healthwatch
Nottinghamshire

Insight

Renal patients' experience of the patient transport service

March 2015

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1 Summary of evidence

1.1 Introduction

We wanted to understand renal patients' experience of the patient transport service going into and home from the Nottingham City Hospital renal dialysis units. To do this we did the following:

- spoke to 45 people who use the transport service, collecting over 12 hours of feedback;
- gathered diaries of journeys from 7 patients covering 50 journeys;
- collected 50 completed surveys from renal dialysis patients; and
- collected surveys from 17 members of the renal unit staff to get their experiences of the service.

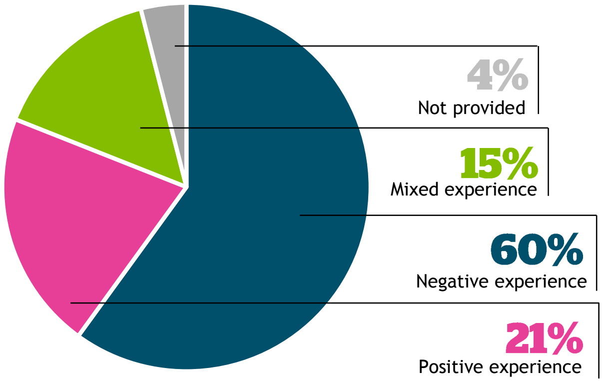
These activities were conducted and supported by a group of Healthwatch Nottinghamshire volunteers and staff. Every effort was made to encourage all patients to participate, but as this was voluntary it is possible that some patients not engaged in our project had different experiences of the patient transport service.

This section details the main findings across all of these sources of evidence.

1.2 Main findings

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

Figure 1 Overall summary of experience for all patients



Note: Based on 45 interviews

★☆☆☆☆

Most frequent overall rating provided by patients in survey
(Base = 25 patients)

★★☆☆☆

Most frequent overall rating provided by renal unit staff
(Base = 17 staff members)

Patients needing special requirements for their transport and the time patients attend for dialysis makes 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

50% of patients having dialysis in the evening had a negative experience

These experiences reported by patients 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 have not had their full prescription of dialysis. Some patients identified that whole sessions had been missed, they told us that this was a choice they made based on previous poor experiences of the patient transport service.

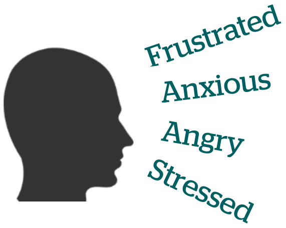
Patients and staff agreed that this is detrimental to patients' physical health.

> 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

> Some don't do full time, that's when you start to impact on people's lives, it's going to get dangerous.
> Renal dialysis patient

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.

Waiting for transport was a cause of distress for many renal dialysis patients.



These are the words used to describe emotional feelings across all sources of evidence.

These were not only significant in themselves but there was a feeling that these emotions exacerbated the impact on physical health.

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. It was obvious that many were very conscious of this and felt anxious about it.

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:

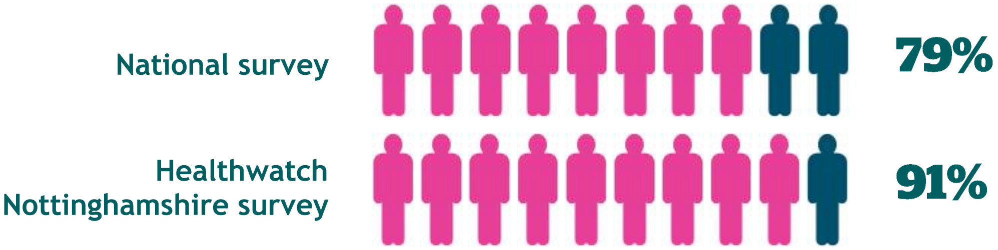
- When patients called on them for transport to and from the dialysis unit when the patient transport service did not arrive.
- When they were at home waiting anxiously for patients to return from dialysis.
- Living with the time commitments that their family member has to devote to cover the transport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

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. They were quick to point out that the Arriva transport crews played no part in their negative assessment.

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. The drivers were seen as improving the patient experience of dialysis treatment, and some see them as part of their treatment.

Figure 2 % happy or very happy with friendliness of staff



Note: National survey is National Kidney Care Audit Patient Transport Survey 2010

We found that renal dialysis patients in Nottinghamshire are happier with their patient transport staff than other patients across the country. As illustrated in figure 2 91% of our survey respondents indicated that they were happy or very happy with the friendliness of their staff, compared to 79% of patients in the national kidney care audit patient transport survey 2010.

Experience of taxi drivers was less positive. Patients reported issues with the care and support they provided and gave examples of when they had turned away from their homes without them.

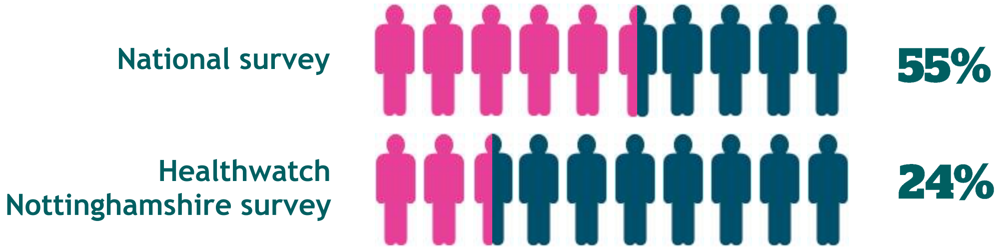
> They have come and they have actually gone away saying that I am not there…a neighbour tells me oh yes he was there for a few minutes but he did not get out the car.
> Renal dialysis patient

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.

Figure 3 shows that renal dialysis patients in Nottinghamshire were much less happy with the punctuality of the patient transport service, when compared to the national survey. 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.

The long waits were a source of distress for many patients, they talked frequently about feeling angry, frustrated and stressed. This was also confirmed by staff. Such feelings were exacerbated by poor communication as patients and staff had no information or had been given inaccurate estimations of collection times.

Figure 3 % happy or very happy with the punctuality of the service



Note: National survey is National Kidney Care Audit Patient Transport Survey 2010

For vulnerable patients particularly, the waiting had very concerning consequences. We heard examples of patients 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 wondered 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-one's 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.

> They know what jobs they've got to do that day, they book it all the time so they know. I come four days a week, same time so why can't they come at the same time to fetch me?
>
> Renal dialysis patient

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 reported by patients using the transport service (when compared to those who make their own transport arrangements). This was also identified as one of the reasons why some patients had stopped using the transport service to get to their dialysis appointments.

Both patients and staff linked poor planning to the poor punctuality and perceptions of inefficiency, and most frequently recommended that this aspect of the service needed to be improved. Training and development for planning staff was suggested to improve their geographical knowledge of the local area.

Improving this aspect of the service for renal dialysis patients was identified by patients and staff as having the potential to improve experience of the service.

2 Conclusions and recommendations

Conclusion 1:

Renal dialysis is a treatment which places significant demands on a patient's quality of life and their experience of the transport service increases this demand.

> It takes so much of your time, for some people, this just becomes your life, just this, and it doesn't have to be, it's just a little part of your life, not the whole of your life. Transport doesn't help make it a little bit of your life."
>
> Renal dialysis patient

A recent improvement acknowledged by a small number of patients is encouraging and has impacted positively on their most recent experiences of the service. For the majority, the unreliable nature of the service and the unpredictable waiting times patient's experience, mean 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. We believe that this would significantly reduce the feelings of frustration and stress felt by everyone involved, thereby improving their experience of the service.

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. This would reduce feelings of frustration that result in some patients choosing not to receive their full prescription of dialysis.

Conclusion 2:

Inequality of experience is evident, but all patients should experience a good quality service, particularly those patients managing other chronic health conditions.

When the service is good it's very good, illustrated by the positive ratings in many of the journey diaries. But our evidence across all sources indicates inequality in waiting times for those people needing special transport requirements; the level of care and support provided by taxi drivers; 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.

The current service is placing these patients at a substantial disadvantage in relation to their experience of, and impact of the patient transport service in comparison with other patients. 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. Consideration could be given to whether a set of quality standards could be written into their contracts, and processes developed through which this could be rigorously monitored and enforced. This is important given the rise in the use of taxis reported by ten patients we interviewed.

Conclusion 3:

The transport service for renal dialysis patients is inefficient.

> ...an elderly gentleman who lives near me... the transport came for him, and it was a car so four seats...They sent me a minibus...all the way from Worksop which arrived five minutes after with two crew...I said to these guys, can I ask why you're taking me, they said we've been asked to come all the way and take you home...That's a ridiculous waste of time, money and effort.
>
> Renal dialysis patient

Our evidence includes many examples provided by patients and renal unit staff, 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.

3 Introduction

At the end of December 2012 approximately 27,000 adults in the UK were undergoing some form of dialysis, with over 22,000 receiving this therapy in hospital (National Kidney Foundation, 2014). Dialysis is a form of treatment for patients suffering from kidney failure, which replicates many of the kidney's functions. Over 450 people were receiving dialysis (UK Renal Registry, 2013) at the Nottingham Renal Centre based at the Nottingham City Hospital (UK Renal Registry, 2013) at this time.

Many patients need to have dialysis on a long term basis, possibly for the rest of their lives, and those receiving Haemodialysis (the most known and used form of dialysis; UK Renal Registry, 2013) need to undertake three four-hour sessions every week (NHS Choices, 2013). Some people receiving dialysis are eligible for transport to and from hospital for this treatment, and the National Institute for Health and Care Excellence (NICE) has a quality standard for renal replacement therapy services, which states that this transport service must be effective and efficient. They acknowledge that poor transport can undermine good dialysis care and can have a major impact on a person's quality of life (NICE, 2014).

We started this project because we had received a number of comments about renal patients' experience of Patient Transport Service going into and out of the renal dialysis units at the Nottingham City Hospital. Our prioritisation panel (a group of volunteers who help us make decisions about where we focus our work) scored these comments as a high priority and asked us to undertake a project so that we could understand more about patients' experiences of this service. We want our findings to be used to identify if and how the service could be improved over the remaining term of the contract.

3.1 Our approach

We wanted to gain a deep understanding of patient's experiences and perceptions of how this experience impacts on their wider life. The main focus of our project was therefore on talking to patients face to face. Working with the renal dialysis unit staff we identified a week in November 2014 when we could go into the units and talk to the patients whilst they were receiving their dialysis treatment.

We planned our attendance on the two dialysis units to ensure that we covered as many dialysis sessions as possible, and had the opportunity to speak to all patients who used the service. We covered eight dialysis sessions in total, ensuring that we had morning, afternoon and evening sessions for patients who attended on a Monday/Wednesday/Friday pattern, and those who attended on a Tuesday/Thursday/Saturday pattern. Across these eight sessions we conducted 45 semi structured interviews with patients using the transport service provided by Arriva Transport Solutions Ltd. Participation in interviews was on a voluntary basis and patients were informed that they could withdraw from the interview at any point. Before interviews were conducted patients were fully informed about the project and gave consent for their interview to be recorded. Interviews were conducted by a Healthwatch Nottinghamshire volunteer or member of staff.

We also wanted to understand if patients' experience of dialysis treatment and care changed depending on how they travelled into the renal dialysis units. To gather this information we put together a survey for all patients on the renal dialysis units to complete. The survey focused on rating different aspects of the service and included some questions which had been asked as part of the National Kidney Care Audit Patient Transport Survey in 2010; this was so that we could compare our findings with the national results. Patients were given the option of completing this survey whilst on the unit, or at home, returning it to us in a freepost envelope. A total of 50 completed surveys were returned, with an even distribution of patients who currently used the transport service and those who made their own transport arrangements. Participation in the survey was voluntary, and whilst we made every effort to encourage all patients to complete the survey, there is inevitably an element of nonresponse bias. It is possible that those who did not participate have different experiences of the patient transport service.

Staff working on the two renal dialysis units were given the opportunity to contribute to this project through a paper survey of open ended questions. These allowed staff to tell us what they thought about various aspects of the renal patient transport service. The surveys were left on the renal dialysis units, and staff were asked to put completed surveys into a sealed 'post box' which was collected from the units the following week. A total of 17 completed surveys were returned, but as with the patient survey, the voluntary nature of participation means it is possible that the staff who responded had more experiences of, and stronger feelings about, the transport experiences of renal dialysis patients.

Patients were also given the opportunity to complete some paper-based diaries to tell us about their journeys and how they're feeling during a normal week of dialysis. The diaries were requested by and sent out to 16 renal dialysis patients, they were asked to complete them in the two weeks after our interviews at the hospital. Seven patients returned diaries for 50 journeys. Self-selection bias was likely as patients identified themselves for participation in this element of the project.

Arriva Patient Transport Solutions were given the opportunity to participate in a survey of their attendant crews but this was declined.

3.2 Our team

The use of our Enter and View volunteer team was a key part in collecting individual stories of patients in the dialysis unit. Enter and View is a power laid down in law and given to local Healthwatch through the Health and Social Care Act 2012. It enables Authorised Representatives of local Healthwatch to go into health and social care premises to see and hear for themselves how services are provided, and collect the views of service users at the point of service delivery.

Within Healthwatch Nottinghamshire it was decided that Authorised Representatives would carry out Enter and View visits as an outcome of an issue being discussed at the Prioritisation Panel and would be planned into larger pieces of work about quality, where it would form part of the evidence gathering or add value to the work being done.

Recruitment for these Enter and View Authorised representatives was done through our usual networks: existing volunteers, newsletters, Voluntary and Community Sector (VCS) websites and social media. We also had a list of potential volunteers who had expressed an interest before we were ready to recruit. We went through a formal selection process, including the taking up of references, a Disclosure and Barring Service (DBS) check and an interview with a panel of Healthwatch Nottinghamshire staff and a representative from Nottinghamshire County Council's market development and care standards team.

We recruited seven people into the team. All received training over two days, which covered the role of an Enter and View Authorised Representative and how that would fit in with our Insight Projects, of which this project is one, confidentiality, safeguarding, equality and diversity and Dementia Friends awareness. The final part of the training was a practical task, which took the form of the Enter and View Team interviewing some fictional patients in a mock up renal dialysis unit. We wanted staff and volunteers to be as prepared as possible for what they were about to find, including dialysis machines and blood moving backwards and forwards from the patients arms. During the week we were onsite at the renal dialysis units, five volunteers took part in interviewing patients alongside three staff members.

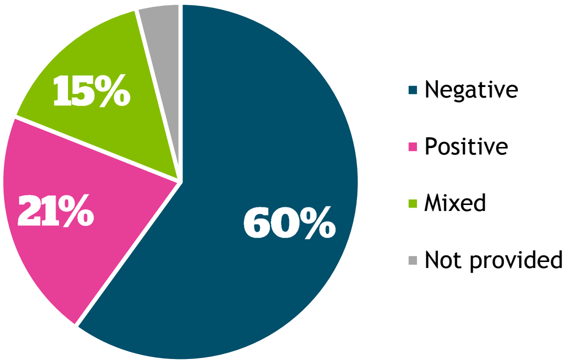
4 Findings from our patient interviews

During the week beginning the 3rd November 2014 our team of volunteers and staff attended both renal dialysis units at the Nottingham City Hospital to talk to renal patients about their experiences of the patient transport service. Only patients who used the service were interviewed. 45 interviews were conducted and transcribed, totalling over 12 hours' worth of feedback from patients. The transcripts were analysed and what follows are the key findings.

4.1 Overall experience

Patients were asked to summarise their overall experience of the patient transport service and figure 4 shows that almost two thirds (60%) provided a negative rating, almost three times more than the number of patients providing a positive assessment.

Figure 4 Overall experience of interview patients



Note: Based on 45 patient interviews

Table 1 Overall experience by patient group

Patient group	All	Special requirements*	Morning	Afternoon	Evening
Number of patients	45	11	17	16	12
Negative	60%	**73%**	59%	**75%**	50%
Mixed	15%	9%	12%	6%	17%
Positive	21%	18%	18%	12%	33%
Not provided	4%		12%	6%	

** relates to transport requirements*

Table 1 illustrates that there was some difference between patient groups:

- Patients needing special requirements for their transport, and patients attending dialysis in the afternoon sessions were more likely than any other patient group to identify their overall experience as being negative.
- Patients attending the evening dialysis sessions were less likely to identify their experience as being negative and more likely than any other group of patients to identify a positive experience

4.2 Waiting times after dialysis session

90% of all patients we spoke to talked about the waiting times for transport home after their dialysis session. It was the most talked about theme of people's experiences. However, it should also be noted that nine people acknowledged that there had been a recent improvement in waiting times after dialysis sessions.

All patients who identified that they needed special transport requirements talked about waiting times for transport home, as did all patients who attended the afternoon session of dialysis.

The longest waiting time identified was almost three and a half hours, but many people talked about waiting times of between one and a half hours and three hours, the following are some examples of this.

> We often wait over an hour. Week last Thursday I finished at 4.30pm and it was 9.00pm when we got home. We left here at 8pm. We kept ringing, they rang three times, and they kept saying a taxi was coming for us. Three times she rang, taxis on its way. It never turned up at all so we had to have an ambulance car in the end it was 7.55pm when they came for us.
>
> ...but sometimes it doesn't come until one hour or two hours after we come off the machine and I have known it to be three hours.
>
> As I say I mean waiting one and a half hours to two hours was nothing.

The majority of people used words such as *'often'*, *'very often'* and *'most of the time'* when asked whether they had ever been picked up more than 30mins after coming off the machine. These responses were typical:

> Oh yes, that happens quite often yes. Most of the time, more than half an hour.
>
> Yes, many times. Probably about 80% of the time.
>
> ...you sit there an hour, hour and three quarters is the most I've waited. It don't happen now and again it happens a lot.

Waiting for long periods of time after having dialysis was the cause of distress for many people, patients frequently talked about feeling frustrated, angry and stressed.

Poor communication characterised this situation. Negative feelings were made worse as patients had no information as to if and when transport would arrive, or were given inaccurate estimations. For example:

> Sometimes they ring and say taxi will be 10-15mins and it's an hour.
>
> But she can't tell me how long they're going to be, they just say they're on their way. Somebody is on the way. Not a clue how long it's going to be.

The time spent waiting for transport extended the time dialysis treatment requires from patients. For many who were in the later years of their life, this was a significant issue and one which not only affected themselves but also their family waiting for them at home.

> So I'm not finishing till say 12.45pm to 1pm and then I have to sit in there for about an hour or so. It's getting, well when you've been up since 4.50am in the morning, it's a long day.
>
> Well it really makes me feel quite ill actually, cos I've eaten at 5.30am to be ready then it comes to 1.45 – 2.15pm, it really is a long day. I mean particularly at 84.
>
> I know I'm going to wait out there and the family at home is beginning to expect that. On occasions, well not on occasions most of the time, I reach home at about 12am midnight. An hour and a half to wind down after this...I've asked them to go to bed, they usually do cos they have to go to work the next day but I disturb them when I get in.

The impact of waiting went beyond feelings and emotions. Patients described physical impacts on their health such as increased blood pressure and sickness or nausea. For those balancing other long term illness, being late home had potentially serious implications. For example:

> ...my blood pressure, when I'm thinking about what's going on, my blood pressure goes up.
>
> "Plus I'm diabetic...I've got to be having meals at certain times and if I got to be waiting two to two and a half hours out there I'm going over...me sugars are up.
>
> I have problems preparing meals and things at night, as I'm arriving home sometimes very late and by the time I've got in the house I'm just not wanting to face up to cooking and eating and consequently I'm not getting the quality of nutrition if you like.

There was also a feeling that the negative effects of waiting for transport 'undid' the good work of the dialysis:

> You sit and steam, all the good is gone by the time you get home.

When waiting times got too much for some people they made their own way home. For some, this meant calling on friends and family. For other patients their use of public transport or walking was a concern to their safety. For example:

> 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.
>
> I don't know really, I don't know I'm doing it. They know about it and the doctors. Me daughter gets really mad with me, [she says] you keep ringing me to tell me you've wondered 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.

The combined effects of this experience and its impact also affect the way some people feel about their dialysis treatment. For example:

> I've often waited, the longest I've waited to get picked up from here is two and a half hours which really annoys a person, especially when you've had dialysis you want to go home and rest to wait out there for another two and a half hours is ridiculous, you do find the whole experience becomes quite unpleasant.
>
> If I could go home by bus I would, some days I can't, you know, I get tempted to say look you know what forget it...
>
> You just wish that you didn't have to have it.

4.3 Transport crews

84% of all patients we interviewed spoke about their positive experiences of the transport drivers and attendant crew.

The majority (76%) of patients who had a negative experience of the service overall, still talked about drivers and attendants in a positive way. They were quick to point out that they played no part in their negative assessment of the service. The following are typical examples of this:

> Yeah I've got no complaints with those.
>
> The drivers are marvellous, can't fault them at all, they're brilliant.
>
> I think they do a great job.

Patients clearly felt that the drivers cared for them, evidenced by stories of drivers helping them in and out of vehicles, walking them to their doors and ensuring they entered and exited their property safely.

> Sometimes, they have some people to help you to your door. They take them inside. Sometimes some of them help me well, unlock the door and see that I lock up proper so nobody can get in.
>
> Well, I mean, they often see you to the door when you're going home, make sure you're in the house, lights on and everything, that sort of thing. Help you in and out the ambulance if you need it so you can't fault them.

Drivers play an important role in patient's experience of dialysis treatment. They can improve the experience of the treatment and are seen by some people as being a part of their treatment. For example:

> They're important in having a good experience, if they're committed to being an attentive person that translates into the service you get from them.
>
> ...like I say some have got a great sense of humour, it picks you up when you're you know. Laughter is the best medicine, no matter what you get in here.
>
> Staff are extremely important, as you get to know people. You see them more than your own family. People are seeing these drivers eight times a week, six times a week. You get to know the people really well.
> It's part of the social part of treatment.

Arriva drivers and crew members were singled out for praise by over half (51%) of all patients. When compared with taxi drivers patients felt Arriva drivers:

- had a better understanding of their needs;
- had a more positive attitude towards them, which meant they were more friendly and talkative; and that
- they were more knowledgeable about the routes into and out of the Nottingham City Hospital.

There were a number of people who felt safer and more confident travelling with Arriva drivers and attendants than when travelling by taxi, as explained by these two patients:

> The ambulance is the best one, as you're with a guy who knows what's wrong. Let's be honest we're all ill people, very poorly people, if someone falls ill in a taxi what's he gonna do? I hope they understand that point, cos it's very major point, that is.
>
> They're all trained. But as I said, if you go with a taxi and feel bad or what, what are they going to do? They don't have a clue.

The positive relationships developed between Arriva drivers and some patients has a negative consequence for a small number of others. They felt some drivers had 'favourite' patients who they would wait for, despite other patients being ready and waiting for their own transport home.

> There are some who have their own favourites maybe they've know some patients for a longer period of time they prefer those routes perhaps.
>
> ...them drivers are always sitting waiting for them to come off the machine. I'm sitting there watching them waiting while they could take me home and be back in time for them.

Four patients questioned that the times they were made to wait for transport were a consequence of them making a complaint or only using them for journeys when necessary. This felt personal, like they were persecuted, and was not a nice feeling for patients to bear. For example:

> ...so they decided they weren't gonna take me no more all because I complain.
>
> Sometimes I wonder if it's because I'm not using them to go home that I have to wait longer. That's just me. It's not a nice thought.

There were negative comments about taxi drivers from over 40% of patients. Many people gave examples of when taxi drivers had not knocked on their door or did not offer any help support getting in and out of vehicles.

There was also a considerable number of people who stated that a taxi had turned away from their house without them, after not signalling to the patient that they were there or not waiting long enough for the patient to come out of their house. For example:

> …when you get a taxi, it's just that sometimes they don't even ring your doorbell. Because I had experiences with drivers who come and they beep the horn and then if I don't come out within a certain time they just go.
>
> There have been occasions where they have come and they have actually gone away saying that I am not there – they have sat in the car, not come and knocked on the door and I cannot see they're there…A neighbour tells me oh yes he was there for a few minutes but he did not get out the car so I mean that's poor.

A number of patients didn't feel safe when travelling by taxi, this was as a result of poor driving standards and lack of consideration of patient needs. The following quotes explain this:

> Not so with the taxis. Because I live on a very busy road, sometimes, plenty of times, they put you on the other side of the road. And they don't wait to see that you cross over safely. It's dangerous it is.
>
> I went home in a taxi the other night, it was in a line of traffic, he hadn't got patience to wait so we overtook 12-14 cars butted in and joined the traffic again…its nerve wracking.
>
> Well I've had many a taxi driver who I'm not joking, have gone down the side streets and over the humps, I'm not joking, at about 20 miles per hour. They've not thought there's passengers the car, its vroom, vroom, you're bouncing about in the back of the cab…

Patients also gave examples of when taxi drivers had told them they did not want to pick them up as they received less payment for the hospital transport than they would earn from other jobs. This had a negative effect on how people felt about themselves and their treatment.

> Often when they pick me up they make a point that they're only going to get like £8 for my journey when the official price or price they would charge is closer to £12 or something.
>
> No it doesn't affect your treatment but it affects how you feel inside, which is sometimes not a nice feeling. You feel like you've been put on by someone else who doesn't understand.
>
> A lot of the drivers are saying they would rather not pick us up because it doesn't pay enough for them.

4.4 Waiting times for transport before dialysis

Two thirds of patients (67%) talked about the waiting times they experienced for their journey into the hospital. They were less frequently late being picked up than going home but many people still talked about this using words such as *'half the time'* and *'sometimes'*.

Patients feelings about this wait were similar to those reported when waiting for transport to take them home, but there was a recognition that being able to wait in the comfort of your own home made this wait easier to bear.

> But at least I'm sitting there in my own chair in comfort not here.
>
> Coming in to the hospital are easy, you're losing time because it isn't a punctual service, but you're actually doing your own thing at home so you're not losing so much on that journey.

Half of all patients who talked about waiting times before their dialysis session reported that transport was never sent to collect them and that they had been 'forgotten', for some this happened more than once:

> I've had at least four occasions when I've not been picked up.
>
> Sometimes they forget about you, you see.
>
> My name just didn't come up, and that was it, you know. Just missed it off, forgot me, for want of a better word.

Patients were sometimes forced to arrange their own transport into the dialysis unit which was an inconvenience for their family and friends, but patients most commonly identified that taxis were then dispatched to collect them.

A lack of consistency and unpredictability of the time patients would be picked up from their homes was very frustrating. Some patients claimed to never have been told an expected collection time whilst many more felt that having to be ready for collection from two hours before their dialysis appointment was too long. This was particularly the case for:

- patients attending dialysis in the morning, who were required to be ready for collection from 5am; and
- patients needing special transport requirements.

> So if we're on at 7am in the morning, we have to get up at 5am to be ready. And then they'll come and pick you up, other times they're late for you and that's just not fair.
>
> I've had them come at 5.15am one morning…if you're on at 7am that means you're up and ready for 5am, who's gonna get up at 4.30am just to hope they'll turn up.
>
> I have to be up at 5am to be ready for 6am, sometimes I am not picked up until 7.45am and then other times they will come at 6.10am…

The most frequently identified impact of this wait was being late onto their dialysis machine. Every patient who talked to us about waiting for transport to get them into hospital identified that as a consequence, they have not had their full prescription of dialysis. In many instances this decision was made by the patient born out of their frustration with the transport service. A small number of patients commented on how they have missed complete sessions, they told us that this was a choice they made based on previous poor experiences of the patient transport service.

> Sometimes if I'm frustrated I ask for a shorter time on dialysis.
>
> So like I say I've had times when Arriva have picked me up and I've been so frustrated when I've got home that I've refused, that next time I will not come in.

For patients attending the evening dialysis session this decision was often taken out of their hands and was a result of the water supply to the dialysis machines automatically shutting down before they had their full prescription.

The majority of patients felt that this did have a direct impact on their health:

> On Wednesday in particular I'm due to go the machine at 6.45pm. Arriva didn't pick me up until 7.30pm. Which meant I can't have my full complement, full hours so I have to reduce the amount of time that I'm on the machine. That's not good for me, it affects my health as you need your four hours dialysis.
>
> ...some don't do full time, that's when you start to impact on people's lives, it's going to get dangerous.
>
> When a patient's late at night it's a knock on to their health as they're not getting their prescribed dialysis, it's not acceptable.
>
> ...so you're not getting your proper treatment. That can have detrimental effects on your health, if that happens often, then it wouldn't be very good at all.

The impact of being late onto the dialysis machine was not confined to them, patients identified that staff on the renal unit also suffered and there was a knock on effect to other patients attending the following dialysis session. It was obvious that many patients felt anxious about this. For example:

> Of course, not only my treatment but the people who come after me as well because I do my four hours, four and a half hours, they have to change the equipment, clean the machines, wipe down all the chairs and get everything ready for the next person who comes in. If the next person comes in late, it means the person after that comes in late. It's an ongoing thing. It's not good at all.
>
> When you're having to wait on transport coming to you because it's late, then you're late coming in here and then, late in coming off, which has a knock on effect for the timeslots after, people are late. So it's unfair for everybody.

4.5 Planning and co-ordination of journeys

Almost two thirds of patients (62%) commented on how they felt the planning and co-ordination of journeys was negatively affecting their experience of the patient transport service. This was mostly due to spending long periods of time in vehicles travelling across the city and county:

> It's a tour of Nottingham before I get home.
>
> But I don't really understand why they have to send them such a long way away to take you home when you only live a stone's throw away.
>
> ...sometimes we go to Arnold to pick up a chap from there then come back to Sherwood to pick someone up from there, and then go over to Basford to pick someone up from there...it can be quite a long time.

The inconsistency and unpredictability of the transport journey doesn't match with the routine of dialysis treatment. Many patients gave examples of when they had not been collected, or who were no longer routinely collected with people who lived in their locality.

> They know what jobs they've got to do that day, they book it all the time so they know. I come four days a week, same time so why can't they come at the same time to fetch me?
>
> Its things like, how can you not be planned, we come three times a week every week. It annoys me when you phone up and say you're waiting. How they are not planned, why not? That's the one I can't understand. The terminology is that you're planned or not planned, surely you should be planned unless the hospital or someone else informs them you're an inpatient or passed away.
>
> The people I used to come with still come in via somewhere else. It's you know, there's no logic. I can give you an example Mr <X> and Mr <Y> live in the same area, same estate, same housing place. And they get two cars to pick them up...they live four doors from each other, the logic in that is tell me what? I aint got a clue.

The majority of patients felt that bad planning and co-ordination of journeys was also responsible for the waiting times they experienced for either their journey into dialysis, or their journey home again. Patients found it frustrating when transport would come to collect someone who either was not yet ready to be collected, or who lived near or on the route of other people who were being collected. For example:

> I think it's really the planning. Because a lot of the time, I know there are a couple of people who are on a route that can be used for all of us, four or five people, rather than take a taxi for each one, I mean that, those five people could fit in an Arriva ambulance and go home.
>
> What it is, they drop him off first they drop the old lady off after, and then me next. But they never do it like that they pick him up, her up and I'm still sitting there waiting, It's the same area why don't you just pick, the three of us came in this morning, why can't they do it like that.
>
> When it's time to go home they picked the other three people I usually travel with and leave me, it was another hour and half before they pick me up. The transport it like hit and miss.

Poor communication between drivers, the call centre and patients was adding to people's frustrations. Contacting the call centre was a negative experience for 17 of the 20 patients who had made contact with them directly. They talked about not being able to get through on the phone, being placed on hold for lengthy periods of time and being told conflicting information.

Patients believed that the poor planning of journeys was responsible for the widely held perception amongst patients that the service is not efficient. There were examples of poor communication which resulted in transport either not turning up, being sent to collect the same person twice or being sent to collect patients who have already told the call centre they do not need transport.

> On another occasion they picked me up at 6.30am and half an hour later they sent another car but of course I had gone then so that was a complete waste of money.
>
> ...my neighbour tells me 10mins later a driver came to pick me up.
>
> Arriva have even come to pick me up when I've not ordered transport on several occasions.

The lack of flexibility of the transport crew in being able to arrange journeys based on the observed need at the renal dialysis units was also a frustration. Five patients identified occasions when they had asked the driver to share transport home with someone who lived on or near their route but were refused.

> I mean I don't want to have any, what they call, privileges before anybody else, I'll take my turn obviously, but it just seems silly when they've only got one in the car going the same way but they're not allowed to pick you up and take you. I know they'd take me if they were allowed to. They often say sorry <name> I can't take you, they go and ask them but they come back saying they can't take me, someone else is coming to get me.
>
> I have sat in this waiting room at 11 o'clock at night, and this is the honest truth, this was Arriva, I've had a friend, an elderly gentleman who lives near me, and the transport came for him, and it was a car so four seats, they took him in and he said oh <name> lives near me, they said <name> wasn't on the list, fair enough. They sent me a minibus, alright, from Worksop, all the way from Worksop, which arrived five minutes after with two crew one driver and one in the back, all for me. I said to these guys, can I ask why you're taking me, they said we've been asked to come all the way and take you home. I said that man who's leaving now he lives a few doors from me, they said we'll ring and tell them so he rang and they said we've already got you there so you'll have to take him home. That's a ridiculous waste of time, money and effort.

4.6 Transport requirements and preferences

11 patients indicated that they needed some form of special transport requirement, the majority of which were related to mobility issues that impacted on their ability to get into and out of transport vehicles.

Eight of these 11 patients (73%) had experienced the wrong type of transport that did not match their requirements. Wheelchair patients had been sent cars that could not accommodate their chairs resulting in additional waiting times. Others felt that their needs were not being listened to resulting in poor experiences.

> I have to have a front seat. But they're not listening, so they'll put two front seat passengers in together, who gets the seat?
>
> I'm asthmatic, I don't smoke, and I kept coming with a lady who smokes so heavy I was having to use my inhaler, and I said don't put me with her again and they did. They're not listening. I'm not trying to be awkward.

When asked about preferred transport type, patients most frequently identified Arriva cars as providing a more comfortable and quicker journey.

Negative experiences of taxis was the most common reason for patients who indicated a preference for any type of Arriva vehicle.

A quarter (24%) of all patients stated that they didn't have a preferred transport type, they would be happy to use any vehicle available if it arrived on time or reduced the time they were waiting for transport.

> I don't mind as long as it turns up on time
>
> It doesn't bother me what type of transport, it's just if they're there.
>
> They pick me up on time.

4.7 Effective, efficient and reliable service?

At the end of the interviews patients were asked to summarise their experience and consider whether the renal patient transport service is an effective, efficient and reliable service.

> It brings me here and takes me home, you can't fault that side of it.
>
> They're good when they get here.

Opinion was equally divided as to whether the service was effective, 18 patients stated yes and 18 stated no. Where reasons were provided the positive evaluations were due to an acknowledgement that the service did fulfil its transport role, patients did get into hospital and did get back home.

Almost half of all patients (49%) we spoke to concluded that the service wasn't efficient. Where explanations were provided, people talked about the poor planning of journeys and inefficient use of transport vehicles. For example:

> If it's an ambulance with five seats they need to use those five seats to use it efficiently enough. Rather than send a taxi out for three of them and take an ambulance for two of them which is why it's costing so much.

62% of all patients felt that it wasn't a reliable service, and justified this response by identifying a lack of confidence in the service and examples of when transport had not arrived to collect them.

4.8 Improving the renal patient transport service

The patients we interviewed were asked how they think the renal patient transport service could be improved. Only five patients were unable to identify any improvements or felt that the service did not need to be improved.

4.8.1 Better planning of journeys

The most frequently identified improvement was the planning of journeys, suggested by 18 patients we interviewed (40%). When making this suggestion people talked about the current inefficiencies of the service and their evidence of journeys being poorly planned.

Seven of these patients suggested that staff who were planning the journeys needed further training and development, they questioned whether these members of staff had sufficient knowledge of the city and county, for example:

> Make sure that planners are trained and know the area.
>
> Retrain the people that are in charge of routing the transport, make sure they understand the geography of the county, of taking people to and from the unit.
>
> I used to do deliveries, colour code the map. Don't cross colours with patients. So like, Clifton would be yellow, and the Meadows would be yellow cos that's close. Colour code the map by patients.

One patient suggested that improving knowledge and understanding of the dialysis process and how the transport experiences impacts on patients would help.

> What needs to happen is that they need to see what the patients go through to understand, the times I've been picked up and asked how long are you dialysing for? Four hours. How long for? For life!

If the planning of journeys was improved patients believed that their experience of the service would improve as they would feel less stress and frustration.

4.8.2 Improved punctuality

When talking about the planning of journeys, 14 patients suggested that this would improve the punctuality of the service. The majority of these people (10; 71%) talked about it overall, whilst four specifically identified that this needed improving for their journeys after dialysis:

> When people finish dialysis you don't want to wait, you spend three to four hours sitting here. Punctuality is number one on my list.
>
> I genuinely feel, when we finish, we need transport.

The most frequently identified impact of this would be an improvement in renal dialysis patients' quality of life. The unpredictable waits for the transport service restricted patients' activities for the remainder of their dialysis day. This is something which particularly impacted on patients attending the morning dialysis session.

> If you are not worrying about transport it makes life so much more pleasant, if you have got to think when am I going to get home? I mean, it's a silly thing, well it's not a silly thing, to have an appointment for the doctors or the nurse at your own practice, you can't make one on a Monday, Wednesday or Friday afternoon because you have got no idea whether you are going to get home or not and that's a big thing because sometimes they can only give you an appointment on a Monday, Wednesday or Friday afternoon and then you are waiting weeks to get the appointment because you can't guarantee you getting home.
>
> A punctual service means I wouldn't be wasting half of my life.
>
> If I got home sooner definitely. If you don't get home till 7-8pm it's time to go to bed isn't it.

4.8.3 Further training and development for drivers

Eight patients recommended that drivers undertake some additional training to improve their understanding of renal dialysis and how this impacts on patients.

More than half of these patients specifically identified that taxi drivers needed further training to get them up to the standard of the Arriva drivers.

> I'm not so sure whether the taxi drivers are trained. What if something happens to you like you're bleeding, would they know what to do? An ambulance driver would know how to do those things if you're feeling faint or anything.
>
> Yeah. We need the taxi drivers to be better.

Simple improvements such as ensuring taxi drivers knock on patients' doors and greet patients with a friendly smile would make a big difference to some patients' experience of the service, and how they feel in themselves.

> A lot better, don't feel good when they don't say thank-you. Speak to everybody friendly...and everybody feel better.
>
> ...there's a lot more going on in dialysis than can be seen, and I'm sure they deal with all sorts of patients, I respect that, but the drivers can be worn down, worn down in a way that they don't feel this job, like doing it, and they have to rise above it, I respect that.

4.8.4 A dedicated renal dialysis transport service

Five patients specifically requested that there is a transport service dedicated to getting patients into and out of the renal dialysis units. The routine of the dialysis schedule was seen as enhancing the ability to co-ordinate these patients' journeys and subsequently improve their experience.

> ...the renal transport used to just do renal and if the driver came in and somebody was ready they used to take them without any hassle, now whether that would work now or not I have got no idea but they should be able to sort the renal out because people are coming in on the same days at the same time and they are going home at the same time so they should be able to sort that out without too much trouble I would have thought.
>
> Erm, just, if I was in charge I'd put all dialysis patients, we're all up in the same time each week, all have appointment times. If they put those people together, if they could do that it would be better really you know...

It is because of this routine, the effects of being late on their health, and the health and experience of other patients that they felt it important to give renal dialysis patients dedicated transport resources.

> ...don't pick anyone up who is going to a ward or clinic, just pick dialysis up together, it's important we get on because if we're late, the next one's late, the next one's late and some don't do full time, that's when you start to impact on people's lives, it's going to get dangerous.

5 Findings from our patient journey diaries

Patients were also given the opportunity to complete some paper-based diaries to tell us about their journeys and how they're feeling during a normal week of dialysis. The diaries were requested by and sent out to 16 renal dialysis patients, they were asked to complete them in the two weeks after our interviews at the hospital. Seven patients returned diaries for a total of 50 journeys, 25 journeys into the dialysis unit and 25 journeys home.

5.1 Journeys in to the renal dialysis units

Of the 25 journeys into the renal unit patients identified that they were late on four occasions (16%), with the longest delay being 30 minutes.

One patient reported that transport had not arrived to collect them from home and that they had to make their own transport arrangements in order to reduce the delay to them getting onto the dialysis machine.

79% of journeys into hospital were identified as being shared with others, most frequently through ambulances (58%). Patients were most likely to give these journeys a four star rating (when using a scale of one to five where one is the worst and five is the best).

Three quarters (76%) of journeys described were positive, with no problems or issues experienced. When this happened, journeys were rated very highly, with patients most frequently providing a four star rating (when using a five star scale, where one is the worst and five is the best).

Negative journeys resulted in very negative feelings, patients wrote about feeling anxious and upset.

5.2 Journeys out of the renal dialysis units

Of the 25 journeys out of the renal dialysis units patients identified that they were waiting longer than 30 minutes for the transport on seven occasions (28%).

The longest wait was 90 minutes, whilst the shortest wait was five minutes. Waiting times between patients were variable, one patient waited an average of 17 minutes compared to two other patients each waiting an average of 55 minutes.

Overall, the average rating for journeys home was 4.10 (when using a scale of one to five where five is the best and one is the worst), patients most frequently provided a five star rating.

Over half (57%) of all journeys home were shared with others, most frequently in ambulances. These shared journeys received an average rating of 4.17.

There was a particularly negative journey identified where a patient had a journey of just over three miles to get home, which took a journey time of 1 hour 15 minutes, after waiting 45 minutes to be collected from the hospital. During this waiting time the patient identified very negative feelings and frustration at having to see drivers waiting for other patients to come off their machine whilst he was ready and awaiting collection. The patient identified that this was a frequent occurrence.

6 Findings from our patient survey

During the fieldwork week patients visiting the renal dialysis units at City Hospital were asked to complete a patient survey regarding their experiences of travelling into the unit. Patients could either complete it during their dialysis session with the help of a volunteer or complete it at home and return it to us in a freepost envelope. 50 completed surveys were returned.

6.1 Profile of respondents

Just over half were from current users of the patient transport service, as identified in table 2.

Table 2 Profile of respondents

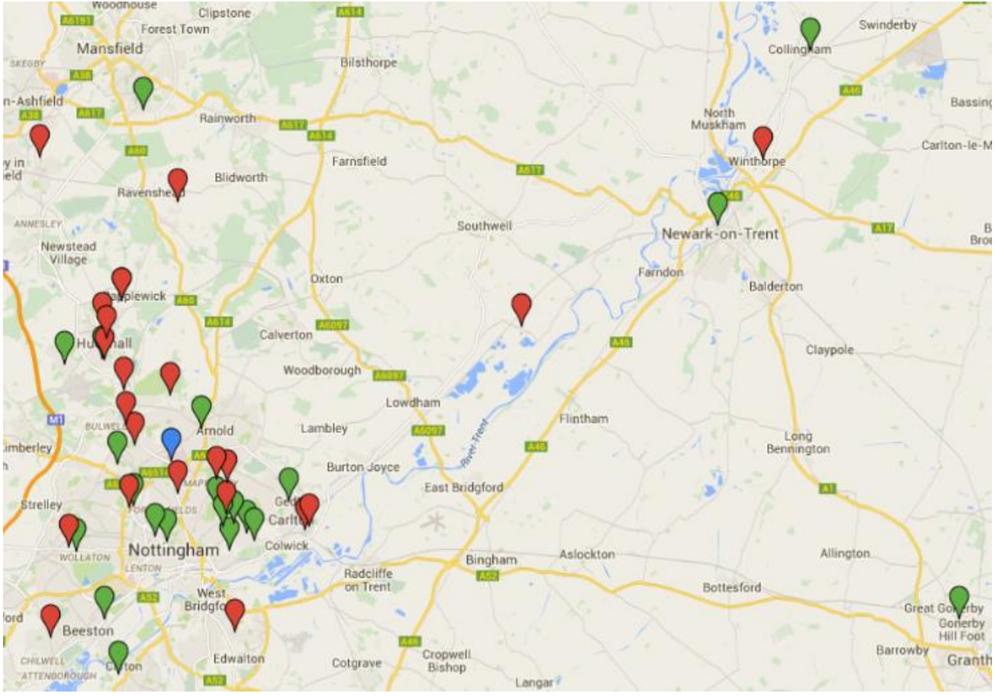
	Count	%
All respondents	**50**	**100**
Currently use the patient transport service	26	52
Not current users, but have been in the past	11	22
Not current users, never have been	12	24
Users needing special transport requirements	15	30

Note: one patient did not respond to this question

A third (30%) of all respondents needed special requirements for their transport to and from dialysis. The majority (60%) stated that needed a wheelchair, and others identified mobility issues which impacted on the type of vehicle they could travel in.

Patients travelled between one and 31 miles for a one way journey to or from the renal dialysis units, the average distance travelled was six miles. The postcodes of all respondents are shown in figure 5.

Figure 5 Map showing postcodes of survey respondents and Nottingham City Hospital

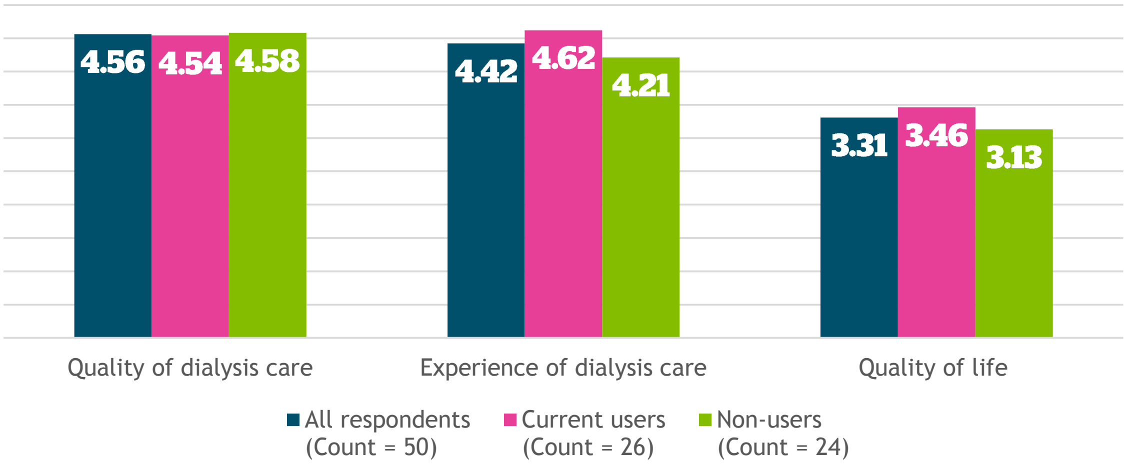


Source: Patient survey respondents. Base = 50
Green markers = Transport service users; Red markers = Patients arranging their own transport; Blue marker = Nottingham City Hospital.

6.2 Ratings of care and experience

As illustrated in figure 6, all responding patients rated the dialysis care they received very highly, most frequently rating both the quality and experience of this care as five star (when using a five star rating where one is the worst and five is the best).

Figure 6 Average* ratings of care and experience



** calculated from a scale of one to five where one is the worst and five is the best*
Source: Patient survey responses. Base = 50.

Patients rated their quality of life lower, most frequently giving a three star rating.

As shown in figure 6 there was no significant difference in ratings provided by patients using the transport service.

There was also no significant difference between the ratings given by those needing special requirements for their transport and those who didn't.

6.3 Travelling into and out of the renal dialysis units

Patients were asked to provide their postcode and the average and longest time it has taken for them to get into and home from the renal dialysis units at the City Hospital. A summary of this data is presented in table 3.

Table 3 Average distance and time travelling into the renal dialysis units

	Own transport arrangements	Transport service user
Average miles	5.44	6.53
Shortest miles	1.0	1.1
Furthest miles	22.6	31.2
Average usual minutes into hospital	19.79	35.68
Maximum usual minutes into hospital	60	140
Average usual minutes to get home	18.57	46.08
Maximum usual minutes to get home	50	145
Average longest minutes into hospital	34.47	83.96
Maximum longest minutes into hospital	120	210
Average longest minutes to get home	45.63	110.60
Maximum longest minutes to get home	180	300

Patients using the transport service travelled an average of one mile further to get to the dialysis unit than those patients who arranged their own transport.

The furthest distance travelled by a patient using the transport service was 31 miles, compared to 22 miles for patients who made their own travel arrangements.

Patients using the transport service took an average of 15 minutes longer to get into the hospital and 28 minutes longer to get home, compared to patients who made their own transport arrangements.

The longest journey times were 50 and 65 minutes longer for patients using the transport service than patients who arranged their own transport.

6.4 Ratings for the patient transport service

Patients using the transport service provided by Arriva Transport Solutions were asked to rate this service using a five star scale, where one is the worst and five is the best.

The average overall rating for the transport service was 2.44. Patients most frequently provided a one star rating.

Patients who need special requirements for their transport into the renal dialysis units were less positive than those who didn't. They most frequently provided a one star rating compared to a four star rating for those who didn't, as illustrated in table 4.

Table 4 Overall ratings of transport service by patients

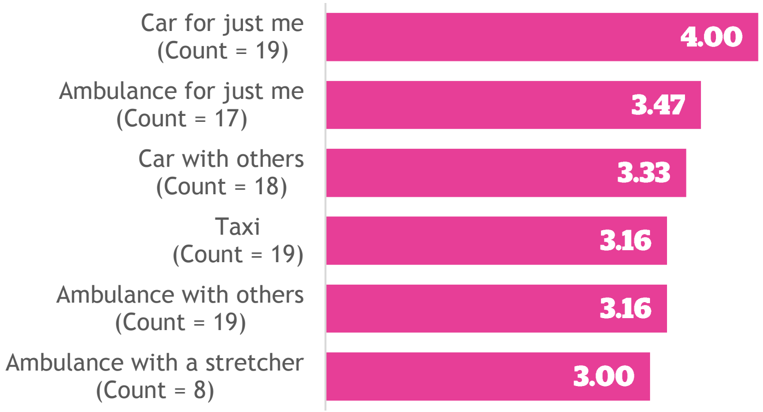
		No. of ratings provided					
	Total	1-star	2-star	3-star	4-star	5-star	Average* rating
All patients	25	10	3	4	7	1	2.44
Special requirement patients	10	6	0	3	0	1	2.00
Patients with no special requirements	15	4	3	1	7	0	2.73

** Calculated using a score of one to five where one is the worst and five is the best*

6.5 Types of vehicle

Patients using the patient transport service were also asked to provide ratings of the different types of vehicles they had experienced. This was using the five star rating where one is the worst and five is the best.

Figure 7 Average* ratings of transport type



** calculated when using a scale of one to five where one is the best and five is the worst*

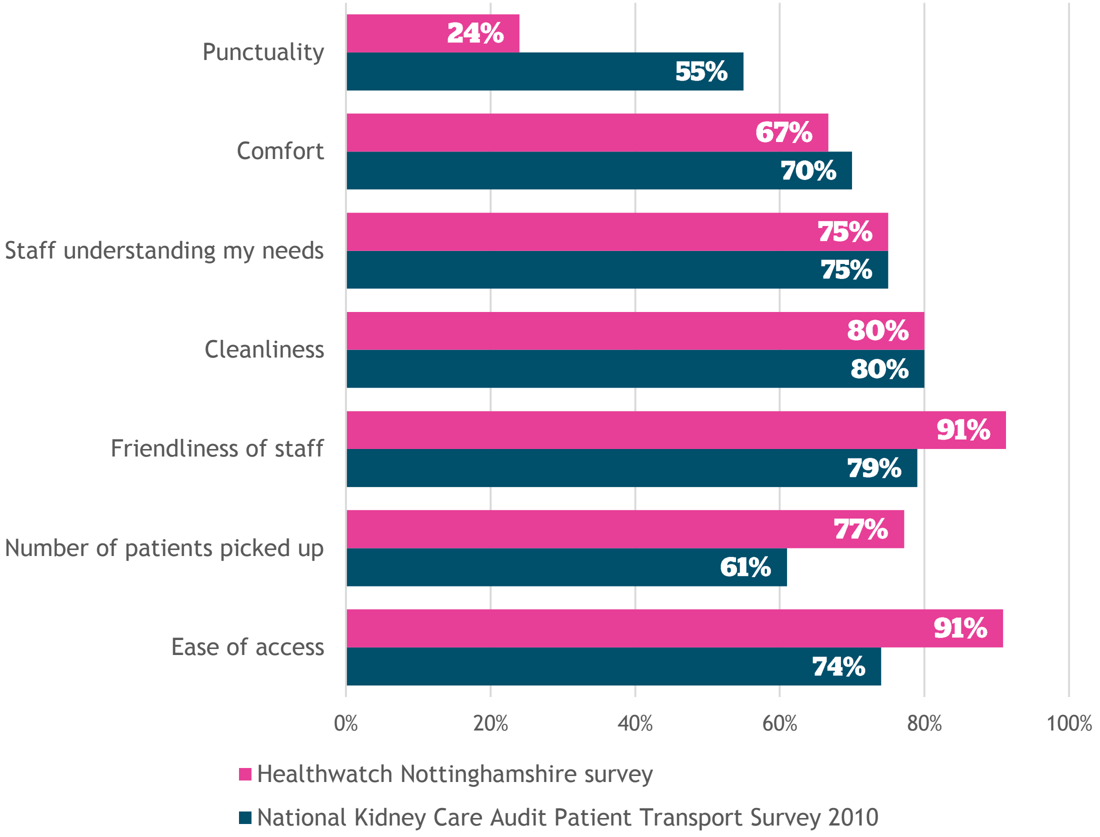
As illustrated in figure 7, individual cars were the most highly rated form of transport with the lowest rated being the two types of ambulances.

Patients were also asked to rate their satisfaction with aspects of the service that also featured in the National Kidney Care Audit Patient Transport Survey 2010.

Figure 8 shows that patients in our survey were more positive about the Arriva Patient Transport service than the national findings with regards to the number of patients picked up, ease of access and friendliness of staff.

Levels of satisfaction with the punctuality of the patient transport service were low in the national study, with only 55% of patients stating they were happy or very happy. In this project, the findings were worse, with just under a quarter (24%) being satisfied with this aspect of the service.

Figure 8 % happy or very happy with aspects of transport service



Note: When using a five point response scale from very happy through to very unhappy

When asked what are the best things about the patient transport service, the most frequently identified aspect was the drivers. Almost two thirds (63%) of respondents leaving comments wrote about the drivers and crew being friendly and helpful, for example:

> Drivers who are cheerful and doing a thankless job, can be pleasant and helpful.
>
> Reliable and friendly drivers.

The other consistently identified positive was that it got them into the hospital and home, and provided a service which they would otherwise have to source themselves if possible.

There were two main areas for improvement identified by respondents:

1. **Improved planning and co-ordination of journeys** – identified by 48% (10 out of 21) of respondents. This included training for staff who undertake this role.
2. **Improved punctuality** – identified by 48% (10 out of 21) respondents, four people specifically identifying reduced waiting times following their dialysis session.

6.6 Reasons for not using the service

Patients who identified that they had stopped using the transport service were asked to identify why. Of the 11 patients leaving comments all but two referenced that they had made this decision because of a poor experience of the service.

Waiting times were the most frequently identified specific reason, with patients writing about the two hour wait before being picked up or the wait for transport home after their dialysis session.

Long journeys caused by indirect routes and picking up or dropping off other patients were also identified by multiple patients who had stopped using the service.

These issues were identified as causing stress and anxiety, resulted in meals being missed and patients were, on occasion, travelling very late into the night.

7 Findings from our renal unit staff survey

Administrative and clinical staff working on both renal dialysis units at Nottingham City Hospital were invited to participate in a paper survey to provide their feedback on the Arriva Patient Transport Service. Surveys were available at a central location and completed surveys were collected in a box which was available during the week after the patient interviews were conducted. 17 completed surveys were provided.

7.1 Overall service ratings

Staff were asked to provide an overall rating of the patient transport service for renal dialysis patients using the same five star rating scale as patients, where one is the worst and five is the best. Staff were also asked to provide a rating of the Arriva Transport Call Centre.

Staff most frequently provided a two star rating for the service overall, and a slightly higher rating of three stars for the call centre.

When asked to explain their ratings half (52%) of staff commented on a poor experience of contacting Arriva on behalf of patients. The time taken to get through to speak to someone or being **placed on hold for long periods** of time characterised this poor experience. For example:

> It takes up time to chase up and rebook transport for patients on Arriva's contact number. Much of this time is spent on hold.
>
> ...it takes such a long time to get through to Arriva on the phone.
>
> Sometimes you are put on hold for far too long.

When writing about poor experiences, staff also commented on poor communication between the Arriva call centre and their drivers, which resulted inaccurate estimations of waiting times.

> Each time they say a different story then the drivers say something else.
>
> But most of the time I am kept waiting on the phone and the responses are unhelpful, i.e. saying a car is allocated when we know this is not the case because one hour later they still haven't been picked up...and it doesn't seem that the office/admin staff at Arriva can get in touch with the drivers to find out their exact location.
>
> If we ring the office they are helpful but I find they exaggerate how long we will be waiting for drivers to arrive.

7.2 Impact on the role of staff on the unit

All but one member of staff completing a survey stated that calling the Arriva call centre does impact their role on the unit. There were two main effects identified:

1. **Diverting time and attention from nursing duties**; identified by six members of staff. This was due to the time required to query existing transport or make new transport arrangements on behalf of patients.

2. **Dealing with angry and frustrated patients**; three staff members specifically identified that patients can be very angry and upset when arriving on the unit late and that they can, '…*take it out on staff*'.

Only one of the responding staff on the renal dialysis units identified that they had not called Arriva transport office themselves.

When asked to indicate the frequency with which they had to call, almost two thirds (63%) stated that this was either '*most*' or '*every day*' or '*every shift*' they worked.

Over half (59%) of responding staff identified that transport issues were most likely during the afternoon and evening sessions.

> …once we get to lunch time and evening time there are very long waits…
>
> Afternoon and evening.

Three members of staff specifically identified that wheelchair patients frequently experienced delays with their transport home following dialysis sessions.

> …normally wheelchair patients wait for long periods.
>
> …particularly wheelchair patients lunchtimes and evenings.

7.3 Impact on patients

15 out of the 17 responding members of staff specifically identified that a poor experience of the patient transport service does impact on patients' renal dialysis treatment. The two main reasons for this were patients:

- either **reducing the time** the patients have on the dialysis machine; or
- **missing** complete dialysis sessions.

The decision to reduce the dialysis time was taken by the staff on the dialysis unit when:

- the delay would impact on patients in the following session; or
- when the unit was due to close and the water supply to the unit (required for the dialysis process) would be automatically shut down.

> Sometimes they have to do less time on the machine to enable other patients to get their treatment.
>
> …if they are late in, they can't have full dialysis.
>
> The evening patients have to be off by 23.30 as the purified water for the machines switches off.

Staff identified that patients were also making this decision to reduce their dialysis time for themselves. Patients were anxious that being late off the machine would mean they would miss their pre-booked transport home, resulting in a very long wait until another driver and vehicle was able to collect them. For example:

> They often ask to have less treatment time as they are afraid of missing their transport home, that it will not wait or that they will have to wait for a rebooking.
>
> They feel that they will be left waiting for two hours to go home so they ask for their time to reduce.

Many staff specifically identified that not getting the full dialysis session or missing sessions completely was detrimental to their physical health, as explained by this member of staff:

> If patients sat on the unit doing nothing for two to three hours after their treatment they are missing out on sleep, food and possible medications which all contribute to overall health.

Staff also talked about the impact of dialysis on their patients' quality of life, when delays result in additional time being added to that which they already give up for their treatment. Some patients felt that the impact was too much on their lifestyle and family commitments. Staff felt that this resulted in some patients wanting to reduce or stop this treatment:

> The quality of life impact is huge as prevents keeping employment, affects family life puts a huge strain on relationships and has made patients want to stop dialysis.
>
> These patients already spend around four hours three times per week at the dialysis unit… This is a considerable commitment of their time which must affect other commitments such as jobs and families.

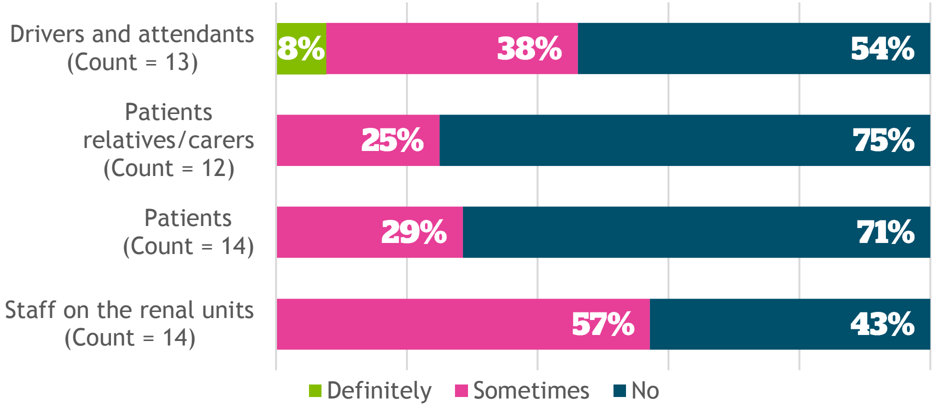
7.4 Improving the experience

Staff were most likely to indicate that they didn't feel Arriva listened to people in order to make improvements to their service, as illustrated in figure 9. They felt that other staff were more likely to be listened to, rather than patients or their relatives/carers.

Comments provided as explanation for ratings most frequently identified that they felt the problem lay with the planning of journeys and not the drivers themselves.

Some staff specifically identified that complaints and issues were listened to, but that no actions were taken which many found frustrating. There was a perception from some that this was due to a lack of capacity.

Figure 9 Perceptions of how much Arriva listen to others to improve their service



Note: 'I don't know' responses removed

All but one responding member of staff provided suggestions as to how the transport service could be improved for people attending renal dialysis. The most frequently identified suggestion was improving punctuality, 69% made reference to reducing the time patients were waiting for transport. The following are examples of this:

> Better timekeeping, less waiting to get patients in on time.
>
> Less waiting time.

Improved punctuality was typically talked about for both the journeys but there were slightly more specific references to the journey into the renal dialysis unit than the journey home after their dialysis session.

For a number of these respondents (four; 36%) improving punctuality was linked to improving the planning of journeys, for example:

> Plan they journeys better. Send patients in vehicles that are going in the same direction.
>
> Patients in same area need to have the same transport.

It was felt that this would reduce the time spent by patients in vehicles as journeys would be more direct.

Six members of staff (38%) identified a need for more drivers and vehicles operating for patients waiting times to be reduced:

> More staff/cars would resolve the length of time patients wait to go home.
>
> More cars and drivers.

Having a dedicated or allocated dialysis transport service was suggested by five staff (31%) as something that would improve the patient experience of the service.

Staff identified that this would benefit both the patients and the driving staff who would get to know each other and frustrations arising from long journeys and waiting times would be reduced.

> Dedicated drivers who know patients. This would make a massive improvement in patients' experience.
>
> ...it would make drivers lives easier and it would help to lessen patients' frustration.

Improving the communication between all involved, i.e. patients, renal unit staff and Arriva drivers and call centre was requested by four members of staff. An increase in the flow of information and an improvement in the accuracy of estimated collection times were identified. For the latter, one member of staff suggested a digital timing system similar to that seen at bus stops.

8 What next?

8.1 Official responses

This report has been sent to:

- Arriva Transport Solutions Ltd who currently run the patient transport service.
- Nottingham University Hospitals NHS Trust who run the Nottingham City Hospital.
- Mansfield and Ashfield Clinical Commissioning Group who oversee the contract for the Patient Transport Service in Nottingham and Nottinghamshire.
- The Greater East Midlands Commissioning Support Unit, who support the commissioning process for the contracting of the Patient Transport Service.

Responses to our report are included below.

8.1.1 Arriva Transport Solutions Ltd
(Current providers of the patient transport service in Nottinghamshire)

We welcome this report from Healthwatch Nottinghamshire looking at renal patient experiences and renal unit staff experiences when using the patient transport service. It provides in-depth insight from both perspectives. As a UK wide provider of patient transport services we fully understand the impact that transport can have on the lives of renal patients who regularly travel to and from hospital for haemodialysis and as such have already put in a number of measures over the last 6-8 months that focuses on improving patient experience for this group of patients. This includes, daily, weekly and monthly meeting with renal units to discuss issues arising with transport - this includes discussions around any patients whose dialysis has been shortened as a result of transport. We understand that on the occasional occurrences of shortened treatment time, a full clinical assessment will take place to ensure this is appropriate under the circumstances. As part of our most recent improvement plans we will be conducting an observation day in conjunction with the Nottingham renal unit to analyse each section of the patient's journey to determine what factors cause delays and how these can be mitigated. We have invested in additional staff in our control and planning centre and extra vehicles. We have made a concerted effort to reduce our reliance on taxi providers and endeavour to undertake more journeys with our own staff.

This report now gives us additional insight into the specific areas that really cause concern for patients and will enable us to focus on areas that will specifically improve patient experience further. We are aware that patients who travel home in the afternoon can be impacted by other patient journeys taking place more than any other time of the day and this report confirms that. This is an area of work that we are working in partnership with our NHS colleagues to try to reduce the amount of on the day journeys that are booked elsewhere in the system as the more we can plan the journeys in advance, the better service we can deliver for all.

We are very pleased to see the comments about the excellent quality of care delivered by our staff. This is testament to their hard work and commitment and reflective of the patient centred business ethos that we operate.

There are useful recommendations made about better communications with patients and NHS staff and we have just developed new patient literature to help with this process and we would be happy to work with Healthwatch on further ideas regarding this. The other recommendations focus on improved planning and dedicated vehicles which we will consider fully alongside our NHS commissioners of the service. We regularly survey our patients on the areas of comfort, communication and care as well *as gathering feedback on patient experience through our concerns, compliments and complaints team. We will use the information in the report alongside the feedback we gain directly to focus on areas that matter most to our patients.*

8.1.2 Nottingham University Hospitals (NUH) NHS Trust (providers of Nottingham City Hospital)

Alison Kinchin, Renal Dialysis Unit Manager, Nottingham City Hospital, said:

We welcome the work that has been undertaken by Healthwatch to seek the views of renal dialysis patients who use the transport service to get to and from our hospital. The findings provide a powerful account from patients of the impact of late and often unpredictable transport on their overall experience and the wellbeing on them and their families and carers. It is clear that renal dialysis patients require very specific transport arrangements, recognising the frequency of their treatment and individual needs of these patients. We have carefully considered Healthwatch's report and recommendations. We will work ever closely with our partners at Arriva during the remaining course of the existing contract and beyond to improve the experience of our patients, their families and carers.

Recommendation one response:

Staff in our renal unit will work with partners to introduce changes to how we do things that improve communication for the benefit of patient and staff experience. We would specifically encourage transport providers to consider introducing the use of innovative technology (such as text messaging reminders) to keep patients better informed about their transport arrangements. The introduction of such technology has proved successful in other clinical areas across NUH from which we can learn.

Recommendation two response:

We are concerned to learn that each of the patients who took part in this important work described how transport delays too often lead to a poor experience and a reduction in treatment time for patients. This is frustrating for patients and can, if it occurs frequently, could have an adverse impact on the health of patients (dialysis treatment time has been directly linked to outcomes in haemodialysis patients). We strongly support this recommendation which mirrors the commissioning model that exists in other parts of the country. Such an improvement would improve the health and wellbeing of our patients.

Recommendation three response:

We acknowledge the difficulties for Arriva when it comes to providing non-emergency transport for such a large organisation such as NUH and the competing priorities colleagues face when it comes to providing transport. This includes substantial numbers of requests for transport daily for renal dialysis patients, inpatients (from ward discharges) and return journeys home after outpatient appointments. Nevertheless, renal dialysis patients remain the largest user of this patient transport and do have very specific and individual patient needs which require this group of patients to be prioritised for home journeys after their treatment. Given the national commissioning intention to promote more home dialysis, it is highly likely that patients attending hospital dialysis units will continue to increase in dependency. This does need to be factored into both commissioning and provision of renal patient transport services. We agree that renal dialysis patients are not presently getting the transport service, nor experience, they deserve. We would be fully supportive of any work undertaken to progress this recommendation.

Recommendation four response:

Staff on our renal unit fully understand the complexity of renal dialysis patients. They are therefore well-placed to assist in any training which would raise awareness (to taxi companies) so that colleagues better understand the detrimental impact their service can have on the overall experience of our patients.

Recommendation five response:

We concur that the drivers and attendants are the biggest asset of the patient transport service. They are extremely caring towards our patients and this is demonstrated by this Report. The renal unit wholly supports any recommendation which allows nurses more time to care for patients and reduces the considerable amount of time that is currently spent dealing with patient concerns about transport and getting in touch with Arriva staff to enquire about transport.

Recommendation six response:

Putting yourself in patients' shoes is often the best way to understand their experience. Staff on the renal unit are willing to help with any training that would help our partners to better understand the impact of a poor and often unpredictable patient transport service on the impact of our patients.

8.1.3 Mansfield and Ashfield Clinical Commissioning Group

(Lead commissioner for the non-emergency patient transport service in Nottinghamshire)

Mansfield and Ashfield Clinical Commissioning Group (CCG) is the lead commissioner for non-emergency patient transport services for patients registered with Nottingham and Nottinghamshire (including Bassetlaw) GP's. The service we commission from Arriva Transport Solutions Ltd for patients travelling to and from dialysis appointments includes a number of key performance indicators (KPI's). These KPI's include arrival times, travel time and pick up times following treatment. The service levels commissioned are not being achieved. The CCG's are working with Arriva on a revised service improvement plan.

We value this report, which is comprehensive and has used a variety of methods to illicit the important views of both patients and staff in relation to their experience of patient transport services. It draws out a number of concerns which need addressing with the provider. We note that overall the report indicates that patient and staff experience of the current service is unsatisfactory. The principal cause of the concern seems to be punctuality and the timeliness of the current transport service. We also note that drivers and attendants are highly valued by patients. The report highlights that the experience of those patients with special requirements is particularly poor, with service being particularly problematic in the afternoon and evenings. We feel the report outlines the physical and emotional impact that this has on patients and also staff who are working in the renal service.

The CCG's will consider the recommendations contained within the report and will discuss these with Arriva to identify how the service and KPI levels could be improved over the remaining term of the contract.

8.2 Additional recommendations

Following on from the responses provided by the organisations involved we have identified two further recommendations.

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 will also need 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 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.

8.3 Future actions

We will ensure that our report is circulated as widely as possible in addition to publishing the report on our website. Patients involved in the project who requested a copy of the report will sent a hard copy in the post, and reports will be sent to both renal dialysis units.

This report isn't the end of our work.

We are currently in the process of setting up meetings to discuss the actions identified in the official responses to our findings and the implementation of these new recommendations and those identified in section 2.

We will return to the renal dialysis unit in the coming months to identify whether improvements reported to us in November have been sustained and identify any impact of actions taken since the publication of this report. We remain committed to ensuring that change happens and patient experience of the service improves.

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.

To the staff on the renal dialysis units, thank you for looking after us during our week on the dialysis units and for your feedback through the surveys.

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

Who are Healthwatch Nottinghamshire?

Healthwatch Nottinghamshire is an independent organisation that helps people get the best from local health and social care services. We want to hear about your experiences, whether they are good or bad.

We use this information to bring about changes in how services are designed and delivered, to make them better for everyone.

Why is it important?

You are the expert on the services you use, so you know what is done well and what could be improved.

Your comments allow us to create an overall picture of the quality of local services. We then work with the people who design and deliver health and social care services to help improve them.

How do I get involved?

1. Have your say

We want to hear your comments about services such as GPs, home care, hospitals, children and young people’s services, pharmacies and care homes.

You can have your say by:

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✉ Freepost RTES-TCEC-JTBR, Healthwatch Nottinghamshire, Unit 2-3 Byron Business Centre,Duke Street, Hucknall, Nottingham NG15 7HP

2. Join our mailing list

We produce regular newsletters that feature important national health and social care news, as well as updates on local services, consultations and events.
You can sign up to our mailing list by contacting the office by phone, email or by visiting www.healthwatchnottinghamshire.co.uk

3. Become a Healthwatch volunteer

We need enthusiastic volunteers from around the county to promote the Healthwatch message, to feed information to and from groups, and help us collect people’s experiences. We also need insight volunteers to help us to assess services through Enter and View and other projects like this.

Interested? Get in touch and we’ll let you know what roles are currently available and what to do next.

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