



NATIONAL RURAL
HEALTH
ALLIANCE INC.

24 May 2007

Mr Elton Humphery
Committee Secretary
Senate Community Affairs Committee
Parliament House
Canberra ACT 2600
By email: community.affairs.sen@aph.gov.au

Dear Mr Humphery

Re: Inquiry into the operation and effectiveness of patient assisted travel schemes (PATS)

The National Rural Health Alliance welcomes the Senate Community Affairs Committee's inquiry into the operation and effectiveness of patient assisted travel schemes. We acknowledge the work of Senator Judith Adams and others in bringing the matter before the Committee.

The National Rural Health Alliance (NRHA) is the peak non-government organisation in Australia advocating for improved health outcomes for rural people. It comprises 27 Member Bodies, themselves representing rural consumer, health professional and health provider organisations. These are detailed in Appendix 1 on the last page of this document. The NRHA has had improved patient transport and accommodation assistance for country people as a priority for a number of years. In 2005 we published a position paper identifying and detailing scheme shortcomings, consumer imposts and possible improvements to these State and Territory based schemes. That document is included separately as Attachment 1 to this submission (*Transport and accommodation assistance for health patients from rural and remote areas*, October 2005).

This submission is informed by the NRHA's own published work (Attachment 1 and, see below, Attachment 2), the speakers and outcomes from a public seminar convened in October 2006 to address the issue, and the proceedings and recommendations from the 9th National Rural Health Conference held in March 2007. It represents the agreed views of the NRHA but not necessarily the full or particular views of all of its Member Bodies.

The submission is in three parts: this covering letter, which includes sections on specific priorities and issues, brief statements in relation to the nine areas of inquiry under the Committee's terms of reference and one appendix, and the two attachments.

A responsive and well-resourced patient accommodation and travel assistance scheme is an integral measure in improving health outcomes and equity for rural people. Both anecdote and evidence demonstrate a need for improvement. 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.

Approximately 30 percent of Australians live in rural and remote areas. Health outcomes for rural Australians are poorer than for their city colleagues. There is evidence of:

- up to 4 years lower life expectancy
- up to 20% higher mortality
- lower survival rates for cardiovascular disease and cancer
- higher rates of morbidity and hospitalisation
- 50% higher mortality rates for men from occupational injury
- over 50% higher mortality rates for men from motor vehicle crashes and suicide.

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. The Alliance's position paper, *Principles for maternity services in rural and remote Australia*, October 2006, is included separately as Attachment 2 to this submission.

In more remote areas, there is little or no public transport, limited private transport, and roads which are often of poor quality. This severely limits options in relation to non-urgent patient transport both in terms of affordability and flexible transport options.

This submission identifies significant issues to consider, presents possible solutions and suggests some alternative policy responses that could be considered.

In terms of the schemes' operations, there is a widespread view that significant improvement is needed in a number of aspects.

- **Eligibility:** attention needs to be given to the health conditions and health care services for which assistance is available, the circumstances under which people are eligible, and the extent of support provided. Regulations on these matters need to be transparent and defensible, and include provision for local discretion where unusual or unforeseen circumstances warrant it.
- **Access:** there should be equivalent or even uniform accessibility provisions across all jurisdictions, with eligibility widely promoted, so that those who are eligible for support gain optimum service and benefit from the scheme and thus from the health care they require.

- **Safety:** the schemes should allow eligible patients to travel to and from the place of care delivery, receive their care and, where necessary, be accommodated without delay or unnecessary duress. This is an issue of particular significance for many Aboriginal and Torres Strait Islander people, whose arrangements require special attention. Consideration of an escort in order to ensure safe travel and return is essential. Similarly, maternal and child safety requirements for many people living in remote areas require them to move to be near a suitable birthing service for a period of about six weeks prior to the birth. This is especially difficult for Aboriginal and Torres Strait Islander people living in remote communities, and is addressed in our position paper ‘Principles for maternity services in rural and remote Australia’, pp 9-10. Essentially, patient safety for all people needing the scheme must be assured.
- **Financing:** the levels of patient travel and accommodation assistance do not match patients’ needs under contemporary health care protocols, in particular for complex and chronic conditions such as cancer. The schemes are almost certainly under-funded at both the patient and service levels, with reimbursements for travel and accommodation being far less than, for example, gazetted rates for government department employees or politicians. At the administrative level, there is generally inadequate patient support and guidance available during the patient’s care pathway, and data collection for service and system evaluation. Furthermore, the schemes generally do not ‘compensate’ adequately for the mal-distribution of the health workforce and health services. Nor are they designed for certain 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.

In terms of administration, several areas need development:

- **Administrative governance:** the schemes should be better integrated into the health system at both the financial and patient continuum of care levels. Financial expenditure for patient travel and accommodation should be accounted for within the referring health service’s financial system and budget. Health care provision – the continuum of care – for any individual patient, where shared or delegated between two distant health services and requiring patient travel assistance, should be regarded as an episode of care with respect to patient safety and cost of care. There is a need for better integration of travel schemes within patient care provision, and at the same time, 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.
- **Risk management:** there is a need for adequate administrative support to allow risk management, including that eligible patients receive relief, the patient journey is safe for those who access the system, and that adverse outcomes are monitored and analysed with efforts made to reduce the likelihood and severity of recurrence.

- **Performance monitoring and feedback:** a commonly reported complaint is that eligibility and access decisions are dependent on referring clinicians and, generally, junior administrative staff. A common consumer view is that significant arbitrariness in decisions about eligibility to the schemes' support exists, and that receipt of entitlement often requires repeated follow-up by the patient. Treating doctors, although generally strong advocates for their patients, are often busy in their own practice with direct patient care and not familiar with scheme administration. These factors suggest that a patient advocate function, whether or not within the schemes or external to them, should at least be considered as an improvement measure. Beyond this, reporting on scheme performance will encompass governance and risk management and contribute to improved operation. An integrated approach should include data collection through health services, patient/consumer advocacy groups, health ombudsmen and complaints instruments, regional health advisory councils and the collection and reporting of relevant financial information. Use of ambulance and other patient transport service utilisation should be included where relevant (for example, Royal Flying Doctor Service). Careful analysis and interpretation of this information would identify ways to control loss, which includes direct financial loss (missed journeys, repeat journeys for follow-up appointments not kept etc) and from sub-optimal health care delivery (courses of care not completed, follow-up appointments not made etc). Opportunities to reduce patient risk; and for improvements in patient care and system management would be realised.
- **Continuous improvement:** system improvements would occur if the environment suggested in the preceding points was created.

The place of private health insurance (PHI) entitlement and the Medicare safety net arrangements should be considered with respect to people living in rural, regional and remote Australia. In the case of PHI, there is unpublished evidence that the rate of uptake by rural people is similar to that for urban people. However, for rural people the benefits are generally less accessible, and the drivers for retaining PHI perhaps more related to 'Lifetime Cover' incentives than perceived benefit or need. Rural people in general have fewer direct benefits from holding private health insurance.

With regard to the Medicare Safety Net, specified travel and accommodation costs, where otherwise borne directly by the rural patient in the first instance, could be included as a relevant expense under safety net provisions. Consideration of these parallel financing arrangements would reflect the higher costs of care for rural people and possibly include better accountability measures than those within the existing arrangements.

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.

Healthy Horizons, the rural health improvement framework, could incorporate reference to patient travel and accommodation arrangements as an essential rural

health determinant. Healthy Horizons is due for evaluation and revision during 2007, which might prove timely with the release of the report of the current Inquiry into Patient Travel Assistance Schemes. Progress reports for Healthy Horizons would capture relevant performance data (see Healthy Horizons section on page 8 of this submission for further detail).

A patient in need of health care is generally both under significant personal stress and with limited control over decisions and direction for care. Further, for rural people, choice is often more limited than for urban people. A realisation that necessary care may require significant travel away from one's own home, family and community is yet another distressing prospect. For these reasons, for rural people, patient travel accommodation and assistance schemes must be designed and operate with minimal additional impost on the patient and their family. As far as possible the schemes should function as seamlessly as practicable in contributing to optimal health care for rural Australians.

We are conscious of the potential political sensitivity relating to action on schemes which are managed by the States and Territories, following from your national inquiry. The Alliance has two thoughts on this matter. First, the Australian Government Department of Health and Ageing's 'Rural Health Strategy' would be a suitable program through which Australian Government funding could support better arrangements in patient assisted travel schemes. Secondly, we believe that the next round of Australian Health Care Agreements offers a vehicle which might be used to tie the Commonwealth and States, in a collaborative fashion, on arrangements they might make for such schemes.

We look forward to the prospect of presenting evidence to the committee of inquiry and wish the committee all the best for this important and complex task.

Yours sincerely

Gordon Gregory
Executive Director
Att.

SPECIFIC ISSUES

Cross cultural access and safety

The NRHA notes that improvement of patient travel and accommodation schemes (the schemes) with respect to Aboriginal and Torres Strait Islander people is a particular priority. 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. This deficit probably exists for many rural people from a non-English speaking background, not just for Aboriginal and Torres Strait Islander people, and is applicable for residents of the nation's islands and island territories as well as mainland residents.

Complex, chronic, enduring and progressive illnesses

In general the schemes were not introduced and have not evolved in such a way as to provide travel or accommodation suitable for contemporary management of certain cancers. 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.

Similar inadequacies can be identified for other severe, progressive or life threatening chronic diseases, including progressive renal failure which extends to the need for renal dialysis.

Coordinated care for complex conditions

Although health service providers will generally make every effort to enable coordinated care to occur efficiently and effectively for rural people, ineligibility for and poor access to travel schemes are barriers to fair and reasonable coordinated care. This may not be a direct fault of the scheme, but result from other limitations in health care provision.

GENERAL ISSUES

Health outcomes are poorer for rural people

Our submission is made in recognition of the fact that health outcomes for rural people are inferior to those of their city colleagues. In particular survival measures for cardiovascular disease and cancer are poorer. Lack of access to suitable travel and accommodation support probably contributes to delayed diagnosis, incomplete course of care and inadequate follow-up, all of which impact on survival rates.

Cost of care and income differential

Personal income levels are lower for rural people in comparison with their city colleagues. Relative health care costs are therefore higher, and this difference is exacerbated where non-refunded travel and accommodation are needed to enable diagnosis, management or completion of a course of care, and these costs are borne in part or full by the rural patient.

Levels of reimbursement

In general, levels of reimbursement for travel and accommodation are both inadequate and without consistency across jurisdictions. While rural people often rely on social and family networks to access health care services distant from their home, not all have this opportunity. Realistic cover for travel and accommodation costs will contribute to improved compliance with treatment, increased treatment benefit and improved health service efficiency.

Place of carers

Some patients will need a carer to accompany them when travel to a distant health service is required. This may be necessary due to incapacitation caused by their condition, other burdens of their condition or its treatment, cultural or linguistic background or the need for child care. This matter is a point of significant concern for patients, carers, referring and treating clinicians and scheme administrators. Consistency between schemes and a scheme improvement framework would help identify relevant service failures and means of improvement.

Alternative financing arrangements

The NRHA notes that expenditures for patient travel and accommodation assistance, where eligible, should be better integrated into the cost of care financing and acquittal. However, alternatives for particular circumstances should be considered.

- Under private health insurance, eligibility for reimbursement of specific travel and accommodation costs could be considered for rural people.
- The Medicare safety net could be expanded to cover travel for eligible treatments, courses of care or diagnostic tests for rural people.

Clearly, benefit would need to be assigned and accessible from one source only. It is beyond the capacity of the National Rural Health Alliance to establish the feasibility of such arrangements.

- 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.

SCHEMES' PERFORMANCE

Health Ministers' Council

Consistent eligibility, access and rebate levels, and reporting on targets and performance indicators should be developed through the Australian Health Ministers' Council.

Australian Health Care Agreements

For rural Australians, travel and non-inpatient accommodation some distance from home may be necessary for equitable access to a standard of care comparable to that available to urban people. 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.

Healthy Horizons

Healthy Horizons establishes the framework for improving the health of rural, regional and remote Australians. Healthy Horizons 2003 – 2007 is now due for review and succession. Patient travel and accommodation arrangements fit naturally within goals 2, 4 and 6, addressing health improvement for Aboriginal and Torres Strait Islander people, developing flexible and coordinated services, and developing needs-based flexible funding arrangements respectively. Summary level reporting in progress reports made against the Healthy Horizons framework could reflect rural people's improved access to safe and quality care through the schemes.

MISCELLANEOUS

Patient travel and accommodation assistance should be exposed to the quality improvement process, including health service accreditation surveys. The Alliance understands that these schemes generally fall outside the accreditation surveys of health care services. This is a notable limitation.

As noted elsewhere, support for patient travel and accommodation should be recognised as an essential part of delivering best practice care to rural people. It is neither a luxury nor an add-on to rural health service.

The use of private vehicles for patient transport, whether belonging to the patient/family or to a volunteer, friend or community member seems to be common in some areas. These arrangements should not be seen as alternative to the basic obligations of health care providers. Although they possibly provide some degree of flexibility, choice and comfort to the patient, there is the risk of responsibility for patient safety in the course of their care to be diffused. Where responsibility and liability are diffused, this needs to be clear to all parties. Where patients exercise a choice as described here, this should not necessarily negate entitlement to reimbursement of expenses.

In October 2006, the NRHA convened a public forum in Canberra addressing the matter of patient travel and accommodation assistance schemes. Presentations and transcripts from keynote speakers, which do not form a part of this submission

directly, can be accessed at the 'October 2006' link under the 'PUBLIC SEMINARS' heading at www.ruralhealth.org.au.

The 9th National Rural Health Conference was held in March 2007. An essential part of that conference is to invite recommendations from participants, to collate all received, and to create a set of priority recommendations published as part of the final conference communiqué. The full and priority lists are available at www.ruralhealth.org.au under the 9th National Rural Health Conference banner. Other than those reproduced below, they do not form part of this submission but they are available in the public domain. From the conference, nine recommendations addressing patient travel and accommodation assistance schemes were received. Of the 18 priority recommendations, two address patient travel and accommodation issues. These are reproduced here.

Recommendation 9

The Commonwealth Government and the State and Territory Governments should support, through COAG, a regional cancer care reform program built around cancer centres of excellence in larger rural centres. These would significantly reduce the distance travelled by isolated patients and have spin-off benefits in other areas of rural/remote healthcare. Remote patients would be further supported through improved funding and coordination of patient travel and assistance schemes (see 14).

Recommendation 14

The Commonwealth Government should exercise leadership, including through a national inquiry, to develop more uniform and better funded patients' assisted travel schemes (PATS) in all jurisdictions. A rigorous, fully funded system designed to achieve cross-border equity and improved patient outcomes should be written into the Australian Health Care Agreements for endorsement of all jurisdictions.

BRIEF STATEMENTS ADDRESSING THE COMMITTEE'S TERMS OF REFERENCE

- 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.

There is a need for uniform national consistency or equivalence between State and Territory schemes. This should have the effect of bringing all schemes to a standard to provide equitable access to care and best practice, and not diminishing access to the level of the lowest common denominator. In many instances, patients have little choice of destination for care. Where it becomes necessary to receive care in a State or Territory other than where the patient lives, confusion and distress often result, and this applies both to the patient and the health service employee/s responsible for the travel or accommodation arrangements.

Where assisted patient travel results in treatment services being provided in a State or Territory other than where the patient resides, funding responsibilities for all necessary travel need to be determined in order that patient care is not compromised by disputes between jurisdictions over liability for expensive transport and/or accommodation costs.

- b) The need for national minimum standards to improve flexibility for rural patient access to specialist health services throughout Australia

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.

- 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.

Efficiencies in service delivery could be anticipated through better and consistent scheme governance. For example, the whole of the Kimberley (Western Australia) population is geographically closer to Darwin than to Perth. Likewise, both areas enjoy a tropical climate and possibly a similar population health profile. Transport links are well established. It is possible that certain conditions would be more frequently managed in Darwin than in Perth, and that greater capacity exists for their comprehensive care. Similar cross-border efficiencies are likely in other parts of rural Australia, and there might be cost and outcome benefits if these are identified. The opportunity for superior care for certain low prevalence conditions and in a closer centre of excellence would result in cost savings.

- 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.

The NRHA strongly supports this direction of inquiry in terms of scheme utilisation and further detail is provided on page 2 and on page 3 of this submission under the broad areas of scheme operation and scheme administration. With respect to marketing, it is important that all reasonable means are utilised to inform consumers, carers and citizens as to the eligibility, access and entitlement arrangements; and about complaints and appeals protocols.

- 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.

The NRHA strongly supports this direction of inquiry. As detailed in the section on complex and chronic or enduring illnesses on page 6, receipt of care for certain cancers possibly exemplifies the limitations of existing schemes, identifies the hardships that many rural people in this situation would experience and perhaps explains in part the differential health outcomes between rural and urban residents.

- 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.

The NRHA's vision is for equivalent health and wellbeing in rural, regional and remote Australia by 2020. Health outcomes for rural Australians are currently inferior to those of urban people. As a general principle, rural people should be able to access health care in a manner comparable to urban people, and with minimal additional financial disadvantage. They should be able to access second opinions and coordinated care from a multidisciplinary team.

- g) The relationship between initiatives in e Health and Patient Assisted Travel Schemes.

There is need for significant infrastructure development and health system reform before e-health developments will extend widespread benefit and health care efficacy to people living in rural and, more importantly, remote settings. There is little doubt that benefits could be gained from investment and reform in this area, reducing the consumer and system imposts including from patient travel and accommodation assistance 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.

The urban bias of health workforce distribution means that for many rural people, access to enhanced primary care services is limited or denied. Cost burdens on schemes and patients mean that those treatments or interventions with a strong evidence base of demonstrated benefit are those for which resources should be allocated. The extra costs on travel assistance schemes of extending support to enable access to all treatments listed on the Medicare Benefits Schedule would need to be established.

- i) The role of charity and non-profit organisations in the provision of travel and accommodation assistance to patients.

The NRHA acknowledges the essential role filled by charities and non-profit organisations in the area of patient travel and accommodation assistance. A strategic approach in this area could extend and diversify their role and bring benefit for rural people needing city-based services. For example, organisations with a disease-specific focus could work in the community to broker alternate transport and residential accommodation that is close to a relevant centre, on behalf of patients and carers. The Alliance understands that this happens to a limited extent in some places. This approach should be used to enhance services and improve patient choice and not to cover gaps in essential care. The organisations, volunteers and benevolent providers would need suitable preparation including public liability cover for such activities to be considered.

APPENDIX 1 – MEMBER BODIES OF THE NATIONAL RURAL HEALTH ALLIANCE

ACHSE	Australian College of Health Service Executives (rural members)
ACRRM	Australian College of Rural and Remote Medicine
AGPN	Rural Sub-Committee of the Australian General Practice Network
AHA (RPG)	Rural Policy Group of the Australian Healthcare Association
AHPARR	Allied Health Professions Australia Rural and Remote
AIDA	Australian Indigenous Doctors' Association of Australia
ANF	Australian Nursing Federation (rural members)
APA (RMN)	Australian Physiotherapy Association Rural Member Network
ARHEN	Australian Rural Health Education Network Limited
ARNM	Australian Rural Nurses and Midwives
ARRWAG	Australian Rural and Remote Workforce Agencies Group
CAA (RRG)	Council of Ambulance Authorities - Rural and Remote Group
CRANA	Council of Remote Area Nurses of Australia Inc
CRHF	Catholic Rural Hospitals Forum of Catholic Health of Australia
CWAA	Country Women's Association of Australia
FS	Frontier Services of the Uniting Church in Australia
HCRRRA	Health Consumers of Rural and Remote Australia
ICPA	Isolated Children's Parents' Association
NACCHO	National Aboriginal Community Controlled Health Organisation
NRHN	National Rural Health Network
RACGP (NRF)	Royal Australian College of General Practitioners (National Rural Faculty)
RDAA	Rural Doctors' Association of Australia
RDN	Rural Dentists Network of the Australian Dental Association
RFDS	Australian Council of the Royal Flying Doctor Service of Australia
RGPS	Regional and General Paediatric Society
RPA	Rural Pharmacists Australia - Rural Interest Group of the Pharmacy Guild of Australia, the Pharmaceutical Society of Australia and the Society of Hospital Pharmacists of Australia
SARRAH	Services for Australian Rural and Remote Allied Health