



Victoria
125 Cecil Street
South Melbourne VIC 3205
GPO Box 9993
Melbourne VIC 3001

www.kidney.org.au
vic@kidney.org.au
Telephone 03 9674 4300
Facsimile 03 9686 7289

**KIDNEY
HEALTH
AUSTRALIA**

Kidney Health Australia Survey: Challenges in methods and availability of transport for dialysis patients

The purpose of this survey was to describe the transport options provided by dialysis units for consumers who are unable to provide their own dialysis transport, and to outline the costs to consumers and dialysis units for these services.

This analysis is important for providing information to dialysis units and is critical to Kidney Health Australia's advocacy work regarding service gaps and/or areas of best performance in dialysis patient transport.

Introduction

Kidney Health Australia is the peak national body for kidney disease and advocates on matters relating to the welfare of kidney stakeholders and the delivery of services to people affected by Chronic Kidney Disease (CKD) in all its stages. Furthermore, Kidney Health Australia has close ties with consumers/patients, the medical community, and dialysis units around the nation. Kidney Health Australia is committed to achieving its mission through engaging with dialysis sector professionals and consumer stakeholders in all initiatives and linking with other key chronic illness programs in an integrated way.

Kidney Health Australia's work is carried out in consultation with the nephrological community and with significant input from our national network of consumers. In its 46-year history, Kidney Health Australia has built a substantial evidence base to support its activities, and strong support from the community to continue to initiate efforts to reduce the incidence and impact of CKD.

It is with this mind that Kidney Health Australia sought input from dialysis units around the country on the issue of transport for dialysis patients.

Patients with end-stage kidney disease (ESKD) face many challenges in undertaking life changes necessary to accommodate a dialysis routine. Approximately 8,000 Australians undertake their dialysis treatment in a hospital or satellite centre. This routine, at minimum, encompasses three weekly visits to a hospital or dialysis centre for a four to five hour dialysis treatment.

ESKD is strictly unique in the sense that through the requirement of dialysis, it is the only condition with a repeating high frequency and potentially lifelong dependency on transport to survive. Feedback from consumers and dialysis units has indicated that access and availability of transport to dialysis is an ongoing issue.

Method of Survey

Kidney Health Australia used an online platform to deliver a survey to all 200 Australian dialysis units with more than 5 patients recorded as under their care on the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA). The survey examined multiple dimensions of patient transport, including method of transport, current usage and gaps in provision of current transport methods. Questions were framed to provide the ability for Kidney Health Australia to reveal what issues were

at the forefront of dialysis units' concerns and are causing financial implications to patients, and the health system overall. The survey also incorporated a number of open-ended questions to collect qualitative experiences in patient transport.

The Nurse Manager at each dialysis unit was sent an email link inviting them to participate. This was followed up by a phone-call where initial responses were not received.

Results

Demographics

A total of 105 surveys were received, which represents a national response rate of 53%. 100 were actually completed and included in the analysis, 5 surveys did not provide any data in their responses so they were excluded in the analysis. Based on current data provided by the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) these units who dialysed a total 4168 patients represented 52% of total centre-based patients within Australia. The jurisdiction response rate varied from 100% in the ACT to 25% in NSW (see Figure 1). The total number of responding units is shown in Figure 2. It can be seen that the number of responding units is low in some jurisdictions, and therefore caution should be taken when interpreting their results.

Figure 1

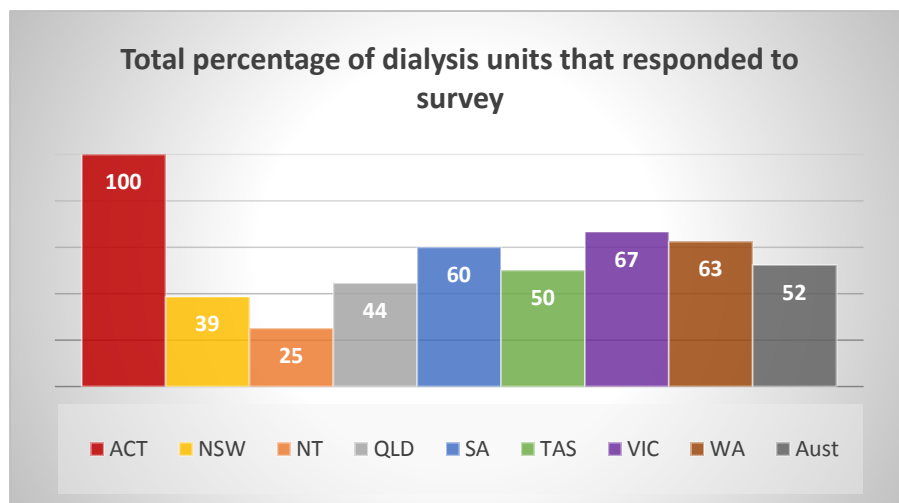


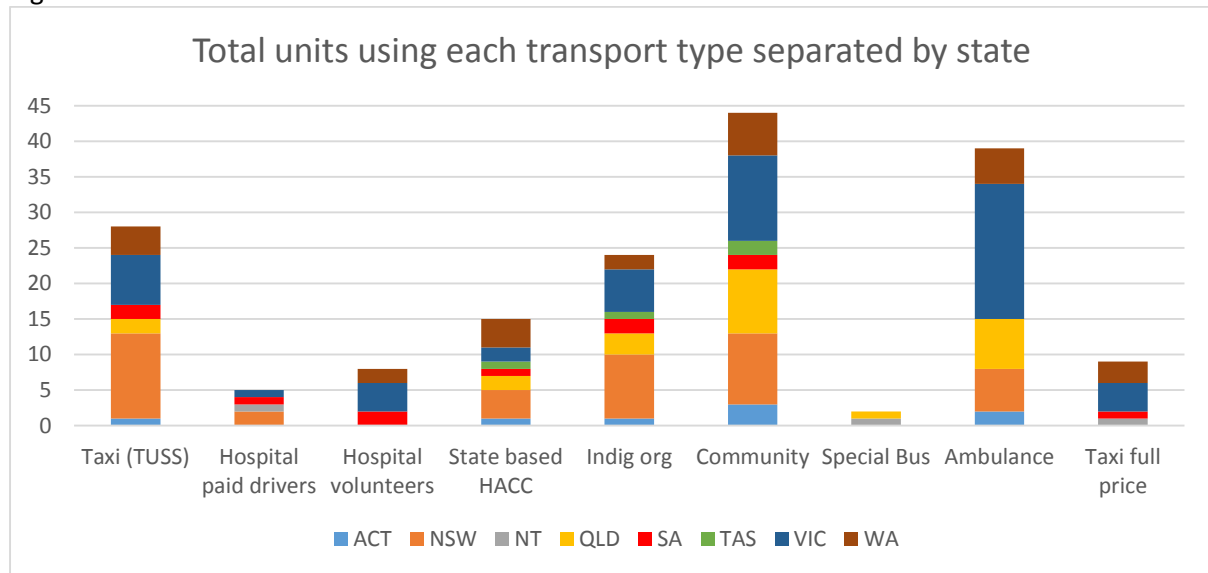
Figure 2

	<u>Total units</u>	<u>Responding units</u>	<u>Percentage</u>
ACT	4	4	100
NSW	62	24	39
NT	8	2	25
QLD	27	12	44
SA	10	6	60
TAS	4	2	50
VIC	60	40	67
WA	16	10	63
Australia	191	100	52

I. Types of Transport Used

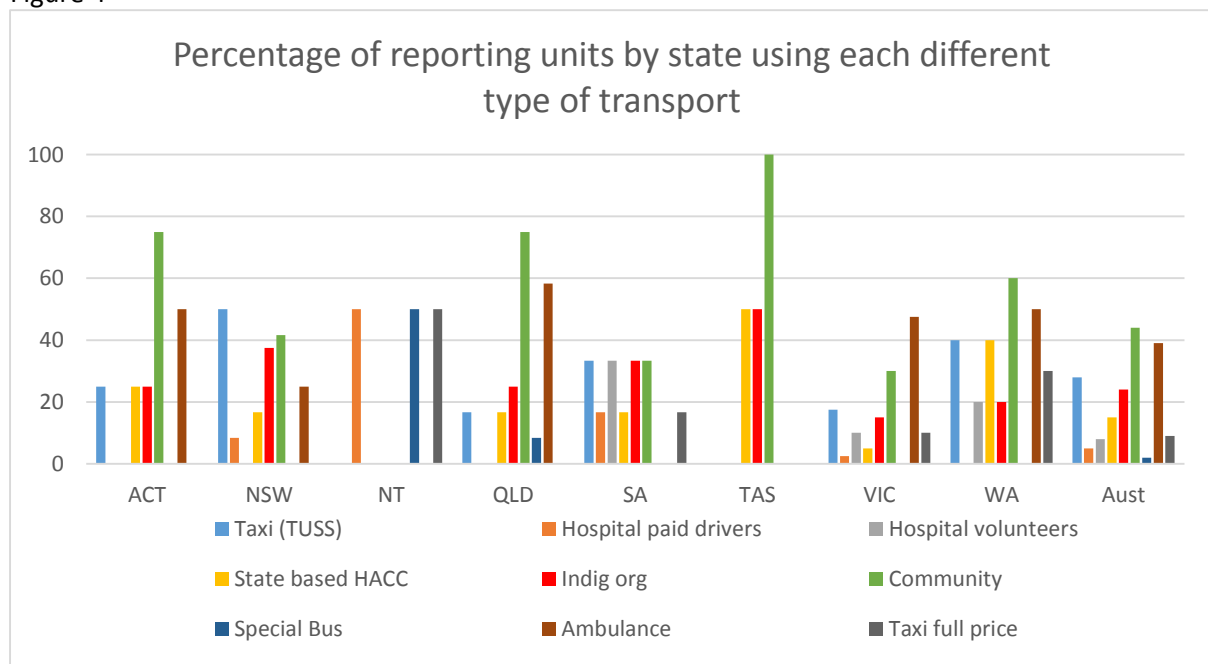
The survey showed that community transport is the most common source of dialysis transport offered (44% of units), followed by ambulance services (39%) and taxis (36% for full price and half-price combined) (Figure 3). However only 9% of units reported giving taxi vouchers to meet the full price of a taxi fare. It was more frequent (28%) for units to offer taxi vouchers to those who are eligible for the subsidised taxi voucher scheme.

Figure 3



The results demonstrate the wide variability in transport usage between the jurisdictions. Notably three jurisdictions (based on those surveyed) provide no ambulance transport. (Figure 4).

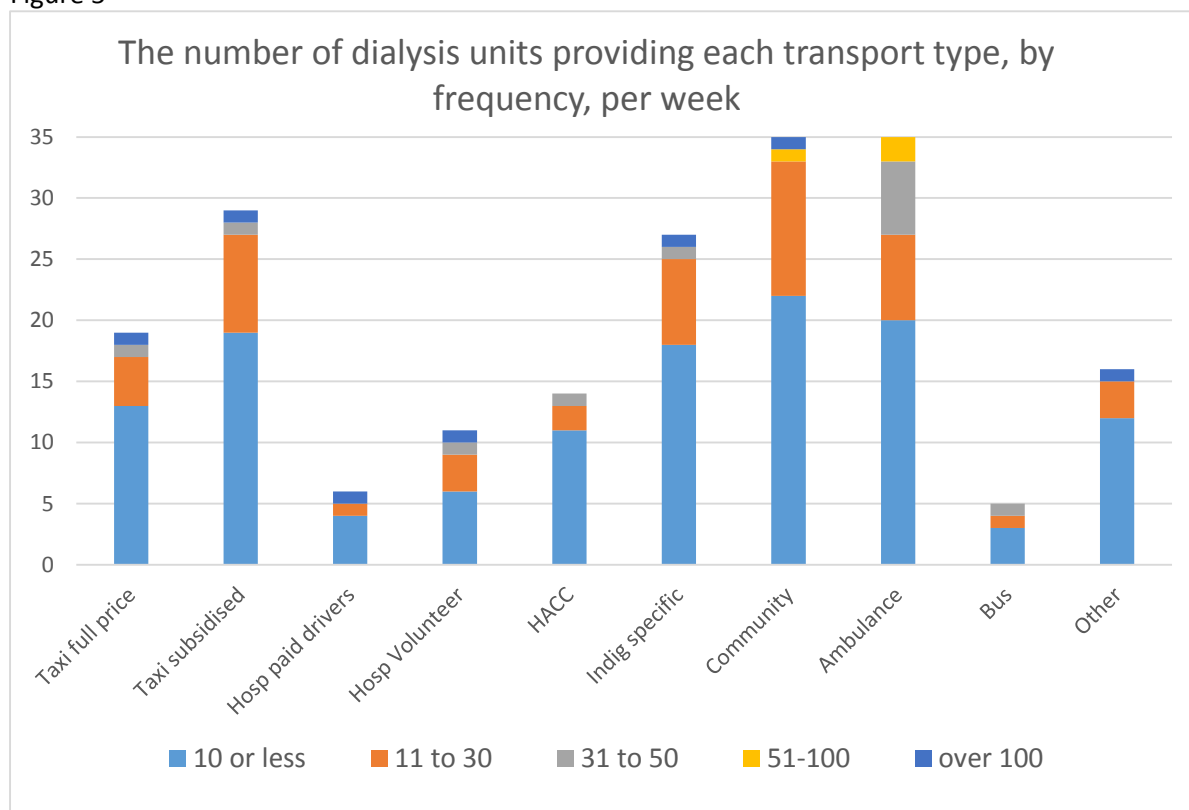
Figure 4



Frequency of usage of each transport type

The overall patient journeys provided per week by the responding units is estimated at 2500. This represents an average 1.7 journeys (where journey equals one way trips) per dialysis patient per week in this particular cohort. This does not include journeys assisted by relatives.

Figure 5



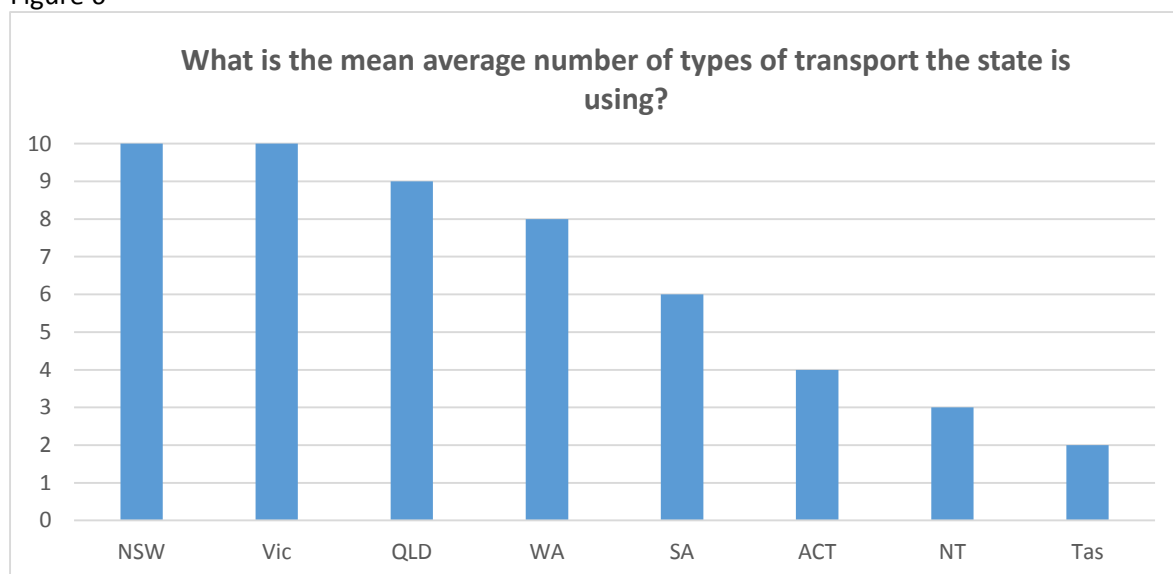
As shown in Figure 5 the majority of units use each transport type 10 times or less per week. High frequency usage (more than 11 times) was reported for ambulance transport (15 units), community transport (13 units) and taxi vouchers (16 units).

A jurisdictional breakdown of estimated number of patient journeys using each form of available dialysis transport is provided in Appendix 1.

Number of types of assisted transport being used within the state

As shown in Figure 6, there is variance between jurisdictions in the average number of transport services offered by dialysis units in each state/territory, ranging from an average of 10 different types of transport options in NSW and Victoria, to 3 or fewer options in NT and Tasmania. However each unit uses on average uses only two different types of transport (range 1-2.6).

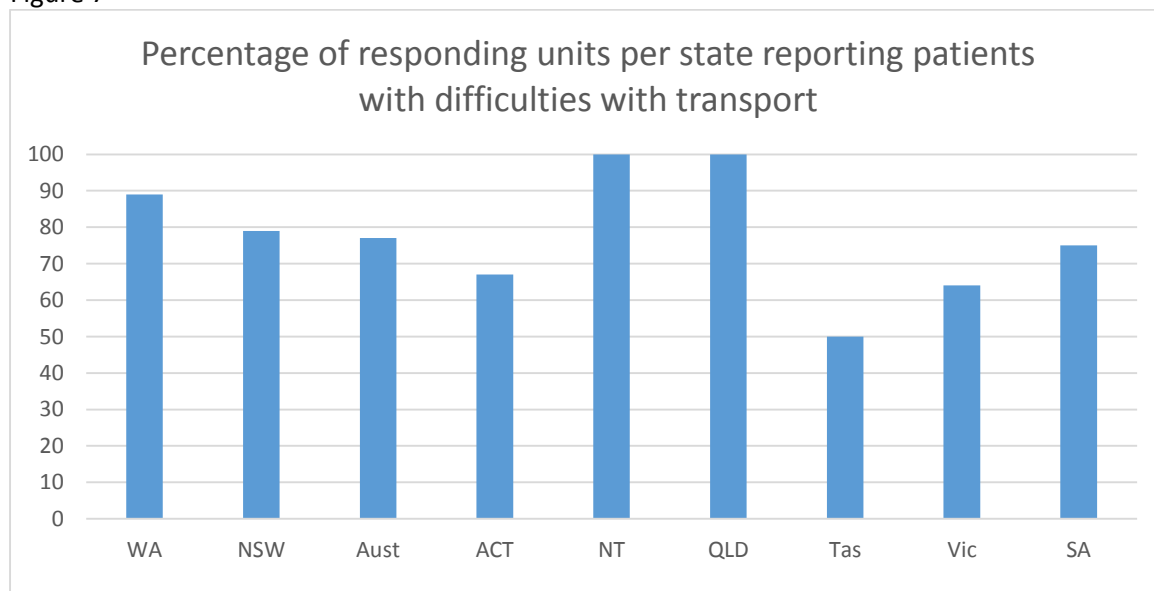
Figure 6



II. Accessibility of Transport

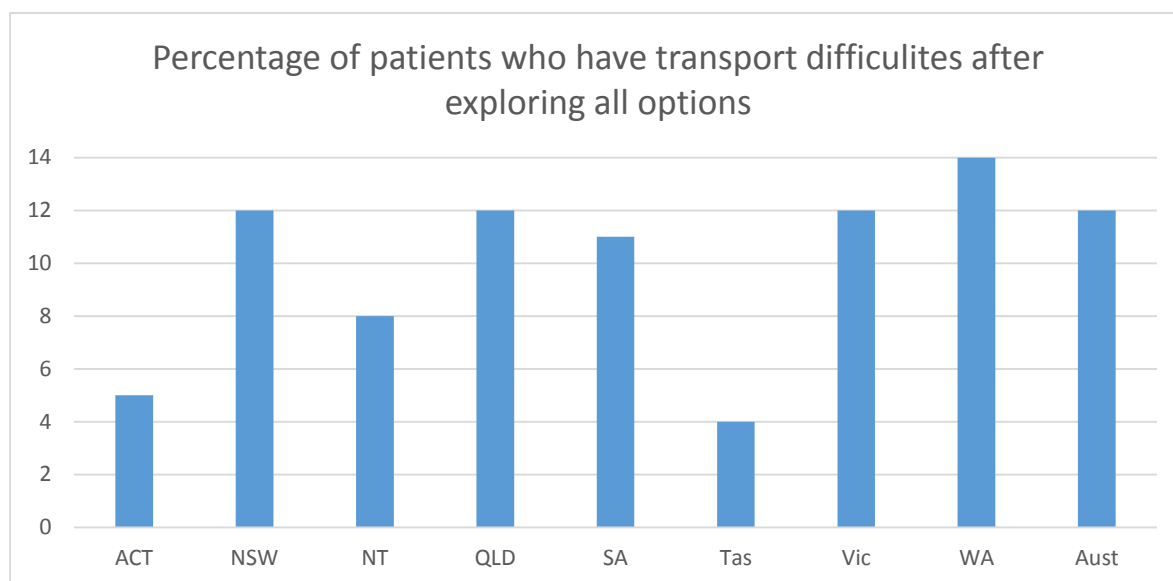
Accessibility of transport was one of the largest issues identified by the survey results. As shown in Figure 7, across Australia 77% of the 81 dialysis units who answered this question identified some level of difficulty for patients on dialysis in accessing transport and these were in every jurisdiction.

Figure 7



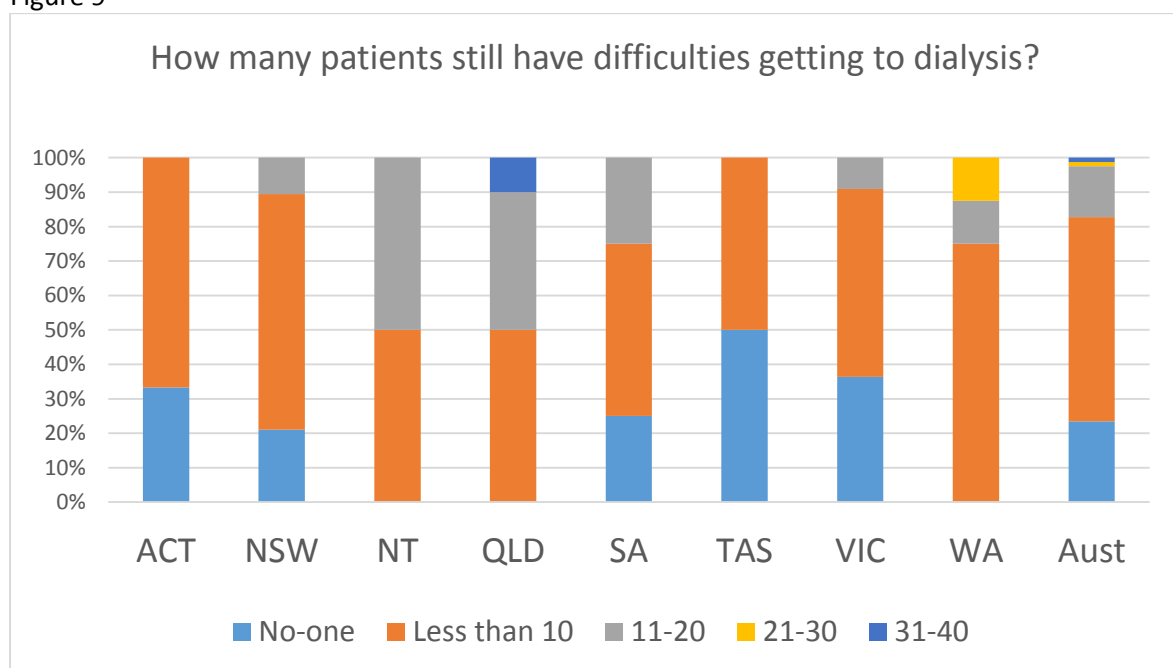
It was calculated that overall dialysis units perceive an average of 12% of patients have transport difficulties after exploring all options (Figure 8). As shown in Figure 8, dialysis units in WA report that 14% of patients experience ongoing transport difficulties.

Figure 8



One dialysis unit in Queensland indicated 31-40 people have ongoing issues accessing transport and one unit in WA has 21-30 patients with ongoing issues. Ten dialysis units from five states reported 11-20 patients with ongoing issues.

Figure 9



Qualitative answers revealed that when trying to utilise a service, return journeys have been identified as more difficult to obtain. Around 25% of dialysis units identified the unpredictability of ambulance arrivals and departures for transport to be an ongoing issue. The same issue has been identified for community transport outside of business hours. The availability of transport in the

evening is a particular concern if after 5pm, or if a dialysis appointment falls on a public holiday. Community transport and volunteer drivers were an important part of the transport provision which leads to uncertainty for patients. These services are often not available outside business hours, public holidays or at the weekend. Three units specifically identified that the availability of transport can be unreliable and the waiting time can be long.

Lack of transport availability is felt more acutely in rural areas. The lack of subsidised transport for regional and rural patients was mentioned by 46% of dialysis units as a concern (mentioned more with QLD and WA dialysis units).

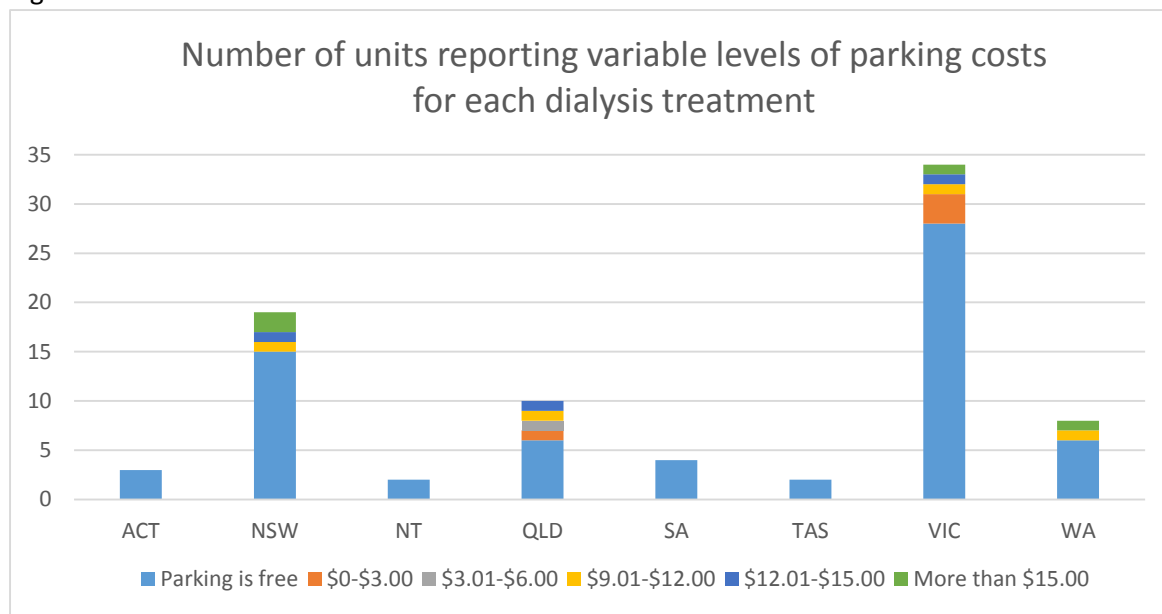
Waiting Times

Transport issues can contribute to significant delays and waits for dialysis patients. The qualitative feedback obtained in the survey indicated that it is not unusual for patients who drove themselves or who were brought in to the unit by relatives to spend up to two hours waiting for dialysis to be initiated - this delay being unrelated to transport issues. Those who travelled by ambulance were found to spend up to four hours of their dialysis day waiting for dialysis to commence at the start and for transport home at the end of dialysis.

III. Parking

The survey identified around 10% of dialysis units indicated patients pay \$10-\$15 for parking during dialysis treatments. This is a significant cost when considering the regularity of dialysis treatments, and the socioeconomic status of dialysis patients. As shown in Figure 9, the survey showed that parking is free for dialysis patients from 80% of units. The highest cost for parking was recorded in NSW, where two dialysis units cited more than \$15 per visit, while both VIC and WA reported one unit each where the cost was above \$15 per visit.

Figure 10



The survey found that for costs of parking:

- NSW: 21% of respondents indicated parking costs at minimum \$9 per visit (up to \$15), meaning a cost of up to \$45 per week

- WA: 25% of respondents indicated parking costs at minimum \$9 per visit (up to \$15), meaning a cost of up to \$45 per week
- QLD: 40% of respondents indicated parking costs at minimum \$3 per visit (up to \$15), meaning a cost of up to \$45 per week
- VIC: 17% of respondents indicated parking costs at minimum \$3 per visit (up to \$15), meaning a cost of up to \$45 per week

The other states did not report fees for parking.

The qualitative answers also found that:

- 66% of all dialysis units surveyed who identified free parking was available on site indicated there was not enough spaces to meet demand.
- 25% of respondents in the qualitative section of the survey indicated issues for patients due to no dedicated dialysis parking onsite.
- Where free parking was available, there was often no dialysis specific parking - meaning often the spots are taken on a first come first serve basis.
- Parking close to hospital was reported as an issue for at least three dialysis units, all in different states/territories.

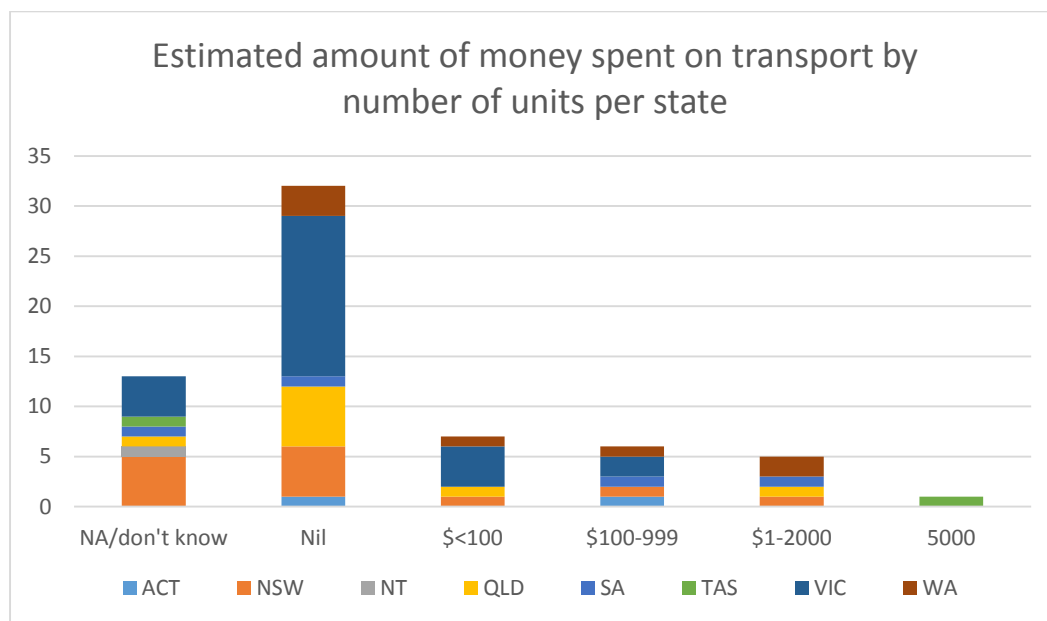
IV. Cost of transport to dialysis units

Providing transport as a service to patients is a significant cost but this cost is not directly born by the dialysis units. Only 18 units reported any costs and as Figure 11 shows, the direct costs known to dialysis units per week, are with 8% spending less than \$100, 6 units spending \$100-\$999 and 5 units spending between \$1000-\$2000 per week.

Dialysis centres also identified significant ebbs and flows in access to both hospital community transport, during peak periods such as school holidays and public holidays. This incurred cost increases due to lack of community transport options forcing centres to use other methods (such as a taxi voucher system).

Qualitative feedback provided by two units is that rural and regional centres overall identified a higher cost for patient transport due to longer distance of travel required by some patients. This is compounded by availability of taxis in regional areas being much less frequent than metropolitan counterparts.

Figure 11



Discussion

Dialysis is a unique treatment – the only treatment for which there is both a lifelong dependency and high frequency of travel required to survive. Understanding the barriers and problems with current transport methods will assist those who utilise the system and those who assist patients to navigate the system and plan transport.

This survey has found a high variance in transport provision and parking with a lack of equity across the various jurisdictions in Australia. Expensive options, such as ambulance, are widely used and community services are extremely varied. Despite this 14% of patients still have difficulty getting to or home from dialysis treatments.

These challenges in transport have a profound impact on the quality of life and treatment burden for those undertaking dialysis. For dialysis units it represents a significant issue with regards to patient management and cost.

Providing transport as a service comes at a significant cost, and as previously stated, overall patient journeys provided per week by the responding units is estimated at 2500. The data is showing a dichotomy within the results in that we know the number of high frequency of journeys taken, yet the amount of money spent on transport by unit per state is reported as low to nil. It is unclear exactly how the expense process is occurring for transport to dialysis units, as the data shows no direct costings. The data does not suggest that there are nil costs associated with transport to each unit, rather that the zero response by some indicates they are not paid for by the renal unit.

In the qualitative responses, one unit specified that outside of clinical costs, transport is one of the single biggest burdens on dialysis units and patients.

Empowering dialysis patients through adequate compensation for using their own transportation, and/or providing free parking to all patients could go a long way to assisting with the cost of transport to each dialysis unit.

Impact on unit functioning

Patient transport is a critical enabler – the step without which dialysis and therefore treatment – would not occur. The average patient required 1.7 assisted journeys per week. From the health care system perspective, inadequate patient transport means higher administration costs with potential problems to the delicate scheduling required for rolling dialysis appointments, particularly when capacity is strained. For example, one of the surveyed dialysis units identified that community transport or taxi services not running on time can cause significant delays for future dialysis appointments. Also, a dialysis unit identified that not having adequate parking at a hospital can cause great concern for health care workers watching elderly or frail post-dialysis patients being forced to walk long distances back to their vehicle.

Ambulance use

Patients who access ambulance transport typically do so because they are people who are infirm or immobile and do not have relatives to bring them in. Ambulances are booked for specific times, but because they are an emergency service, they offer a pick-up that is within two hours of the specified time. In reality it is often a lot longer than that, with outward journeys being more difficult to secure. Ambulances also run at a significant cost to state health care systems and are often used in the absence of other transport types being available. The inconsistency of ambulance use and the known consistent demographics of dialysis patients would suggest that ambulance transport may be being used where other options are not available.

Unaffordable burden of cost

On the patient side, many patients are required to pay for parking or transport in addition to all the out-of-pocket costs and socioeconomic disadvantage they may already be experiencing. The recently published State of the Nation report highlighted that lower socioeconomic status is associated with a higher prevalence of CKD; 13.5% of people with the lowest socioeconomic status have clinical evidence of CKD compared with 8.4% of people with the highest socioeconomic status.¹

The high frequency and length of time of dialysis places an additional burden to carers or family members that may need to provide transport when no other methods are available, or they are considered too expensive. Subsidy rates on kilometres for personal transport are inadequate in most states; all are well below the NSW NRMA standard operating cost for small and medium cars. Variations in state run-patient transport scheme subsidies can vary significantly with kilometre reimbursements ranging from 16 cents to 30 cents, as do the minimum threshold limits.

Parking

Jurisdiction dictates whether parking must be paid for or not. Kidney Health Australia is a strong advocate for free parking at dialysis units for all dialysis patients. In recent weeks the cost of parking

¹ Kidney Health Australia, "State of the Nation" 2014
<http://www.kidney.org.au/LinkClick.aspx?fileticket=WfW5Z6H5Rt4%3d&tabid=846&mid=1962>

has been the subject of recent correspondence from Kidney Health Australia to various state governments.

Alternative models

One model worth further consideration applies in Western Australia where there is a private dialysis facility that has been allowed to use its State Government funds (for subsidised taxis) to purchase a vehicle, and employ a part time driver and deliver a much more flexible, reliable and successful transport solution. This strategy is also being used in some Indigenous communities.

Summary/conclusion

Dialysis units who responded to this survey confirmed that the patient transport system is largely inconsistent, difficult to navigate and inadequate for patients who use both private and other transport methods.

There is little evidence of work by governments to ensure national consistency in the area of dialysis patient transport. Additionally, as with many other sections of the health sector more broadly those in regional and rural areas are more disadvantaged than those living in metropolitan areas.

The survey has outlined scope for future opportunities for policy in order to pursue improved outcomes for those on dialysis. It is imperative that changes occur for both the well-being and quality of life for those travelling to dialysis and also for the health care system and dialysis units across the country.

Kidney Health Australia therefore recommends the following be applied in the area of dialysis patient transport:

- 1. An analysis of transport costs by modality should be completed within each state to determine the most cost-effective model for dialysis transport provision.**
- 2. Parking at dialysis centres (regardless of location) should be provided in designated spaces, clearly signed, and provided free of cost.**
- 3. New dialysis units should always be considered with patient transport access and parking at 'front of mind' to governments. Proximity to road/transport/community links will reduce the burden and difficulties for units and patients.**
- 4. Patients travelling longer distances should be adequately compensated for out-of-pocket expenses when travelling to and from dialysis, such as through kilometre reimbursements that are on par with NRMA costings of running a vehicle.**
- 5. Dialysis units should maintain data about the transport services that patients are accessing. Issues surrounding eligibility for vouchers, community transport and any issues around performance should be monitored.**
- 6. Alternative policy solutions should be considered, such as redirecting ambulance transport costs to community transport, or allowing community transport providers to 'pool' the funds made available for their patients who are eligible for assisted transport and use that to subsidise community transport instead.**
- 7. Consideration of flexibility in funding arrangements with the conversion of funds already provided to an option of vehicle purchase and paid drivers committed to dialysis transport.**

APPENDIX 1

The number of dialysis units providing set numbers of journeys per week (10 or less, 11-30, 31-50 or 51-100). Data separated by State and transport type.

