



# Insight

Renal patients' experience of the Patient  
Transport Service:  
Follow up report

**April 2016**

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# 1. Summary of findings

## 1.1. Introduction

In November 2015 we went back to the renal dialysis units at Nottingham City Hospital to speak with dialysis patients about their experience of the Patient Transport Service. In November 2014 our first visit found that experiences were poor, so we wanted to see whether there had been any improvement for patients following our first report. We spoke to 73 patients, 66% of all patients using the transport service that week, about their experiences during August, September and October 2015.

## 1.2. Main findings

There have been some encouraging improvements in patients' overall experience, which is linked to improvements in punctuality as shown in the figures below. However, there still remain some concerning reports of poor punctuality arriving into the unit which has impacted on the treatment those patients receive.

Figure 2 Most frequent 5-star rating for overall experience

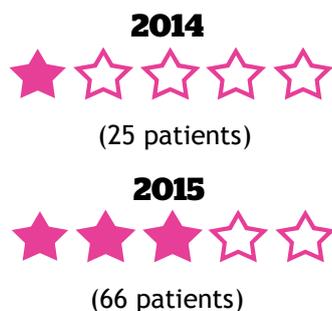
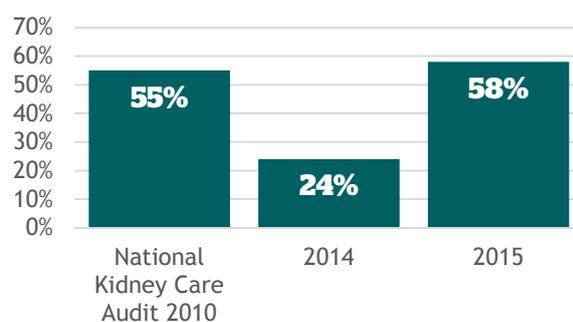


Figure 1 Percentage of patients happy/very happy with punctuality



71% of patients stated that they had arrived in the renal unit after their appointment time and although for the majority this was an occasional experience, there were a small but significant number of patients for whom this was the 'norm'. Our follow up visit found that during the three months previous to our visit:

**15** patients had lost minutes of dialysis due to arriving late

**615** was the estimated minutes of dialysis lost due to arriving late

This equates to an average of **41** minutes per patient

The appointment of a Renal Transport Co-ordinator working in the renal units has provided an immediate face to face contact to help resolve transport issues as they arise. But their limited availability means the benefits are not felt by all patients, particularly those receiving dialysis in the evenings.

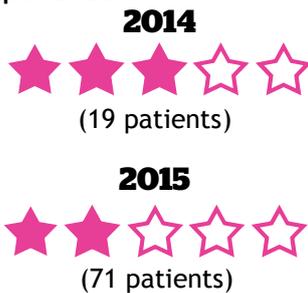
Three times as many patients in the evening session talked about the poor availability of the co-ordinator, although comments were received across all sessions. Their limited availability and the continued frustrations reported by over a third of patients in contacting Arriva means that patients are still calling the renal units to report and deal with transport queries.

But since this lady took over here, the ambulance lady, the transport system for Arriva has been a lot better. I must say that.

Patients continue to conclude that the service is inefficient, with poorly planned journeys still a feature of their experience for almost half (48%) of the patients we spoke to. The use of taxis remains high, seven out of ten patients (70%) had been sent taxis and negative experiences still outweigh the positive, with poor quality care remaining the central issue.

Feedback on the carry-by system developed by Arriva in response to our first report was mixed. Patients were more likely to state that travelling with the same people was inconsistent than it was consistent, and opinion was divided as to whether this system actually improved their experience.

Figure 3 Most frequent rating of taxi experience



Not only was taxi use high, but over half of patients indicated they were frequently sent this type of transport, despite Arriva's stated intentions for the service to move away from taxi use. Feedback indicates experiences of taxis are slightly worse, with many stories of drivers often not assisting patients to and from vehicles. As with our original visit there were still examples provided of when taxi drivers had turned away from patients' homes and the renal units without waiting.

...they send a taxi they just sit in the car and if you're not looking out they actually go and say you weren't there.

...Sometimes they've just driven away. They've honked, not come and knocked and just driven away.

## 2. Conclusions and recommendations

There have been encouraging signs of improvement in renal dialysis patients' experience of the Patient Transport Service, but the experience of improvement is not equal.

It is particularly pleasing that half of the patients we spoke to requiring special transport arrangements reported better experiences; a group we recommended were the focus for improvements in our previous report. However, we now find patients attending dialysis in the evening are being disadvantaged due to how remedial actions by Arriva have been implemented. Improvements must be extended to these patients and the improvements reported sustained.

**Recommendation 1: Ensure the renal co-ordinator role is extended, particularly into the evening dialysis shift.** Positive experiences show the potential for this role to improve experiences, it is important that all patients have access to the improved communication and punctuality that this role has already brought to others.

**Recommendation 2: Raise awareness of the presence of the co-ordinator by improving their visibility across both units.** Ensuring the co-ordinator proactively engages with all patients during their dialysis sessions to monitor start and finish times and the co-ordinator being seated in the waiting areas with clear signage to advertise their presence would all help to raise awareness of the role. This would encourage patients to make full use of the enhanced service they can deliver.

**Improvements haven't gone far enough to stop patients' treatment being affected. It is very concerning that the majority of patients reported arriving into the renal unit after their appointment time and that we heard stories of patients not receiving their full prescription of dialysis treatment.**

In our first report we recommended that data on when patients do not receive their full prescription of dialysis or miss complete dialysis sessions was recorded. We believe that a process has been put in place but despite requests have not had sight of this data. This means we are unable to cross reference this with the evidence we collected directly from patients. We re-iterate again the importance of this in order to accurately monitor the impact of the service on dialysis treatment and patients' health.

**Recommendation 3: Continue to collect and routinely monitor data on patient arrival times and dialysis treatment minutes lost.** Working closely with the renal unit staff and continuing to develop a positive working relationship will be essential in embedding this process.

**Recommendation 4: When contracts for re-commissioning of the service are developed ensure that targets are included for late arrival into the renal unit and minutes of dialysis treatment lost.** These are important measures of service impact that have the potential to be detrimental to patients' health. This should be reflected through their inclusion as contractual performance measures.

### **3. Introduction**

In November 2014 Healthwatch Nottinghamshire took a team of staff and volunteers into the renal dialysis units at Nottingham City Hospital to explore renal dialysis patients' experiences of the Patient Transport Service. We found that for the majority of patients their experience of the service was poor, which affected patients both physically and emotionally, causing much distress for patients and their relatives/carers. We made eight recommendations to Arriva, the company who provide the Patient Transport Service across Nottinghamshire, who provided a detailed response to our report and committed to actions to improve the patient experience of their service. A summary of this report can be found in appendix 1.

In November 2015, exactly one year after our first visit, we went back to the unit to speak with dialysis patients again. We wanted to see whether there had been any improvement in their experience of the Patient Transport Services following the actions put in place by the service provider after our first report. A summary of actions identified during a meeting following our first report can be found in appendix 2.

#### **3.1. Our team**

A team of nine Authorised Enter and View Representatives and staff members were deployed to collect this evidence. Two of the volunteers involved were also part of the team who visited the renal unit in 2014. A project orientation session was delivered the week before the visit to ensure that team members were familiar with the documentation and equipment to be used. Team members who had not been involved in the visit the previous year also visited the renal unit to prepare them fully for the environment in which the interviews would take place.

#### **3.2. Our approach**

Talking to dialysis patients face to face whilst they were receiving their dialysis treatment remained the key method of this project. As with our first visit, our attendance at the unit was planned to ensure that we had the opportunity to speak to as many patients as possible. We covered 14 dialysis sessions, including morning, afternoon and evening sessions, and spoke to 73 patients who use the Patient Transport Service to get to or from their dialysis treatment. Using data provided by the renal units we are able to establish that this was 66% of all patients using the Patient Transport Service during the week of our visit. Participation in the interviews was voluntary and patients were informed that they could withdraw from the interview at any point. Before the interviews were conducted, patients were fully informed about the project and gave consent for their interview to be audio recorded. Where consent to record was not provided written notes of their response were taken. Interviews were conducted by a Healthwatch Nottinghamshire volunteer or member of staff. At the end of the week we had gathered data from 73 patients, 60 of which were detailed recordings.

The focus of the interview was to discuss their experience over the previous three months of August, September and October 2015, some key questions asked in 2014 were replicated to identify any changes from 2014 and questions using an improvement scale were asked. We also included questions related to the specific actions identified by Arriva in their response to our first report.

This report is structured in line with the key findings from our 2014 report to identify patients' recent experiences and identify any improvements.

## 4. Overall experience of the service

In 2014 the majority of patients identified that their overall experience of the transport service had been and continued to be poor. This section provides the findings from asking patients to use the five star scale to rate their overall experience over the three months of August, September and October 2015 and a direct question as to whether they felt the service had improved over this period.

As in 2014 we asked renal dialysis patients to rate their experience of the Patient Transport Service using a five star scale where one is the worst and five is the best. Ratings were provided by 66 of the 73 patients we talked to.

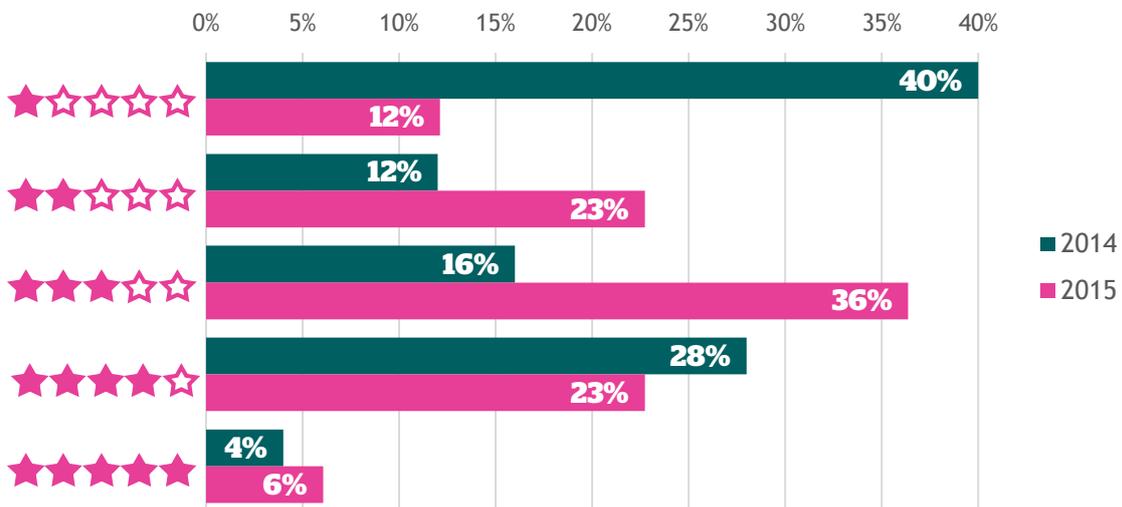
Figure 4 Most frequent five star ratings for overall experience over time



Source: 2014 patient surveys, 2015 patient interviews

Figure 4 shows that there has been an increase in the most frequent rating of the service, moving from 1-star in 2014 to 3-stars in 2015. We can see from figure 5 how the distribution of star ratings has changed, with very poor one star ratings substantially reduced. The pattern of response was similar for those who had used the service for 12 months or less compared to those who had been using the service for longer.

Figure 5 Breakdown of star ratings over time



Source: 2014 patient surveys (count = 25); 2015 patient interviews (count = 66)

We also asked patients to rate whether their experience of the Patient Transport Service had improved over the three months of August, September and October 2015. The results of this can be seen in figure 6 and confirms the improvement in experience demonstrated in figures 4 and 5. Almost half (48%) of the patients we spoke to who had used the service for longer than three months felt that their overall experience of the service had improved to some extent.

**Figure 6 Improvement of overall experience**



Source: 2015 patient interviews (count = 57 patients using the service longer than three months)

In 2014 we found that patients with special requirements for transport and those having dialysis in the afternoon were more likely to have a negative experience of the transport service. Through our return visit we found some encouraging findings:

- Half of all patients with special transport requirements reported that there had been some improvement in their overall experiences;
- Over half (52%; 12 patients) who receive dialysis in the afternoon sessions reported that their overall experience of the service had improved to some extent.

However, we also found that patients attending dialysis in the evening sessions were less likely to have experienced any improvements in their overall experience. Evening patients were:

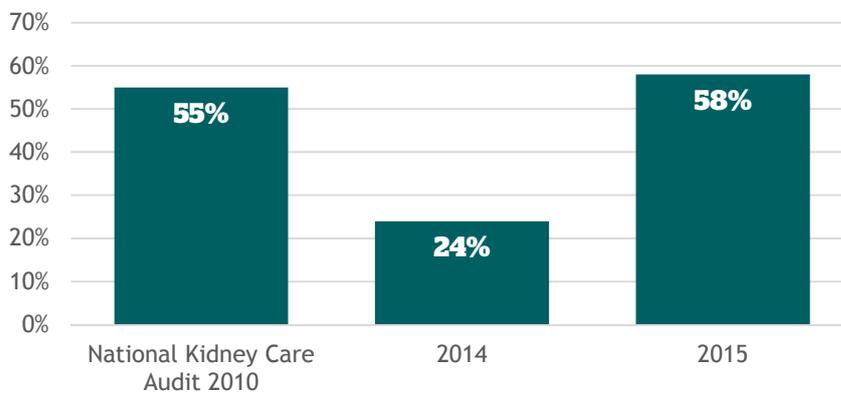
- Only half as likely as patients in other sessions to identify any improvements to their overall experience; and
- Twice as likely to indicate that their experience had got worse.

## 5. Punctuality of the service

In 2014 we found that punctuality of the service was the central issue contributing to negative experiences. 90% of patients talked at length about long waiting times after dialysis and 67% mentioned being picked up late before dialysis. This section of the report details findings from our return visit in 2015 that are specifically related to the punctuality of the service.

Satisfaction with the punctuality of the service has improved, as illustrated in figure 7. Over the three month period of August, September and October 2015 the percentage of patients who were either happy or very happy with the punctuality of the service had more than doubled to 58% and is now just above the average reported in the national survey.

**Figure 7 Percentage of dialysis patients happy or very happy with punctuality of Patient Transport Service**



*Note: When using a five point response scale from very happy through to very unhappy*  
 Source: 2014 patient surveys (count = 25); 2015 patient interviews (count = 64)

**Figure 8 Improvement in punctuality of the service**



Source: 2015 patient interviews (count = 56 patients using the service longer than three months)

Although there have been reported improvements in punctuality, there were indications that patients were now resigned to the fact that they were going to be late either getting into the renal unit or going home. They had accepted this as a feature of using the Patient Transport Service. A quarter of patients (26%; 16 patients) talked about how they had to accept this, that they had no other option and that there was nothing that they could do about it.

I've just got more used to it. I know they're going to be late.  
 I've got no choice but to take it, have I?

This acceptance was evident in patients who still remained dissatisfied and those who reported improvements.

## 5.1. Arriving into the renal units

As with our previous findings, over half of the patients we spoke to still talked about not knowing or an inconsistency in when they were going to be picked up from their home to be taken into the renal units. There was no indication from patients that any additional clarity had been provided on this since our last visit 12 months previous. Patients still made reference to having to be ready two hours before their appointment time, but that the actual time they were collected was hugely variable. For a small number of patients there were still references made to transport not collecting them within this time period and patients being ‘forgotten’. For example,

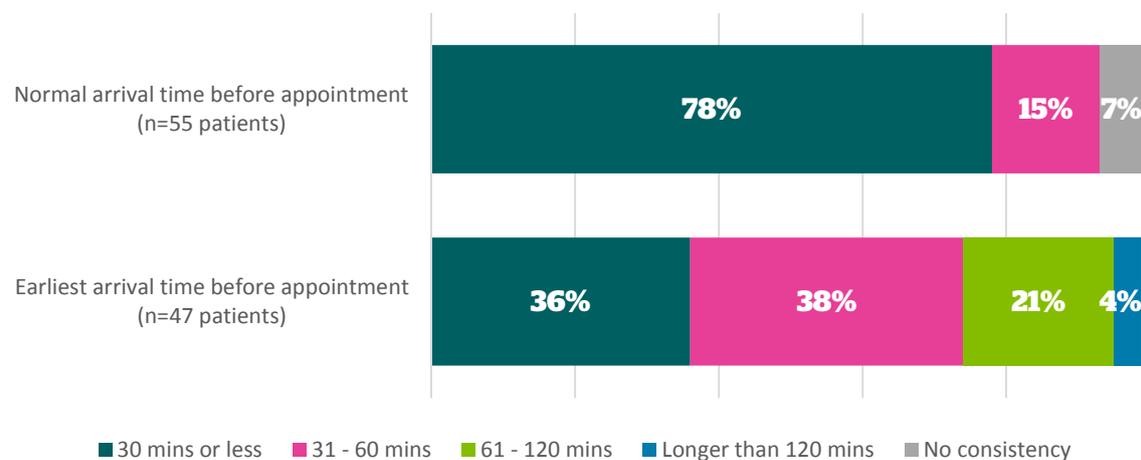
They sometimes will come early and other times they’ll come late and there’s other times they’ll forget about you.

No, they just say they can come up to how many hours you actually go on dialysis but they don’t come in those hours.

Sometimes for instance last week one came quite earlier than normal and I hadn’t got my shoes on or anything and sometimes they’ve not turned up at all and they’ve been late and I’ve had to ring up here and say where’s my transport and then they have to send a taxi out.

Patients were asked to identify how long before their dialysis appointment time they normally arrived at the renal unit and the earliest they had arrived in the three months of August, September and October 2015; the results of this are presented in figure 9.

Figure 9 Normal and earliest arrival times before dialysis appointments



The majority (78%; 43 patients) identified that they normally arrive in the unit within the 30 minutes of their appointment time, and for over a third (36%; 17 patients) this was the earliest they had arrived in the unit for the three months leading up to our visit.

However, there were still almost a quarter (22%; 7 patients) who were ‘normally’ arriving earlier than 30 minutes before their appointment time, or felt that the arrival times were too variable to provide a normal arrival time, indicating arrival times of anything up to an hour before their appointment time. Almost two thirds (63%; 30 patients) had experienced an early drop off in the previous three months i.e. arriving earlier than 30 minutes before their appointment time.

The most frequently referenced impact of arriving early into the renal units was the additional waiting time this incurred either before the patient can start their dialysis, due to machines not being ready, or after their dialysis has been completed. This was because return journeys have not been booked to account for early arrival and a potentially earlier start to their dialysis session. Patients indicated that they gained very little from this.

If you do get here early sometimes the machines aren't ready so you can be sat around waiting for the machines so you gain nothing at the end of the day...

The problem is if I get here early then I'm waiting at the end so both times I'm waiting. It's rubbish either way.

In addition to patients arriving early to the unit, patients were also arriving late. Over seven out of ten (71%; 51 patients) stated that they had arrived in the renal unit after their appointment time during the previous three months. 24 patients were able to talk about how frequently this happens, and for the majority a late drop off after their appointment time was only an occasional occurrence. They used words such as 'not often' or happening less than once a month where numerical estimates were provided. However, there were a significant but small number of patients who talked about this happening more frequently, with some indicating it was the norm.

It happens 2 out of 3 times I get picked up. Literally nearly all the time.

Wednesday and Friday are totally different - usually I'm here for 6.30 instead of 6 o'clock. So usually I'm really late.

### 5.1.1. Impact of late arrival

The most significant impact of a late drop off is patients not receiving their full prescription of dialysis; our follow up visit found that during the three months previous to our visit:

**15** patients had lost minutes of dialysis due to arriving late

**615** was the estimated minutes of dialysis lost due to arriving late

This equates to an average of **41** minutes per patient

This excludes an estimate from one patient that they had lost 'a few hours' of dialysis due to transport arrangements. A further six patients indicated that they hadn't lost any dialysis time because the hospital had arranged for them to stay on machine for their prescribed time.

One of the recommendations from our initial visit was for any lost minutes of dialysis time to be officially recorded. We have asked to have sight of this data but have not yet been provided with it.

## 5.2. Leaving the renal unit

Evidence from our return visit indicates there has been some improvement in the times patients are picked up from the renal unit during the three months prior to our visit:

Two thirds (67%; 40 patients) provided at least one example of waiting longer than 30 minutes, compared to 90% of patients in our original visit.

Over a quarter (28%; 17 patients) indicated that they were usually picked up within 30 minutes.

10 patients (6%) specifically identified that the pick-up times after dialysis had improved.

Despite these signs of improvement, the patients we spoke to were more likely to identify that being picked up longer than 30 minute after their dialysis was a frequent (63% of patients) rather than occasional (37% of patients) experience. For those indicating that this happens frequently, the majority identified this happens at least once a week or most of the time and others used words such as *'normally'* or *'often'*.

Patients who experienced this occasionally used words such as *'not very often'* and indicated that this had happened once or a couple of times during the three month period we asked about. Three of these patients specifically identified that there had been a recent improvement

Almost a quarter of all patients (22%; 13 patients) we spoke to mentioned that their pick up time was variable, with some patients identifying waits of anything up to two and a half hours.

Varies from day to day. I've waited two and a half hours.

Sometimes on the odd occasion I'm picked up straight away but on the other hand I'm not. It's variable.

It varies. Sometimes they're here before I'm off, and another like on Saturday night I was off at 4 o'clock and it was 6 o'clock when I left here.

### 5.2.1. Impact of late pick up

As would be expected the emotional impact of being picked up late remains the same, and over half (52%; 31 patients) of those we spoke to talked about this. The overriding feeling was that after dialysis patients just wanted to get home, and that waiting longer than half an hour left them feeling very tired, annoyed, frustrated and upset.

It makes me annoyed when I'm waiting to go home - all I want to do is go home and go to bed.

It's irritating especially if I'm on early the next day for work. I want to go home, I want to be able to relax for half an hour before I go to bed. I don't want to be wondering about what time I'm going to get home and waking up in the morning for my shift at work.

You just want to get out and get home because you're so tired once you've had dialysis.

As in our original visit there was evidence to suggest that these waiting times continued to impact on patients' physical health, their lifestyle and other people:

**Impact on physical health:** Diabetic patients still talked about needing food and feeling hyperglycaemic, others referenced raised blood pressure and nausea. People living with other medical conditions could be delayed taking medication and receiving care and support in their home.

**Impact on lifestyle:** Waiting times after dialysis extended the time commitment for treatment which affected patients' social life and employment.

**Impact on other people:** Family members were being called upon to provide transport when waiting became intolerable, and patients worried about family members waiting for them at home with no indication as to when they would return.

One of the most worrying impacts of waiting times after dialysis was patients leaving the renal units unaccompanied. Our return visit found evidence that this is still happening with a small number of patients providing recent examples of getting so frustrated they call their own taxis or use public transport to get home.

It took me about 15 minutes or so to walk because I'm not ever so good on my feet and I had to walk over to the far side to where my bus runs.

I'd finished my treatment, come off the machine at 5 and at 7 o'clock I was still there waiting. I just got so angry that I walked out and went and caught a bus.

## 6. Communication with patients

In 2014 we found that communication between the patients and Arriva about transport arrangements was poor, resulting in patients feeling frustrated and stressed. We recommended that new processes were put in place to improve this, and this section of the report details findings related to these actions.

Despite a very small minority of patients who felt that there had been some level of improvement in Arriva's communication with patients and that they were listening to their patients in order to improve the service, our return visit found that many of the frustrations reported in 2014 remained. Over a third of patients (36%; 22 patients) we spoke to talked about poor communication with Arriva, whether it was to sort out transport problems as they happened or complaining about them retrospectively. Patients still reported:

- Not knowing the right number to call to sort out transport issues;
- Difficulty getting through on the phone e.g. being placed on hold or getting no answer;
- Being given inaccurate estimates of collection time;
- Having delayed and dissatisfactory responses to complaints.

When I've tried to ring from home I just can't get through. It's like they've got a phone they know is complaints and they just let it ring.

Well sometimes I think it was last week I sat there an hour and a half and they phoned. They said someone was going to be there in 20 minutes. 20 minutes came and nobody came. The nurses went for a break, came back, and are you still here? Phoned again and they said someone's on their way and it was the third time they phoned and then I got my transport.

I've told them about the irregularities of what time I'm getting in, I've told them about the wrong journey and routes they've taken me. Nothing ever happens. The complaints I've been putting in nothing has happened. I've had a letter back from them saying we'll work on your times and stuff like that but I'm still here and nothing's happening. They just go oh yes we'll do it and then nothing happens.

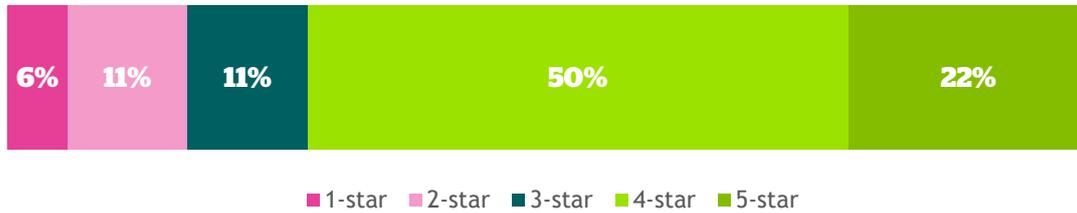
As a consequence of these poor communication experiences patients are still calling the renal unit; 42% (25 patients) made reference to calling and asking the renal unit staff to sort out transport issues on their behalf.

### 6.1. Arriva Renal Transport Co-ordinator

In response to our recommendation to invest time and capacity into developing new systems and processes for communication Arriva appointed a Renal Transport Co-ordinator to work in the renal unit. Arriva felt that this role would enable a real-time assessment of transport needs and would improve communications between all parties, most importantly the patients. The co-ordinator role was operational from early summer 2015.

18 patients we spoke to indicated that they had interacted with the co-ordinator in the renal unit and figure ten shows that for the majority of patients their experience was positive with almost three quarters (72%) providing a four or five star rating.

Figure 10 Five star rating of Arriva Renal Transport Co-ordinator



Source: 2015 patient interviews (Count = 18)

Note: When using a five star rating where one star is the worst and five stars is the best

Patients talked about how the co-ordinator had been able to resolve their transport issues and how this had led to improvements in their experience of the service.

She is helpful. Positive improvement by getting a car to take me home. But since this lady took over here, the ambulance lady, the transport system for Arriva has been a lot better. I must say that. When she's on she always comes to look at your clock to see how long you've got left. Usually when you come off it's about 20 minutes before they come but when they don't come and look at your clock you're always here a long while.

The improvement in communication was specifically acknowledged by a small number of patients who appreciated having someone face to face in the unit to find out how long their transport would be and keep them updated.

However, there were four patients who indicated that they were unaware of the co-ordinator and had no knowledge of the new role, the majority of which were evening patients. This relates to the most talked about aspect of the co-ordinator role which was their limited presence in the unit.

These comments were made by patients across all dialysis sessions but twice as many comments were received from evening patients as from any other dialysis sessions. Evening patients felt that it was unfair that the co-ordinator was not present for their sessions, for example,

They got an Arriva person over there in the next unit which is great for all the people in the next unit but she goes home before I even get here. That's no good to me. It's all the time as well, there's no time I can go and see her because when I get here she's gone. I don't understand why there shouldn't be somebody there until everybody's gone anyway - it's like that's half a job. So what about the rest of us, all us lot oh no they're evening lot. Don't worry that we don't want to get home see families and everything else.

## 7. Planning and co-ordination of journeys

In 2014 we found that patients perceived poor planning and co-ordination to be responsible for long waiting times and journeys. Our evidence included examples provided by many patients of poorly planned journeys and poor use of vehicles. We asked about these issues again in our return visit and this section reports on the findings.

When we returned to the renal units in 2015 poorly planned journeys were still one of the most talked about issues with the Patient Transport Service. Almost half (48%; 29 patients) of the patients we interviewed provided examples of poor planning and co-ordination of journeys. There were only four patients who were able to identify that there had been a recent improvement.

Patients most frequently talked about their journey routes and length of time in the vehicle. We heard many more stories of journeys which took them in the opposite direction to where they lived which increased journey time and there were two examples given of when patients had actually been driven past their own house to drop someone else off before them. For example,

Instead of dropping me off at Gedling which is the first stop they went right round and it took me about an hour to get home.

Sometimes we have to take [name removed] home in the direction opposite to me and that doubles the time.

...go past house to take someone else home and come back. Route not planned very well.

The inefficient use of vehicles was also a key talking point, 17 patients made reference to this, expressing frustration at:

- seeing vehicles which could take multiple patients home being used to transport only one person;
- coming in with other people but being transported home in separate vehicles;
- seeing taxis being sent to pick up patients when Arriva vehicles were outside the units;
- multiple vehicles being sent to collect them.

In addition to the under occupancy of vehicles there were also three examples provided of patients being 'squeezed' into vehicles, resulting in negative experiences.

Many a time we've had problems about 3 or 4 people in a car...You've got guys that are struggling to get in because they've got a walking stick. They're only a tiny car you know. I'm stuck in the middle and can't even put my seatbelt on. It's happened 3 times in the last 3 months and it's not a pleasant experience.

One day the driver had 2 of us and another 3 passengers, so if somebody sitting in the front I sit in the back then I take 2 people's place I'm too big - they have to squeeze in. Uncomfortable.

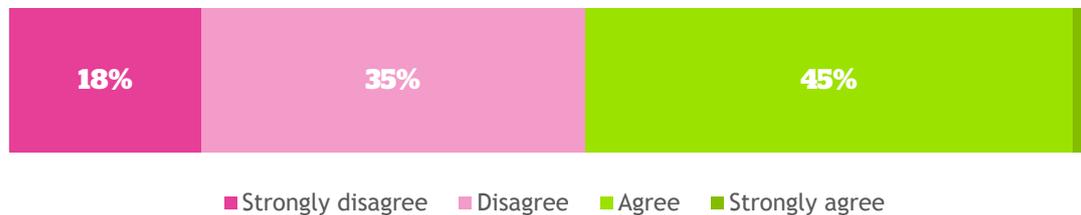
In 2014 we heard stories from patients of being ‘forgotten’ or when no transport was booked for them; this was still happening in 2015. Seven examples of this were provided, the following are illustrative.

In fact there was once I rang up and I wasn’t allocated transport.  
It was 4 o’clock when they came because they forgot me.  
They didn’t have me down on the list but they were the ones who brought me in.  
Well it’s strange, it’s a regular occurrence because every now and then they just seem to forget I exist. They don’t bother to come and pick me up at all.

Many patients were quick to acknowledge that they felt the poor examples of planning and co-ordination were not the fault of the Arriva transport crews, attributing responsibility to the Arriva control centre. There remained frustration that the transport crews still had little flexibility to respond to patient need and requests for transport when in the unit. Only two patients identified a recent improvement in their planning of journeys but these were both attributed to drivers who had made decisions to change the route.

In 2014 almost half (49%) of the patients we spoke to concluded that the service wasn’t efficient. In 2015 we asked patients to rate their level of agreement with the statement that the service was efficient. The result mirrored that found in 2014; 53% of patients either strongly disagreed or disagreed with the statement, as illustrated in figure 11.

Figure 11 Level of agreement with statement 'Is the service an efficient service?'



Source: 2015 patient interviews (count = 62)

## 7.1. Carry-by system

In 2014 we recommended allocated transport for renal dialysis patients given the regularity and routine nature of their dialysis transport requirements. Arriva responded by agreeing to develop the ‘Carry-by’ system where patients are grouped and travel to the unit together.

In 2015 we specifically asked patients whether they regularly travel into or home from dialysis with the same people. Patients were more likely to report that this was inconsistent (40%; 24 patients) than consistent (35%; 21 patients). The patients reporting inconsistency stated that they only ‘sometimes’ travel with the same people.

There's no consistency. Then some nights there's just me.

Might get a different set of people - it depends.

It depends because I can come in with both of them and then on the way back I'm only going back with one of them because the other one they haven't booked them in to the same vehicle which seems stupid to us.

This was frequently linked to poor planning and co-ordination at the control centre.

For those who did travel regularly with the same people and gave some indication of frequency they used words such as 'often' and 'mostly'. A small number of these patients talked about how they were happy to share their journey.

Opinions on the impact of the system were divided amongst the patients we spoke to. Nine patients talked about how this had no significant impact on either their journey time, experience, or the punctuality of being dropped off in the unit or picked up to return home. An equal number made reference to the system having a negative impact, resulting in longer waiting times for transport and longer journey times.

It takes longer for me because they pick me up first... more hassle.

If they've booked me out with the same people I normally go out with, I've got to wait for them to finish...

## 7.2. Use of taxis

In 2014 we found that although the Arriva transport crews were almost universally praised, experience of taxis was less positive. We recommended that the quality of this service is improved and monitored through a set of quality standards. Arriva responded by confirming that they were reviewing the agreements with taxi companies, and that they planned to move away from using taxis as much as possible.

We found in our return visit that taxis were still being used; 70% (42 patients) of the patients we spoke to had been transported by taxi either into or out of the renal unit in the three month period directly before our visit. Over half of these patients (60%; 24 patients) indicated that this was a frequent occurrence, travelling by taxi more often than with Arriva transport crews, or for at least half of their journeys.

Sometimes you've got a taxi coming for you, say 7 times out of 10 it's a taxi and 3 times out of 10 it's Arriva.

I mean to be honest with you it's mostly taxi drivers that you get just lately, I've not had any Arriva pickings up.

Negative experiences of taxis outnumbered positive experiences. When we asked patients who had travelled by taxis to rate their recent overall experience of this, they most frequently provided a two star rating.

The poor quality of care provided by the taxi service was once again central to discussions. We heard many examples of how taxi drivers were not assisting patients to and from the vehicles and waiting in vehicles rather than knocking on patients doors

to let them know they had arrived. There were indications that these were frequent rather than occasional features of their experiences. The following comments are illustrative of the many received.

You get one or two who'll walk you to the door but you get others, I think young ones, who just sit there and he's like looking at the door as if to say well come on then. Open door and bye - that's it just drive off.

Pretty shocking - the Arriva drivers are taught to go up to the door and knock - half the time they don't even bother they just sit there and honk the horn - that's the taxis.

They just stay and beep their horn. One or two come to the door but not the majority.

There were a small number of examples provided of how taxi drivers had turned away from patients' homes without them, failing to sufficiently notify the patient that they were waiting for them. There were also examples of how taxi drivers had not waited for patients not ready to be collected following their dialysis session, some of these failed to return.

Safety concerns were raised by a small number of patients who did not feel comfortable or confident in the care of taxis should a medical need arise.

They're not taught to medical standards. I mean we are patients at the end of the day and we should be treated like patients not just get them in, chuck them out.

It makes a difference to me. Because I say if somebody by chance starts bleeding, do the taxi drivers know what to do? Whereas where the Arriva transport they, I think, would have a better idea of what to do.

Although the majority provided negative experiences of taxis, this wasn't universal and there were a minority of patients who have positive experiences of this form of transport. These experiences were characterised by drivers who do escort patients to their doors and '*do all they can to help*'. Our evidence suggests that positive experiences of taxis result when regular drivers are used. This allowed patients to get to know the driver and the driver became familiar with and understanding of their needs.

## **8. Official responses**

### **8.1. Arriva Transport Solutions Ltd (Current providers of the Patient Transport Service in Nottinghamshire)**

Andrew Cullen, National Head of Patient Transport Services

*I would like to thank Healthwatch Nottinghamshire for sharing this report with us and for their continued support in helping to further improve the non-emergency Patient Transport Service. We understand the impact that regular treatment has on the lives of dialysis patients and this report has given us a valuable insight into the transport service from their perspective.*

*We worked closely with Healthwatch to put in place a number of improvements based on the recommendations contained in their 2014 report and it is pleasing to see that this has resulted in real benefits for our patients. Our overall rating in this report has increased from one-star to three-star and, while we acknowledge there is more work to do, it is extremely encouraging to know that our patients are feeling the positive effects of the improvements we have already made.*

*One of the key recommendations made by Healthwatch in their previous report was the introduction of a renal coordinator and I am pleased to see that patients feel this has had a positive impact on their experiences of transport. This is a great example of how by working collaboratively with both Healthwatch and the dialysis unit we have been able to make significant improvements.*

*The report does however highlight areas where further improvements are needed and we are committed to continuing to work closely with Healthwatch to discuss their latest recommendations, highlight the steps we have already taken since the Enter and View in November and also agree on what we must now do to build upon the progress we have made.*

### **8.2. Nottingham University Hospitals (NUH) NHS Trust (Providers of Nottingham City Hospital)**

Alison Kinchin, Dialysis Unit Manager at Nottingham City Hospital

*Colleagues from the NUH Renal Service welcome the publication of the second report by Healthwatch into transport provision for renal patients. Whilst there has been some overall improvement in the transport service for our haemodialysis patients, significant issues still remain. It is very disappointing that 71% of patients stated that they had arrived in the renal unit after their appointment time with a small but significant number who stated this was the 'norm'. Patients arriving to the unit after their treatment time not only impacts on their dialysis time and experience but also that of the patient following them. In addition, patients arriving too early for their appointment adds to pressure on the dialysis unit staff who have additional patients to deal with and means that patients are away from home for longer than necessary.*

*Transport provision for dialysis patients is a vital part of their treatment and sub-optimal transport provision may have a significant negative impact on patient experience. We remain committed to working with the transport providers and CCG colleagues who commission the Patient Transport Services to try to improve the service for patients. We have specialty management representation at the NUH Transport Working Group (the next meeting is planned for 9 June 2016), where outstanding issues can be addressed. While we acknowledge the improvements noted*

*in the report we remain concerned that the overall level of service remains well below what we would wish to see for our patients.*

### **8.3. Mansfield and Ashfield Clinical Commissioning Group (Lead commissioner for the non-emergency Patient Transport Service in Nottinghamshire)**

Neil Moore, Director of Procurement and Market Development

*Clinical Commissioning Groups continue to work with Arriva on improving the service to patients. The report from Healthwatch highlights some areas of improvement and we acknowledge the work Arriva have undertaken to achieve this. The outstanding issues will be raised through further meetings to explore Arriva's plan in light of the findings and to set appropriate mechanisms for assuring commissioners and patients as those actions are implemented. We would like to thank Healthwatch for their continued support in identifying areas for improvements for users of Arriva.*

# Appendix 1: Summary of report from March 2015

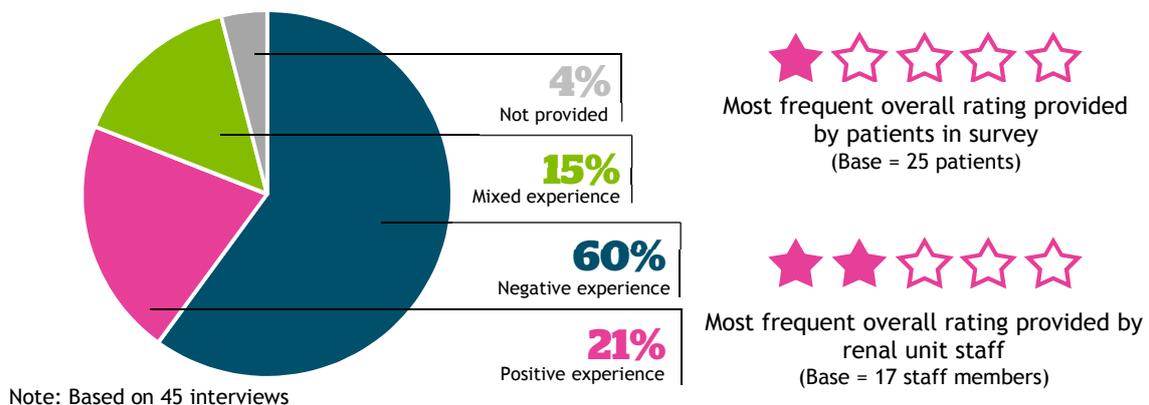
## Introduction

We wanted to understand renal patients' experiences of the Patient Transport Service going into and home from the Nottingham City Hospital renal dialysis units. To do this we spoke to 45 patients, gathered journey diaries from seven patients, and collected 50 surveys from patients and 17 from members of the renal unit staff.

## Main findings

A recent improvement in experience was acknowledged and praised by a small number of renal dialysis patients. For the majority of patients, their overall experience of the transport service had been poor.

Figure 12 Overall summary of experience for all patients



Patients needing special requirements for their transport and the time patients attend for dialysis made a difference to their overall experience. Compared to 60% of all patients, 73% of patients with special requirements for transport had a negative experience, 75% of patients having dialysis in the afternoon had a negative experience and 50% of patients having dialysis in the evening had a negative experience. These experiences were reinforced by renal staff, who suggested that wheelchair patients and those attending the afternoon sessions can be waiting for transport longer than others.

**Poor experiences affected patients physically and emotionally.** Every patient who talked to us about waiting for transport into the renal dialysis units, identified that as a consequence of being late they had not had their full prescription of dialysis. Patients and staff agreed that this is detrimental to patients' physical health.

Patients sat on the unit doing nothing for 2-3 hours after their treatment they are missing out on sleep, food and possible medications which all contribute to overall health.  
Renal dialysis unit staff member

Patients talked about raised blood pressure and nausea and for those suffering other long term health conditions, the long days and being late home impacted on their diet and nutrition.

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**The impact of a poor experience doesn't just affect that patient. Staff on the renal dialysis units, other patients attending after them and family and carers of relatives can all be affected.**

**Patients** were quick to recognise that if they were late on machine it had an impact on patients attending the subsequent dialysis session.

**Renal dialysis unit staff** confirmed the impact on other patients and identified that poor transport experiences impacted on them in two ways:

- Querying and re-arranging transport issues diverted their attention from nursing duties.
- Having to frequently deal with angry and frustrated patients.

**Carers and relatives** were affected in three identified ways:

- When patients called on them for transport to and from the dialysis unit when the Patient Transport Service did not arrive.
- When they were at home waiting anxiously for patients to return from dialysis.
- Living with the time commitments that their family member has to devote to cover the transport requirements in addition to their prescribed dialysis time.

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**The transport crews were universally praised, 84% of all patients we interviewed talked about their positive experience of transport drivers and attendants. Almost two thirds of survey respondents identified them as the 'best' part of the Patient Transport Service.** The majority (76%) of patients who had a negative overall experience of the Patient Transport Service still talked about the drivers and attendants in a positive way. Patients clearly felt that the Arriva drivers cared for them, evidenced by frequent stories of drivers helping them in and out of vehicles and walking them to their doors.

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**The punctuality of the service was the central issue contributing to negative experiences. 90% of patients talked at length about long waiting times after dialysis and 67% mentioned being picked up late before dialysis.** Renal dialysis patients in Nottinghamshire were unhappy with the punctuality of the Patient Transport Service. Patients used words such as 'very often' and 'most of the time' when asked whether they had been picked up more than 30 minutes after coming off the dialysis machine. For vulnerable patients particularly, the waiting had very concerning consequences. Some patients gave examples of using public transport or walking to get home. For example:

My daughter gets really mad with me, [she says] you keep ringing me to tell me you've wandered off...why don't you stop where you are. I said I don't know duck!" I'm sitting in that waiting room and there's only me in so I think oh no-ones coming to fetch me, so off I went.

**Renal dialysis patient**

Well with me suffering from dementia, the hospital ask me to go by their transport but sometimes when I get so mad I end up walking to the bus stop.

Sometimes when I have to walk down there I forget which number bus. I end up walking from the forest to St Anns where I live. And it's really bad when I get home.

**Renal dialysis patient**

**Poor planning and co-ordination of journeys was perceived by patients and staff as being responsible for long waiting times and long journeys.** For many patients the inconsistency and unpredictability of the transport service doesn't match the routine of dialysis treatment. This was illustrated through the range of collection times reported in the patient journey diaries.

Patients gave examples of travelling on routes which crossed several areas of the county and city, which could be responsible for the longer travel times reports by patients using the transport. This was also identified as one of the reasons why some patients had stopped using the transport service to get to their dialysis appointments.

## **Conclusions and recommendations**

**Conclusion 1: Renal dialysis is a treatment which places significant demands on a patient's quality of life and their negative experience of the transport service increases this demand.** For the majority, the unreliable nature of the service and the unpredictable waiting times meant that a four hour dialysis prescription can frequently require up to the same amount of time for transport. This can then demand three full days of a patient's week, rather than the 12 hours of dialysis time prescribed. Patients not receiving their full dialysis treatment and missing complete dialysis sessions could be serious implications of a poor service, which have the potential to negatively impact on the physical health of patients.

**Recommendation 1: Invest time and capacity into developing new systems and processes for communication between drivers, the call centre, the dialysis units and patients.** This would help to ensure that all were more informed about the transport arrangements in place and expected collection times and would significantly reduce the feelings of stress felt by everyone involved.

**Recommendation 2: Allocate drivers and vehicles to provide transport primarily for renal dialysis patients.** The routine nature of dialysis lends itself to fixed arrangements which could improve punctuality. When combined with the frequency with which patients need their treatment, improved punctuality could help ensure that their renal dialysis treatment has a smaller impact on their life.

**Conclusion 2: Inequality of experience is evident, but all patients should experience a good quality service, particularly those patients managing other chronic health conditions.** Evidence across all sources indicated inequality in waiting times for those people needing special transport requirements and the overall experience for patients attending morning and afternoon dialysis sessions compared to those attending evening sessions. These are frequently resulting in very poor experiences and are having potentially serious impacts on vulnerable patients, managing other chronic health conditions.

**Recommendation 3: Put in place some safeguards to ensure that the patients managing other chronic health conditions and who need special transport requirements are prioritised for journeys home after dialysis sessions.** Prioritising these patients would help to reduce the potential impact of waiting times on physical health conditions and ensure that the service is carrying out its duty to make arrangements for these patients under the Equality Act 2010.

**Recommendation 4: Improving the quality of service provided by subcontracted taxi companies is necessary to ensure they provide a service comparable to Arriva transport crews.** This could be achieved through a programme of training and development to improve their knowledge of the routes into the City Hospital and their understanding of the dialysis process and how it impacts on patients.

### **Conclusion 3: The transport service for renal dialysis patients is inefficient.**

The data collected details instances of poorly planned journeys and poor use of vehicles. This is creating inefficiency, which patients and staff felt was in some part responsible for the poor punctuality of the service. Staff and patients were both quick to suggest that planning and co-ordination of journeys could be improved and would reduce the frustration they both felt.

**Recommendation 5: Arriva transport crews are an asset to the service, and should be given more opportunity to use their initiative, and act on the observed real-time transport needs in the units.** This could reduce the occasions when ambulances transport single patients, and journeys are duplicated. It could reduce waiting times for some patients and lessen the frustration experienced when drivers are unable to take some patients living near to, or on the route of others. This could also help to reduce the time renal unit staff are spending on the phone to the call centre being diverted from nursing duties.

**Recommendation 6: Further training for drivers and the staff who plan journeys, which includes an element of seeing first-hand renal dialysis patients experience of the transport service would be beneficial.** This could help to improve their understanding of dialysis treatment, the impact of this on patients and the consequences of a poor transport experience. The improvement in service delivery that this could potentially achieve could impact directly on renal patients' experience of the service.

### **Additional recommendations identified following stakeholder responses**

**Recommendation 7: Data needs to be collected to identify when patients do not receive their full prescription of dialysis or miss complete dialysis sessions.** This requires patients to communicate with staff on the dialysis unit when making decisions at home about their dialysis treatment as a result of their Patient Transport Service experiences. Collecting and routinely monitoring this data will allow medical staff to act upon the impact this could or is having on the health of renal dialysis patients.

**Recommendation 8: Dialysis patients waiting for transport home after their dialysis treatment need to be provided with a level of care during this time to ensure their safety.** This would mean that all patients, particularly those managing other chronic health conditions, do not experience unnecessary and preventable negative impacts to their physical health. Their overall experience of dialysis treatment would be improved and carers/relatives would be less concerned about the physical and mental state of their loved one when returning from hospital. There needs to be a greater level of communication between all parties, patients, renal dialysis unit staff and the transport service for this happen.

## **Appendix 2: Summary of Arriva response to recommendations in 2014 report**

**Recommendation 1: Invest time and capacity into developing new systems and processes for communication between drivers, the call centre, the dialysis units and patients.**

Arriva are looking at the role of transport co-ordinator in the Renal Unit as a way of improving communication between patients, the unit staff, the call centre and the drivers. This role would enable a real-time assessment of what is needed and would improve communications across all parties. They are also proposing that transport is part of the initial care planning for new patients using the unit.

This recommendation is also linked to recommendation 5. There can be wider problems if individual drivers make decisions about changing schedules, but someone on the ground in the unit would be able to see the bigger picture.

Arriva is also looking at how to keep people informed about delays in being picked up. They are looking at a dedicated ‘where is my transport?’ phone line or other means of keeping people up to date if delays occur.

**Recommendation 2: Allocate drivers and vehicles to provide transport primarily for renal dialysis patients.**

Arriva is looking to develop the ‘carry by’ system, whereby people agree to travel together and agree a time for this. This links to developing dedicated travel plans for individual patients. They are going to discuss with the unit about setting up pairings or groupings of patients and adjusting their appointment times to accommodate them travelling together. Again an on-site co-ordinator could monitor this.

**Recommendation 3: Put in place some safeguards to ensure that the patients managing other chronic health conditions and who need special transport requirements are prioritised for journeys home after dialysis sessions**

Arriva believe that better planning and co-ordination of journeys will help with this recommendation and will monitor this.

**Recommendation 4: Improving the quality of service provided by subcontracted taxi companies is necessary to ensure they provide a service comparable to Arriva transport crews.**

Arriva staff said they are getting a lot of feedback about taxis. They are currently reviewing the agreements with taxi companies and the procedures for using taxis. The plan is to move away from using taxis as much as possible and to try and develop the carry by system.

They were asked if taxis are used in a planned or reactive way. Currently both, but the aim would be to use taxis as an exception e.g. if a vehicle breaks down. Esther pointed out that the taxi service can work well e.g. for people who go to Lings Barr.

**Recommendation 5: Arriva transport crews are an asset to the service, and should be given more opportunity to use their initiative, and act on the observed real-time transport needs in the units.**

See 1

**Recommendation 6: Further training for drivers and the staff who plan journeys, which includes an element of seeing first-hand renal dialysis patients experience of the transport service would be beneficial.**

Arriva confirmed that controllers and planners do spend time on the road as part of their induction.

**Recommendation 7: Data needs to be collected to identify when patients do not receive their full prescription of dialysis or miss complete dialysis sessions.**

Healthwatch discovered that information about when patients have their sessions cut short due to transport delays is not being reported. Arriva will now be keeping their own logs of people delayed due to transport and will also make a record of aborted journeys e.g. when people make their own arrangements. This is going to be rolled out across the whole of the Arriva network.

Some patients told Healthwatch that they sometimes missed going to their dialysis sessions because they could not face the travelling to and from. Again this is not recorded or reported, but Arriva would make sure that they log this if they are made aware.

**Recommendation 8: Dialysis patients waiting for transport home after their dialysis treatment need to be provided with a level of care during this time to ensure their safety.**

Healthwatch also identified that sometimes vulnerable people are left on their own in the waiting area, which is not in sight of the rest of the unit. This can be particularly difficult for people who have chronic conditions and also for people with dementia. Arriva do not feel that the welfare of people in this area can be their responsibility and that this is an action that needs to be followed up by the unit staff.

## **Acknowledgements**

We would like to take the opportunity to thank everyone involved in this project.

To all patients, thank you for giving up your time to talk to us, and to the staff, thank you for welcoming us into the dialysis units again.

To our volunteers, thank you for also giving up your time to prepare for and undertake the interviews with patients.



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