (Deputy Chair)

Senator Judith Adams

Senator Sue Boyce

Senator Carol Brown

Senator the Hon Kay Patterson

Senator Helen Polley

Witnesses**Tasmanian Government**

Mr John Smith, Director, Resources and Systems Performance, Acute Health Services

Mr Tony Sansom, Manager, Planning and Performance Review, Acute Care Strategies and Reform Unit, Acute Health Services

Ms Peggy Tsang, Project Officer, Planning and Performance Review, Acute Care Strategies and Reform Unit, Acute Health Services

Mr Peter Renshaw, Director of Clinical Services, Launceston General Hospital

Campbell Town Health and Community Services Board

Mrs Margaret Crisp

Mrs Anna Lovitt, Board Member (Staff Representative)

King Island Multi-Purpose Centre Advisory Committee (*via teleconference*)

Mr David Brewster, Chairman

Mr Andrew Wardlaw, General Manager

Kidney Health Australia's Tasmanian Consumer Participation Committee

Ms Sarah Challenor, Member

Mrs Susanne Henry, Member

Mrs Carolyn Mackintosh, Health Services Manager

Mr William Radford, Member

Ms Pamela Walker, Member

Mrs Myra Wightman, Member

Australian Medical Association Tasmania

Dr Donald Rose, Branch Councillor

Country Women's Association

Mrs Ailsa Bond, Former National President

Beaconsfield District Health Service Community Advisory Board

Mr Michael Perkins, Chairman

Monday, 6 August 2007

Hotel Grand Chancellor, Brisbane

Committee Members in attendance

Senator Gary Humphries (Chair)

Senator Claire Moore (Deputy Chair)

Senator Judith Adams

Senator Sue Boyce

Senator the Hon Kay Patterson

Witnesses

Southern Queensland Rural Division of General Practice

Dr Eduard Roos, Board Member

International Program of Psycho-Social Health Research (IPP – SHR)

Dr Pam McGrath, NHMRC Senior Research Fellow

Frontier Services

Ms Marina Izatt, Regional Manager

Mater Health Services

Ms Jeniffer Petty, Senior Social Worker

Leukaemia Foundation of Australia

Ms Anne Williamson, General Manager

Ms Sandy McKeirnan, Support Services Manager

Mr Ron Bolton-Wood, Manager - Patient Accommodation

Ms Barbara Hartigan, Director – Patient Support Services

Breast Cancer Association of Queensland

Mr Roger Traves SC, Chairman

Mrs Sandy Cassidy, Vice Chairman

Mrs Tracey Plumridge, Secretary

Queensland Rural Women's Network Inc (via teleconference)

Ms Moya Sandow, State Treasurer and Health Working Party Member

Australian Rural Nurses and Midwives

Professor Desley Hegney, Member, Committee of Management

Ms Betty Moore (via teleconference)**Aspley Lions Club**

Reverend Michael Veary, President

Dr John Gough

Mr Henk Horchner, Project Coordinator and Facilitator

INSPECTIONS AND PRIVATE BRIEFING

Wednesday, 4 July 2007

The Committee visited the following:

The Central Australian Aboriginal Congress – held informal discussions with Ms Maxine Chaseling Branch Manager and Mr Matthew Strangeways.

The Alice Springs Base Hospital – held informal discussions with Ms Vicki Taylor, General Manager, Dr Meredith Arcus, Director of Clinical and Medical Services, Mr Chris Burrows and Mr Leon Spurling.

Western Desert Dialysis Unit – held informal discussions with Ms Sarah Brown about the operation of the unit.

The Committee held a private briefing with Ms Sabina Knight, Senior Lecturer, Nursing and Remote Health Practice, to discuss issues relating to patient assisted travel and access to medical facilities by people living in remote areas.