Dialysis Transport – Finding a Way together

Executive summary

This guidance provides recommendations on standards for transport for patients who require haemodialysis and is intended to support patients, commissioners, providers, and kidney services. It has been produced in response to needs identified by patients. The guidance emphasises that dialysis transport is part of dialysis care, has an enormous influence on quality of life for patients and is modifiable. By following it, current variance should be addressed and the experiences and quality of life of people with kidney failure who need unit-based haemodialysis improved. The standards are focused on quality and generalisability, while ensuring value for the NHS.

In the UK almost 24,000 people with end-stage kidney disease (ESKD) receive haemodialysis treatment three times a week at a hospital or standalone dialysis facility to preserve life; most will need this treatment for the rest of their life. Dialysis is a medical treatment that removes both poisons and fluid from the patient. The effects include variations in blood pressure, mental state, and exhaustion. People often feel at their worst immediately after treatment. The majority are elderly. Many are frail. One in three have clinical depression.

People who receive haemodialysis treatment in hospitals or satellite units say that transport to and from the dialysis unit is one of the most important issues affecting their quality of life. However many report poor experience; the national survey of Patient Reported Experience Measures shows that transport has the greatest variance of all.

A comprehensive survey of dialysis units in the UK commissioned for this report confirmed these differences. Half of responding units reported that eligibility criteria for patient transport were being used; only 60% of services utilise key performance indicators. There are differences between units in how transport is organised; there is variance in reimbursement policies.

The standards are a consensus from all relevant national stakeholders, comprising a broad range of patient groups, professional bodies, commissioners, and providers. The evidence for these recommendations is provided.
Recommended guidance for transport for patients choosing haemodialysis treatment at a dialysis centre

1. Transport to and from a dialysis unit is considered part of the episode of care
   • Early identification to the patient that transport is an important part of their dialysis health care episode
   • Clinical services, commissioners and providers work together to ensure that the episode of care is joined up - that is, co-ordinated around the patient.
   • Simplify the delivery of transport and ensure transparency of provision

2. No patient should contribute to treatment costs by paying for transport
   • Self-funding is against the NHS constitution as it would mean charging patients for a component of their care
   • Clinical services, commissioners and providers should work together to share good practice and ensure cost viability
   • Do not use transport of a higher specification (and cost) than the patient requires

3. Patients should be enabled to control their own transport
   • Each patient should have a care plan that includes their transport requirements and how these are delivered
   • Adequate governance arrangements must be in place to safeguard patients, providers, and services

4. Clinical services, commissioners and providers should work together to ensure good and cost viable services
   • Ensure central co-ordination of transport; consider a dialysis transport communication hub for the service
   • Map and zone patients so they receive treatment in their nearest and/or most accessible dialysis unit
   • Limit ambulance based non-emergency patient transport to patients with a medical need

5. Key Performance indicators (KPIs) should be used to assure the service alongside the contract
   • These should be developed and agreed by all partners including patients and their representatives
   • A review of patient reported experience measures should be included in the KPI
   • A regular monitoring structure involving all partners, including patients, should be used
This document includes background, supporting evidence, details of the standards, and assistance for implementation of the standards

1. Introduction

Over 63,000 people in the UK receive treatment for end-stage kidney disease (ESKD) with a functioning kidney transplant or with long-term dialysis treatment; of these, around 24,000 receive haemodialysis treatment at a hospital or a satellite dialysis unit away from home.

People who receive long-term dialysis treatment have a major health care burden. Their average age is 65. They are more likely to be frail and vulnerable and usually have multiple long-term chronic disease, including one or more of diabetes, stroke, heart disease. They are more likely to develop and do badly from cancer, infections, and chronic disease. Around one-third of patients who receive dialysis have clinical depression.

One in 8 patients who receive haemodialysis die each year; this risk is well in excess of that for individuals of the same age who do not have kidney disease.

There are multiple considerations for supporting the care of patients with ESKD requiring haemodialysis. People on dialysis report that the provision of transport to allow them to attend a dialysis unit for treatment is essential, and kidney healthcare professionals support this.

Patients also report major differences in the provision of transport to dialysis units. These reports were confirmed by units themselves in our survey: in some kidney services, all patients have support for transport (e.g. through a mileage allowance) or provision of transport; in other kidney services this is not the case and variable eligibility criteria are applied. Patients, health-care staff, and healthcare providers are concerned that there is evidence accumulating that this variance may worsen in this period of time due to increasing financial pressures on commissioners.
These factors led to the establishment of a working group, which aimed to develop a guideline document to support standards for the provision of transport for patients requiring haemodialysis. The group comprises a broad partnership that includes representation and inputs from all stakeholders from patients through to commissioners and providers.

The approach used for this is inclusive and recognises that this is a complex area: colleagues in all sectors are focused on providing a quality service in a challenging financial environment.

The report is formally endorsed by the constituent organisations, Kidney Care UK, the Renal Association, the British Renal Society, and the National Kidney Federation.

The standards recommended in this document are to support patients, commissioners, providers, and kidney services.


Based on the work of the stakeholder group and the information provided in this document we recommend five core standards to ensure the provision of good quality patient transport which is responsive to the needs of patients.
1. Consider transport to and from haemodialysis treatment as part of the episode of care

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<th>Rationale</th>
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<tr>
<td>• Preparation for haemodialysis treatment for many patients involves the time prior to attendance at the dialysis unit&lt;br&gt;• Some patients have medical needs around the journey itself&lt;br&gt;• The physical and cognitive health of many patients can be affected by the transport component&lt;br&gt;• Attendance for the complete treatment time is essential to wellbeing&lt;br&gt;• Close working between commissioners, providers, and the service will align delivery of transport with patients’ needs&lt;br&gt;• There is current over-complexity in contracting for and provision of transport&lt;br&gt;• Transport is a major patient reported experience measure. It is perceived by patients as part of their episode of care</td>
<td>• Early identification to the patient that transport is an important part of their ongoing health care will ensure accurate provision from the start of haemodialysis treatment&lt;br&gt;• Provision of early patient information and enabling a care plan that integrates transport into the patient episode. These should be developed with the local patient group and advocates. This could comprise a welcome pack for patients and a meeting with a designated transport officer for the service.&lt;br&gt;• A designated transport officer at the level of the unit OR a nominated transport champion from the provider.&lt;br&gt;• Assessment of need based on both journeys, to and from the haemodialysis unit. This should be done by the kidney service.</td>
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2. No patient should contribute to the costs of treatment by paying for their transport

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| • Self-funding is against the NHS constitution as it is charging patients for a component of their care  
• Clinical services, commissioners and providers work together to share good practice and ensure cost viability  
• Do not use transport of a higher specification (and cost) than the patient requires | • Services should work to share good practice for schemes that are cost viable.  
• Provision of nominal transport support (mileage or allowance) based on the travel in and out requirements.  
• Access to free parking or drop-off zones.  
• Assessment of the needs of patients may identify those receiving transport of a higher specification than required.  
• Identify schemes which support the patient to travel and assess for both the inward and outward journeys: where the patient can use public transport, assess if they can do so for both legs of the journey. This may require input from the responsible nursing and medical staff for the patient.  
• Ensure ability to book unplanned transport is in place for those who are unable to get home by any other route due, for example, to a bleed from vascular access.  
• Ensuring that communication is focused on enabling the patient to have control. This is an area of major focus for kidney patients and kidney services. |
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<th>3. Patients should be enabled to control their own transport</th>
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<td>• Each patient should have a care plan that includes their transport requirements and how these are delivered</td>
<td>• Patient control, which links with activation and self-care is highly enabling. A focus on this should contribute to better patient experience and patient outcomes.</td>
<td>• Each patient to have a care plan that is individualised for their needs</td>
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<td>• Adequate governance arrangements must be in place to safeguard patients, providers, and services</td>
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<td>• Novel models of transport delivery can be used, which may include:</td>
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<td>(i) Transport sharing (e.g. travelling with one or more other patients)</td>
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<td>(ii) Tailored transport provision (community transport providers including volunteer organisations or local taxi companies)</td>
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<td>• Transport should be integral to the care experience, with the associated attention to quality. It should be centred on the experience of patients ensuring services are neither specified or too general</td>
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<td>• Transport should be expedient, high quality, and suited to needs.</td>
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<th>4. Clinical services, commissioners and providers should work together to ensure good and cost viable services</th>
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<td>• Ensure central co-ordination of transport; consider a haemodialysis transport communication hub for the service</td>
<td>• The importance of ensuring a cohesive system where all parties are working together, should improve efficiencies.</td>
<td>• Separate the delivery of kidney transport from non-kidney NEPT. That would mean no shared services unless there was exception reporting against that service.</td>
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<td>• Map and zone patients so they receive treatment in their nearest and/or most accessible dialysis unit</td>
<td>• All groups should be working together to ensure that there is a seamless process that can be used to deliver the service</td>
<td>• Aim to consolidate transport providers for each satellite dialysis unit. Whilst this may be a single provider, different levels of transport may be contracted by different groups (e.g. an ambulance service for patients with high dependency; a local</td>
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• Taxi service for patients with limited needs
  • Mapping and zoning of patients for the purposes of dialysis. This is consistent with high quality care, where the patient receives dialysis at the kidney unit that is local to them, in the catchment area of the hospital that will manage them if they become acutely ill. This is the responsibility of the local kidney service
  • A system for one-way travel arrangements should be in place - some patients may have a higher dependency level on the return journey compared to the journey out
  • A taxi service for patients who are mobile. These are in place in some, but not in all kidney services. There are different models for that could be used; these include
    - Trust run volunteer taxi service
    - Local taxi firm(s) which have been accredited for the purposes
  • Use modern communications to update patients on transport timings. Focus on efficiency of use of vehicles and journey: e.g. using technology for lift sharing
  • Further accuracy and efficiencies can be gained by
    - Smart routing
    - Accurate volume data by postcode district and mobility classification
    - Annual reviews
    - Ensure strong communication so that
transport does not attempt pick-up for people who are inpatients and do not currently require it
- Tendering exercises to focus on partnership models that can include taxi companies, community transport operators, and volunteer services including those working within hospital trusts.
- Working with local patient support groups, advocacy officers and kidney patient associations to shape this work, design consultations and seek views on any proposed changes
- Experiential learning - comprising an open culture that allows the trialling of models of care, and understanding that discarding, adapting, or adopting models with time is a sign of maturity of service
- Sharing of models from different units

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<th>5. Key Performance indicators should be used to assure the service</th>
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<td>• These should be developed and agreed by all partners including patients</td>
<td>• Services with agreed performance indicators that are relevant, reasoned, justified and transparent ensure that all partners are contributing to the delivery of a high quality service.</td>
<td>• A service charter should be in place and signed off by the responsible officers for the partners in the delivery of transport</td>
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<td>• Patient reported experience measures should be included in the KPIs</td>
<td>• These should apply to the clinical service, providers, and commissioners, working together in a local kidney transport board.</td>
<td>• The charter should include: Care plan individualised for the patient and developed with the patient by the kidney unit. Care plan review</td>
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<td>• A regular monitoring structure involving all partners, including patients, should be used</td>
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<td>• Whilst time between the journey and the start of dialysis is important, it should be locally agreed and follow the principle of no more than a 30 minute</td>
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<td>• The group drawing up the KPIs should decide whether they are enforceable and whether and how penalties may apply.</td>
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| wait for pickup, a 30 minute journey and to arrive no more than 30 minutes before an appointment.  
• KPIs can reflect the differences in average journey time. Some units in rural areas have patients travelling 20+ miles for dialysis units. Some urban dialysis units are in areas where road travel is very slow and even short journeys can be prolonged.  
• Patient reported experience measures should be a key part of the performance indices that are collected.  
• Appropriate structure for and review process for patient complaints  
• Inclusion in the national specification model for kidney services  
• Inclusion by the quality surveillance team (QST) in any peer review of renal services |
3. Why transport is so important for patients who receive haemodialysis treatment

Patients see transport to and from haemodialysis as being part of their care. Any change to the journey can increase anxiety and distress associated with the treatment itself. Transport time makes a major contribution to the time of the treatment episode; there are patients in the UK who, when combined with the transport time, are receiving episodes of care which last more than 10 hours. Even for patients who live close to the dialysis unit in which they receive their treatment the average length of treatment time is more than 6 hours.

If patients are not able to access patient transport, anxieties associated with this include: concern about how to get to dialysis, over-burdening family and friends, how to pay for the costs of transport. Additional anxieties for those who may have a car or are being dropped off include being able to access car parking or drop off zones, and the cost of parking.

Some kidney units in the UK enable patients to have full access to patient transport for dialysis. Other units have transport providers who are commissioned to apply fixed national criteria where patients receiving dialysis are being assessed in the same way as a patient who requires a single outpatient appointment: this is causing distress for significant numbers of patients and leading to major variance.

For those patients who are receiving transport there are a number of themes that have been identified: which include;
- Uncertainty about pick-up time
- Waiting time post-dialysis often exceeds guidelines
- Excessive time on transport
- Drivers are not aware of specific needs.

An important audit of a single dialysis unit, recorded 25 incidents over a 12 month period recorded where patient’s clinical condition has been affected by problems with transport: These comprised 9 hypoglycaemic-related events in waiting area as a result of delayed transport; 16 adverse clinical incidents that put the patients at risk clinically.

Of the incidents reported in this audit, three resulted in hospital admissions, one patient died during the consequent admission and one died in the months following admission.

4. What is haemodialysis?

Haemodialysis is a treatment that removes waste products and excess fluid from the body for patients with kidney failure. It is used to replace the function of the kidneys for individuals who have complete kidney failure (also known as end stage kidney disease (ESKD)). Without sustained haemodialysis treatment those affected by ESKD are likely to die of kidney failure within about two weeks.

A usual haemodialysis prescription is treatment for approximately four hours three times a week. Most haemodialysis provision in the UK is at a dialysis unit away from home. To receive treatment blood is removed from the patient’s body through a major blood vessel, usually in
the arm, that is accessed following an operation or a procedure to produce a fistula, or a graft, or a line. This allows blood to be accessed, usually by needles, so that it can be pumped out of the body and through a dialysis filter (dialyser) at a rate of several hundred mls a minute and then pumped back into the body.

Concerns and symptoms can include:

- Anxiety and pain associated with the insertion of large bore needles into a fistula or graft
- Low blood pressure during and after dialysis
- Change in mental state (cognition) during and after dialysis
- Cramps and other physical symptoms
- Exhaustion in the hours after dialysis
- Instability of diabetes control associated with dialysis

The average cost of dialysis unit based haemodialysis treatment is around £30,000 per patient per year\(^4,10\).

Many patients sleep for the rest of the day when they go home after dialysis. This means that they may only be able to function effectively with good energy levels on a non-dialysis day. There is a high level of depression and family members and carers are also deeply affected. In younger patients the ability to work or complete education is curtailed.

The longer term consequences of repeated dialysis include

- Progressive heart failure
- Vascular damage including increased risks of strokes and vascular disease leading to amputation
- Increased risk of infections
- Increased risk of cancers

People who receive dialysis have a significant likelihood of requiring inpatient admissions. Kidney services are advised to have available to them one inpatient bed for every 10 patients requiring dialysis treatment. Patients who receive dialysis treatment are less likely to be able to access appropriate quality of healthcare to both prevent and to manage conditions other than their kidney failure; care from psychosocial support through to management of complications associated with diabetes is not well provided for.

Patients receiving haemodialysis are usually from lower socio-economic groups, far more likely to be unemployed when they are of employable age, and more likely to be vulnerable adults. People with ESKD are therefore exposed to the inverse care law that states, “The more complex a patient’s health care needs the less likely these needs are to be provided”\(^11\)

### 5. Patient reported experience of transport

The outcomes of greatest importance for healthcare professionals for patients with ESKD are mortality and hospitalisation. However patients themselves report that their highest priority for healthcare is their quality of life; they rate this as more important to them than ‘conventional’ outcomes. Patient experience of care is a crucial element of healthcare quality alongside
patient safety and clinical effectiveness. The measurement of experience of care is central to evaluating healthcare quality and is now being collected nationally from patients with kidney disease. Patient experience of care can be measured using patient-reported experience measures (PREMs); PREMs are focused on details of care and specific processes and/or events rather than satisfaction with care. By adopting this approach, bias and subjectivity that arise from patients’ expectations are minimised.

Kidney Care UK and the UK Renal Registry (as part of the UK Renal Association) co-designed and implemented a national PREM survey with 43 questions across 13 areas: these include (i) how the kidney team treat you (ii) access to kidney team (iii) support (iv) communication (v) patient information (vi) diet and fluid intake (vii) tests (viii) sharing decisions about your care (ix) privacy and dignity (x) scheduling and planning (xi) transport (xii) the environment (xiii) your overall experience.

Patients report their experience of transport as second from bottom in terms of overall experience. Transport has the widest variation of all the reported experience measures. Experience differs greatly across the country, confirming what patients have been reporting to local and national representative organisations and local clinical and operational teams for many years.
This Figure shows the Patient Experience scores for 2018 for transport from individual kidney services and how much variation there is between dialysis units, according to patients. On the left hand side are kidney units whose patients took part in the survey, in which patients could score their experience between 1 and 10. The average score was 5.6, but there was variation between units with the lowest at 4.2 and highest at 6.7. Over 13,000 patients took part in the 2018 survey.

6. Medical and social implications of variances in transport

Being normal and maintaining independence were top priorities for haemodialysis patients in a recent paper from the SONG initiative, which included UK participants. Focusing on the contribution of transport to this is important, as there is supportive evidence that indicates that variances in transport have impact both on quality of life and traditional health outcomes.
Patients who have a longer journey time are more likely to miss dialysis sessions than patients who have a shorter journey time. Patients who miss dialysis sessions are more likely to die as a consequence of missing dialysis.

7. Non-Emergency Patient Transport – eligibility, current provision and current status

Eligibility

Eligibility is based on medical criteria. Financial status or poor public transport do not provide entitlement to NEPT. This is an important consideration, as some patients who are receiving haemodialysis treatment may not be seen as having automatic entitlement to patient transport services.

The NHS Choices website explains that NEPT is designed for people whose condition means they need additional medical support during their journey. This can vary from patients who can walk to those who require a stretcher to support them and includes people who find it difficult to walk and parents or guardians of children who are being transported.

This means the current formalised NEPT provision can be interpreted as ‘for a medical need’.

Most non-kidney patients require few hospital visits for any specific treatment; there are exceptions to this but there is no equivalent in any other disease area for three times a week attendance over a number of years, to continue unless the patient with ESKD receives a kidney transplant or until the end of life. As each CCG and/or NHS Trust can extend eligibility and offer discretionary journeys, there are significant variances in what is available for dialysis patients and this is largely determined by where you live. In many places the requirement for repeated visits against a background of complete organ failure is not considered. The combination of frequency of visits, demanding nature of treatment, and the need for safety requires a transport system that supports patients reliably.

Current provision of Patient transport in the UK - Non Emergency Patient Transport

The 2007 Department of Health document, Eligibility for Patient Transport Services (PTS) describes non-emergency patient transport as: ‘...the non-urgent, planned, transportation of patients with a medical need for transport to and from premises providing NHS healthcare and between NHS healthcare providers. This can and should encompass a wide range of vehicle types and levels of care consistent with the patient’s medical needs.’ This means that patients can be transported by a range of vehicles from ambulance through to car schemes, while some transport requires medically trained staff and equipment.

The main focus is for provision when medical or mobility needs would make it difficult for people to travel by other means, such as public transport. Non-Emergency Patient Transport (NEPT) is primarily for planned transportation, although it is also used to manage demand, both through getting people away from hospital, and to manage appointments that have not been routinely scheduled; for example, to an urgent outpatient appointment.
Current status of NEPT for patients who require haemodialysis treatment

There is currently no specific criteria or standardised approach for NEPT that includes patients who require haemodialysis treatment. The national transport guidelines do not account for ‘frailty’, or mental vulnerability due to the requirements of your treatment, even if a patient can physically access it. Recently there is evidence that CCGs that historically have provided access for dialysis patients to high quality transport are tightening inclusion criteria for patients to address financial constraints.

Other transport providers operate to support haemodialysis patients. These include community transport volunteer organisations, friends, and family members. Local services that have been sensitively developed for the needs of patients are being scored highly by patients.

Patient transport services at the two highest scoring units were run as standalone services at the time of the last patient experience survey. Changes for some services reporting as high quality have been made and some have been proposed. The highly rated Truro service, which included volunteer drivers organised by the local NHS Trust, was a major local, regional and national focus for patients and supporting stakeholder organisations in 2017. Proposed changes to this service were stopped after intense lobbying by patients and the local clinical team, supported by stakeholder organisations.

8. Commissioning, costs and viability arrangements for haemodialysis transport

Commissioning

Transport is commissioned either by a Clinical Commissioning Group (CCG) for patients registered in their geographical area, or by the NHS Trust directly. The CCG involved is that responsible for healthcare provision for the patients’ home address. As there are more CCGs than dialysis services, individual haemodialysis units can often sit across different CCGs. A patient’s CCG may be different to that within which their haemodialysis unit is positioned.

Dialysis units may be served by multiple CCGs, who may have different providers with different criteria for transport eligibility. This leads to major variations even within a single kidney service.

In some parts of the country NEPT is rigidly adhered to and some haemodialysis patients have to self-fund. In other areas all haemodialysis patients can receive patient transport. Not all patients choose to receive transport for haemodialysis. This is an important principle of care, in that patients should be supported to find a model of transport provision that works for them.

Aborted and cancelled journeys can lead to substantial and increased costs for providers – coordination of the transport requirements can address this issue. At a transport study day in Nov 2015 (as part of the Department of Transport Total transport programme); 66% of 35 CCGs indicated that their transport provider was not meeting any Key Performance Indicators (KPIs).

Costs and how to ensure viability

The overall cost of NEPT in the UK is at least 150 million pounds a year. Patients receiving haemodialysis treatment receive around half of all NEPT. This means that the average costs for a
haemodialysis patient of NEPT may be around £3,750/year. The average haemodialysis patient is making 306 journeys a year, which is 153 return journeys. However as some patients requiring haemodialysis are not receiving NEPT, the costs for patients who are receiving transport are higher than this.

A recent report by Community Transport Action, Total Transport: A Better Approach to Commissioning Non-Emergency Patient Transport[1] found that the NHS could save up to £74.5m per year if transport was commissioned in a more joined up way. Although there was no dialysis associated work in the report, the overall spend on patients requiring haemodialysis is undoubtedly high, which may suggest significant inefficiencies in the system.

Addressing transport inefficiencies is an opportunity to improve transport provision without any cost implications. It is recognised that the funding for patient transport comes from CCG budgets, and that these are stretched.

**Important considerations for haemodialysis transport that impact upon the costs of the service:**

1. Kidney transport is an intermittent process; early morning, lunchtime and early evening. For patients who require ambulance transport it may be challenging to run a separate kidney NEPT contract. However for patients who do not need ambulance transport, either a separate commissioning process or ensuring that there is a component of the NEPT contract that is orientated to this will help.

2. Getting the set-up for the delivery of the services is crucial; as some services fail or are delivered poorly; some of this may be due to a gap between the number and type of journey that are incorrect.

3. Whilst many units use local taxi services around 40% of those surveyed do not. This is a concern as this indicates over-specification of services. There is a general recognition that the best way to transport many haemodialysis patients may be via local taxi or voluntary drivers. The specification for this component of a service should be flexible. There is no reason why successful providers shouldn’t outsource this.

4. Different models could be used utilising cost per journey or block contract. A block contract for mobile patients may encourage innovation; cost per journey paid for this category is not very high in some contracts. For patients with mobility or medical needs cost per journey may make more sense

5. The split between CCG/specialised commissioning/kidney services requires careful attention. It is important to have the right stakeholders present when discussions are carried out at the contract preparation stage and then during the management of the contract. This allows everyone to understand the issues from the beginning and work collaboratively through issues arising for all concerned. Patient advocates should also be included in these discussions.

6. Kidney services need to play their part in being as organised as possible for the transport services to allow efficiency for all.
7. Utilising integrated care models. The healthcare travel scheme should be more easily accessible and used by more. At present, patients often have to claim in retrospect, having accumulated large spend and go to the hospital cashiers to deal with it. This is simply not feasible for many. Also this is part of social care and therefore a different ‘pot’. Personal travel budgets are one option to address this.

9. A national survey of kidney services

As part of our background work to inform the recommendations kidney units were asked to participate in a national dialysis unit survey. Invitations were sent to 71 UK kidney services, via their clinical directors, with the request that an individual with knowledge of and responsibility for patient transport who worked within the service completed the survey. Forty six (46) of 71 units replied to the survey. The full report is shown in the appendix.

Key findings included:

- 40% reported that trusts commissioned transport; 63% said that CCGs commissioned it. Combined contracting was reported by some services; CCGs are contracting ambulance services.
- Different arrangements are in place for different satellite units that are the responsibility of one NHS Trust. 39% had more than one transport provider.
- In some cases different CCGs were commissioning different transport providers to provide transport in a single unit. 91% reported having an agreed provider and 59% of units used a local taxi company; 9% lift sharing.
- There was a large variation in the proportion of patients receiving hospital-provided transport; from 7% of units reporting less than 40% to 33% of units reporting 80-99%.
- NHS contracts were reported with local ambulance companies, private ambulance services, volunteer drivers, voluntary community transport, use of own or carers transport was seen as a specific group for transport provision.
- Twenty two units reported that there were no eligibility criteria and all patients had access in these units to patient transport.
- Twenty four units reported that eligibility criteria were being used. The commonest of these were mobility, reported as being used as a basis for eligibility in 10 units. In some units distance from the unit is being used as eligibility criteria.
- Where there is more than one transport provider in a single unit, over 50% of the time they use different eligibility criteria.
- 60% reported using Key Performance Indicators and 40% provider reports; some units used both. Patient survey was used by 76%; 10% of units did not report a governance mechanism.
• Individual units report (i) variable report monitoring by patient complaints, (ii) that they do not commission the service so improving a very poor service is very difficult, (iii) KPI data not shared adequately (iv) monitoring by commissioners and not Trust (v) incident log (vi) Problems are recorded using an incident reporting and risk management system such as Datix.

• 59% report that there is reimbursement of travel costs available for patients receiving in-centre dialysis treatment. 91% report reimbursing travel costs for patients, 65% reimburse for family providing transport, and 49% for friends. Per mile reimbursement where quoted ranged from 10p a mile to 49p a mile. Some units report having to pay the cost of taxi services.

• 7% of units report that patients who have to drive themselves to dialysis pay for parking.

• 29% of units were aware of patients claiming from the healthcare travel costs scheme.
10. Appendices

APPENDIX 1 – Terms of Reference

Transport Guidelines project – terms of reference

Purpose of the group: to produce standards for the provision of transport for patients who require long-term dialysis treatment in the UK

Aims:

To produce a framework document that with recommendations for best practice in dialysis transport provision aimed at an audience the group will define, to include patients, commissioners, CCGs, relevant stakeholders and kidney unit staff.

The document will include:

- Recommended eligibility criteria for transport for patients who require haemodialysis
- Proposed governance structures required to support the delivery of haemodialysis treatment, linked as appropriate to the NHS England service specifications for dialysis
- A toolkit for the delivery of transport for patients that require dialysis treatment

The following work streams will provide the basis for the work

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<td>• Collating models that are exemplars of good practice</td>
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<td>• Modelling the financial impact of models for the provisions of transport</td>
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<tr>
<td>• Establishing core standards for Non Emergency Patient Transport (NEPT) for patients on dialysis requiring transport and quality standards and integration of these quality standards into local care specifications (to include peer review etc.)</td>
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<tr>
<td>• Stakeholder Engagement, Communication &amp; Dissemination (including electronic resources)</td>
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Membership of the group

UK patient and professional charities, patient representatives, transport providers, dialysis providers, kidney doctors and other multi-professional experts at the discretion of the chairs.

Member names and affiliation

Chairs: The working group shall be co-chaired by Kidney Care UK (Fiona Loud) and the Renal Association (Paul Cockwell) supported by representation from the British Renal Society.
Operational considerations

- The co-chairs will be responsible for inviting new members to the group either directly or in agreement with existing group members.
- The group will run initially for up to one year, i.e. until December 31st 2018.
- The group will have two face-to-face meetings and monthly conference calls.
- Quorum for a meeting will be one third of membership and includes at least one of the co-Chairs
- The group will focus on transport arrangements for people on unit-based haemodialysis.
- The group may consider arrangements for those with transplants, or training for Peritoneal Dialysis (PD), or home Haemodialysis (HHD) but not as its primary purpose.
- The group will store documents and resources it produces in a secure Dropbox folder.
- Any materials placed in the folder remain the intellectual property of the organisation that have supplied or collected it and cannot be shared without their permission.
- The co-chairs will be responsible for keeping the group up to date with information about minutes of meetings and other relevant documents.
- Members of the group will be expected to attend its calls and meetings and will contribute actively to the work of the group. Members are expected to attend >50% of scheduled meetings and to send apologies if they are unable to attend a meeting.
- A number of work streams have initially been agreed but can be changed at the discretion of the co-chairs.
- The leaders of the work streams are encouraged to seek relevant skills and information for their sub-groups.

APPENDIX 2 – How the Work was done

- The group was instituted following discussions between Kidney Care UK and The UK Renal Association, with support from the British Renal Society. There were then discussions with other stakeholders including the National Kidney Federation.
- We worked with services where there are active current issues in the provision of NEPT for patients who require dialysis
- We held an initial meeting where the terms of reference were agreed; these were followed by regular teleconferences
- A national kidney service survey was held to identify the current status of NEPT for patients with end-stage kidney failure requiring dialysis treatment
- A stakeholder session was convened at UK Kidney Week 2018
- A workshop was held with commissioners and providers
A draft of this document was shared with the stakeholder group twice for their input before opening it out to wider consultation. This feedback has been reflected within.

APPENDIX 3 – Acknowledgements

This report acknowledges the help and support from the following individuals:
Fiona Loud, Prof Paul Cockwell, Allie Thornley, Karen Jenkins, Dr Clara Day, Paul Bristow, Tracey Rose, David Marshall, Rachel Hucknall, Deborah Tobin, Guy Richards, Alan Finlayson, Nick Flint,
Dr Will McKane, Wayne Spedding and Chris Melson.

This report also acknowledges the help and support from the following organisations:
Kidney Care UK
Renal Association
Welsh Clinical Renal Network
British Renal Society
Diaverum
Exeter and District Kidney Patients’ Association
National Kidney Federation
Queen Elizabeth Hospital Kidney Patients’ Association
Sheffield Area Kidney Patients’ Association
Fresenius
Decideum

Appendix 4 - Dialysis Transport in Wales

The Welsh Clinical Renal Network delivers services through a Renal Services Delivery Plan. This builds on previous work related to the Renal National Service Framework and its Strategic Frameworks providing a framework for action by Local Health Boards and Trusts. It sets out the Welsh Government’s expectations of the NHS in Wales to commission and deliver high quality patient centred care for anyone affected by CKD. It focuses on meeting population needs, improving access to services and reducing inequalities in outcomes across 7 themes:

- Delivery Theme 1: Preventing the development of CKD
- Delivery Theme 2: Early identification and management of CKD
- Delivery Theme 3: Delivering fast, effective care
- Delivery Theme 4: Meeting People’s Needs
- Delivery Theme 5: Caring at the end of life
- Delivery Theme 6: Improving Information
- Delivery Theme 7: Targeting research

It has produced a series of Service Specifications as part of a formal national consultation http://www.wales.nhs.uk/sites3/page.cfm?orgid=773&pid=89638 which include a Transport Specification. This document reflects much of what we found during the research for this report, including the high level of harm which will result from a poor transport service. As a consequence of the wish in Wales to improve transport standards this specification states that it is a key National Policy statement that

- No patient should experience harm as a result of poor transport arrangements to and from unit haemodialysis
Under scope of service it states that under Welsh Government guidelines (WHC 005 2007 http://www.wales.nhs.uk/documents/WHC(2007)005.pdf) patients receiving unit-based dialysis are automatically eligible for transport to and from appointments.

This patient video https://vimeo.com/119186976 was key to creating the improvements in transport times and experience in Wales, which are monitored every year. By achieving significant patient and political support, and continued reporting of every reduced or missed session of dialysis (as a result of transport) to the Local Health Board patient safety teams and to Welsh government they have achieved significant progress in delivering a good service, which despite a growing cohort of patients has not cost more.

Our recommendations include much of the learning from the progress in Wales in kidney transport. We thank Kate May from the Cwm Taf Health Board for the insight.

Appendix 5 - Personal Health Budgets

NHS England have made personal health budgets available to a small number of patients; these are “an amount of money to support the identified healthcare and wellbeing needs of an individual, which is planned and agreed between the individual, or their representative, and the local clinical commissioning group (CCG).”

https://www.england.nhs.uk/personal-health-budgets/what-are-personal-health-budgets-phbs/

These will only work where personalised care and support planning is available to establish whether such a budget would be what a patient wants and needs, and is a developing programme and so not available everywhere.


North East and West Devon CCG have successfully piloted a personal health budget for dialysis transport, to enable to management of a patient’s own transport arrangements and have more choice and control over how that is delivered. Such innovation is welcome and worth consideration by other CCGs as one of a range of improvement opportunities.

APPENDIX 6 – MODEL KPI
APPENDIX 7 – MODEL CONTRACT

APPENDIX 8 - GLOSSARY

Chronic kidney disease
Loss of kidney function (measured using the estimated glomerular filtration rate) or damage to the kidney (usually albuminuria, but there can be other signs such as an abnormal appearance of the kidneys on scanning) that is sustained over time. In a minority of people it is progressive and leads to end-stage kidney disease.

Clinical Commissioning Group (CCG)
NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England.

Conservative care
Full supportive treatment for those with advanced kidney failure who decide against starting dialysis or choose to discontinue dialysis.
Datix
A web-based incident reporting and risk management software for healthcare and social care organizations. The application is widely used by staff including clinicians in more than 80% of the NHS to report clinical incidents.

Dialyser
An apparatus in which dialysis is carried out consisting essentially of one or more containers for liquids separated into compartments by membranes.

End-stage kidney disease (ESKD)
The stage in kidney disease when a person’s kidneys fail and dialysis treatment or a transplant is required to sustain life.

Fistula
An abnormal passageway or tube between two or more body parts that are not normally joined together.

Graft
A transplanted organ.

Haemodialysis (HD)
A treatment for kidney failure in which the blood is cleaned outside the body by a machine that passes the blood across a filter.

Home haemodialysis (HHD)
Where people have haemodialysis treatment at home. Special plumbing usually needs to be installed in the house, although portable machines have also been developed.

Hypoglycaemic event
When blood sugar decreases to below normal levels, also known as low blood sugar. This may result in a variety of symptoms including clumsiness, trouble talking, confusion, and loss of consciousness, seizures or death.

Peritoneal dialysis (PD)
A treatment for kidney failure, which uses the body’s natural membrane in the abdominal cavity to clean the blood.

Renal replacement therapy (RRT)
Life supporting treatments for kidney failure, encompassing all forms of dialysis and also kidney transplantation.

Self-care dialysis
Where people perform their own dialysis treatment, or some aspects of it. It includes peritoneal dialysis, self-care haemodialysis, and home haemodialysis.

Self-care haemodialysis
Where people carry out some or all of their own dialysis treatment in a dialysis unit.
SONG Initiative

The Standardised Outcomes in Nephrology (SONG) initiative aims to establish a set of core outcomes and outcome measures across the spectrum of kidney disease for trials and other forms of research.

APPENDIX 9 - References
