

‘Staying Alive’: Transport to treatment for people living with a chronic disease



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This report focuses on the unmet health transport needs associated with two of the most prevalent chronic diseases impacting individuals, families, communities in our society: cancer and chronic kidney disease.

About NCOSS

The Council of Social Service of NSW (NCOSS) is a social justice advocacy organisation and is the peak body for the social and community services sector in New South Wales. We work with our membership, comprising a vast network of service delivery and consumer groups, on behalf of people and communities experiencing disadvantage in New South Wales.

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Executive summary

Non-emergency health transport makes a significant difference to the lives of people living with cancer or undergoing treatment for chronic kidney disease in NSW.¹ For many of these people it is a lifeline, reducing the burden of travel and improving access to healthcare services.

However, there are gaps in the current system which result in inequities in access to these services for those who need it most. This includes people with limited financial means, fewer public transport options, and those who fall outside of specified criteria to access the services they need, within accruing a significant financial burden themselves. The NSW Health *Transport for Health Policy 2006-2011* has itself noted: “current public transport services and private transport are often not available or accessible to a significant number of people living in NSW.”² Notwithstanding this growing realisation, the level of unmet need for non-emergency health transport services in NSW is currently not known.

In response to this gap in the evidence-base, this report examines the level of need for community transport services for people with cancer or chronic kidney disease. The findings are based on a national survey of health professionals engaged in cancer and kidney disease care during the period between May 2014 and July 2014, from which data pertaining to NSW was extracted.

Disparities in access to transport have significant implications for people living with cancer or undergoing treatment for kidney disease. This situation is exacerbated by changes and transitional arrangements across Aged Care and Disability Programs at State and Commonwealth levels. There are significant concerns, which have been raised by NCOSS and other groups, about the acknowledged gap in health related transport funding models and funding commitment. Recent changes to the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) by the NSW Government will make a significant difference to remedying this issue in the interim.³

This report reveals that:

- **77%** of respondents in dialysis units, **and 81% of respondents in cancer centres**, reported that their patients experienced **some level of difficulty accessing transport** to and from treatment.
- Whilst free parking was available at 80% of dialysis units, **66% indicated that there were not enough parking spaces to meet demand**;
- The **greatest burden of unmet non-emergency transport needs** was borne by older people (77%) people on low incomes (74%), people living in rural and regional areas (66%), people with a disability (44%), Aboriginal and Torres Strait Islander people (29%), and people from culturally diverse backgrounds (21%).

¹ The definition of ‘non-emergency health transport’ adopted in this report encompasses all community based transport services for people experiencing chronic conditions, including government-funded services through Local Health Districts, unless otherwise specified.

² NSW Health (2006). *Transport for Health Policy 2006-2011*. Sydney: NSW Health.

³ See: <https://wnswlhd.health.nsw.gov.au/UserFiles/files/Hot%20Topics/150208%20IPTAAS.pdf>

Recommendations

1. That NSW Health develop clear information pathways for clients concerning their transport options, including in clinical and community settings.
2. That all political parties commit to supporting a needs assessment for all non-emergency health transport services in NSW and actively consider:
 - a. the potential benefits gained by contracting health transport services for ambulant patients to a properly resourced community transport sector; and
 - b. an immediate increase in funding to community transport providers to meet the growing need for non-emergency health transport services
3. An immediate, significant expansion of clinic parking to ensure that it is more widely accessible and provided free of charge.

1 Introduction

[T]ransportation barriers may mean the difference between worse clinical outcomes that could trigger more emergency department visits and timely care that can lead to improved outcomes.⁴

Transport to and from health services is fundamental to ensuring equitable access to quality health care.⁵ It is also a critical enabler of both an efficient and effective health system, ensuring that people can access the care they need, when they need it.⁶

But many of the most vulnerable members of our society have limited transport options. This can lead to inequitable access to health services and contribute to inequitable health outcomes. A lack of transport can result in people missing appointments, skipping preventative treatment, being diagnosed later, and not receiving effective care. The consequences for individuals and their families can be devastating.

A failure to adequately invest in health transport services also has cost implications for the health system as a whole. In the absence of alternatives, ambulance services and other expensive transport options may be used in lieu of cheaper, more appropriate forms of transport.⁷ Missed appointments result in reduced service efficiency.⁸ Conditions diagnosed at a more advanced stage can be more expensive to treat. And unnecessary hospitalisations place a heavier burden on our health services.

NCOSS has published several reports outlining gaps in our current health transport system. These included the [2012 Provided there's Transport Report](#), which drew on findings from stakeholder workshops to document major current and ongoing issues relating to health transport,⁹ and the [2007 No Transport No Treatment Report](#) which presented the findings of a major study examining the pressures of non-emergency health-related transport faced by community transport providers in NSW.¹⁰

This report focuses on the unmet health transport needs associated with two of the most prevalent chronic diseases impacting individuals, families, communities in our society: cancer and chronic kidney disease.

In accessing treatment for these two diseases patients are often required to travel frequently and over extended periods of time. In the case of dialysis patients, dependency on ongoing treatment can be life-long.

But for many patients, organising transport to and from treatment is challenging or even impossible. Worryingly, both cancer and chronic kidney disease disproportionately impact lower socio-economic

⁴ Syed, S.T., Gerber, B.S., Sharp, L.K. (2013) 'Traveling Towards Disease: Transportation Barriers to Health Care Access,' *Journal of Community Health*, 38(5): p. 989

⁵ NSW Health (2006). *Transport for Health Policy 2006-2011*. Sydney: NSW Health.

⁶ Corcoran, K., McNab, J., Girgis, S., Colagiuri, R. (2012). 'Is Transport a Barrier to Healthcare for Older People with Chronic Diseases?' *Asia Pacific Journal of Health Management*, 7(1): 51-56. See also: Alzheimer's Australia (2014). *Meeting the Transport Needs of People with Dementia*. Sydney: Alzheimer's Australia.

⁷ The Reform Plan for NSW Ambulance notes that of the 420,000 non-emergency patient trips delivered by NSW Health in 2011/12, approximately 104,000 were conducted using emergency ambulances. NSW Health (2012) *Reform Plan for NSW Ambulance*. Sydney: NSW Health.

⁸ For example, 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. Cf. Transport for Sick Children (2009). *The Cost of Did Not Attend to the Greater Manchester NHS*.

⁹ NCOSS (2012) *Provided there's Transport: Transport as a Barrier to Accessing Health Care in NSW*. Sydney: NCOSS.

¹⁰ NCOSS, Community Transport Organisation (CTO), & Cancer Council NSW (2007) *No Transport, No Treatment*. Sydney: NCOSS.

groups. And people experiencing health and socio-economic disadvantage are also more likely to experience difficulties with transport.

The reality of living with a chronic disease can be confronting, and problems accessing transport to treatment further compounds the stress and anxiety that accompanies these life-threatening diseases.

1.1 Aims

The aim of this research was to examine the level of unmet need for community transport for people living with Cancer and Kidney disease, and to establish gaps in research, knowledge and policy, from the perspective of healthcare providers.

In particular, this project aimed to:

- Identify the level of need for assistance with transport experienced by dialysis and cancer patients and examine how these needs are met;
- Identify and analyse the various non-emergency health transport services available to dialysis and cancer patients; and;
- Assess the extent to which transport issues specific to dialysis and cancer patients are incorporated into both treatment and transport arrangements.

1.2 Method

This study involved the collection of information from health professionals working in dialysis units and cancer centres from across New South Wales.

A health transport survey targeting dialysis units across Australia was developed and distributed by Kidney Health Australia (KHA) as part of an independent research project. The full results of this research are available on [Kidney Health Australia's website](#) and a copy of the survey can be found in Attachment 1. This survey was delivered via an online platform to dialysis units with more than 5 patients recorded as under their care on the Australian and New Zealand Dialysis and Transport Registry (ANZDATA). The Nurse Manager at each dialysis unit was sent an email link inviting them to participate and this was followed up by a phone-call where initial responses were not received. Responses were collected over a 10-week period between May 2014 and July 2014.

The results section of this report relating to renal dialysis is based on Kidney Health Australia's own analysis of its survey results, which can be found at Attachment 2.

KHA's dialysis survey was used as a foundation for a subsequent survey relating to cancer treatment and health transport, found at Attachment 3. The original survey was amended to apply to cancer treatment: several questions were added to the survey and a number of questions were altered while attempting to maintain comparability across surveys.

Contact details for cancer centres across NSW were sourced from the website *Canrefer*,¹¹ a directory set up by the Cancer Institute NSW to help general practitioners, other health professionals, patients and their family members find cancer services. Where email addresses were not listed on the site

¹¹ Canrefer 2014, *Canrefer - Chemotherapy*, Cancer Institute NSW, accessed 14 October 2014, <http://www.canrefer.org.au/service-type/chemotherapy>

NCOSS contacted the cancer centres via telephone to source a contact email address for each unit. An email inviting participation in the survey via an online platform was then sent to each email contact, with a request that it be forwarded to other health professionals working in the same unit. Responses were collected over a three-week period between 15 October and 4 November, 2014. The survey was also distributed via a number of professional networks including the New South Wales Social Workers in Oncology Group (OSWA NSW), Palliative Care NSW, and the Nursing and Midwifery Unit Managers' Society.

1.3 Analysis

Survey data was analysed in a step wise, two-stage process. Quantitative data was analysed via SurveyMonkey[®] utilising the online analysis function, producing tables and graphs for relevant survey responses. Qualitative data was inductively coded and dominant themes were identified, forming the basis for further discussion.

2 Context

In New South Wales people travelling to and from health services may receive assistance with transport in a number of forms. Along with the Ambulance Service, which provides health transport in emergency situations, non-emergency health transport services play a critical role in ensuring people are able to access the health system, and receive adequate care. The main types of non-emergency health transport include:

- **Travel subsidies**

The Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS) provides financial assistance to people who have to travel significant distances to access specialist medical treatment not available locally. The scheme is available to people travelling in private vehicles or on public transport, but is not available to people accessing other forms of subsidised travel such as community transport. Recent changes to IPTAAS by the NSW Government are likely to improve access to the service, particularly through reimbursements for those travelling long distances to undergo treatment.¹²

- **Community transport**

Community transport providers are funded to address the needs of people experiencing transport disadvantage. They receive the majority of their funding through the Home and Community Care program which provides services for people over the age of 65 living at home and younger people with a disability. Some Community Transport Providers also receive small amounts of funding from NSW Health or their Local Health District to deliver non-emergency health transport services.

- **NSW Local Health Districts (LHD) and Speciality Health Networks (SHN) transport**

NSW Health funds and directly provides health transport to varying degrees, which include Health Transport Units, own fleet vehicles, funding to non-government providers, and/or taxi vouchers for patients.

- **Non-Emergency Patient Transport (Green Fleet)**

NSW Health also provides Non-Emergency Patient Transport through its 'Green Fleet' of ambulances. This service is available to patients who require transport to or from a health facility and who are assessed as medically unsuitable for other forms of transport, yet are at low risk of deterioration. A centralised booking and dispatch system for all non-emergency patient transport is in the process of being implemented.

- **Private and other not for profit providers**

Taxi services, helicopter and fixed wing medical retrieval services, such as CareFlight, the Royal Flying Doctor Service of Australia and transport services and subsidiaries provided under the Department of Veteran Affairs, also provide health transport to patients. Additionally, a number of non-government organisations such as the Cancer Council of NSW and Aboriginal community-controlled organisations provide health related transport.

¹² See: <https://wnswlhd.health.nsw.gov.au/UserFiles/files/Hot%20Topics/150208%20IPTAAS.pdf>

2.1 Gaps in the Current System

If Health is going to build services that creates travel and transport issues then providing that transport should be part of the service and not left to volunteer and community services to stretch themselves unreasonably. Health provides more and more clinical services but not the infrastructure to support it.

- Survey respondent (social worker)

Despite the various forms of non-emergency health transport assistance available in NSW, the system as a whole is complex, poorly coordinated, and difficult to navigate. Some parts of the system are struggling to cope with growing demand and are chronically under-funded. As a result, many people are missing out on the transport assistance required in order to receive timely and appropriate health care.

Of particular concern is the fact that many of those people who experience transport disadvantage are likely to be those already experiencing the greatest socioeconomic and health disadvantage. Community transport has historically played an important role in providing transport assistance to people who do not have access to private transport or other public transport services. Yet community transport's ability to provide services to people experiencing transport disadvantage is limited by the eligibility criteria applied to the programs through which services are funded, and by inadequate levels of funding. This is discussed in more detail below.

Non-Emergency Patient Transport services also provide some assistance to people who have no other transport options. In most cases, however, this service is only available to people who are very unwell and who require specialised assistance. Furthermore, the existence of this service is not advertised to the public.

Effective treatment for both cancer and kidney failure frequently involves regular attendance at a hospital or clinic over a sustained period of time, and meeting the transport needs associated with this type of treatment can be particularly problematic. Services that have limited capacity to meet demand for assistance with non-emergency transport, for example, may be able to accommodate occasional requests for assistance such as an annual trip to a specialist, but they are unable to commit the resources required in order to meet requests for the transport assistance many people require in order to access frequent and ongoing treatment.

2.2 The role of Community Transport

Community transport attempts to fill some of the gaps in the non-emergency health transport system. However, it is not adequately funded to meet growing demand.. In 2007 alone, an estimated 90,000 requests to community transport providers for transport to health services were left unmet, with capacity constraints accounting for 75% of refusals.¹³ And in 2013-14, although 30 per cent of community transport trips were health-related, only 3% of community transport funding came from NSW Health.¹⁴

The service gap in terms of non-emergency health transport is problematic in and of itself; and it is also impacting community transport providers' capacity to deliver transport assistance for other purposes. For example, the HACC program – which accounts for 75% of community transport providers' annual funding¹⁵ – provides transport services to frail older people and younger people with

¹³ Cancer Council NSW, Council of Social Service of NSW (NCOSS), Community Transport Organisation (CTO) 2007, *No Transport, No Treatment*, pp.34-35

¹⁴ Community Transport Organisation (CTO) 2014, *Annual & Financial Report: 2013-2014*, Community Transport Organisation (CTO), p. 25.

¹⁵ Community Transport Organisation (CTO) 2014, *Annual & Financial Report: 2013-2014*, Community Transport Organisation (CTO), p. 25.

disability living at home. Yet while transport plays various roles under this program – such as supporting clients to maintain social contacts and supports and to be more independent in the community – these roles are at risk of being compromised by attempts to meet the growing and often more immediate need for health transport.

From 1 July 2015, HACC services for people over the age of 65 will be incorporated into the Commonwealth Home Support Programme (CHSP). A review of Community Transport undertaken to inform the development of this program found that increasing demand for non-emergency medical transport was having a negative impact on the availability of transport to support other aspects of the activities of daily living.¹⁶ The subsequent *Key Directions for the Commonwealth Home Support Programme Discussion Paper* therefore proposes focusing on community transport's role in enabling older people to access the community and suggests that transport for non-emergency medical purposes (for example, outpatient services such as oncology, renal dialysis and other hospital based treatments) should sit outside the scope of the Programme.¹⁷

While NCOSS recognises and supports the intent behind this proposal, we are concerned that should these changes occur in the absence of an agreement between the State and the Commonwealth government about responsibility for health transport they will exacerbate what is already a major service gap.

¹⁶ Verso Consulting (2014). National Review of Community Transport under the Commonwealth HACC Program: Final Report. Sydney: Verso Consulting.

¹⁷ Department of Social Services (2014). *Key Directions for the Commonwealth Home Support Programme Discussion Paper*. Canberra: Commonwealth of Australia.

3 Renal Dialysis Treatment

3.1 About chronic kidney disease

Chronic kidney disease (CKD) is the reduction or damage of a person's kidney function, and was the 9th leading cause of death in Australia in 2012 (up from 10th the previous year).¹⁸ Approximately one in ten Australians, or 1.7 million Australians aged 18 years and over, have indicators of CKD, such as "...reduced kidney function and/ or the presence of albumin in the urine". Often called a 'silent disease,' it is not uncommon for people to lose up to 90 per cent of their kidney function before noticing any symptoms.¹⁹ It's at this stage, when there is less than 10 per cent function left, that kidney replacement therapy (KRT) is needed to treat end stage kidney disease (ESKD). These therapies consist of dialysis or kidney transplants. In 2013, over 21,000 Australians were receiving KRT. Of these, the majority (11,774) relied on dialysis for treatment²⁰. Approximately 8,000 Australians undertake their dialysis treatment in a hospital or satellite centre.

3.2 Relationship between chronic kidney disease, ethnicity and socio-economic disadvantage

Chronic kidney disease is associated with individual level risk, or lifestyle, factors including:

- Obesity and being overweight
- Physical inactivity
- Poor diet
- Tobacco smoking
- High blood pressure
- Impaired glucose regulation

These risk factors tend to be more prevalent amongst people living in areas of lower socioeconomic status, as well as those living in regional, rural and remote areas.²¹ Overall, 13.5% of people with the lowest socioeconomic status have clinical evidence of chronic kidney disease compared with 8.4% of people with the highest socioeconomic status.²²

Marked disparities also exist between Indigenous and non-Indigenous Australians. In 2007-2008 Aboriginal and Torres Strait Islanders commenced dialysis or transport treatment for end stage kidney disease at almost 8 times the rate of non-Indigenous Australians, with the rate of Indigenous Australians commencing treatment expected to increase by 43% between 2008 and 2020.²³

Limited resources, lack of access to healthy, affordable foods, and living in cycles of food deprivation and overeating, account for poor diets and an increased likelihood of weight issues. Furthermore, lower income neighbourhoods may have fewer opportunities for physical activity, with safety

¹⁸ Australian Bureau of Statistics (ABS) 2014, *Causes of Death, Australia 2012*, accessed 9 September 2014, <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/3303.0main+features100012012>

¹⁹ Kidney Health Australia 2014, 'How Our Kidneys Work,' *Kidney Health Australia*, accessed 9 September 2014, <http://www.kidney.org.au/KidneyDisease/Howourkidneyswork/tabid/590/Default.aspx>

²⁰ ANZData2014 Summary-data to 31 December 2013, http://www.anzdata.org.au/brochures/Anzdata_Brochure_2014.pdf, accessed 4 February 2014

²¹ Australian Institute of Health and Welfare (AIHW) 2013, *Risk factors for chronic kidney disease*, Authoritative Information and Statistics to Promote Better Health and Wellbeing, Canberra, accessed 9 September 2014, <http://www.aihw.gov.au/ckd/risk-factors/>

²² Kidney Health Australia (2014) *State of the Nation: Chronic Kidney Disease in Australia*.

²³ Australian Institute of Health and Welfare (AIHW) 2013, *Chronic kidney disease and Aboriginal and Torres Strait Islander People*, accessed 17 September 2014, <http://www.aihw.gov.au/ckd/indigenous-people/>

concerns, poor amenity and the inability to participate in organised sports due to financial and transport constraints all contributing to inactivity. Higher levels of financial and emotional stress, limited access to health care and a greater likelihood of tobacco smoking are also more prevalent in lower socioeconomic communities.²⁴

3.3 About Dialysis

Renal dialysis involves the filtering of blood to remove excess salt, water and other harmful toxins from your body as your kidneys no longer have the capacity to do this important work. There are two main types of dialysis: haemodialysis, which uses a machine to filter the blood and may be performed at a dialysis unit, and peritoneal dialysis, which occurs inside the body, using your peritoneal membrane as a filter. Although 29% of kidney disease patients chose to dialyse within the comfort of their own homes,²⁵ this is not always possible due to financial constraints and the burden of caring for oneself. The majority of kidney disease sufferers therefore travel to a renal dialysis unit three days each week, with each treatment lasting between three to five hours per visit.

Many dialysis units use a shift system to organise treatment. Patients are usually allocated an early or late shift, three days per week. The early shift often begins at 7 a.m. and finishes around lunch-time while the late shift usually begins in the mid-afternoon and finishes between 7 and 8 p.m. In some units, the late shift starts later in the afternoon and can finish between 10 and 11 p.m.

Common side effects of dialysis treatment include low blood pressure, along with shortness of breath, abdominal cramps, muscle cramps, nausea, vomiting and fatigue.

²⁴ Smith, J.P. 1999, 'Healthy bodies and thick wallets: the dual relation between health and economic status,' *The Journal of Economic Perspectives*, 13(2), p.144.

²⁵ Kidney Health Australia 2014, Kidney Fast Facts, accessed 9 September 2014, <http://www.kidney.org.au/LinkClick.aspx?fileticket=J37xrMBt0PA%3d&tabid=589&mid=1960>

4 Cancer Treatment

4.1 About cancer

Half of Australian men and one third of Australian women will be diagnosed with cancer by the age of 85.²⁶ Cancer is a disease of the body's cells, caused by the uncontrolled division of abnormal cells in a part of the body. When cancer is malignant, these cells spread into surrounding areas and/or to different parts of the body. The number of cases of cancer diagnosed in Australia is projected to rise over the next decade and is expected to reach about 150,000 in 2020 – an increase of almost 40 per cent from 2007.²⁷ These increases will significantly be attributed to population growth and ageing.²⁸

4.2 Relationship between cancer, ethnicity and socio-economic disadvantage

Cancer outcomes vary across population groups, with research demonstrating that, for all cancers combined:

- Indigenous Australians experience higher incidence and mortality rates than non-Indigenous Australians, representing disparities in health that are 'unfair, unjust, unnecessary and avoidable'²⁹;
- People living in remote areas experience lower incidence rates of cancer than those living in major cities but also experience lower survival rates; and
- As a person's socioeconomic status decreases, incidence and mortality rates increase and survival rates decline.³⁰

Many of the known risk factors for cancer at the individual level, similar to chronic kidney disease, are related to specific lifestyle practices and are more prevalent in specific population groups, including Indigenous peoples, people with a lower socioeconomic status and those living in regional areas. Smoking, alcohol consumption, diet, obesity, and physical inactivity, are all examples of lifestyle risk factors linked to cancer. Other structural determinants, which structure the distribution of these risk factors, include: the distribution of economic resources, as well as related factors such as occupational exposure to hazardous environments, as well as environmental pollution.

4.3 About cancer treatment

There are over 100 different types of cancer. These may be treated through surgery, radiotherapy, chemotherapy, hormone therapy and alternative therapies, or by a combination of treatments. Radiation therapy and chemotherapy are two common treatments that often run over a course of time, such as over a few weeks. When accessing these treatments, patients may have to travel to a cancer treatment centre multiple days each week for sessions that last hours at a time. Radiotherapy uses X-rays to destroy or injure cancer cells so they cannot multiply, and can be given from outside or inside the body. Chemotherapy, on the other hand, is the use of anti-cancer drugs to destroy cancer cells. These can be given orally, through injections or through presenting drugs directly into an affected organ or tissue.

²⁶ Cancer Council Australia 2014, *Facts and Figures: Cancer in Australia*, accessed 9 September 2014, <http://www.cancer.org.au/about-cancer/what-is-cancer/facts-and-figures.html>

²⁷ Australian Institute of Health and Welfare (AIHW) 2012, *Cancer incidence projections: Australia, 2011 to 2020*, Cancer Series, No. 66, Canberra: AIHW.

²⁸ Ibid.

²⁹ Whitehead, M. (1992). 'The concepts and principles of equity in health,' *International Journal of Health Services*, 22(3): 429–45.

³⁰ Australian Institute of Health and Welfare (AIHW) 2012, *Cancer in Australia: An overview 2012*, Cancer Series, No. 70, Canberra.

Both radiotherapy and chemotherapy have a range of possible side effects that can usually be managed with medication. Common side effects include fatigue and nausea. Chemotherapy can result in vomiting, diarrhoea or constipation (usually due to anti-nausea medication), muscle weakness and dry or tired eyes, while radiotherapy can leave patients with red, dry or itchy skin, swelling and a cough or shortness of breath.

5 Results

5.1 Respondents

80 responses were received to the cancer and health transport survey; respondents included nurses (41%), social workers (38%), care coordinators (20%), and one receptionist.

For the dialysis and health transport survey, 200 units were contacted and 105 complete surveys were received, representing a national response rate of 53%. In NSW, 39 units responded (a response rate of 25%).

5.2 Difficulties with transport

Survey responses suggest that a large proportion of cancer patients and dialysis patients find it difficult to access treatment.

81% of respondents indicated that at least some of their patients undergoing treatment for cancer encountered difficulties in arranging transport (see Figure 1 for a more detailed breakdown). Five per cent of respondents said that more than half of their patients encountered difficulties arranging transport.

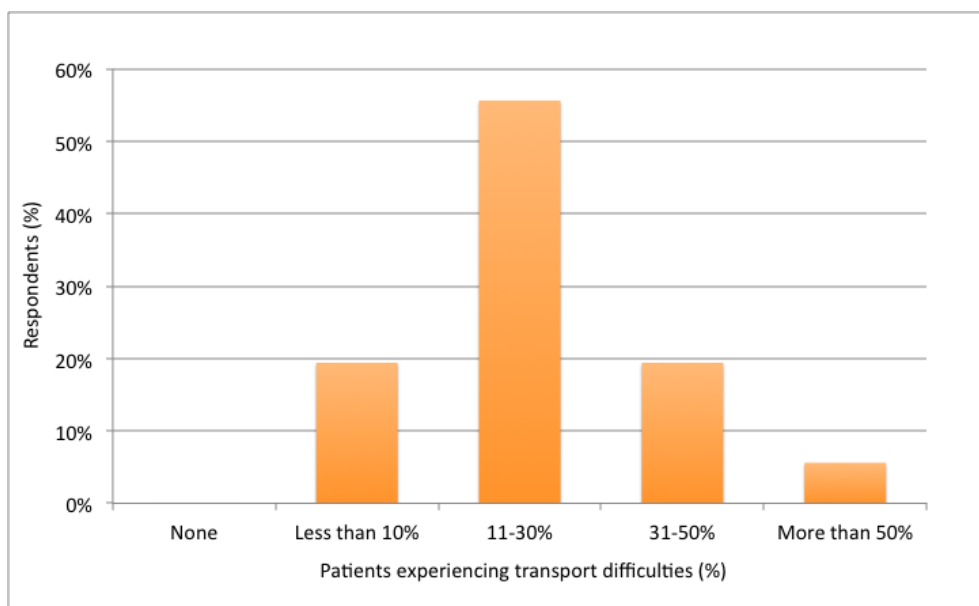


Figure 1: Proportion of patients experiencing difficulties with transport to cancer treatment (n= 80)

Respondents reported that transport issues were more likely to be experienced by the following population groups (see Figure 2):

- Older people (77% of respondents);
- People on low incomes (74%);
- People living in rural and regional areas (66%);
- People with disability (44%)
- Aboriginal and Torres Strait Islander people (29%); and;
- People from culturally diverse backgrounds (21%).

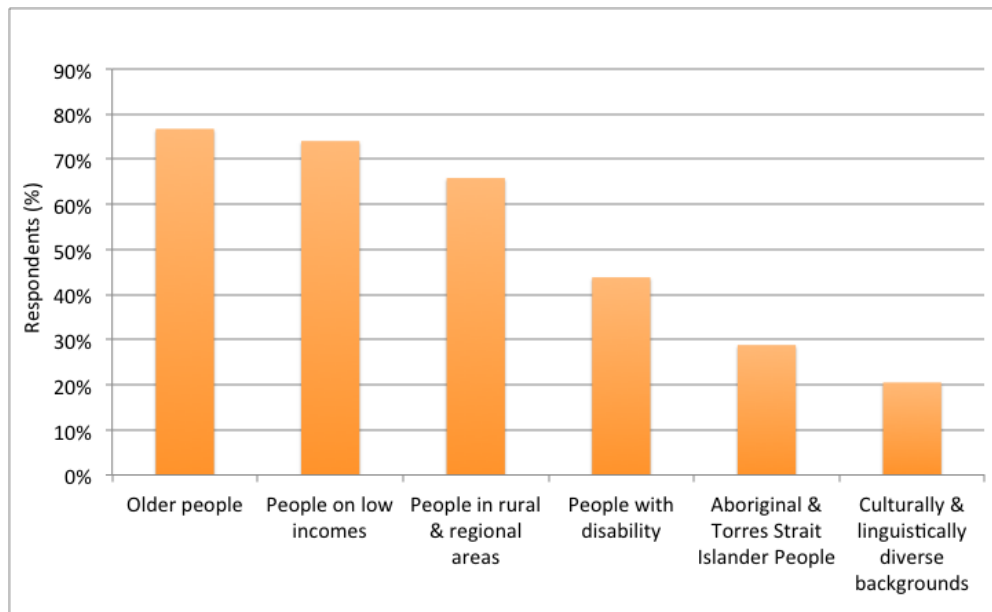


Figure 2: Groups of patients more likely to experience difficulties with transport to treatment (n=73)

Encouragingly, 90% of respondents discussed transport options with patients when exploring treatment pathways. Whilst some reported no transport issues for their patients after their intervention, 84% of respondents indicated that some proportion of their client base experienced ongoing transport issues after commencing treatment.

The survey results suggest that health transport problems are not isolated to just a small proportion of patients: 77% of dialysis units identified some level of difficulty for patients on dialysis in accessing transport, while more than half of the cancer care professionals estimated that up to 30% of their patients had difficulties arranging their own transport to and from treatment.

These findings suggest that transport difficulties can be either exacerbated, or reduced with access to the right services. Developing solutions to clients' transport problems, however, often involved a significant investment of time and resources. Furthermore, both surveys suggest that a small but significant proportion of patients still experience difficulty with transport even after all options have been explored.

5.3 Transport options

Cancer treatment health professionals said they were able to offer their patients a range of transport options, addressing differing needs during treatment. Referring patients to other forms of community transport was the most commonly utilised option at 85%, followed by referral to HACC community transport (32%), use of non-emergency patient transport (24%) and use of ambulances (15%). Four respondents said their unit did not offer any transport assistance (Figure 3).

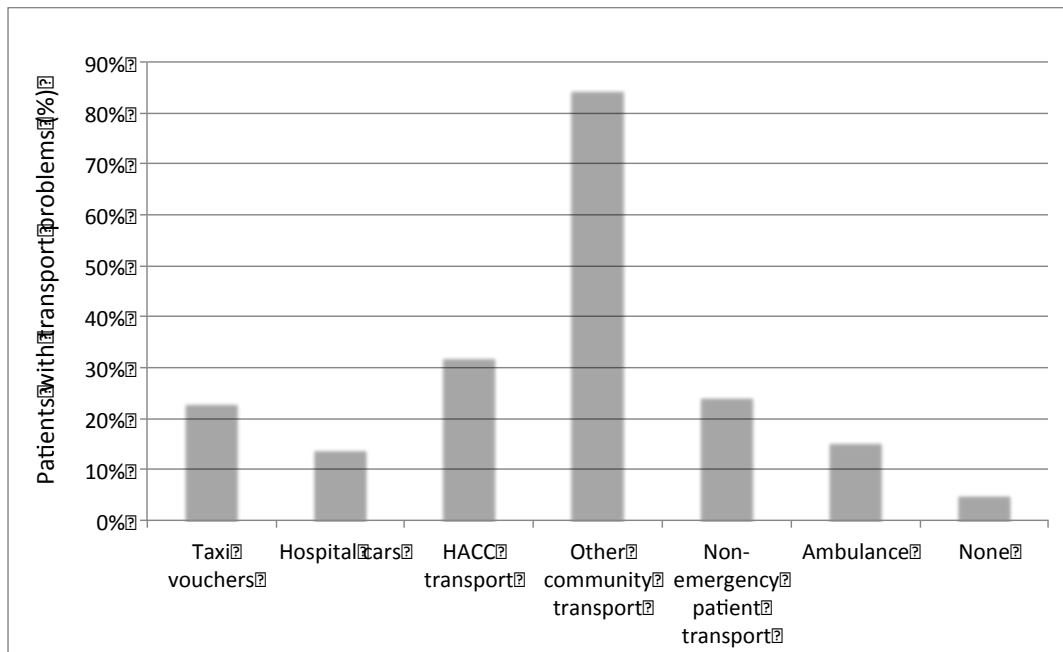


Figure 3: Types of transport offered to cancer patients unable to provide their own transport (n=65)

For patients experiencing side effects from treatment, such as nausea or fatigue, 52% of cancer units said they were unable to arrange alternative transport at short notice. Qualitative responses indicated that when assistance was offered, it came in the form of taxi vouchers, community transport or transport operated by the Cancer Council or Leukaemia Foundation.

The dialysis survey showed that nationally, community transport was the most commonly used type of transport, with 44% of units referring to community transport. In NSW, however, taxis were used by a slightly higher number of units, followed by community transport and indigenous organisations.

5.4 Patient costs

The majority of respondents to the cancer survey (64%) indicated that free parking was available to cancer patients being treated by their unit.

However, qualitative responses identified parking as a major transport issue. Many respondents said that although free parking was available, the number of spaces allocated to free parking for cancer patients was limited and failed to meet demand. Many patients therefore competed with visitors for parking; paid for parking; and/or were forced to walk long distances to reach the hospital from their parking space. For instance, one respondent, a social worker, commented:

Whilst parking is theoretically provided free of charge to patients having treatment, parking spaces are extremely limited and most people still experience difficulties finding a spot. This may force them to go to paid parking, which is on a sliding scale depending on time, but is up to \$16 per day. Additionally, paid parking is often full for much of the day.

In addition, parking costs were very high in a number of locations, with nine respondents indicating that parking costs were in excess of \$15.00 for one radiotherapy or chemotherapy treatment. All eight of these responses came from metropolitan hospitals located in Sydney, highlighting the costs associated with accessing cancer treatment in urban areas.

Although the dialysis survey showed that free parking was available at 80% of dialysis units, 66% indicated that there were not enough spaces to meet demand, and 25% said that the lack of dedicated dialysis parking spots was problematic. And although free parking was available at the majority of units, a significant proportion said parking was expensive, with 1 in 10 dialysis units reporting that parking cost \$10-\$15 for each treatment session. The highest parking costs were recorded in NSW, where parking costs exceeded more than \$15 per visit at two dialysis units.

5.5 Service costs

The majority of respondents to both surveys said they were unable to estimate how much transport provision cost their unit per week.

The qualitative responses, however, indicate an enormous reliance by the health system on not for profit organisations that provide the bulk of transport assistance for cancer patients. Many respondents indicated their gratitude for the staff and volunteers who operate these services, but also expressed a fear that these resources are increasingly stretched due to the growing number of patients.

It was not possible to estimate how much dialysis units and cancer centres spend on health transport based on the responses to both surveys. Of the 18 dialysis units who were able to provide information on transport costs, 8% reported spending less than \$100, 6 units spent \$100-\$999 and 5 units spent between \$1000 to \$2000 per week. Qualitative feedback also suggested that these costs increased during peak periods, such as school holidays and public holidays, when access to community transport was restricted.

5.6 Other Issues

Responses to both surveys suggested that community transport operating hours were a major issue, with many community transport providers only operating within limited hours. The length of time taken for treatment to be administered meant that many patients were not able to utilise community transport.

The qualitative responses to both surveys also suggested that waiting times and service unpredictability were significant transport issues. For example, respondents to both surveys said that patients using the non-emergency ambulance services were often required to wait for between four and five hours after treatment before transport back home became available.

Qualitative answers also suggested that patients from regional, rural and remote areas experience additional transport challenges including lack of access to suitable public transport; fewer taxis; higher community transport fees due to longer distances between home and hospital; and lack

The role of social workers

"...I am the only oncology social worker at my unit but organising transport is taking over my job and it is not part of my job description..."

"I am a social worker at a tertiary oncology hospital and spend a significant amount of my time arranging and discussing transport with patients. This means there are a huge number of other patients whom I am not able to see (but often have been referred) for other reasons, which have a higher social work priority. However, if patients don't have transport they can't get to treatment. It would have a huge impact on social work service and patient care if there were other staff, such as a transport officer, that could assist patients in this way."

of access to volunteer based services run by charities due to lower population densities.

A number of respondents – particularly nurses and social workers – also noted that assisting patients with transport consumed significant amounts of their time and detracted from their capacity to perform other important duties. As one respondent, a social worker, asserted that community transport providers:

[M]eet [...] a variety of needs and is not only available for just cancer patients. Also they are finding transporting patients for health related issues taking them away from their core business. I am the only oncology social worker at my unit but organising transport is taking over my job and it is not part of my job description.

A number of respondents suggested that it would be more efficient to employ a transport coordinator whose role it was to organise transport, while others suggested that transport services should be funded to coordinate access to treatment.

Violet's story

"I heard about the Community Transport service through a friend of mine when I found out I had bone marrow cancer.

I have to get weekly treatment now at Concord hospital and there's no public transport from where I live to Concord. I've now had 15 of the 30 treatments that I need. If I didn't have access to Community Transport, I'd be up the creek without a paddle. I just couldn't get to my treatments.

I go every Wednesday, they pick me up at 9:30 and I try and get the 2pm service home again. It only costs me \$10 to get there and back.

It's a very important service, not just for me but for a number of other elderly people who live in the area. We just couldn't get around otherwise. I know a lot of other people who use it for shopping or other errands.

It's better for people to be able to stay at home for as long as they want, and without services like this it wouldn't be possible."

6 Conclusion and recommendations

People receiving treatment for cancer or chronic kidney disease are often required to travel frequently, over sustained periods of time and for long distances. For many people – and particularly for vulnerable and disadvantaged populations – making the necessary transport arrangements can be difficult or impossible.

Problems with transport can compromise the effectiveness of treatment, contributing to poorer outcomes for some population groups, and exacerbating existing inequities in health.³¹⁻³² They can also mean that the treatment in itself has a much more detrimental impact on people's lives. For example, transport problems create additional stress, result in additional costs, and make accessing treatment much more time-consuming. This affects individuals, and also their family and friends. It limits people's opportunity to engage in other activities such as employment whilst accessing treatment.

NCOSS and CTO have recommended that the NSW Government ensure that transport does not continue to act as a barrier to accessing healthcare in NSW. On the basis of the findings of this report, NCOSS and CTO recommend the following actions:

1. That NSW Health develop clear information pathways for clients concerning their transport options, including in clinical and community settings.
2. That all political parties commit to supporting a needs assessment for all non-emergency health transport services in NSW and actively consider:
 - a. the potential benefits gained by contracting health transport services for ambulant patients to a properly resourced community transport sector; and
 - b. an immediate increase in funding to community transport providers to meet the growing need for non-emergency health transport services
3. An immediate, significant expansion of clinic parking to ensure that it is more widely accessible and provided free of charge.

³¹ New Zealand Ministry of Health (2002). *Reducing Inequalities in Health*. Wellington: New Zealand Ministry of Health, p.15

³² Syed, S.T., Gerber, B.S., Sharp, L.K. (2013) 'Traveling Towards Disease: Transportation Barriers to Health Care Access,' *Journal of Community Health*, 38(5): p. 989

7 Attachments

- 1: [KHA Survey \(to and from dialysis\)](#)
- 2: [KHA Transport Survey Analysis 18 Nov 14](#)
- 3: [NCOSS Cancer Treatment Transport Survey.](#)