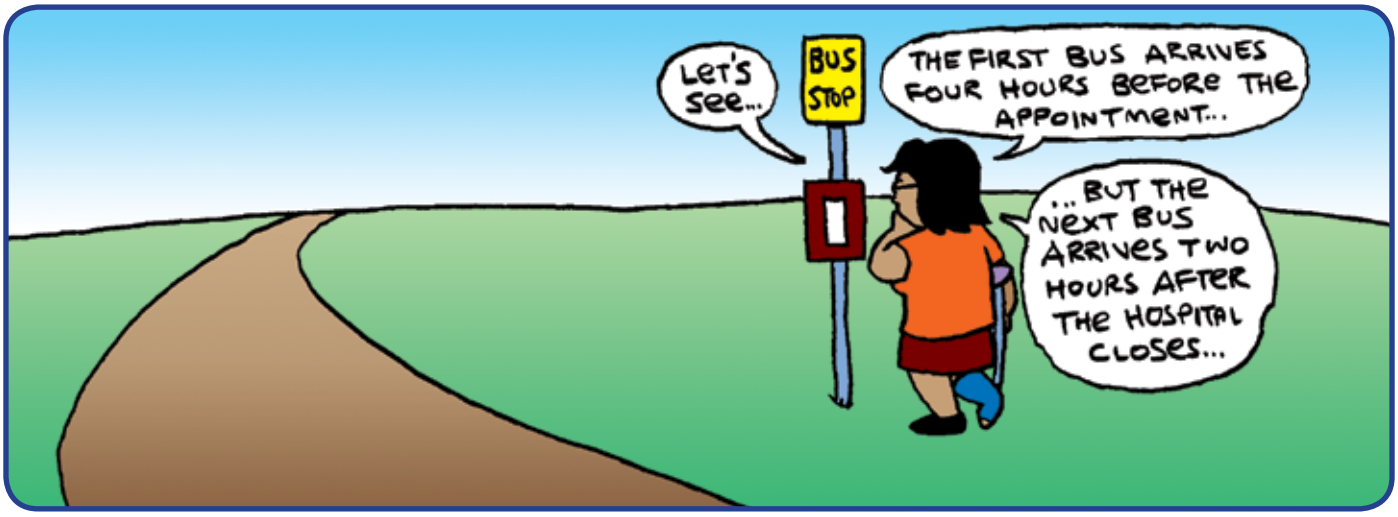
Provided there's Transport:

Transport as a barrier to accessing health care in NSW



NCOSS
COUNCIL OF SOCIAL SERVICE OF NEW SOUTH WALES

The Council of Social Service of New South Wales (NCOSS) is the peak body for the social and community services sector in New South Wales. NCOSS works with its membership on behalf of disadvantaged people and communities towards achieving social justice in New South Wales.

NCOSS was established in 1935 to promote cooperation in the provision of community services and influence social legislation. Today our constituents are:

- disadvantaged and low income people and communities in NSW
- our members
- other peak community service agencies in NSW
- service providers
- other agencies working in the social policy and social services field
- individual members interested in social policy and social service issues .

NCOSS provides an independent voice on welfare policy issues and social and economic reforms and is the major co-ordinator for non-government social and community services in NSW.

We act as a channel for consultation with government and between parts of the non-government sector with common interests and diverse functions.

NCOSS is a membership organisation. Members range from the smallest community services to the largest major welfare agencies, state and regional level peak councils, churches, hospitals, local government and consumer groups.

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Executive Summary

Transport plays a vital role in enabling access healthcare. Yet for many people, it is a major barrier; impacting their ability to receive the health care they need.

Over the last decade and a half, the lack of support for health transport has been regularly identified as a significant gap in the health system. It is of particular concern to the community services sector working on behalf of people experiencing disadvantage in NSW, and for organisations supporting people with chronic illness.

There have been many efforts to tackle transport as a barrier to accessing health services and in 2006, the development of NSW Health's *Transport for Health Policy*[1] was considered an overdue, but significant step forward. Disappointingly, however, many elements of the policy were implemented poorly, if at all.

In 2012, following consistent reports from the social and community services sector highlighting health transport as an ongoing and growing concern, NCOSS hosted two health transport workshops in Sydney and Lismore to examine the current state of play. Attended by representatives from health services, government departments, community transport groups, and other non-government organisations, these workshops confirmed that for the people who most need transport assistance, there has been little real change.

Participants expressed frustration at the lack of support for health transport and concern over a widening gap. Funding for health transport has failed to keep pace with demographic changes, and transport needs continue to be largely ignored in the delivery of health services.

Many of those people and organisations involved in the workshops have made significant contributions to the delivery of health transport services in their local areas. Yet they feel they are fighting an uphill battle. While successful initiatives were identified across NSW, it became clear that too often they rest on the passion and commitment of an individual, and are not adequately supported by Government policies, structures and resources.

This report documents the issues raised during these workshops and draws on the existing literature to demonstrate that the key issues relating to health transport have not been addressed, and provides recommendations towards a more efficient and equitable health transport system.

We hope that this report will act as a catalyst for action; that the NSW Government will take this opportunity to work in partnership with the community services sector and other stakeholders to build a better system; and that individuals and organisations will find it a useful resource as they continue to advocate for improvements.

Acknowledgements

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The Lismore workshop was run in partnership with the Northern Rivers Social Development Council. NCOSS would like to thank Kate Geary from NRSDC for her role in organising this workshop with support from Linda Wirf and Linda Mills. We greatly appreciate their contribution, and the contribution of the presenters at this workshop: Phil Barron from Tweed Byron & Ballina Community Transport, Amanda Lucantonio, North Coast shuttle, Judy Kolesnyk and Julie Dodds from the Northern NSW Local Health District, and Steve Blunden and Steve Terrey from Casino Aboriginal Medical Service.

We would also like to thank everyone who attended the two workshops, and the many others who took the time to share their knowledge and experience with the intent of contributing to a more equitable and accessible health transport system.

This report has been endorsed by the following organisations:

Summary of Recommendations

1 The 2006 *Transport for Health Policy* should be immediately reviewed and a revised policy developed. This process should occur in close consultation with community groups and consumer representatives.

2 The NSW Government should clearly define policy and funding responsibilities in relation to health transport.

3 Adequately staffed and resourced Health Transport Units and Health Transport Networks should be established or maintained in each Local Health District.

4 Local Health Districts, through their Health Transport Units and Population Health and Planning Units, should work with Medicare Locals to undertake joint planning on the health transport needs of the local community and develop coordinated responses across the full range of transport options.

5 Health Transport Units as a central point of contact for consumers should be well-promoted, with contact details published on Local Health District websites, in consumer information materials and at appointment booking desks.

6 Health Transport Units should be responsible for developing and disseminating easily accessible information resources on health transport and affordable accommodation close to major health facilities.

7 The NSW Government should, as a matter of urgency, increase funding for non-emergency health related transport. Where the need for health transport is met by community transport providers, adequate funding should be allocated for this purpose to ensure other transport needs are not compromised.

8 NSW Health and Local Health Districts should work with transport providers to develop more systematic funding processes and simplify current funding arrangements.

9 Transport needs should be considered during the development of all public health services and programs and funding provided accordingly.

10 Processes should be developed to support health staff to routinely consider health consumer transport needs when booking appointments.

11 The block booking of health consumers travelling from one location to the same health service should be facilitated, with adequate resources allocated to implement these processes.

12 Local Health Districts should develop car-parking policies that ensure easy access for people likely to experience transport disadvantage (particularly patients requiring treatment for chronic illness) and for community transport providers.

13 Health transport stakeholders should be consulted during the building or redevelopment of health facilities to ensure proper consideration of transport needs.

14 Designated drop-off zones for community transport vehicles and other non-emergency transport vehicles should be established near the entrance of every major health facility in NSW.

15 Transit lounges should be established at every major health facility in NSW.

16 The NSW Health *Care Coordination Policy* and associated materials should be amended to ensure transport is considered early in transfer of care planning process; embed transport as a consideration of risk; and improve communication with transport providers. No patient should be discharged without ensuring appropriate transport is available.

17 Fitness to Travel certificates should be implemented on a broader scale, with their roll-out facilitated by NSW Health and Local Health Districts.

18 Aboriginal people, communities and services should be actively engaged as partners in the planning and delivery of all health transport services.

19 An Aboriginal Health Transport strategy should be developed in partnership with Aboriginal people. This strategy should allow for a more flexible approach that recognises Aboriginal concepts of health and wellbeing, and should include the identification of strategies to ensure equitable access to IPTAAS.

Section 1: Introduction

This report documents major current and ongoing issues affecting the health transport system, and makes recommendations to address these issues. It draws on the findings from the 2012 Health Transport Workshops (described in more detail below), which provided an opportunity for stakeholders to discuss issues relating to health transport, and to examine the problems, and potential solutions, from a range of perspectives.

The workshops clearly demonstrated that significant change is required to improve the delivery of health transport services.

The evidence gathered confirmed many of the findings of previous investigations into the delivery of health transport services. This report also draws on this earlier work, particularly the 2001 report[2] that informed the development of the 2006 Health Transport Policy, and the 2007 *No Transport, No Treatment* report published by Cancer Council NSW, the Community Transport Organisation (CTO) and the Council of Social Service of NSW (NCOSS).[3]

The first section of this report provides background information on current health transport services and on the 2012 Health Transport Workshops. The second section outlines the role of transport in ensuring equity of access to health care. The following sections (three - six) each address specific health transport issues that were the focus of discussion at the 2012 workshops. The relevance of the issues raised in relation to Aboriginal people is considered throughout the report. Given the extent of transport disadvantage experienced by Aboriginal people, and the importance of access to health care in closing the gap in health outcomes, an Aboriginal perspective is given further attention in the final section of this report.

1.1 Current transport to health services

NSW Health currently provides some assistance to support people who are travelling to access health services. Table 1 summarises the types of transport that people might use to access services, and the way in which NSW Health may provide funding support for these transport services.

A large proportion of transport assistance is provided through the Health Transport Program, which includes the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS), the Health Related Transport Program (HRTP), Inter-facility transport (non-Ambulance), and the Statewide Infant Screening-Hearing Program (SWISH).

Table 1: Non-Emergency Health Related Transport

Transport Service	Health System Involvement
Public Transport Private Transport	Eligible patients travelling in private vehicles or in public transport can apply for subsidies for travel to health services through the Isolated Patients Transport and Accommodation Assistance Scheme.
Community Transport	Some community transport providers receive grant funding to provide health transport services. The Local Health District may also broker community transport services.
Other NGO-based transport services	Many small NGO-based transport services provide transport to treatment to address specific needs within the community.
Health Transport Services (vehicles operated by the health service)	A health service may directly operate non-emergency health transport services.
Taxis	Both health services and community transport providers may distribute taxi vouchers to assist with transport to or from health appointments.
Ambulance Services	In some cases ambulances may provide non-emergency health related travel.

The IPTAAS scheme, which subsidises travel via public or private transport for people required to travel long distances to specialist appointments, accounts for the majority of funding allocated to the Health Transport Program. Following the 2011 State election, the NSW Government made some welcome changes to this scheme including increasing the available funding, expanding the eligibility criteria and streamlining the administrative requirements.

However, there remains a significant gap in assistance for people who do not have access to public or private transport, and who are therefore unable to benefit from this scheme. While this report touches on issues related to transport to health services that affect people who are able to catch public transport or have access to a private vehicle, its primary focus is on those people for whom these forms of transport are not an option – either because they are unaffordable, inaccessible, or are culturally inappropriate. For this reason this report has been prepared in close consultation with the community transport sector, who provide transport for many people who have no other transport alternatives.

1.2 The 2006 Transport for Health Policy

In 2001, following extensive advocacy on health transport issues, the NSW Health Department commissioned a report on health transport issues, and conducted extensive consultation with the sector. Eventually, these activities led to the development of the 2006 *Transport for Health Policy*,[4] which integrated all non-emergency health-related transport service provision into one program. The policy recognised that NSW Health is a major generator of demand for passenger transport and aimed to assist NSW Health to simplify and improve patient access to health services including by:

- Responding to the health transport needs of patients in a consistent, strategic and efficient manner,
- Developing and maintaining effective working partnerships with transport providers and stakeholders,
- Facilitating recognition and consideration of the role and importance of health transport in service planning and delivery within the New South Wales health system.

Significant elements of the policy framework included:

- The establishment of Health Transport Units as a central point of contact within each Area Health Service (now Local Health District),
- The establishment of Health Transport Networks to provide a formal channel of communication with health transport stakeholders in order to achieve better collaboration in the planning and provision of improved patient transport solutions,
- The development, implementation and monitoring of Transport for Health Implementation Plans.

David's Story

David lives in Batemans Bay and travels to Moruya to undergo dialysis three times per week: a round trip of over 50kms. Being legally blind and a dual amputee below the knee, David relies on family to transport him each way. In order to reduce the burden on his family, David investigated other ways to get to the unit and tried everything from local buses to taxis.

A local bus did service his area, but the only option was to leave home at 9.00am and change buses before continuing the rest of the way. The bus (when on time) would arrive at Moruya hospital at 2.25pm. With the need to dialyse for 5 hours each session and the unit closing at 7pm, this would leave David a little short of time.

While taxis were available to do the trip to Moruya, the fare one-way would cost an average of $75. Even with a taxi voucher, David would be out of pocket around $70 per day. If he used a taxi for the three required return trips each week it would cost around $450.

David also looked into the volunteer run Euro-transport service. However, this would not provide transport home due to possible medical problems.

In the end, David travelled to and from Moruya three times per week at his expense. This issue has been current for many years and has shown no signs of improving. David knows many other patients in his area who have been similarly affected.

Despite initially being lauded as a much-welcomed and much-needed advance, more recent reports suggested that implementation of the Transport for Health policy had been less than successful. With the policy due for review by the end of 2012, the Health Transport workshops provided an opportunity to gain an initial understanding of the success or otherwise of the *Transport for Health Policy*. During the course of developing this report it became clear that many stakeholders believe the policy has resulted in little change: the same issues that prompted action over a decade ago are still a concern today.

Recommendation 1: The 2006 *Transport for Health Policy* should be immediately reviewed and a revised policy developed. This process should occur in close consultation with community groups and consumer representatives.

1.3 The 2012 Health Transport Workshops

In 2012, NCOSS hosted two Health Transport Workshops: one in Sydney and one in Lismore. Although other stakeholders expressed an interest in attending workshops in their local area, the number of workshops was limited to two due to resource constraints.

Prior to each workshop, participants were asked to critically examine the health transport system in their local area and to prepare examples of ongoing issues and/or examples of good practice initiatives implemented in their local area. Examination of these initiatives during the workshop helped to identify where they could be applied more broadly to improve the efficacy of the health transport system.

Each workshop was structured around a number of themes. These included coordination; funding; appointment scheduling; drop-offs, pick-ups and parking; transfer of care (discharge); and Aboriginal health transport. For each of these themes an introductory presentation or case study was provided, followed by small group discussion drawing on participants' experiences with the health transport system in their local area. The outcomes of these discussions were documented and have been outlined in this report.

1.4 Defining Health Transport

There is no clear definition of health transport, and this has contributed to misunderstandings about what might be classified as a health transport trip.

This report focuses on transport from a person's home to a health service. It does not address transport between health facilities. It concentrates on transport to those health services provided by Local Health Districts or directly funded by NSW Health. We note, however, that this definition can be problematic; and that some groups have a broader understanding of what might constitute health transport.

Section 2: Health Transport and Health Inequality

Ensuring equity of access to health services has been an important policy goal in NSW and Australia. Overcoming barriers to timely access to care is particularly important in closing the gap in health outcomes for Aboriginal people and for people living in rural and regional areas.

Yet one major barrier to access has been largely overlooked: transport.

The best health services and most advanced clinical care cannot be effective if people are not able to get to them. A lack of transport reduces the likelihood that people will access preventative treatment, receive effective care, or be diagnosed early.

Those people most likely to experience difficulties travelling to and from health facilities are those who also experience socioeconomic and health disadvantage. The 2012 workshops also identified a range of transport issues unique to rural and regional communities, where long distances and poor public transport infrastructure compounds existing transport disadvantage.

2.1 Who is missing out?

People in rural and regional areas

People living in rural, regional and remote Australia have lower life expectancy than people in metropolitan areas.[5] They also have higher reported rates of only fair or poor health and higher rates of injury and disability.[6]

Evidence from the workshops confirmed that the centralisation of services has exacerbated the difficulties people in rural or regional areas experience when travelling to health services. A visit to a medical specialist may require travelling hundreds of kilometres: For many this is prohibitive. Long distance travel is particularly problematic for people who require frequent treatment such as chemotherapy or dialysis. During the workshops, some service providers reported cases in which people had been forced to move in order to access treatment as there were simply no appropriate or accessible travel options to meet their needs.[7]

Aboriginal people

Aboriginal people in NSW have a life expectancy at birth of between 9 and 10 years less than the general population.[8] Aboriginal people also experience a higher burden of disease (largely due to preventable diseases such as cardiovascular disease, type 2 diabetes, mental disorders, chronic respiratory disease and cancer) and are 1.7 times more likely to be hospitalised.[9]

Transport to health services presents particular difficulties for many Aboriginal people due to low levels of car ownership, and difficulties obtaining licences. Nationally, more than one quarter of Aboriginal people cannot access a vehicle when needed.[10]

The high participation of Aboriginal stakeholders in the Lismore workshop reflects the particular problems that Aboriginal people in rural and remote regions experience in accessing health services. A large number of Aboriginal people live in isolated locations or in communities located on the outskirts of town (often the sites of former missions) and must therefore travel further in order to access health services. Yet these areas are often poorly serviced by public transport: In many areas the only form of transport is the school bus. The *Aboriginal People Travelling Well Report* found that:

> 'in rural and remote areas, infrequent or non-existent public transport to major centres may prevent access to tertiary and specialist health services, or inhibit regular treatment and assessment. In this situation, many Aboriginal people go without health services that the majority of Australians see as a right, and those who are assisted to travel to treatment are often left in the major centre with no means of return home'.[11]

Discrimination and a lack of cultural understanding can also make it more difficult for Aboriginal people to use the limited public and community transport services that may be available. Many examples were given in the Lismore workshop to support this finding.

"The best health services and most advanced clinical care cannot be effective if people are not able to get to them."

People on low incomes

For people on low incomes, the cost of transport presents a barrier to accessing health services. When people and families are finding it difficult to cover the cost of housing, food and essential bills, the additional costs associated with travelling to and from a health service may simply be unaffordable, resulting in missed or delayed appointments.

People with disability

The transport choices for many people with disability are limited, particularly for those people who are unable to drive, and who find travelling on public transport difficult or impossible. Research has found that people with disability face greater barriers in accessing health care than people without disability.[12] Many people with disability must also travel more frequently to health appointments, and may therefore experience difficulties with access on a more regular basis.

The number of people with disability is rising, with the growth rate in the population with severe or profound disability expected to outstrip the (general) population growth rate by two to three times over the next 70 years.[13]

Older people

A growing number of older people are no longer able to drive – particularly when they are unwell. In many cases public transport is not a viable alternative due to limited mobility, the distances to the nearest stop or station, and poorly timed services.

Thus at a time in their lives when people are likely to require additional health care services, transport options may be severely curtailed. A recent review of international research found that a lack of transport has the potential to negatively influence the ability of older adults to access a variety of health services.[14]

While a large number of older people rely on family or friends for transport, in many cases this may not be an option. Additionally, some service providers expressed concern that older people may be choosing to miss appointments rather than risk burning out their social networks. Some older people may be eligible for transport through the Home and Community Care program, yet many others fall outside the eligibility criteria for this program. As such, older people can find themselves in a position where they simply have no transport choices.

As the population ages, so too will the number of older people requiring assistance in order to access health services. The number of people aged 65 years and over in NSW is projected to double to nearly 2 million people by 2036, at the same time as the number of people providing informal care (including transport assistance) is expected to decline.[15]

Centralising services

Decisions to open or close a service can have a huge impact on health transport needs. For example, the closure of a dialysis chair may result in savings to the health system, but can have a significant impact on transport, forcing people to travel much further for treatment. This can give rise to greater inequities, as some people do not have access to transport, or cannot afford the transport options that may be available.

For this reason, transport needs should be taken into considering during health planning processes. When decisions are made to withdraw or centralise services, transport costs should be considered and factored into decision-making processes as a matter of routine.

Carers

The responsibility for providing transport often falls to carers, particularly when alternative transport options are limited.

In 2009, for example, it was found that approximately 255,800 people with a disability in NSW required assistance with transport, and 82 per cent of this group of people received this assistance from informal carers.[16]

The responsibility for providing transport is a particular issue for working carers whose participation in the workforce may be affected due to the need to provide transport to health appointments during business hours. Long distances and waiting times associated with health appointments can add to the difficulty of balancing work and care obligations.

People with chronic disease

Chronic diseases are prolonged conditions such as diabetes, dementia, cancer, kidney disease, congestive heart failure and asthma, which often require ongoing treatment and may be medically managed but are often not curable. Evidence suggests that transport is a barrier to accessing appropriate treatment for many people with chronic disease[17] while for others the effort required to resolve transport problems adds an additional layer of stress. Research carried out by the NSW Renal Service Network, for example, found that of those people currently undertaking haemodialysis in either a hospital or satellite unit in NSW, about 20% experienced difficulty in coping with the transport burden.[18]

The incidence of chronic disease is increasing, and by 2020 it is expected to account for 80 per cent of the disease burden in Australia.[19]

2.2 Policy responsibility

A lack of clear policy responsibility for transport to health services has contributed to a system in which there are significant gaps. While responsibility for delivering mainstream transport infrastructure and services sits with Transport for NSW, there is a need for supplementary transport services to ensure equity of access to health care. In the same way that responsibility for ensuring disadvantaged students can access transport to school lies with education departments, responsibility for supplementary health transport services should sit within the health portfolio.

The 2006 *Health Transport Policy* recognised that Health services in NSW are major generators of passenger transport demand. Yet when people are injured or unwell, they are often unable to use the transport services that would normally be appropriate.

Changes to the way in which health care is provided – such as the consolidation of health services, the use of day surgery,[20] and moves towards earlier discharges[21] – also have implications for health transport services and have contributed to growth in demand.[22] Yet these impacts are rarely factored into decision-making processes. If NSW Health is not accountable for considering these impacts, there is the danger that emerging needs may fall through the gaps, or that other agencies and services will be impacted as a result (see, for example Section 4.1).

Recommendation 2: The NSW Government should clearly define policy and funding responsibilities in relation to health transport.

"...when people are injured or unwell, they are often unable to use the transport services that would normally be appropriate."

Section 3: Coordinating health transport services

A major criticism of health transport emerging during the 2012 Health Transport Workshops is that the current system is poorly coordinated. This adds to the difficulties many people – particularly those who are marginalised or vulnerable – experience in accessing the support that may be available.

The lack of a systematic approach also means that those resources currently available to support the provision of health transport are not always well-utilised. Workshop discussions identified a number of ways in which the absence of a coordinated approach is hampering efforts towards efficient service delivery. These included resources not being used to capacity; the form of support provided being more expensive than necessary due to a lack of alternatives; and processes that inhibit efficient service delivery.

3.1 Towards a partnership approach

Although the 2006 *Transport for Health Policy* aimed to support Area Health Services (now LHDs) to be more strategic in identifying, consolidating and integrating transport services and resources to increase efficiencies and reduce duplication, it has not been wholly successful.

The policy created two important mechanisms designed to engender greater coordination in the delivery of health transport: Health Transport Units, and Health Transport Networks. Health Transport Units were to be a central point of coordination for health transport services, while Health Transport Networks were to provide a formal channel of communication between Area Health Services and health transport stakeholders.

Workshop outcomes indicate that in some areas these mechanisms have played an important role in facilitating improvements to the delivery of health transport, but that more work is needed. There was a perception amongst stakeholders that in some cases Health Transport Units were not sufficiently staffed or resourced to provide an adequate service. In others, the Units and Networks were never established or were tokenistic and resulted in little real change.

Using existing resources efficiently

Many workshop participants expressed frustration that the current system means that vehicles operated or purchased by different providers may travel similar routes at similar times, yet not be filled to capacity.

Workshop participants also suggested that in the absence of a systematic approach to the delivery of health transport services, more expensive forms of transport are sometimes used where a cheaper alternative would be appropriate. For example, in order to attend a hospital appointment a client may call the ambulance service – one of the most expensive forms of transport – because they are unaware that community transport may be available. Similarly, a client may be allocated a taxi voucher to assist with transport, when this is not the most cost-effective mode.

The 2006 *Transport for Health Policy* aimed to address these problems by providing an opportunity to coordinate transport support internally within the public health system, and to improve coordination both with, and between, external stakeholders.

Where Health Transport Units have taken on the role of booking all transport services provided through the public health system, there have been significant improvements in the coordination of services directly operated or purchased by Local Health Districts. Attempts at coordination have been less successful in taking into consideration the large component of the health transport task falling to external providers. (See box text for an example of a proposal for coordinating internal and external health transport services.)

Despite this, there was strong agreement among workshop participants that NSW Health should continue to support Health Transport Units and Networks. It was recognised that these mechanisms, should they be adequately supported, had the potential to play a more active role in facilitating coordination

"Attempts at coordination have been less successful in taking into consideration the large component of the health transport task falling to external providers. "

Coordinating non-emergency transport

In 2009, a scoping study conducted by Great Community Transport and South West Area Health Service (SWAHS) tested the premise that a coordinated approach to non-emergency transport would be more efficient.

The scoping study involved the simulation of non-emergency transport between patients' homes and SWAHS facilities in the Penrith area over a period of a week – a task currently carried out by three separate fleets: vehicles housed at Nepean Hospital and managed by Health West Transport, vehicles housed at Governor Phillip Hospital and managed by the Day Care team and the Great Community Transport's fleet.

Using Responsive Transport software, the study showed what might be possible should the booking scheduling and coordination functions of both SWAHS and GCT be combined, and the existing fleets of vehicles and drivers treated as one.

The simulation found that significant savings could be made through a more coordinated approach to the provision of non-emergency transport. This included savings of 67 operational hours per week, and a potential reduction in the number of vehicles required to satisfy requested bookings. The average was a reduction of 3 vehicles per day.

The study concluded that a centralised booking and scheduling system should be introduced, with all of the relevant information about where and when patients need to travel managed by one agency. The existing fleets would continue to operate and be housed separately.

While there was some willingness to proceed with these recommendations, management and structural changes within SWAHS meant that a coordinated system did not eventuate.

between external providers. The North Coast Shuttle, for example, was provided as an example of cross-agency collaboration to address a transport need originally identified through the Health Transport Network. The shuttle now provides a joint service, involved three community transport providers, along a strategic transport corridor (Ballina to Brisbane).

The changing landscape of health service provision has created an added impetus to better coordinate the delivery of transport services. In particular, the establishment of Medicare Locals, whose remit it is to improve service coordination and integration to meet local community needs, provides an opportunity for joint planning across different levels of service provision.

Although still relatively new, many Medicare Locals have already identified transport as a major service gap and have found it necessary to either provide or purchase transport services to make it possible for patients to access the services they need. For example, the Closing the Gap Care Coordination program aims to improve health outcomes for Aboriginal people with chronic health conditions through better access to coordinated and multidisciplinary care. Run at 25 Medicare Locals in NSW, the program takes a holistic view of a person's health, with flexible funds available to assist patients as needed. Care coordinators delivering the program have found that arranging transport to enable patients to access services has become a significant part of their core role.[23] The flexibility of the program allows care coordinators to address a broader range of transport needs than those that are the responsibility of Health Transport Units, yet there is some overlap in service provision.

In the future, as Medicare Locals become more fully established there is the potential for them to become important stakeholders in the delivery of health transport services. If this is not carefully managed there is also the potential for further duplication.

Improving communication channels

The need for better communication between health services and transport services also emerged as a common theme during workshops and discussions that informed the development of this report.

Many of the problems transport providers reported encountering when dealing with the health system stem from a lack of awareness. (A number of these problems are documented in more detail in Sections 4 and 5 of this report). This means that processes are often developed and implemented with little consideration for the role of transport in enabling access to health services, and of the broader issues relating to transport disadvantage.

Some organisations reported that the establishment of a strong working relationship with an individual within a health service had meant they were able to improve existing processes. Yet these relationships often represented significant investment on the part of transport services, and were frequently lost due to high staff turnover. It was not always possible to continue or to re-establish a relationship, particularly when there was no central point of contact with responsibility for patient travel.

According to the 2006 *Transport for Health Policy*, Health Transport Units were to maintain Health Transport Networks, with membership including representatives from health services, (including social workers and discharge planners); and transport providers. The Networks were to hold regular meetings, facilitating communication between health and transport stakeholders, and providing a reliable forum in which issues could be raised and addressed.

Recommendation 3: Adequately staffed and resourced Health Transport Units and Health Transport Networks should be maintained or established in each Local Health District.

Recommendation 4: Local Health Districts, through their Health Transport Units and Population Health and Planning Units, should work with Medicare Locals to undertake joint planning on the health transport needs of the local community and develop coordinated responses across the full range of transport options.

3.2 Accessing the system

Many people either do not know they may be eligible for assistance with health transport, or find it difficult to access the relevant information. Investigating health transport options can be both time-consuming and stressful – usually at a time when people are unwell and are not well-placed to cope with additional pressure. As one workshop participant noted, "consumers have to make a number of calls to find out about available transport options and establish their eligibility - they may cancel their appointment as it is just too difficult to find transport". This experience does not appear to be uncommon. While some people may give up and miss out on receiving the help they need, others may delay treatment until absolutely necessary, or may access a service that is inappropriate to their needs. Concerns were raised that those people

Eligibility

The eligibility for the various transport services people may use to access health services is confusing and inconsistent across areas.

Health transport provided through the Local Health District is not available for people who are receiving other forms of assistance – such as packaged care, or transport support provided through the Home and Community Care (HACC) program. The patient contribution for trips varies depending on the program, and some people have difficulty understanding why they are not eligible for what appears to be a less expensive form of transport. In addition, the HACC program does not normally provide transport to address chronic health needs (e.g. dialysis).

Because transport providers do not receive adequate health transport funding they are often forced to 'ration' their services, and the eligibility criteria used to do this varies from provider to provider. For example, some providers will not provide any transport for chemotherapy or dialysis, while others place a cap on the number of trips for which a client is eligible each year. Further complicating the issue, some transport providers may receive a grant to address a particular health need (such as renal transport). Once this money has been allocated, they may not be able to use other funding sources to meet requests for assistance from other clients with the same need.

In some cases a client's health transport needs are met by 'patching' together a number of services – a process that is both time-consuming and stressful.

most likely to miss out are those who are already vulnerable, including Aboriginal and Torres Strait Islander people, the unemployed, and people with disability.

Accessing services is made more complicated by the fact that eligibility criteria for health transport differ between services (see text box *Eligibility*).

While it was intended that Health Transport Units would provide a central point of contact that would assist consumers to navigate the system, reports indicate that these units are not always well promoted, and that many health consumers are unaware of their existence.

Workshop participants also raised the need for easily accessible resources containing detailed information about options for health transport. Participants at the Lismore workshop noted that the availability of affordable overnight accommodation close to major health facilities can significantly increase transport options for regional and remote patients, who may not have public transport available at appropriate times. But even where accommodation is available, health consumers and transport services are often unaware of its existence.

Recommendation 5: Health Transport Units as a central point of contact for consumers should be well-promoted, with contact details published on Local Health District websites, in consumer information materials and at appointment booking desks.

Recommendation 6: Health Transport Units should be responsible for developing and disseminating easily accessible information resources on health transport and affordable accommodation close to major health facilities.

"While some people may give up and miss out on receiving the help they need, others may delay treatment until absolutely necessary..."

Section 4: Funding Health Transport Services

4.1 Funding for non-emergency health transport

In 2012-13, the budget for the NSW Transport for Health Program was $28.2 million. Of this, a significant majority ($19.7 million) was allocated to the Isolated Patient Travel Assistance and Accommodation scheme (IPTAAS). The NSW Budget papers do not report how much of the remaining $8.5 million is allocated to non-emergency health related transport, or of this amount, how much flows to community transport providers.

Our research suggests that in 2010, community transport providers received a total of $4.9 million in grant funding for health transport, and there have been no reports of any increased funding since. In fact, although demand for health transport has more than doubled over the last decade, the funding allocated to non-emergency transport has remained relatively static in real terms aside from a small injection of funds in 2008-09. The distribution of these funds is based on historical arrangements, and those areas that did not receive funding in the initial allocation round continue to miss out.

Although health funding accounts for only a small proportion of the total budget for community transport, health trips are consuming a large and growing proportion of community transport resources. In NSW, the bulk of this funding is received through the Home and Community Care (HACC) Program.[24] The transport services funded through this program should enable older people and people with disability to go shopping, to participate in their communities, and to stay connected to social networks. Yet providers report that attempts to accommodate health transport needs are impacting their ability to deliver the much broader range of social inclusion services for which they primarily funded.

Current demand for health transport now well exceeds available funding. A community transport provider at the Lismore workshop revealed that the funding his organisation spends on health trips is almost double the amount they receive for this purpose. Similarly, the Northern Sydney Region reports that requests for medical trips now account for 70% of all new enquiries, yet there has been no increase in the proportion of health funding received.[25]

In 2007, the *No Transport, No Treatment* report found that NSW Health provides only 10% of the funding for the 680,000 trips provided by community transport providers to health services.[26] This will have long-term social and health implications as people who rely on community transport become increasingly isolated.

Despite the fact that community transport providers are spending more of their budgets on health transport than they are actually funded for, they are still unable to meet demand: the 2007 *No Transport, No Treatment* report also estimated that up to 90,000 requests for transport to health services in NSW are refused each year by community transport providers.[27]

Recommendation 7: The NSW Government should, as a matter of urgency, increase funding for non-emergency health related transport. Where the need for health transport is met by community transport providers, adequate funding should be allocated for this purpose to ensure other transport needs are not compromised.

4.2 Funding agreements

The allocation of health transport funding appears to be ad hoc, making it difficult to gain an understanding of which services are providing what type of transport, and how the system works together as a whole.

Transport providers who are unable to provide a service to a client due to their particular funding agreement will often advocate on a client's behalf and attempt to find the right services for them. The time taken to do this, however, is not acknowledged and is therefore not reflected in funding arrangements.

Providers also reported that although their funding agreements with Local Health Districts might entail relatively small amounts of money, the reporting and auditing requirements were at least as onerous as larger funding agreements.

Recommendation 8: NSW Health and Local Health Districts should work with transport providers to develop more systematic funding processes and simplify current funding arrangements.

4.3 Funding gaps

Overall, the workshops found that health transport is severely under-resourced, contributing to significant inequities in access to health services. While the lack of funding was a concern in relation to all aspects of health, the following were identified as particular gaps:

- Transport for preventative health activities and programs,
- Transport for chronic diseases, particularly for renal dialysis, and chemotherapy and radiation treatment. (Note that transport is identified as an important factor in plans developed by NSW Health to address major chronic diseases such as cancer[28] and kidney failure.[29]),[30]
- Transport for people who fall outside the Home and Community Care eligibility criteria,
- Transport for young adults. This was of particular concern in relation to Aboriginal people,
- Transport for pre- and post-natal care.

The absence of appropriate transport is most likely to impact vulnerable and marginalised groups even when they are the target audience for health promotion or early intervention programs. Representatives from a range of services at the workshops reported that while effective preventative health programs might be available, many of the people at which they were targeted were missing out simply because they were unable to get there. This was a particular concern in relation to Aboriginal people. Workshop participants were especially frustrated by the absence of any transport support that would enable young parents to attend antenatal and early childhood health promotion programs, as it was felt that these would be of significant benefit.

It was agreed that transport should be considered during the development of health services and health programs, with community stakeholders and consumer representatives consulted early in the process.

Recommendation 9: Transport needs should be considered during the development of all public health services and programs and funding provided accordingly.

4.4 Costing the Benefits

Internationally, there is growing recognition that the benefits of providing health transport services may well outweigh the costs.

Analyses of returns on investment have identified two main pathways for cost savings resulting from the provision of non-emergency health transport – reductions in the cost of missed appointments, and the cost savings associated with access to preventative health care or early medical intervention.

The cost of missed appointments

One reason someone may miss an appointment is because they are unable to find suitable transport. In Britain, approximately one in ten hospital appointments are missed, costing the health system millions of pounds.[31] The UK charity Transport for Sick Children estimate that by providing transport to disadvantaged families who would otherwise be unable to attend appointments, there is a saving of £4.3 for every pound spent.[32] This analysis is based on lost costs, such as salary costs, that occur when a patient fails to turn up for a scheduled appointment.

Preventative Care and Early Intervention

Many people delay accessing health care as they do not have access to appropriate or affordable transport. In America, it is estimated that 3.6 million people miss or delay non-emergency health appointments each year due to transport disadvantage.[33]

Many conditions, if not treated early, will later require more intensive interventions. This not only escalates the cost of health care, but is more disruptive and distressing for individuals and their families.

A study of the provision of non-emergency medical transport in America found that for four conditions – prenatal care, asthma, heart disease and diabetes – providing additional non-emergency medical transport is actually cost-saving for the system as a whole. For other conditions, such as cancer screenings, preventative dental care and depression or mental health, investing in additional transport was found to be highly cost effective. This means that improvements in quality of life or life expectancy were sufficient to justify investment.[34]

A return on investment study of Florida Transport Disadvantaged Services similarly found that for every $1 invested in medical trips, $11.08 was saved due to avoided hospital stays. This is based on a conservative estimate that one out of every one hundred medical trips prevents a one-day stay in hospital.[35]

"...there is growing recognition that the benefits of providing health transport services may well outweigh the costs."

Section 5: Appointment scheduling

The time and location of an appointment has a significant impact on both an individual's capacity to travel to and from the appointment, and on a transport provider's ability to provide efficient and effective health transport services.

5.1 Appointment Times and Delays

When a health consumer arranges a health appointment they are not routinely asked about their transport choices or told what their options might be. If they are experiencing transport disadvantage this is not flagged in the system. As a result, appointments may be booked at a time that makes arranging suitable transport difficult. During the workshops this emerged as a significant issue that is largely unrecognised within the health professions. Many health consumers are reluctant to advocate for a more convenient appointment, or may not be aware that this is within their rights. A number of workshop participants cited cases where people were not able to make agreed appointments due to the lack of transport at suitable times, and who consequently missed out on the health care they needed.

For some people, a health appointment that has not been scheduled with due consideration to available transport services, can take hours – or even days – longer than necessary. This is of particular concern for health consumers from rural and regional areas who are often required to travel long distances in order to access health services. For appointments scheduled in the early morning or early evening it is frequently necessary to make an overnight stay close to the health facility, making treatment more stressful and unnecessarily expensive.

Many transport services are unable to assist clients attending early or late appointments due to their limited capacity to operate outside office hours, and due to health and safety risks (particularly for volunteer drivers) associated with driving outside daylight hours.

Appointment scheduling can also have a significant impact on a transport provider's ability to provide effective and efficient transport services. In order to make poorly timed appointments, transport providers are sometimes forced to make unnecessary journeys, or find that they are unable to run services at capacity.

Transport providers reported that significant time is often spent negotiating appointment schedules with health providers so that they are better able to meet the needs of their clients. While this process is resource-intensive, it was seen to result in improved transport outcomes. Negotiation worked best in cases where the health service was cooperative – usually where a strong relationship had been established between the transport provider and the health service. In other cases transport providers found it difficult to reach an appropriate contact within the health service, or found health services unwilling or unable to offer flexibility around appointment times.

Workshop participants agreed that increased awareness of available transport services would enable both health consumers and health staff to better consider transport needs when scheduling appointments. Health Transport Units should be resourced to facilitate the development of processes, guidelines and/or training to increase awareness and consideration of health transport needs, and to support health staff to routinely consider transport needs when booking appointments.

Appointments that are not held at their scheduled time are also problematic from a transport perspective. While it is not always possible to avoid late-running appointments, common appointment booking practices mean that delays may occur routinely, rather than during exceptional circumstances. For example, the practice of booking multiple patients at one time (for example, at the beginning of a morning or afternoon session) can mean that a patient is required to arrive at a treatment centre several hours before they are likely to be seen.

Unpredictability in appointment times can be stressful for patients and their carers, and can also impact transport services. Late-running appointments may mean that a significant amount of a driver's time is spent waiting rather than delivering services to other clients. Where a number of clients are travelling in the same vehicle, delays may also be impact others who are forced to wait to accommodate a late-running appointment.

Some community transport providers – particularly those transporting groups of clients over long distances – have found that actively advocating on behalf of the client on arrival at a clinic increases the likelihood that a client will be seen within a specified time frame.

Recommendation 10: Processes should be developed to support health staff to routinely consider transport needs when booking appointments.

5.2 Block Booking

In cases where a service transports a number of clients to one health service they have been able to negotiate block bookings– enabling consecutive appointments for clients travelling from the same or similar locations. This means they are able to operate more efficiently, as they make fewer journeys carrying more passengers. It also reduces waiting times for community transport clients, who might otherwise be required to wait several hours before a service is able to provide a return journey home.

Block booking is particularly beneficial in cases where regular treatment, such as radiotherapy or dialysis, is required.

Recommendation 11: The block booking of patients travelling from one location to the same health service should be facilitated, with adequate resources allocated to implement these processes.

5.3 Referral pathways

When a GP or specialist refers a health consumer for further treatment, transport needs are not always taken into consideration. As a result, a patient may not be referred to the most conveniently located specialist or treatment centre, with referral pathways often based on historical arrangements or personal connections. This can have significant implications for transport. Health consumers experiencing transport disadvantage are not always empowered to advocate for an alternative option, or may be unaware that other options are available.

"Block booking is particularly beneficial in cases where regular treatment, such as radiotherapy or dialysis, is required."

Section 6: Getting there and getting away

6.1 Parking

Parking at health facilities (particularly hospitals) can pose difficulties for health consumers, their carers, and community transport providers. Issues related to parking at health facilities include a lack of parking spaces, time restrictions, the distance between available parking and the health facility, and the high cost of parking.

A lack of parking spaces close to a health facility may mean that a health consumer is required to walk long distances from their parking to receive treatment. This can be difficult, particularly if a health consumer is older or has a condition that leaves them feeling unwell or weak.

While in some cases it has been possible for advocates to negotiate designated parking areas for health consumers (such as those with chronic illness), this is becoming increasing difficult with a trend towards privately operated parking stations at major health facilities.

Some health facilities do set aside parking spots for patients who are unwell and/or health transport providers. However, dedicated parking spaces are not always enforced, and there is some concern that these spaces are often taken by contractors or hospital staff.[36] Improved enforcement mechanisms or the development of a parking permit system may help ensure that where dedicated parking areas are available, they are used for their intended purpose.

The cost of parking at many health facilities (particularly hospitals) can be very expensive. Patients who are receiving treatment several times a week can find paying for parking a severe financial burden, with costs of up to $20 per hour at some hospitals.[37] This is of particular concern for patients with chronic illness, such as cancer or dialysis patients, who may require treatment several times a week, and their carers.

The cost of parking also affects transport providers, who may have to access the grounds of a hospital multiple times a day, and who are required to pay for parking if they need to leave the vehicle to escort a passenger to an appointment, or to find a passenger on pick-up.

Recommendation 12: Local Health Districts should develop car-parking policies that ensure easy access for people likely to experience transport disadvantage (particularly patients requiring treatment for chronic illness) and for community transport providers.

The Long Road to Park

Cancer patients at Westmead Hospital faced serious parking difficulties despite there being a dedicated parking area for patients and their carers outside the facility. Whilst this free parking area was a good initiative, it was unsupervised and most spots were taken by hospital staff, contractors and other hospital visitors, leaving cancer patients with few options but to park in expensive ticketed parking stations. Patients who could not meet these costs were forced to park a long distance from the treatment centre and faced a lengthy and difficult walk to and from the car - including when feeling unwell or weak following treatment.

The Western Sydney Cancer Advocacy Network (WSCAN) identified the difficulties cancer patients faced when parking at Westmead Hospital and began a campaign to ensure the parking area outside the treatment centre was for the exclusive use of cancer patients.

In 2012, after 4 years of campaigning, Westmead Hospital agreed to introduce a parking permit system to enable cancer patients and their carers to access the parking area outside the treatment centre. A parking attendant has also been hired to monitor the parking area and to control access to it, ensuring it is exclusively used by cancer patients and their carers.

6.2 Drop-offs and pick-ups

The lack of suitable drop-off and pick-up areas at health facilities can also exacerbate transport difficulties. Drivers who are transporting people who are frail or unwell may need to leave their vehicle to assist patients into the facility, yet this need has not been factored into the design of many major health services.

Community transport providers report that they are often faced with a difficult decision: to park temporarily in a no-stopping zone or on a footpath or to force their clients to walk long distances. Some community transport operators report receiving parking fines as a result of these decisions.

Other community transport groups have begun recruiting volunteers to escort patients into the health facility while the driver of the vehicle waits outside. While this approach can be effective, it can place additional strain on the already stretched resources of many community transport providers; particularly when many community transport groups already experience a shortage of volunteers.

Despite the importance of well-planned parking areas and drop-off zones in supporting health transport, consultation on these issues during the building or redevelopment of health facilities is minimal. One workshop participant commented: "When Westfield was being redeveloped they made much more of an effort to consult with us around how to accommodate our client's transport needs than did the hospital during its redevelopment".

Recommendation 13: Health transport stakeholders should be consulted during the building or redevelopment of health facilities to ensure proper consideration of transport needs.

Drop-off/Pick-up zones

Well-designed drop-off/pick up zones can make it significantly easier for a health consumer to access a health service. Characteristics of these zones may include:

- Close to the hospital's entrance;
- Undercover and protected from the weather;
- Provisions for short-term parking that allow the driver to leave the vehicle to escort a patient inside a health facility;
- Seating available just inside the door.

An example of a hospital with a well-designed drop-off area is St George Private Hospital in Kogarah.

Recommendation 14: Designated drop-off zones for community transport vehicles and other non-emergency transport vehicles should be established near the entrance of every major health facility in NSW.

Transit lounges

Transit lounges can act as both an area for health consumers to wait for transport once their appointment had ended and as a reception area for health consumers to be received into the health facility. A report prepared for Western Sydney Area Health Service suggests that ideally: "orderly staff would meet patients at the lounge (if they cannot make their own way to the ward or clinic they are attending) thus reducing the need for transport staff or ambulance staff to spend time escorting patients around the hospital site".[38]

Transit lounges can be particularly beneficial for health consumers from rural or regional areas who have travelled long distances to access health services and who may need to wait a number of hours for transport home. Transit lounges give health consumers an area where they are able to wait for transport in a comfortable and sheltered area, and provide access to toilet facilities and refreshments.

Transit lounges also provide a designated area for community transport vehicles to pick up clients after their treatment has ended. These facilities, together with their staff, are especially valuable when a client has been referred from one section of the hospital to another without notice being given to the transport provider.

Recommendation 15: Transit lounges should be established at every major health facility in NSW.

Transit Lounges

The transit lounge at John Hunter Hospital has been in operation since 2005. Health consumers at this transit lounge are provided with toilet facilities and access to refreshments. The lounge offers a designated drop-off and pick-up zone for community transport services.

Besides providing an area for health consumers to wait for transport, transit lounges also offer direct access to medical facilities, which can be reassuring for some health consumers – particularly those with chronic illnesses or the elderly. Transit lounges provide a safe and secure environment for health consumers who might otherwise have to wait for transport services outside or by themselves.

Jason's Story

In 2012 Jason was admitted to Warren Hospital in regional NSW after suffering an asthma attack. Several hours after his admittance, Jason was rushed to the much larger Dubbo Hospital by ambulance some 130kms away to undergo further tests. The next day, after being given the all clear, Jason was discharged from Dubbo Hospital. When he asked hospital staff about how he was going to get home they responded that it was not their responsibility. As Jason had been taken to Dubbo Hospital in an ambulance he did not have access to his car. He was 130kms from his home town and did not know how he would be able to get back home.

The hospital did not provide Jason with any suggestions or alternative transport options; they did not refer him to community transport services or provide him with a cab charge to make his way home. Luckily, Jason had a relative living on the outskirts of Dubbo who was able to pick him up from the hospital and kindly drove him home. Dubbo Hospital have since put up posters declaring that all patients transferred to Dubbo Hospital by ambulance will not be provided with transport back home.

Jason's experience is not an isolated incident and many other patients finding themselves in similar circumstances do not have social networks to call on.

6.3 Transfer of care (discharge)

Workshop participants identified a number of poor practices relating to transport needs during the transfer of care (discharge). These included the discharge of patients late at night or on weekends, the discharge of patients with very little notice, and the discharge of patients with no transport (occasionally with no money and/or wearing inappropriate clothing).

It was evident that transport is not routinely considered during the transfer of care (discharge), and is frequently overlooked during all stages of discharge planning.

Poor discharge processes not only affect health consumers: they also create stressful situations for carers, whose ability to provide transport may be impacted (e.g. due to changes in discharge times at short notice), or who are forced to neglect other responsibilities, such as work or child care commitments, in order to do so. Similarly, transport providers are less able to meet requests for transport when the need for these services is identified late in the discharge planning process, if at all.

Timing and communication

Many workshops participants noted that health consumers are often discharged quite late in the day (especially on Fridays) when transport services are no longer available. This is of particular concern for health consumers in regional or rural areas where there are fewer transport services, and where receiving treatment requires travel over longer distances. In many locations community transport groups do not have the funding or resources to operate outside office hours. In these

Fitness to Travel

The NSW Health Transport for Health Policy recommended that Health Transport Units develop Fitness to Travel Certificates for use by non-Area Health Service Transport for Health providers. The policy directive states that this certificate "should record the certification of an appropriately qualified Area staff member that a patient is fit to travel on a Transport for Health service of a particular Service Classification level after receiving a particular treatment or medical intervention". [42]

Although the use of Fitness to Travel certificates has not been widely adopted, some community transport providers have chosen to use them. NSW Health did not develop a template for this certificate, with community transport groups creating their own versions.

Those community transport providers using the certificates have found that where a driver is unsure whether a patient is able to travel after treatment, asking for medical sign-off prompts medical staff to reassess whether a patient is in fact fit to travel, and provides much-needed reassurance to both paid and voluntary drivers.

circumstances patients may find themselves effectively stranded on being discharged.[39] They may have no choice but to spend money on a hotel room, which they may not be in a position to afford, or may resort to hitchhiking or even sleeping rough.

A presentation by a local hospital discharge planner at one of the Health Transport Workshops provided valuable insight into the ways in which standard hospital procedures contribute to the discharge of patients late in the day or at the weekend when no suitable transport is available. While it was acknowledged that in some cases this could not be helped, it was agreed that improved communication would assist community transport providers to better accommodate client needs, and would reduce the number of requests made with very short notice. Currently, community transport providers report that it is not uncommon to receive notification of a client's discharge only one hour in advance.

The NSW Health *Care Coordination Policy*[40] requires that an Estimated Date of Discharge (EDD) should be established as soon as possible after admission, and within 24 hours of admission. The policy also states that:

> "Discussions with the patient and their family/carer/s, GP, *community health and service providers* should occur early, for effective health planning. Any changes to the EDD for clinical reasons or delays in transfer beyond the EDD are to be recorded and relevant staff informed. *In this situation it is necessary to contact any relevant community service providers to advised them of the altered EDD*".

While this is the official policy, the experience of workshop participants suggests community transport providers are rarely considered as 'a relevant community service provider'.

Transport providers are also not always informed of a health consumer's needs prior to discharge. For health consumers who require specialised care and support, such as bariatric patients, this can mean that the services that turn up may not be appropriate. This can cause stress and embarrassment for the health consumer, and is time-consuming and inefficient for the transport provider. Specialist transport needs should be identified during discharge planning processes, and issues raised with transport providers to ensure that appropriate transport arrangements are in place before discharge takes place.[41]

Recommendation 16: The NSW Health *Care Coordination Policy* and associated materials should be amended to ensure transport is considered early in transfer of care planning process; embed transport as a consideration of risk; and improve communication with transport providers. No patient should be discharged without ensuring appropriate transport is available.

Duty of care and transporting unwell clients

Paid and voluntary drivers delivering health transport services often feel a duty of care when returning a client home. Where discharge planning has been inadequate, this can create unnecessary stress and a blurring of responsibilities. If a client lives alone, they may not be able to replenish basic supplies such as food, or be able to fill necessary prescriptions. While these issues should be identified prior to discharge, community transport drivers are sometimes finding themselves in situations where they feel responsible for ensuring a client's basic needs have been met.

Early discharge practices and the increasing use of day surgery can also mean that patients are discharged before they are fully recovered, and may therefore need more assistance while travelling. The transport of clients who are unwell places an increased expectation on community transport drivers, many of whom are volunteers, and most of whom have no medical training.

Community transport drivers should not be placed in positions where it is necessary to assess whether a client is well enough to travel. In order to safeguard both drivers and their clients, some community transport providers request that the medical practitioner sign off on a patient's fitness to travel (see text box *Fitness to Travel*). This system is not widely used and some health practitioners are unwilling to certify that a patient is fit to travel due to concerns over liability should anything happen to the patient in transit. Transport providers travelling across state borders have found it particularly difficult to convince health services as to the validity of these certificates.

Recommendation 17: Fitness to Travel certificates should be implemented on a broader scale, with their roll-out facilitated by NSW Health and Local Health Districts.

"Patients who are receiving treatment several times a week can find paying for parking a severe financial burden, with costs of up to $20 per hour at some hospitals."

Section 7: Aboriginal Health Transport

As described in Section 1, the health transport needs of Aboriginal people are compounded by a number of factors. Aboriginal people require greater access to health services yet in many cases do not have the resources necessary to make use of these services. As well as having reduced access to both public and private transport, Aboriginal people do not have equitable access to the support available for health transport services due to the way in which these services are delivered.

Accessing health transport services

Currently, the majority of financial support for health transport is provided through the Isolated Patients Travel Assistance and Accommodation Scheme (IPTAAS). The way in which this program is delivered means that many Aboriginal people are not able to access this assistance. Problems with the current scheme include:

- Subsidies are only available for travel by private vehicle or by public transport – neither of which are available in many Aboriginal communities;
- The complexity of the form and the administration process (although there have been recent attempts to simplify these processes);
- The requirement to make an upfront payment that is later reimbursed.

There is a need to revisit these issues with a view to ensuring Aboriginal people have equitable access to the support available through IPTAAS.

The way in which community transport services are delivered can also present barriers to access for Aboriginal people. For example, many transport providers find it difficult to accommodate requests for transport unless these are made several days ahead of time. This can run counter to Aboriginal culture, and indeed it is not possible for many Aboriginal people to plan health treatment in advance.

Community transport services may not be culturally appropriate and may therefore not be servicing the Aboriginal community adequately or at all. Drivers and other staff members may not be culturally competent, and processes may not be designed to be inclusive of Aboriginal people and culture. In particular, the requirement for a patient co-contribution was often seen as a deterrent, even though service should not be refused based on an inability to pay.

Other types of transport services can also be more difficult for Aboriginal people to access. Some taxi services are reluctant to transport people to and from Aboriginal communities – a problem also affecting the provision of ambulance services in some locations.

Engaging Aboriginal People and Services

In order to improve access to health transport for Aboriginal people, Tweed-Byron Ballina Community Transport have developed a close working relationship with Bullinah Aboriginal Medical Service (AMS).

In 2010 both organisations signed a formal Memorandum of Understanding formalising a commitment to work together to ensure the best outcomes for Aboriginal clients.

As a result of this agreement, the AMS now refers clients directly to community transport who are able to provide assistance as part of their funding agreement with the Local Health District. Previously, clients could only be referred through the Health Transport Unit. A change to this process was only possible because of the working relationship facilitated by the Aboriginal Transport Development Officer and because strong connections with the Health Transport Unit had been established through the Health Transport Network.

Engagement in service planning

Efforts should be made to better engage Aboriginal people in the planning and delivery of health transport services. In cases where this has as occurred – such as in those community transport organisations where an Aboriginal Transport Development Officer has been employed – there have been clear improvements in relation to Aboriginal access to services.

Flexible service delivery

Aboriginal people attending the health transport workshops also identified the need for more flexible service delivery in order to meet the needs of Aboriginal people. Funding guidelines were seen as restrictive and often meant that it was not possible to address areas of greatest need. In addition, Aboriginal people have a more holistic understanding of 'health' that does not align with the western medicine focus of funding for existing health transport services. Aboriginal stakeholders at the Lismore workshop expressed the view that health transport should also encompass Aboriginal concepts of health and *wellbeing*.

The "Closing the Gap Care Coordination program" provides an example of an approach that was welcomed by the Aboriginal people consulted during the development of this report. This program is able to use Supplementary Service funds to:

> "…purchase transport of many types and for many reasons. These vary from directly health-related to other associated reasons such as transport purchased for travel to Centrelink because of the impacts on health of not being able to access that service (not being able to buy medications etc.). Funds are also commonly used to access diagnostic services."[43]

The need for a more flexible approach should inform the development of an Aboriginal Health Strategy and should guide the clarification of responsibilities in relation to the delivery of health transport services.

Recommendation 18: Aboriginal people, communities and services should be actively engaged as partners in the planning and delivery of all health transport services.

Recommendation 19: An Aboriginal Health Transport strategy should be developed in partnership with Aboriginal people. This strategy should allow for a more flexible approach that recognises Aboriginal concepts of health and wellbeing, and should include the identification of strategies to ensure equitable access to IPTAAS.

"Aboriginal people do not have equitable access to the support available for health transport services …"

Conclusion

The 2012 Health Transport Workshops confirmed that there is an urgent need to address the problem of health transport in NSW. The Workshops provided additional evidence that a lack of transport is a major barrier to access, particularly for vulnerable and marginalised people, and is contributing to significant health inequalities within the NSW community.

We ask that the NSW Government work in partnership with community organisations and customer representatives and to develop a more comprehensive, equitable and coordinated health transport system; and commits the resources necessary to make such a system reality.

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[16] ABS (2009) *Survey of Disability, Ageing and Carers, Australia: Summary of findings*. Cat. No. 4430.

[17] See, for example, Evenson K., and Fleury J. (2000) 'Barriers to outpatient cardiac rehabilitation participation and adherence'. *Journal of Cardiopulmonary Rehabilitation*. 20(4): 241-246 and Hoffmann R.L., Rohrer W.M., South-Paul J.E., Burdett R., and Watzlaf V.J. 'The effects of barriers on health related quality of life (HRQL) and compliance in adult asthmatics who are followed in an urban community healthcare facility'. *Journal of Community Health*. 2008; 33(6): 374-383.

[18] NSW Renal Services Network (2008) *Provision of Transport Assistance for Dialysis Patients attending Hospital and Satellite Dialysis Centres.*

[19] NSW Health (2006) *NSW Chronic Care Program: Rehabilitation for Chronic Disease*. Volume 1.

[20] NSW Health Policy Directive PD2011_45 states 80% of all surgery (from the selected Diagnosis Related Groups) should be performed through a combination of a Day Only and Extended Day Only model.

[21] See for example, 'Hospital stays for elderly to be halved in cutbacks', *Sydney Morning Herald,* September 25, 2012.

[22] Cancer Council NSW, Council of Social Service of NSW (NCOSS), Community Transport Organisation (CTO) (2007) *No Transport No Treatment*

[23] General Practice NSW (2012) *Closing the Gap – Tackling Indigenous Chronic Disease: Care Coordination and Supplementary Services (CCSS) Workshop*. 22 May 2012. Retrieved 20 September, 2012, from http://www.gpnsw.com.au/__data/assets/aboriginalhealth/120725_rep_GP-NSW-CCSS-Workshop-Report-22-May.pdf

[24] Note that the Commonwealth Government has now assumed policy and funding responsibility for HACC services for older people, while services for younger people with disability remain the responsibility of the NSW Government, and now fall under the Community Care Supports Program.

[25] Battellino, Helen (2012) *Health Transport provided by Community Transport*. Presentation at the 2012 Sydney Health Transport Workshop.

[26] Cancer Council NSW, Council of Social Service of NSW (NCOSS), Community Transport Organisation (CTO) (2007) *No Transport No Treatment*.

[27] Ibid

[28] The *NSW Cancer Plan 2011-15* states that it will "Enhance practical assistance e.g. in relation to transport, accommodation, equipment etc." p. 27.

[29] *The NSW Renal Dialysis Service Plan to 2011* targets included the development of a "consistent statewide transport framework".

[30] Some health services have attempted to develop plans to address the transport needs of people requiring treatment for chronic disease. These appear to have met with limited (if any) success due to a lack of funding and structural support within the health system. See for example, *North Coast Area Health Service In-Centre Renal Dialysis Transport Plan 2006-2011*, and *Transport Solutions for Renal Dialysis Services in Sydney West Area Health Service*, prepared for Health West Transport by Transport Planning and Management, December 2005.

[31] 'Missed NHS appointments cost millions'. *The Guardian*. 27 August 2012.

[32] Transport for Sick Children (2009) *The Cost of Did Not Attend to the Greater Manchester NHS.* Retrieved September 5 from http://www.transportforsickchildren.org/The%20Cost%20of%20Did%20Not%20Attend_final.pdf

[33] Wallace, R., Hughes-Cromwick, P., Mull, H. & Khasnabis, S. (2005). 'Access to Health Care and Nonemergency Medical Transportation: Two missing links.' *Transportation Research Record* No. 1924: 76-84.

[34] Wallace, R., Hughes-Cromwick, P., Mull, H. (2006). Cost-Effectiveness of Access to Nonemergency Medical Transportation: Comparison of Transportation and Health Care Costs and Benefits, *Transportation Research Record: Journal of the Transportation Research Board*, Vol. 1956, pp 86-93.

[35] The Marketing Institute, Florida State University College of Business (2008) *Florida Transportation Disadvantaged Services: Return on Investment Study*. Retrieved September 5 from http://tmi.cob.fsu.edu/roi_final_report_0308.pdf

[36] Cancer Council NSW (2012) *Car Parking for cancer patients in New South Wales: A survey of patients' access to car parking at cancer treatment centres.*

[37] For eample, parking at Sydney Eye Hospital costs $8.00 for 30 mins or $20.00 for 30 mins to 1 hour while at Royal Prince Alfred it costs $9.00 for 30 mins or $18.00 for 30 mins to 1 hour (NSW Cancer Council, private correspondence).

[38] NSW Health (2006) *Transport for Health Policy Directive* [PD2006_068]

[39] See for example Feain, Dominic (2012) 'Out of it' but still discharged, *The Northern Star*, 12 January 2012. Retrieved August 12, 2012 from http://www.northernstar.com.au/story/2012/01/12/out-of-it-but-still-discharged-lismore-hospital/

[40] NSW Health (2011) *Care Coordination: Planning from Admission to Transfer of Care in NSW Public Hospitals* [PD2011_015]

[41] Cancer Council NSW, Council of Social Service of NSW (NCOSS), Community Transport Organisation (CTO) (2007) *No Transport No Treatment*

[42] NSW Health (2006) *Transport for Health Policy Directive* [PD2006_068], p. 25

[43] GP NSW (2012) *Care Coordination and Supplementary Services Care Coordinators Workshop Report*, May 22, 2012, p. 12.

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Cancer
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COTA


CTO
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ORGANISATION


KIDNEY
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NSW
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ATN
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pdcn
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