

## No transport, no treatment

Samantha Edmonds<sup>1</sup>, Anita Tang<sup>2</sup>, Dave Taylor<sup>2</sup>

<sup>1</sup>Council of Social Service of NSW, <sup>2</sup>Cancer Council NSW

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Samantha Edmonds has been working as Deputy Director at the Council of Social Service of NSW (NCOSS) since January 2008. This role includes responsibility for the policy areas of transport, justice and legal issues. She has over 14 years of experience in working with a range of different people advocating with them and for them around social justice issues. Samantha sits on the Board of Ostara Australia (a consortium of employment agencies that assist people with mental health issues) and the Charles Sturt University, Institute of Land, Water and Society Advisory Board. She also sits on a number of departmental committees as part of her work and she has been involved (personally and professionally) on a number of state and national committees in the past. Samantha holds a BA from Macquarie University, Master of Social Administration (University of Western Sydney), Master of Politics and Public Policy (Macquarie University) and a Master of International Relations (Macquarie University). Samantha has also completed the Macquarie University Global Leadership Program.

Anita Tang has been at Cancer Council NSW since July 2002, first as Manager Policy and Advocacy, then Director of Health Strategies for four and a half years, and now Manager Policy and Advocacy again. During her time at Cancer Council NSW, her responsibilities have included cancer prevention programs and advocacy for government action to reduce the impact and incidence of cancer. Anita has extensive experience across social issues, through advocacy, review, service development, and policy roles. She has a Bachelor of Arts, and a Masters in Administrative Law and Policy, both from the University of Sydney. In 2007 she was awarded a Fellowship for the Stanford University Executive Program for Nonprofit leaders.

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### Background and policy context

Transport to Health Services is a vital part of the health care system and one that is often overlooked. Put simply, people cannot be treated if they cannot get to their appointments. In 2006 three peak state-wide non-government organisations (NGOs) commissioned a major study of community transport in this state—No Transport No Treatment.<sup>(1)</sup> The report, the first of its kind, examined the pressures of non-emergency health-related transport faced by community transport providers. It made a series of recommendations to address ongoing and increasing unmet health transport need.

In 2011, despite ongoing reforms in the health system in NSW, little attention has been paid to the transport needs of patients. Despite increasing demand for access to health services reported by community transport providers there has been little increase in funding to health related transport services. In 2011 these same 3 NGOs are analysing the recommendations of the original report and determining if the recommendations have been implemented and to what extent. This paper will look at the history of transport to health services, the recommendations of the No Transport No Treatment Report and analyse where we need to go.

In 1998 the NSW Government acknowledged that health services in NSW generate significant demand for transport. It also acknowledged that this demand was not being met.

Between 1998 and 2000 a number of reports were released that demonstrated access to health services was limited for transport disadvantaged people and communities. This included a report from NCOSS—Transport to Access Health Services in Rural and Remote NSW. However, the two most significant reports, for NSW Health, were the Ministerial Advisory Committee on Health Services in Smaller Towns (2000) and the NSW Health Council (2000). These reports established ‘that timely and appropriate access to health facilities for transport-disadvantaged people is essential for the cost effective and equitable delivery of health care’.<sup>(2)</sup> The reports also highlighted that ‘a shortage of affordable transport and the centralisation of specialist medical services were the most significant barriers to achieving this goal’.<sup>(2)</sup>

In 2001 the NSW Government Action Plan for Health identified the need to develop an overall coordinated approach to health and health related issues. This resulted in the creation of the NSW Rural Health Implementation Coordination Group (RHICG). The RHICG formed a series of sub-committees to look at specific issues and one of these was the Transport Advisory Sub-Committee, which produced a discussion paper—Non-Emergency Health Related Transport: Facilitating Access to Health Services in NSW.<sup>(3)</sup>

Finally in the 2002 NSW State budget, NSW Health allocated \$2.5m to implement the Transport for Health Project. This resulted in the formation of Health Transport Networks and the employment of Health Transport Coordinators in rural areas only. Metropolitan areas were excluded.

In February 2003 NSW Health established a Transport for Health Implementation Reference Group.<sup>(4)</sup> The purpose of the Group was to develop a Transport for Health Policy Framework.

The Transport for Health Policy Framework was finally released in July 2006. The Policy recognised that NSW Health generates transport demand and that public and private transport was not always available and/or affordable for many people living in NSW. The purpose of the Framework was to 'simplify and improve patient access to health services 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 NSW health system'.<sup>(2)</sup>

The policy also aimed to integrate all non-emergency health related transport into a single program within each Area Health Service. Non-emergency health related transport was identified as:

- Isolated Patients Transport and Accommodation Assistance Scheme
- Transport for Health
- State-wide Infant Screening-Hearing Travel
- Health Related Transport Program
- Inter-facility transport services
- Greater Metropolitan Clinical Taskforce Inter-facility Transport.

An important aspect of the Policy was its recognition of the role played by NGO Community Transport Providers, funded either under the Home and Community Care Program (HACC) or the Community Transport Program (CTP), in delivering a significant portion of health-related trips.

### An independent study

In the same year as the release of the Transport for Health Policy Framework the Cancer Council NSW, Council of Social Service of NSW (NCOSS) and the Community Transport Organisation (CTO) commissioned a study of community transport in the state, with a specific focus on the role of community transport in delivering health-related transport services. The report made five key findings, all of which remain challenges in 2011.

The report found that early discharge policies, the increasing use of day-only surgery, and the centralisation of some specialist medical services, such as radiotherapy, have increased demand for transport for health. Many patients need more assistance upon discharge and while travelling, making public transport or driving themselves unviable. For example, people who receive chemotherapy or radiology treatments are often very ill following treatment and require specialised care and support

Secondly there is inadequate funding for transport to health services with NSW Health only providing 10% of the funding needed to provide health-related trips. Community Transport (funded through Home and Community Care and Community Transport Program) has limited resources to address the health transport needs of individuals. Community Transport providers face a high and increasing demand for health related transport. This reduces the capacity of providers to meet the other essential transport needs of people such as social and recreational needs.

The report also found that both metropolitan and rural areas have health transport problems. Many people located in rural and regional areas who do not own a motor vehicle can face significant difficulties when

travelling to specialist services, some of which can be located 200-300 kilometres away from their home. This creates a significant barrier to seeking treatment.

It can also be a problem in metropolitan areas. For example, consolidation of health services has increased the distance required for specialised treatment. Poor planning for public transport to health destinations, inaccessible transport services, associated financial costs, such as parking and accommodation, and limited resources for community transport all create barriers to accessing health services.

Public transport is not always available to some locations, particularly in rural and regional NSW. Services in some regions can be inaccessible to people with mobility difficulties. Costs can be high—rural and regional bus services are expensive, and do not offer the same range of concessions as metropolitan services. As noted above early discharge, same-day treatment and some types of treatment (such as dialysis and chemotherapy) means that people are unable to use public transport.

Access is exacerbated by Transport for Health funding having a very limited state-wide budget, and inconsistent availability and eligibility across the State.

Another finding of the report is that many Aboriginal communities appear to be the most disadvantaged in terms of access to suitable transport to health services. This is exacerbated by the low number of people in some Aboriginal communities with driving licences or cars; issues of distance and a lack of public transport; low socio-economic status and a reduced ability to purchase transport services; poor health of many Aboriginal people and culturally inappropriate transport services. This means that it is not uncommon for Aboriginal people in isolated communities to walk or hitchhike long distances to attend medical appointments, or routinely miss health appointments because of the poor availability of transport.

Finally the report also noted that people with cancer are also disadvantaged in regards to health transport, especially as transport for cancer patients is considered to be difficult with a need for specialised vehicles and concerns about medication side-effects. The stress caused by a lack of appropriate transport options and the financial burden of travel and associated costs only adds to what can be a time of significant emotional distress and hardship for people who need specialist medical services.<sup>(5)</sup>

The report outlined three solutions and ten detailed recommendations. The solutions were for the NSW Government to—increase funding for non-emergency health-related transport; allocate resources so health transport is available to all; and include transport as part of all health funding.

Specific recommendations dealt with:

- the amount of funding required (an increase from less than \$3m to \$10m per annum)
- more equitable distribution of funding to community transport groups across the state
- a strategy to address health transport for Aboriginal people
- developing demand responsive flexible bus services to serve hospitals and other health facilities
- the need for a regional planning process for health transport
- systems to aggregate demand so that more effective use can be made of available transport resources and services
- reviewing discharge planning procedures to ensure that patient transport needs are addressed
- establishing transit lounges at major health facilities and reserved short-term parking areas near hospital entrances for transport services
- the need for Transport for Health data to be publicly available
- the need for periodic unmet transport needs data collection among funded community transport operators.

## Current state of play

Almost seven years later, there has been little improvement in the funding and provision of community transport services. During the same period, demographic changes have increased pressure on community transport providers, for example the proportion of the population aged over 65 years has increased from 13.1% in 2002 to 13.9% in 2009; and the incidence of cancer (just one of the health conditions that creates a need for health transport), has increased from 32,700 people diagnosed in 2003 to 36,600 in 2008 and is projected to rise steadily over the next decade.<sup>(6)</sup>

The most notable policy change is that in 2006, following intense lobbying by an alliance of NGOs (the Less Distance for Assistance Alliance), the distance eligibility criteria was reduced from 200km one way to 100 km one way, and the vehicle allowance was increased to fifteen cents per kilometre.

In 2007, a Federal Inquiry into the operational effectiveness of Patient Assisted Travel Schemes—*Highway to Health* received 190 submissions and made 16 recommendations designed to improve access to health care for people living outside of metropolitan areas.<sup>(7)</sup> The leading recommendation called on all governments to commit to improving services and for a clear allocation of funding for patient assisted travel schemes.

In order to assess whether there has been a real increase in funding for health transport over the past 7 years, we looked for data on the funding of health transport in NSW, in an attempt to track the changes in funding and transport usage, compared to changes in population as an indicator of need. However, it was not possible to locate a reliable, replicable and constant series of data that included both funding and usage for all community transport programs in NSW. Funding for health transport comes from a range of sources—Home and Community Care (HACC), the Community Transport Program (CTP), Transport for Health (TfH) and the Area Assistance Scheme (AAS). The CTO and NCOSS have collected some crude information about CT providers and usage rates, but as it is based on a survey of CT providers, as a result it is not possible to extrapolate state-wide data or to make comparisons between different years. Sourcing data on the Transport for Health program was particularly challenging, partly because of the amalgamation of all non-emergency health related transport into a single program and budget line following the release of the 2006 Transport for Health Policy Framework. Because of the difficulty in attaining accurate data for the TfH program, it was not included in our results.

The most reliable financing and utilisation data was provided by the HACC program, so the analysis that follows is primarily based on the funding and utilisation data from the transport program under HACC. All funding data was calculated in 2010 dollars by using the Reserve Bank of Australia's (RBA's) inflation calculator.

**Table 1 HACC transport funding in New South Wales (2002–2010)**

Year	Budget	Budget (\$2010) <sup>1</sup>	No. of users <sup>2</sup>	No. of annual trips <sup>2</sup>	Expenditure per user (\$2009)	Expenditure per trip (\$2009)
2002/03	\$14,500,103	\$18,129,068	42,730	1,216,290	\$424.27	\$14.91
2003/04	\$16,729,512	\$20,352,520	46,186	1,380,646	\$440.66	\$14.74
2004/05	\$18,057,479	\$21,465,020	49,186	1,412,191	\$436.41	\$15.20
2005/06	\$21,333,090	\$24,699,590	52,395	1,539,429	\$471.41	\$16.04
2006/07	\$25,334,822	\$28,330,355	62,487	1,674,731	\$453.38	\$16.92
2007/08	\$27,453,292	\$29,999,609	62,224	1,737,398	\$482.12	\$17.27
2008/09	\$29,002,537	\$30,370,623	67,195	1,867,142	\$451.98	\$16.27
2009/10	\$31,424,280	\$32,318,372	72,564	2,006,576	\$445.38	\$16.11
2010/11	\$36,991,280	\$36,991,280	78,362	2,156,421	\$472.06	\$17.15

Sources: (8-23)

Notes:

<sup>1</sup> Figures calculated using the Reserve Bank of Australia's calculator available at: <http://www.rba.gov.au/calculator/annualDecimal.html>

<sup>2</sup> Data for 2008/09-2010/11 was estimated by increasing the previous years figures by the average change in usage between the period from 2003/04-2007/08.

The data reported in Table 1 shows HACC transport utilisation and funding for the period 2002-2010. Data was sourced from Transport NSW Annual Reports.

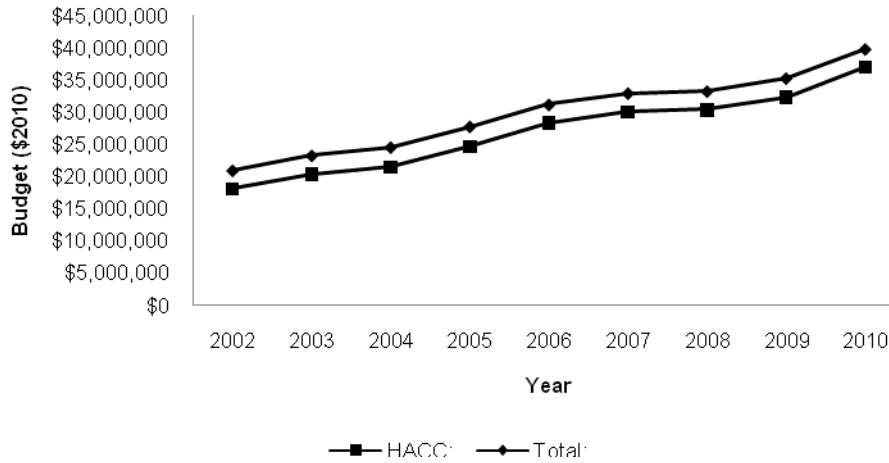
**Table 2 Community transport financing in New South Wales (2002–2010)<sup>6</sup>**

Year	Number of Passengers Carried <sup>1</sup>	Passenger Trips Reported	% Trips that are health related <sup>2</sup>	Kilometres travelled <sup>1</sup>	Program <sup>4</sup>	Funding	Funding Indexed (\$2010) <sup>3</sup>	% NSW Pop. > 65	% NSW Pop. > 85	Sources
2002	82,084 (20%)	1,074,720	26%	N/A	HACC:	\$14,500,103	\$18,129,068	13.1	1.5	(8; 21; 24; 25)
					CTP:	\$1,862,282	\$2,328,358			
					AAS:	\$333,344	\$416,771			
					Total <sup>5</sup> :	\$16,695,729	\$20,874,196			
2003	36,212 (31%)	1,044,000	23%	N/A	HACC:	\$16,729,512	\$20,352,520	13.2	1.5	(9; 18; 24; 26)
					CTP:	\$2,036,617	\$2,477,675			
					AAS:	\$311,909	\$379,457			
					Total <sup>5</sup> :	\$19,078,038	\$23,209,652			
2004	93,730 (55%)	N/A	29%	5,819,444 (55%)	HACC:	\$18,057,479	\$21,465,020	13.3	1.5	(10; 17; 27; 28)
					CTP:	\$2,091,717	\$2,486,435			
					AAS:	\$467,441	\$555,650			
					Total <sup>5</sup> :	\$20,616,607	\$24,507,069			
2005	126,902 (70%)	N/A	25%	19,183,784 (70%)	HACC:	\$21,333,090	\$24,699,590	13.4	1.6	(11; 19; 29; 30)
					CTP:	\$2,148,234	\$2,487,239			
					AAS:	\$467,441	\$541,206			
					Total <sup>5</sup> :	\$23,948,765	\$27,728,035			
2006	92,046 (70%)	N/A	28%	20,210,432 (70%)	HACC:	\$25,334,822	\$28,330,355	13.5	1.6	(12; 23; 30; 31)
					CTP:	\$2,118,790	\$2,369,311			
					AAS:	\$507,299	\$567,281			
					Total <sup>5</sup> :	\$27,862,503	\$31,156,903			
2007	129,123 (63%)	N/A	28%	20,760,539 (63%)	HACC:	\$27,453,292	\$29,999,609	13.6	1.7	(13; 22; 32-34)
					CTP:	\$2,166,207	\$2,367,125			
					AAS:	\$507,299	\$554,351			
					Total <sup>5</sup> :	\$30,126,798	\$32,921,085			
2008	139,103 (82%)	N/A	27%	28,984,164 (82%)	HACC:	\$29,002,537	\$30,370,623	13.7	1.8	(14; 20; 35; 36)
					CTP:	\$2,208,759	\$2,312,949			
					AAS:	\$524,040	\$548,760			
					Total <sup>5</sup> :	\$31,735,336	\$33,232,331			
2009	160,386 (74%)	N/A	27%	31,509,009 (74%)	HACC:	\$31,424,280	\$32,318,372	13.9	1.8	(15; 37- 39)
					CTP:	\$2,310,251	\$2,375,983			
					AAS:	\$541,333	\$556,735			
					Total <sup>5</sup> :	\$34,275,864	\$35,251,090			
2010	160,386 (67%)	N/A	27%	31,509,009 (67%)	HACC:	\$36,991,280	\$36,991,280	N/A	N/A	(16; 38- 40)
					CTP:	\$2,809,452	\$2,809,452			
					AAS:	-	-			
					Total <sup>5</sup> :	\$39,800,732	\$39,800,732			

Notes:

- <sup>1</sup> Figures in parenthesis indicate the percentage of CTO member organisations reporting data for that year.
- <sup>2</sup> Data reported by CTO—% of trips that were health related: aggregate of 'hospital and medical' or 'GP and specialist' designations
- <sup>3</sup> Figures calculated using the Reserve Bank of Australia's calculator available at: <http://www.rba.gov.au/calculator/annualDecimal.html>
- <sup>4</sup> HACC refers to the component of the HACC budget dedicated to transport
- <sup>5</sup> Total refers to the total disbursements made to government and non-government providers for transport services.
- <sup>6</sup> Information on the Transport for Health (TfH) program was not included.

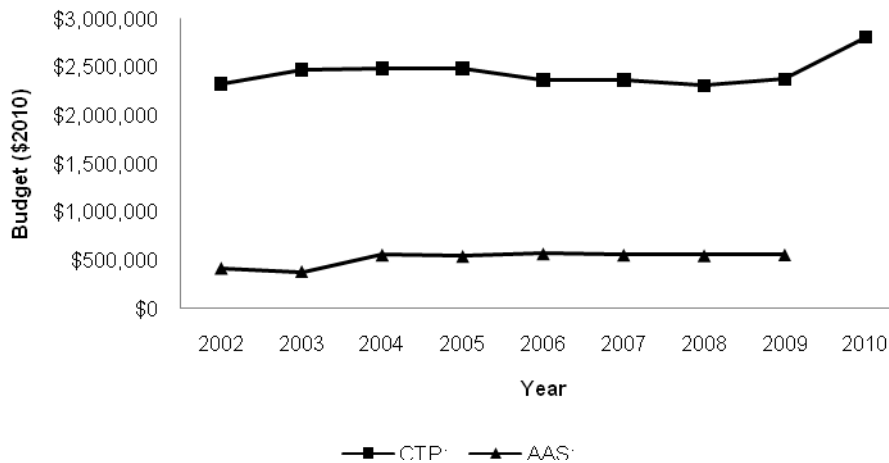
In the last decade, health-related community transport has accounted for between 23-29% of all CT trips (see Table 2.). Our results indicate that there has been very little increase in funding—beyond indexing the funding to the CPI—or capacity, for any of the programs provided in NSW. This is despite CT providers indicating that the current programs are not sufficiently financed enough to meet current capacity.<sup>(1)</sup>



**Figure 1 Financing for HACC transport versus total budget for community transport in NSW (2002–2010)**

Figure 1 shows expenditure on HACC transport in NSW from 2002-2010. The growth in funding over this period has not matched the corresponding increase in demand for services.

Funding for community transport appears to be largely unrelated to CT demand. While there are no reliable figures by which to easily estimate need for community transport, some indicators of relevance include the proportion of people in the population aged over 65, those with a disability, those who are diagnosed with a health condition such as cancer or kidney disease, and those who are transport disadvantaged (e.g. those of lower socioeconomic status, do not own a car, or are single carers). In the last decade the proportion of the NSW population aged over 65 has increased from 13.1% (2002) to 13.9% (2009). This trend will continue as the State’s population ages, yet there has been no increase in capacity over the same period. Figure 2 shows the change in financing for two additional community transport programs financed through Transport NSW. As is evident in the figure, financing has been more or less stagnant for the last decade.



**Figure 2 Financing for ‘Community Transport Program’ and ‘Area Assistance Scheme’ in NSW (2002–2010)**

So despite, numerous independent reports into the poor state of health-related transport over the years, there is little data to indicate that transport services are better able to meet community needs. The only substantive change to have occurred in the past decade was the result of a high profile concerted campaign involving a wide ranging alliance of NGOs. It is time for those involved in promoting the health of rural populations to consider options and opportunities for achieving reforms in health-related transport.

## Options and opportunities

At the time of writing, NSW faces a State election, and both NCOSS and Cancer Council have included health-related transport issues in their election agendas, urging all major parties to commit to much-needed improvements in IPTAAS and community transport. Both organisations have focused particularly on the need to improve the reimbursement rates available under the IPTAAS and to increase funding for Transport for Health program and IPTAAS.

So far, the following public commitments have been announced:

- The NSW Liberals and Nationals Community Transport Policy (June 2009) promises to ‘make community transport a priority’ and pledges to increase funding to the Community Transport Program by \$12 million over 4 years.<sup>(41)</sup>
- The NSW Liberals and Nationals policy Improving Treatment Access for Country Patients (2009) promises to increase funding to IPTAAS by \$28 million over four years. The policy also commits to a review of the administration fee, distance criteria parking arrangements and form complexity.<sup>(41)</sup>

Correspondence from the Minister for Health in December 2010 refers to a ‘recent’ announcement that ‘NSW Health will be undertaking a comprehensive review of the Transport for Health (TfH) Policy Directive, and that a broader review of the IPTAAS subsidy criteria will take place as part of the broader TfH Policy review. Neither NCOSS nor Cancer Council have seen this announcement, and at time of writing, waiting on further details from NSW Health.

In addition to the opportunities presented by an electoral cycle, the poor response of Governments to health-related transport suggests the need for a fundamental rethink of the approach taken by NGOs with an interest in improving access to health care, and particularly those working in rural health.

### A stronger voice

In a policy and budget environment of tight budgets, government fixation on surplus and credit ratings, and strong lobby groups with competing priorities, an issue such as health-related transport is all-too-easily overlooked. Transport to treatment is often viewed as ancillary, rather than integral to, health care. Transport issues are not within the professional domain of clinicians working in the health care system, and do not sit within a particular Ministerial portfolio and does not receive the same media attention as ‘life-saving’ machines or treatments. A stronger voice speaking out about the issue will help focus attention and reverse the tendency of health-transport being overlooked in health service planning, budget allocations and discharge planning.

### Tell our stories, and show the human cost of NOT fixing the system

One aspect to creating a stronger voice about the issue of community transport is to share the experiences of people directly affected by the lack of transport and transport funding. Highlighting the human impact of poor health-related transport validates and illustrates the cost of NOT increasing the funding for health-related transport and of NOT addressing the problems in the system.

### A unified, coordinated approach

There are many groups concerned about the problems of health-related transport—those working in health care (particularly rural health), those supporting people on low incomes or who are otherwise transport disadvantaged, specific health groups where patients require regular trips to hospital, and those concerned with the wellbeing of rural and regional communities.

The success of the Less Distance for Assistance campaign in 2006 shows the value of diverse groups working together for a common end. Substantive reforms to health-related transport may require a similar level of unity and coordination, bringing together the strengths of all groups interested in transport to health care.

### Better data

Our analysis of community transport financing and utilisation rates in New South Wales reveal a significant paucity of data at the State level. The data that is reported by State agencies is not easily accessible, readily

comparable or consistent between programs. Without good data, it is harder to demonstrate the problems in empirical terms. While policy-makers are rarely persuaded on the basis of data alone, its absence makes vulnerable our arguments for better funding.

## Conclusion

It has been eleven years since the NSW Government acknowledged that health services in NSW generate significant demand for transport and that this demand was not being met.

Numerous studies and reports later, there is scant evidence of any substantive improvement in health-related transport. Since the recommendations of Cancer Council NSW, NCOSS and CTO in 2006, little has changed.

The looming NSW election has generated some political attention to the issue, but substantive reforms are needed to ensure that patients can access treatment without undue cost or stress. While NCOSS and Cancer Council look to the next NSW Government to make needed changes, there is a role for the sector in making sure that health-related transport receives the attention and funding it needs.

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