



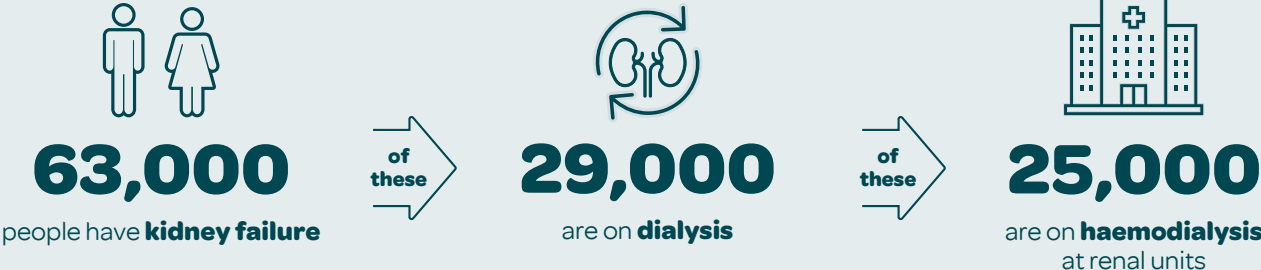
DIALYSIS TRANSPORT

Finding a way together

Fiona Loud, Karen Jenkins & Paul Cockwell on behalf of the Dialysis Transport Working Group



Foreword



“If you have kidney failure, dialysis may be your only option. Not everyone is able to have a transplant and for others it may be years until they are able to receive a donated kidney.

Getting to and from dialysis is not something many people think about, but there are 3 sessions a week of at least 4 hours at a time, which means 6 journeys to get to life-maintaining treatment and back home again. The majority of the 25,000 people on haemodialysis at units rely on transport to enable them to arrive safely.

Time and time again, patients say that transport is difficult. I have seen how important it is to patients in my own constituency, and have been delighted to have worked with them and Kidney Care UK to help inform the NHS’s understanding of this and the impact having this essential service has on their lives. Coping with a long term chronic condition such as kidney failure uses up enormous amounts of time, energy and emotion.

People who depend on dialysis and who work or provide support in this field have come together to give key recommendations to work together to deliver better transport. Transport is integral to kidney care; timely, safe and well-planned transport which is jointly commissioned and monitored by those who understand it, and enables patients some control is the way forward.

I am delighted to commend it to commissioners, trusts and patients.”



Steve Double
Member of Parliament for
St Austell and Newquay

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Executive Summary

This guidance provides recommendations on standards for transport for patients who receive haemodialysis treatment **and is intended to support patients, commissioners, providers, and kidney services**. It has been produced in response to needs identified by patients, renal unit staff, advocates for kidney patients, and commissioners. The guidance emphasises that dialysis transport is an essential part of dialysis care, has a major influence on quality of life for patients and is modifiable. By following this guidance 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 applicability, while ensuring value for the NHS.

In the UK around 25,000 people with end-stage kidney disease (ESKD) receive haemodialysis treatment three times a week at a hospital or standalone dialysis facility to keep them alive; 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 exhaustion, variations in mental state, and variations in blood pressure. Patients often feel at their worst immediately after treatment. The majority of patients 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 Measures¹ shows that transport has the greatest variance of all experiences measured.

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 (KPIs). There are differences between units in how transport is organised; there are also different policies for the reimbursement of patients.

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.



Fiona Loud
Policy Director
Kidney Care UK



Prof Paul Cockwell
Clinical Vice President
Renal Association



On behalf of

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

- An early discussion should be held with the patient about transport as an important part of their dialysis health care
- Clinical services, commissioners and providers should work together to ensure that transport 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 constitution² 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 costs remain appropriate
- 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 achieves what is set out in 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 KPIs
- A regular monitoring structure involving all partners, including patients, should be used

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 25,000 receive haemodialysis treatment at a hospital or a satellite dialysis unit away from home³.

People who receive long-term dialysis treatment have a major health care burden. Their average age is over 65⁴. They are more likely to be frail and vulnerable and usually have multiple long-term chronic diseases, including one or more of diabetes, stroke, heart disease⁵. They are more likely to develop and have poor outcomes from cancer, infections, and chronic disease⁶. Around one-third of patients who receive dialysis have clinical depression⁷.

One in 8 patients who receive haemodialysis die each year; this proportion is well in excess of that for individuals of the same age who do not have kidney disease⁸.

There are many considerations for supporting the care of patients with ESKD requiring haemodialysis including transport. 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, healthcare staff, and healthcare providers are concerned that there is evidence accumulating that these differences may become worse due to increasing financial pressures on commissioners.

These factors led us to set up a working group with a broad range of representatives, from patients to commissioners, in order to develop guidelines to support standards for the provision of transport for patients requiring haemodialysis. The approach used for this was 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.

1 in 8



One in eight patients who receive haemodialysis die each year; this proportion is well in excess of that for individuals of the same age who do not have kidney disease⁸.

2. Recommendations for standards for transport for patients requiring haemodialysis treatment

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

Core principles	Rationale	Delivery principles
<ul style="list-style-type: none"> Discussions should be held with the patient about transport as an important part of their dialysis healthcare, ideally when first planning haemodialysis treatment. Clinical services, commissioners and providers should work together to ensure that transport is coordinated around the patient. Simplify the delivery of transport and ensure transparency of provision. 	<ul style="list-style-type: none"> Preparation for haemodialysis treatment for many patients involves the time prior to attendance at the dialysis unit. Some patients have medical needs around the journey itself. The physical and cognitive health of many patients can be affected by their transport. Attendance for the complete treatment time is essential to wellbeing. Close working between commissioners, providers, and the service will align delivery of transport with patients' needs. There is current over-complexity in contracting for and provision of transport. Transport is a major patient reported experience measure. It is perceived by patients as part of their episode of care. 	<ul style="list-style-type: none"> 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. 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. A designated transport officer at the level of the unit OR a nominated transport champion from the provider. Assessment of need based on both journeys, to and from the haemodialysis unit. This should be done by the kidney team, led by the named nurse for the patient.



50% of non emergency patient transport is for journeys to and from dialysis.



2 No patient should contribute to the costs of treatment by paying for their transport

Core principles	Rationale	Delivery principles
<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> Some patients who require haemodialysis are having to pay for their own transport for life saving treatment that is regular and continuing to the end of the life of the patient (unless they receive a transplant). Any patient or carer for that patient who is funding transport will incur significant long-term costs. These costs are carried by the patients or their family/friend. Inability to undertake full time work and low income are very common in patients who require dialysis treatment. 	<ul style="list-style-type: none"> Services should work to share good practice for schemes that are cost viable including for those few who wish to drive or have family/friends providing a lift. Provision of nominal transport support (mileage or allowance) based on the travel in and out requirements. Standardisation of reimbursement. Access to free parking and drop-off zones. Identify schemes which support the patient to travel and assess for both inward and outward journeys: where the patient can use public transport, assess if they can do so for both journeys. This may require input from the responsible nursing and medical staff. Ensure that 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 problems. Ensure that communication is focussed on enabling the patient to have control. This is an area of major focus for kidney patients and kidney services. Assessment of the needs of patients may identify those receiving transport of a higher specification than required.



3 Patients should be enabled to control their own transport

Core principles	Rationale	Delivery principles
<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> Each patient to have a care plan that is individualised for their needs. Novel models of transport delivery can be used, which may include: <ol style="list-style-type: none"> Transport sharing (e.g. travelling with one or more other patients) Tailored transport provision (community transport providers including volunteer organisations or local taxi companies) Transport should be integral to the care experience, with an associated attention to quality. It should be centred on the experience of patients ensuring services are neither specified or too general. Transport should be expedient, high quality, and suited to needs.



4

Clinical services, commissioners and providers should work together to ensure good and cost viable services

Core principles	Rationale	Delivery principles
<ul style="list-style-type: none">• Ensure central co-ordination of transport; consider a haemodialysis transport communication hub for the service. Including transport providers in this hub would help to coordinate services.• 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.	<ul style="list-style-type: none">• The importance of ensuring a cohesive system, where all parties are working together, should improve efficiencies.• All groups should be working together to ensure that there is a seamless process that can be used to deliver the service.	<ul style="list-style-type: none">• Services are encouraged to work towards separating the delivery of kidney transport from non-kidney non-emergency patient transport (NEPT). Where this is not planned there needs to be a clear rationale as to why the services are shared. It is recognised that logistical considerations for providing a kidney specific NEPT service could be challenging.• 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 taxi company.• 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 taxi service for patients who are mobile. These are in place in some, but not all, kidney services. There are different models for that could be used; these include:<ul style="list-style-type: none">- Trust run volunteer taxi service- Local taxi firm(s) accredited for 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:<ul style="list-style-type: none">- Smart routing- Accurate data by postcode and mobility classification- Annual reviews• Ensure strong communication so that transport does not attempt pick-up for people who are inpatients and to not currently require it. The development of local processes for early alerts could facilitate this.• 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 trialing 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.



5

Key performance indicators (KPIs) should be used to assure the service

Core principles	Rationale	Delivery principles
<ul style="list-style-type: none">• These should be developed and agreed by all partners including patients.• Patient reported experience measures should be included in the KPIs.• A regular monitoring structure involving all partners, including patients, should be used.• The group drawing up the KPIs should decide how they could be enforced, including whether and how penalties may apply.	<ul style="list-style-type: none">• 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.• These should apply to the clinical service, providers, and commissioners, working together in a local kidney transport board.	<ul style="list-style-type: none">• A service charter should be in place and signed off by the responsible officers for the partners in the delivery of transport.<ul style="list-style-type: none">• The charter should include a care plan individualised for the patient and developed with the patient by the kidney unit and a care plan review.• 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 wait for pickup, a 30-minute journey and to wait no more than 30 minutes after treatment to be collected. Transport providers should be held accountable for this target. Local exceptions to this should be clearly justified.• 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 indicators that are collected, evaluated and acted on.• 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.• Accurate and easily accessible information should be available for patients to support their understanding of and access to dialysis transport.



Good practice is the 30-30-30 rule:
no more than 30 minutes to wait to be picked up,
no more than 30 minutes journey,
and no more than 30 minutes to be picked up after treatment.

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. There are additional anxieties for those who may have a car or are being dropped off, including being able to access car parking or drop off zones, and the cost of parking. Remunerated car-parking on showing proof of identity may be a feasible way of achieving no-cost parking without the need for access to specially reserved places. This is used successfully in many Trusts for certain staff groups and could be extended.

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;



An important audit of a single dialysis unit that contributed to the case for the development of the Wales renal service standards for haemodialysis indicates the potential burden that can be sustained by patients when patient transport is sub-standard. The audit recorded 25 incidents over a 12-month period where patients' clinical condition has been affected by problems with transport: These comprised 9 hypoglycaemic-related events in waiting area as a result of delayed transport and a total of 16 adverse clinical incidents that put the patients at risk

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.

Particular attention needs to be given to the way in which services perform for children and parents. Here problems can be particularly serious; for example, when delays in transport occur the impact on families can include stress with childcare provision, including school pick-up of other siblings. In fact, parents often need to bring other siblings to the dialysis treatment when they may not have volunteer childcare options available (e.g. extended family members) to look after other siblings when parents accompany paediatric dialysis patients in long dialysis sessions.



Even for patients who live close to the dialysis unit in which they receive their treatment the average length of time at the unit is **more than 6 hours**.



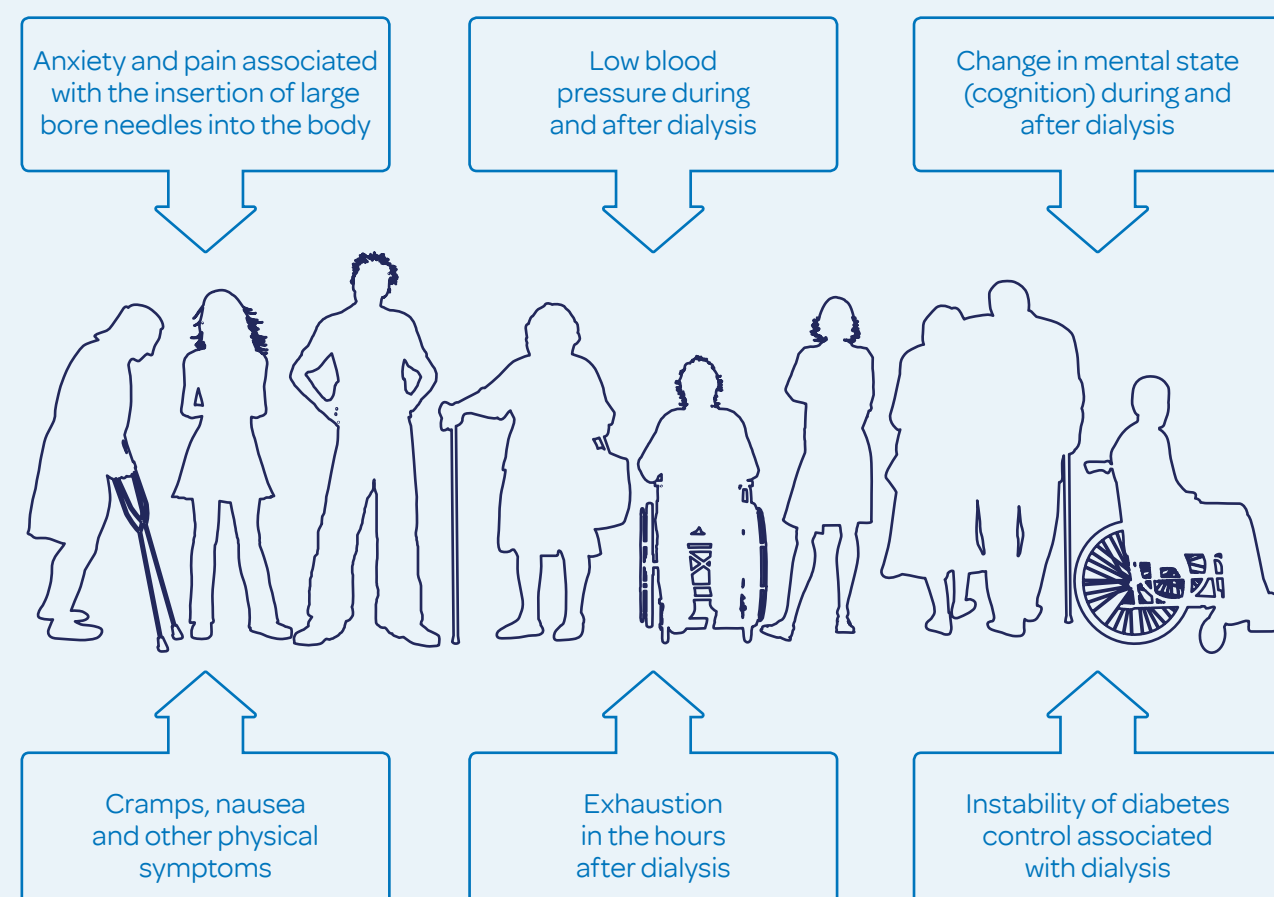
4. What is haemodialysis and what is it like to be treated with it?

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. There is another form of dialysis, which is administered by patients at home after they have been trained to do so, called peritoneal dialysis. Without sustained dialysis treatment those affected by ESKD are likely to die of kidney failure within about two weeks.

A standard 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. The average cost of dialysis unit based haemodialysis treatment is around £30,000 per patient per year^{9,10}.

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 haemodialysis catheter. 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:



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:

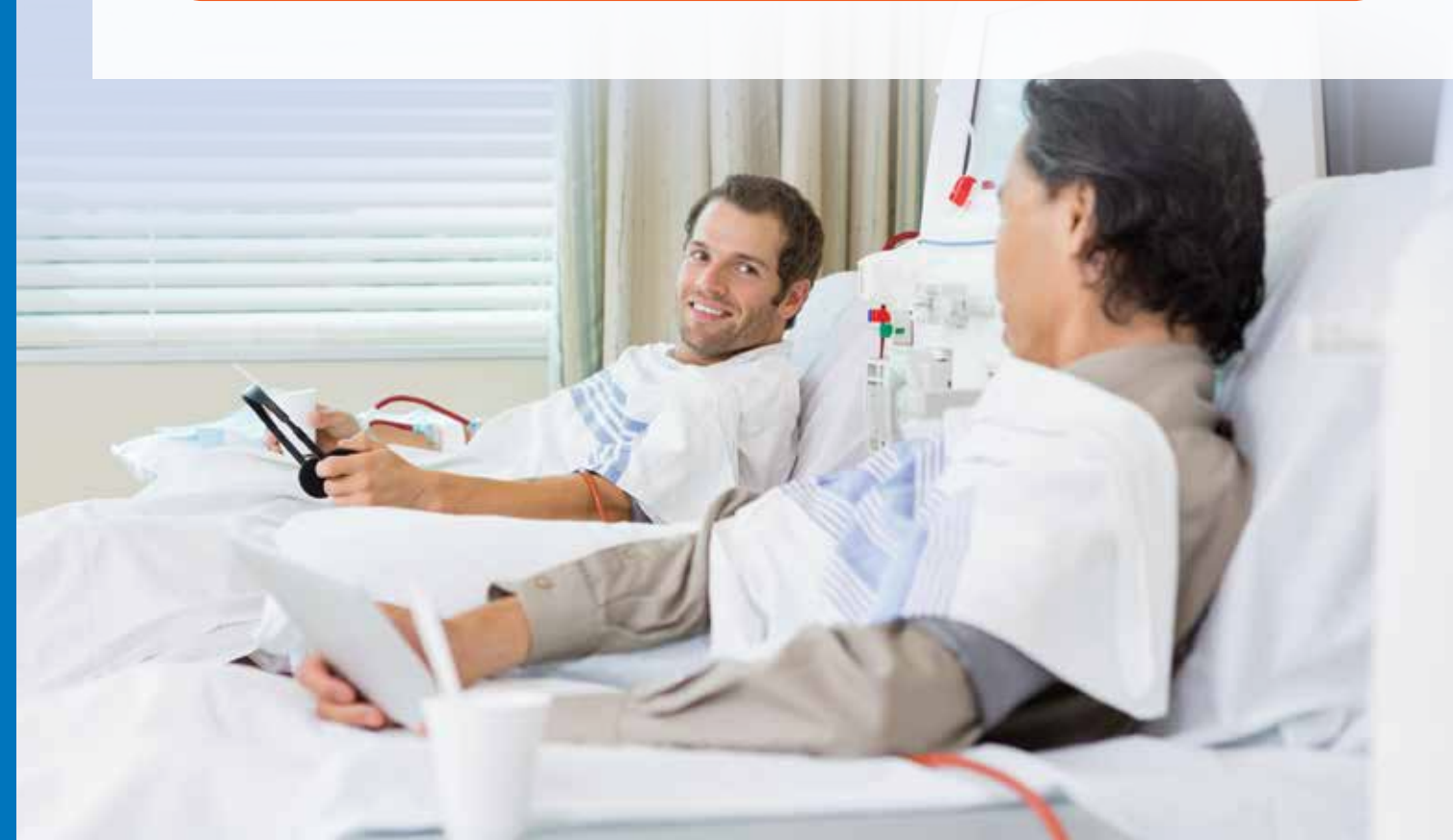
- Progressive heart failure
- Vascular damage including increased risks of strokes and vascular disease leading to amputation
- Increased risk of infections
- Increased risk of cancers

People who receive dialysis have a significant likelihood of requiring inpatient admissions; at any time around one in 20 dialysis patients may be inpatients in a hospital. 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



The average cost of dialysis unit based haemodialysis treatment is around **£30,000 per patient per year**



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 initiative¹³, 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 time¹⁴. 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 Non-Emergency Patient Transport. 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 website¹⁵ 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)¹⁶, 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 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 are currently no specific criteria or a 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.¹⁷



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' GP practice. 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, for example the area covered by Nottingham City Renal Unit means that it must link with multiple CCGs and transport providers.

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. However, 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).¹⁸ Lack of adherence to KPIs continues to be a problem and it is crucial that they are linked to contracts in order to maximise their effectiveness. In some cases only one provider submits a tender for a contract, making this particularly important where no competition exists.

Costs and how to ensure viability

The cost of NEPT is at least £150 million a year in England (www.gov.uk/government/speeches/total-transport-working-together-for-our-communities), although some sources indicate that it could be far higher than this, and up to £500 million across the whole UK. Patients receiving haemodialysis treatment receive around half of all NEPT. This means that the minimum average costs for a haemodialysis patient of NEPT may be around £3,750/year. The average haemodialysis patient is making 312 journeys a year, which is 156 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 Transport¹⁹ 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

- Haemodialysis patient 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. 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 which the service is configured to provide and that which is required.
- 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 (it should be noted that voluntary drivers may be difficult to recruit on evenings and weekends). The specification for this component of a service should be flexible. There is no reason why successful providers shouldn't outsource this.
- Different models could be used utilising cost per journey or a 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.
- 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.
- Kidney services need to play their part in being as organised as possible for the transport services to allow efficiency for all.
- 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

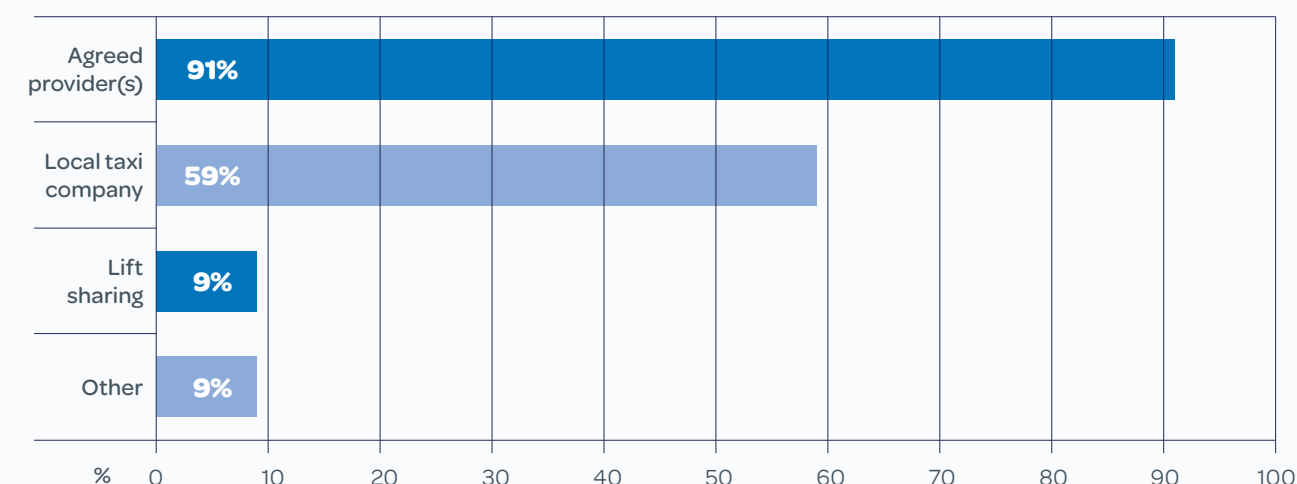
As part of our background work to inform the recommendations kidney units were asked to participate in a national dialysis unit survey. Invitations were sent to 71 UK kidney services, via their clinical directors, with the request that an individual with knowledge of and responsibility for patient transport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

Key findings included:

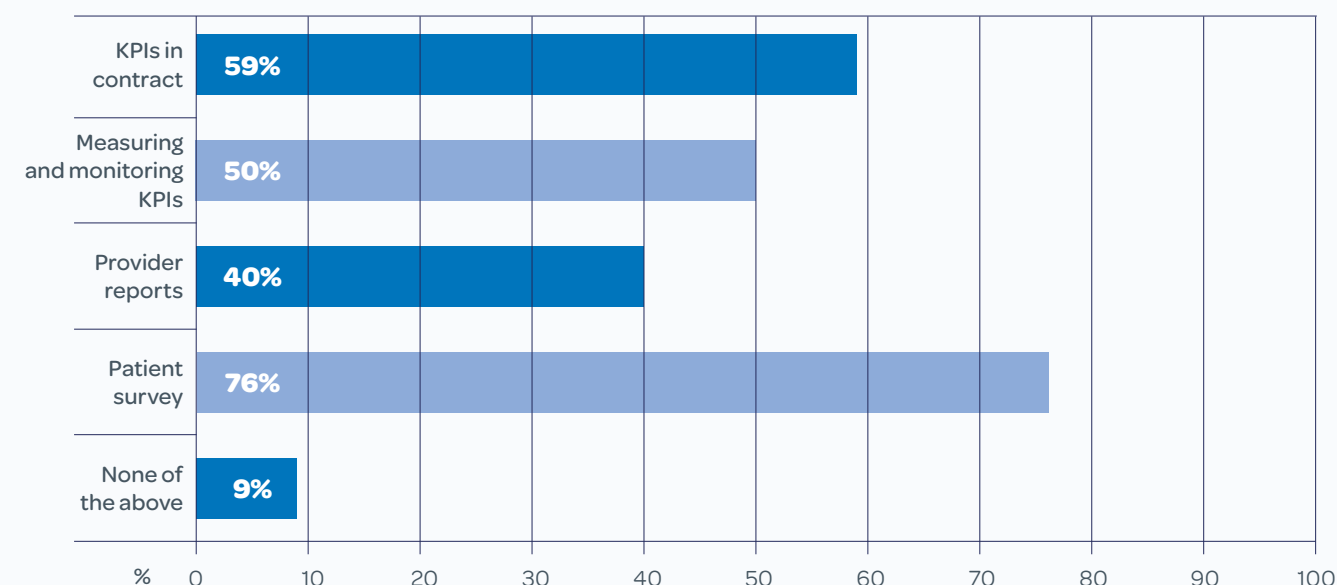
- 40% reported that trusts commissioned transport; 63% said that CCGs commissioned it. Combined contracting was reported by some services; CCGs are contracting ambulance services.
- Different arrangements are in place for different satellite units that are the responsibility of one NHS Trust. 39% had 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 (KPIs) 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.

What type of transport provision is available? (all that apply)



How does the unit monitor the quality of the patient transport service? (all that apply)



10. Future developments

New and innovative models of transport provision are needed and should be encouraged, providing they meet the standards in this document.

For example, during the compilation of evidence for this report, we have received a suggestion for a 'dialysis voucher scheme' for patients to use against their transport of choice which is funded via the NHS to allow greater freedom to choose or use against the most appropriate method and redeemable by the provider. An NHS dialysis account with a private taxi coordinator such as Uber has also been suggested.

The use of remunerated car-parking on showing proof of identity may be a feasible way of achieving no-cost parking without the need for access to specially reserved places. This is used successfully in many Trusts for certain staff groups and could be extended.

Options for new models are likely to be diverse and therefore these standards will play a vital role in ensuring that any new or existing revised model meets the needs of patients and health care professionals as well as being workable for a CCG or a Trust.

In developing new models, as well as in running existing systems, maintaining the close link between transport and treatment services is obviously essential. However, dialysis transport services have a significant cost and it must be ensured that services are used appropriately. Using the Standards, which recommend the inclusion of local kidney patients and groups in the design of services, will help to establish a positive two-way relationship in which patients feel valued and value the services they have helped create.

Access to accurate information for patients and carers is very important in not only explaining the services available but also in ensuring that patients and carers know what they should (and should not) expect.

Promoting shared/self care may help patients to understand more about the various elements that comprise a dialysis service. Some patients may be encouraged to explore their own transport options, subject to various considerations such as an appropriate mileage charge.

Appendix 1 - 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 (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) patients receiving unit based dialysis are automatically eligible for transport to and from appointments. This patient video (www.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 2 - 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).” (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. (www.england.nhs.uk/personal-health-budgets/what-are-personal-health-budgets-phbs/frequently-asked-questions-about-phbs)

North East and West Devon CCG have successfully piloted a personal health budget for dialysis transport, to enable 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 3 - 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 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

Defining the evidence base for transport as part of the episode of care

- Collating models that are exemplars of good practice

- Modelling the financial impact of models for the provisions of transport
- 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.)
- Stakeholder engagement, communication and dissemination (including electronic resources)

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.

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 in the final version of the document

Appendix 4 - 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 in the final version of the document.

Appendix 5 - Acknowledgements

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We are grateful for the comments at consultation stage, from many individuals, that helped shape the final report.

Appendix 6 - 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.



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