GETTING IT RIGHT FIRST TIME

Renal Medicine

GIRFT Programme National Specialty Report

By Dr Graham Lipkin and Dr William McKane
GIRFT Clinical Leads for Renal Medicine

March 2021

GIRFT is delivered in partnership with the Royal National Orthopaedic Hospital NHS Trust, NHS England and NHS Improvement

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Foreword from Professor Tim Briggs

I am delighted to recommend this Getting It Right First Time review of renal medicine, led by Dr Graham Lipkin and Dr William McKane.

Graham and Will have applied the GIRFT approach to renal medicine, which provides life-changing treatment and care to people with kidney disease. It is estimated that up to one in five patients admitted to hospital as an emergency is affected by acute kidney injury. This injury or loss of function can be severe and is associated with high mortality, but can be reversible. Chronic kidney disease affects around 6% of the UK's adult population and can be associated with other serious illnesses, including diabetes, hypertension and cardiovascular disease.

This report comes at a time when the NHS has undergone profound changes in response to the COVID-19 pandemic. The unprecedented events of 2020/21 – and the extraordinary response from the NHS, not least renal services – add greater significance to GIRFT's recommendations. There is a sense of urgency for sustainable recovery and implementation of these clinically-led and patient centred service delivery recommendations to improve future patient outcomes.

Acute kidney injury was seen in unprecedented numbers of patients admitted to critical care with COVID-19 infection. The rates of infection and mortality of patients with chronic kidney disease, those on dialysis and kidney transplant recipients were extremely high. Kidney transplant programmes were suspended and there were wholescale cancellations and delays to treatments requiring catch up.

The recommendations set out in this report are based on Graham and Will's visits to all 52 adult renal centres in England, in addition to detailed benchmarked data analysis and audits. Graham and Will found examples of excellence in every kidney centre they visited, but also unwarranted variation and opportunities for improvement.

The recommendations include establishing regional renal networks to support levelling up access to kidney transplantation, remote and virtual outpatients and home dialysis therapies in large and smaller renal units. Central to these recommendations is putting patient experience at the centre of service design, and embedding quality improvement across the whole multi-professional team. GIRFT aspires to streamlining renal transplant pathways and ensuring that all acute trusts implement patient safety measures for prevention, detection and management of acute kidney injury.

It is very encouraging to hear that, like other GIRFT clinical leads, Graham and Will found clear evidence of strong, ambitious clinical leadership and management and commitment to using the specialty's robust sources of data to drive improvement for patients. That ambition and drive is vital to the GIRFT programme, which can only succeed with the backing of clinicians, managers and everyone involved in delivering care.

My greatest hope is that GIRFT will provide support and impetus for all those involved in renal medicine, including transplantation, to work shoulder to shoulder and continue to improve the outcomes and the lives of people with acute and chronic kidney disease.

Professor Tim Briggs *CBE*

GIRFT Programme Chair and National Director of Clinical Improvement for the NHS.

Professor Tim Briggs is consultant orthopaedic surgeon at the Royal National Orthopaedic Hospital NHS Trust, where he is also Director of Strategy and External Affairs.
He led the first review of orthopaedic surgery that became the pilot for the GIRFT programme, which he now chairs.

Professor Briggs is also National Director of Clinical Improvement for the NHS.

Introduction from Dr Graham Lipkin and Dr William McKane

We have had the privilege to visit all 52 adult renal centres in England and spend time in each service with the broad renal multiprofessional team (MPT), each delivering high quality clinical care with dedication and commitment. It is this unit quality that makes renal medicine stand out and underlies its proud history of innovation in service design and development, research and patient engagement.

No English renal service is perfect and every one has areas of excellence alongside areas where there is scope for improvement. There was clear evidence of strong effective clinical leadership and we are grateful to the renal centre clinical directors, matrons and business managers for hosting us and for providing valuable insight into the processes and practices of their unit. We were able to jointly agree areas of focus for quality improvement over the coming years and develop bespoke deep-dive data packs and reports.

The professional societies, kidney patient charities and in particular the UK Renal Registry (UKRR) and NHS Blood and Transplant (NHSBT) require special mention. High quality registries allow for benchmarking of outcomes for patients receiving dialysis or transplant, especially where linked to Hospital Episode Statistics (HES). The patient portal (Patient View), the acute kidney injury (AKI) master patient index, Patient Reported Experience Measure (PREM) reports and the development and regional project management of the Kidney Quality Improvement Partnership (KQuIP) by the UKRR are collectively remarkable tools. These formed the backbone of data we used to benchmark each of our services.

Together with the patient charities, the renal community has taken the unique opportunity to come together in the Kidney Health Delivering Excellence Group to define a road map with agreed future ambitions and these assisted us enormously.

For suitable patients, kidney transplantation timed prior to dialysis, usually achieved by live donation, is the gold standard of treatment. Likewise, patients identify the benefits of shared decision-making (SDM) with clinicians in choosing their treatments. Shared dialysis or home dialysis treatments for many have major benefits over in-centre haemodialysis (ICHD). After careful discussion and SDM, some frailer, usually elderly, patients choose a planned conservative approach to end-stage kidney disease (ESKD) rather than suffer the rigours of dialysis. Again, this can deliver benefits in terms of quality of life.

Another key aspect of renal care, AKI, frequently results from kidney damage in the setting of other severe illness. Organisation of pathways of care is often co-ordinated by renal services but patients remain under the care of general medicine or critical care. AKI is remarkably common and is associated with substantial mortality.

Despite this knowledge, in all these areas we found significant evidence of unwarranted variation in both patient access to key forms of treatment and in key clinical outcomes. Variation in resource and time plus constraints in access to professional development of staff was a recurring theme, as was poor recognition by trusts of the importance of training in quality improvement and leadership. We must invest in ourselves to improve outcomes. Areas of our practice are enhanced by units working together and learning from each other.

A second theme was the critical importance of regional clinical networks sustaining audit, quality improvement (QI) and continuing professional development (CPD).

Renal patients paid a high price in the first wave of COVID-19 infection with almost 11% of in- centre HD (ICHD) patients infected and more than 1300 deaths. The pandemic has had a substantial impact on our staff with surveys showing high levels of emotional exhaustion and disrupted training, CPD and research, of which we must remain mindful.

Improvement in almost all of the key areas of variation defined in this report would represent a win for all. For patients, improvement would mean greater engagement, better outcomes and an enhanced care. Changes would also be associated with improved healthcare value and reduced costs.

Furthermore we have a responsibility through these changes to lead the way in sustainable kidney care, helping limit climate change. Rarely do opportunities to offer improved care, better value and increased sustainability come together.

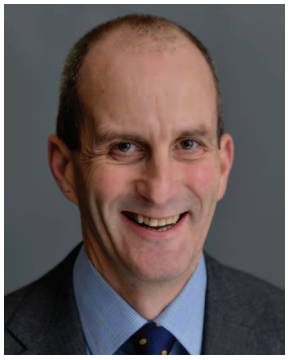
We wish to thank the Getting It Right First Time (GIRFT) team who supported us tirelessly, in particular Lisa Hevey, our dedicated and hardworking policy manager, analytics manager Matt Colmer, the remarkable project managers Sophie Sheard and Neha Patel, and Louise Bell, who supported us in drafting the report.

We firmly believe that the opportunities ahead for the renal community to 'level up' patient outcomes and further improve care by implementing the recommendations in this report represent the most significant opportunity for positive change in the renal community in over a decade. NHS England has simultaneously commissioned the Renal Services Transformation Programme (RSTP), and GIRFT and RSTP are committed to jointly agreeing these recommendations and providing a mechanism for implementation.

Dr Graham Lipkin

Joint Clinical Lead for Renal Medicine

Dr Lipkin is a Consultant Nephrologist, at University Hospitals Birmingham NHS Foundation Trust (Queen Elizabeth Hospital), and President of the Renal Association.



Dr William McKane

Joint Clinical Lead for Renal Medicine

Dr McKane is a Consultant Nephrologist and Clinical Lead for Transplantation, Sheffield Kidney Institute, Sheffield Teaching Hospitals NHS Foundation Trust.

Statements of support

The British Renal Society

The British Renal Society provides its full support to the GIRFT report and the recommendations within the document.

The report suggests many areas of improvement that have been highlighted by the renal community over a number of years. There are a series of very sensible and pragmatic solutions, which the report highlights to drive improvement in kidney care across the UK. The report will also help to support the ambitions of the Renal Services Transformation Programme, the recently published British Renal Society Workforce planning document and the work of the Renal Clinical Reference Group to deliver consistent quality care for people living with kidney disease.

We already see many of the recommendations from the GIRFT report being implemented into clinical practice. The recommendation for the Kidney Quality Improvement Partnership to support regional programmes of quality improvement work is one such example. It is clear that the report and the work done so far by the GIRFT team will be continued with support from the national professional organisations and the renal community as a whole.

Dr Sharlene Greenwood

President of The British Renal Society

The British Transplantation Society

The British Transplantation Society acknowledges the extensive work that has gone into the GIRFT review. We support these recommendations – improving both equity and access to kidney transplantation across the UK – and their integration into commissioning policy and future renal transformation projects.

The Society endorses the collaborative approach to patient care highlighted by GIRFT, and looks forward to improved networking and quality improvement initiatives.

Lisa Burnapp

President of the British Transplantation Society (on behalf of the BTS Executive)

Kidney Care UK

Kidney Care UK is delighted to welcome the publication of the GIRFT report and provide its full support for its recommendations.

Kidney patients have a particularly strong bond with their care teams, and the report provides the impetus and opportunity to strengthen this further, significantly improving patients' outcomes and quality of life. From patients playing a greater role in their own care, greater choice of treatment, earlier transplantation and improved psychosocial support, we believe this report heralds a major period of improvement in kidney care and the reduction of unwarranted variation across the country.

At Kidney Care UK we believe that the publication of this report and the subsequent launch of the Renal Services Transformation Plan provides the best opportunity in recent memory for change - an opportunity that must be seized.

We have always been a strong, close-knit community and Kidney Care UK will play its part in continuing to represent the voice of patients and partner with health and care professionals to ensure we see the changes and improvements that this report advocates become a reality.

2020 was a tough year for kidney patients and their families, and this report and the promise it shows us is what patients deserve and "just what the doctor ordered".

Paul Bristow

Chief Executive, Kidney Care UK

National Kidney Federation

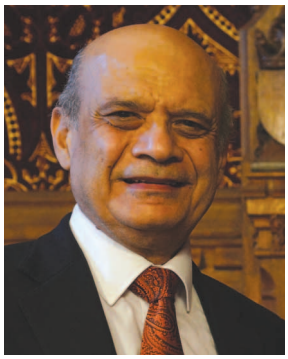
The NKF welcomes the publication of the GIRFT report and fully supports the recommendations. We are in a unique position as a federation of 50 local kidney patient associations (KPAs) to contribute to the implementation of the recommendations and request that a renal GIRFT implementation group be set up to support and monitor the recommendations.

I was invited as Chair of the Lister Area Kidney Patients Association to attend the deep dive meeting at the Lister Hospital and was very impressed by the overall quality of the data and the discussion which took place. The existence of an effective local KPA is an indicator of the importance senior renal staff in hospitals gives to the patient voice locally. We hope that this will be taken on board in future work by the GIRFT team.

COVID-19 has highlighted the importance of increasing home therapies in saving lives of dialysis patients. Following the NKF webinar on this issue, we will soon be publishing a report on it. We look forward to the support from the kidney community in our campaign to increase home therapies.

COVID-19 has also highlighted inequalities within renal services. NKF has been active in addressing BAME issues as a founding member of the National BAME Transplant Alliance (NBTA). Innovative work in empowering BAME community groups to take a lead on addressing inequalities is been done with NHSBT, through the Living Transplant Initiative and the Community Investment Scheme. We appreciate that most of the GIRFT process took place before COVID-19 but we request that the equality issues be included in the implementation of all GIRFT recommendations.

NKF is ready to support the implementation of the GIRFT recommendations. The sooner the better!



Kirit Modi

President, National Kidney Federation

The Renal Association

As renal healthcare professionals we aspire to provide the highest quality of care. This is challenging, however, as the needs of patients with kidney disease are often complex and even outstanding services have clinical areas which can and should be better for patients. The starting point for understanding how our services perform is through measurement; this allows us to benchmark quality, to identify areas for improvement, to capture change (for better or worse) with time, and to evaluate the impact of quality improvement interventions. Measurement is a cornerstone of high quality care.

Measurement is central to the recommendations in this report from the Getting It Right First Time (GIRFT) renal medicine team. By using data returned from all English renal services, GIRFT has identified major unwarranted variation in patient access to care and in clinical outcomes. These findings have led to a series of recommendations to address this variation. These recommendations are supported by an action log, with accountabilities and timelines, and cover all areas of specialist renal care. Thank you to Graham Lipkin, Will McKane, and colleagues in the GIRFT team who have worked so hard to produce this report.

This report should be a springboard to improving care for patients with kidney disease. The Renal Association, now merging with the British Renal Society to form the UK Kidney Association, is committed to work ceaselessly to support the delivery of the recommendations of this report. We look forward to collaborating with all relevant partners in this. Collectively we have established supporting structures for measurement, improvement, implementation, and leadership. By using these to best effect we can work together to ensure that we do the most we can for as many patients with kidney disease as possible.

This GIRFT national report for renal medicine report is an important milestone towards achieving this aspiration.

Paul Cockwell

President elect, the Renal Association

Royal College of Physicians

The RCP welcomes this report. The GIRFT team should be commended in the work put into understanding the quality of clinical care in renal medicine. The specialty has always been data rich but has made many advances in the use of patient data to improve outcomes and safety over the past decade well beyond what most other specialties have achieved. However, there remains significant variation between providers of care and we hope that this report and the work of GIRFT will help reduce such variation.

Professor Andrew Goddard

President of the Royal College of Physicians

Executive summary

The context

Moderate to severe chronic kidney disease (CKD stages 3-5) is present in 6% of the population and acute kidney injury (AKI) complicates over 300,000 admissions per year. Around 56,000 patients in England are on renal replacement therapy (RRT) and this is growing at a rate of 3% per annum; predominantly kidney transplant recipients. The focus of our report is on these more advanced stages of kidney disease, where the disease burden for patients is high, specialist input is necessary and costs of treatment are substantial. This reflects a Getting It Right First Time (GIRFT) approach which is provider and data focused. We have not lost sight of the fact that preparation for and delivery of acute and chronic dialysis and transplantation represents only one aspect of renal care which is inextricably linked with earlier stages of the pathway, where there is a strong link to cardiovascular disease. Nephrologists, in partnership with primary care and other acute specialties, play an important advisory and strategic role in less severe AKI and CKD.

The structure of our report

The sections in this report cannot cover every area of specialised renal care and there are many other aspects of the pathway that we could have included, but the summary below describes the background and findings in the areas that we considered most likely to have an impact. The recommendations that follow from these findings are detailed after this executive summary and are also embedded in the relevant section of the report.

Regional renal clinical networks and quality improvement (QI) implementation

Renal services have a strong track record of quality improvement (QI) and collaborative service development, often on a regional footprint. Many of the more complex interventions which are part of the renal pathway require regional planning and co-operation.

What we found

At the time of our deep dives[1], the funding and regional planning element of network collaboration had been significantly weakened by the demise of the NHS England Strategic Clinical Networks. In their place, regional QI networks (Kidney Quality Improvement Partnership (KQuIP[2]), led by the profession and charitably funded, had filled the void and provided several valuable QI initiatives.

Preparation for renal replacement therapy (RRT) and conservative management

The advanced kidney care clinic (AKCC) is the focal point of the patient pathway for patients with progressive CKD. Shared decision-making (SDM) is crucial and the scene is set in the AKCC for the renal replacement therapy (RRT) pathway that follows. The AKCC, where adequately resourced, can deliver improved access to transplantation, home dialysis and conservative management.

What we found

Most centres have an established AKCC, but the available multiprofessional workforce in these clinics is highly variable, often with inadequate resource for psychosocial aspects of care, conservative renal care and transplant assessment.

[1] *Changes after deep dives, driven by the COVID-19 response, have re-established NHS England renal networks.*

[2] *https://www.thinkkidneys.nhs.uk/kquip/*

Access to kidney transplantation

A kidney transplant is the best form of RRT for suitable patients. It is associated with improved survival, quality of life and healthcare value as compared with dialysis. Living donor (LD) transplantation prior to the start of dialysis is considered the gold standard. Much of the work to reduce variation in this area has been led by the 19 English transplant centres and NHS Blood and Transplant (NHSBT), but many aspects of this pathway are actually delivered in the 33 non-transplanting renal centres.

What we found

There are many sources of centre variation in access to transplantation, operating at the level of the renal centre and the transplant centre. We focused on transplant listing and the likelihood of an LD transplant, where collaborative working between the renal and transplant teams is crucial and where the funding, culture and workforce in the AKCC was not always optimal.

Vascular access for haemodialysis (HD)

Definitive vascular access is a well-established quality target in haemodialysis (HD) care and has been strongly incentivised by NHS England by means of a best practice tariff (BPT). Patients without definitive vascular access have higher rates of infection, hospital admission and mortality. Vascular access interventions are carried out by transplant surgeons in some centres, vascular surgeons in others, and both need adequate interventional radiology (IR) support.

What we found

Few centres achieve the standard for definitive vascular access, both when HD starts and in prevalent HD patients. The organisation of care and culture are important and not consistent, but every centre we visited wanted to improve its achieved rate. In many centres there was insufficient capacity to improve the vascular access service and insufficient IR support for salvage. Regional delivery of vascular access procedures in dedicated cold sites is being considered in some networks.

Home therapies

Dialysis at home, either as peritoneal dialysis (PD) or home HD (HHD), has many advantages for patients in terms of quality of life, autonomy and flexibility. Overall it is good value for the NHS. Patients on a home therapy are much less likely to get transmissible infections, including COVID-19.

What we found

There is wide centre variation in the proportion of new and established dialysis patients that are treated at home. The overall proportion on home dialysis is unchanged over the past ten years, with the rise in HHD being balanced by a fall in PD. There is wide variation in the size of the home therapies nursing and technologist workforce. For PD, a late start programme and an agile catheter insertion service are important. For HHD, adequate training facilities and shared care HD in dialysis centres are necessary.

Acute kidney injury (AKI)

AKI is very common, both in the community and in hospitalised patients, and mortality levels are high. Over 300,000 admissions per annum are associated with an AKI episode. Most are not directly managed by renal services, but this is a key area of interface between renal medicine and other acute specialties.

What we found

There is wide variation in the casemix adjusted centre mortality associated with AKI. Leadership and improvement in AKI care is often led by renal teams and networks, but the organisation of such networks is variable around the country. The potential efficiency and quality gain from improving AKI care is huge. Severe AKI needs specialist input by renal or critical care teams, and inter-hospital transfer is needed from non-renal sites. We found that such transfers are often delayed, with compromise in the quality of patient care and inappropriate use of critical care beds.

Outpatients

A large amount of general nephrology and sub-specialty renal care is delivered in an outpatient setting. As in other specialties, the COVID-19 pandemic has accelerated a transition to non-face to face and other forms of virtual consultation.

What we found

There is wide geographical variation in the volume of new nephrology referrals. At the time of the deep dives, there were centres adopting an innovative approach to outpatient review as well as virtual consultation, but it was not widespread. Access to subspecialty, rare disease and young person clinics is important and is currently incomplete in many centres. Renal services are under-prepared for opportunities afforded by the predicted growth in the volume of genetic testing.

Patient experience

All specialties are developing an improved understanding of the importance of patient experience metrics in the assessment of healthcare quality. Renal medicine is ahead of the curve with a detailed Patient Reported Experience Measures (PREM) analysis published annually.

What we found

There are three areas where the PREM report suggests we should focus our efforts for improvement:

- haemodialysis transport;
- needling of arteriovenous vascular access for HD;
- SDM.

Workforce: building the renal centre of the future

The workforce is constantly adapting to the growth and changing priorities of renal care. Seven day per week working is already established in the renal medical workforce. For effective delivery of the complex pathways described in this report, all centres are striving to develop and maintain an adequate multiprofessional workforce.

What we found

There is wide variation in the size of the medical workforce when indexed to the RRT population, and in many centres physicians are coping with the competing priorities of acute medicine and renal care. As described in the above summaries of specific renal pathways, the completeness of the multiprofessional workforce is variable and this does influence effectiveness. In specialist pathways, advanced clinical practitioners (ACPs) and non-medical consultants are playing an increasingly important role.

Diabetes care in patients with end stage kidney disease (ESKD)

Diabetes is the commonest cause of renal disease and impacts every area of renal care, but we focused on its impact in patients with end stage kidney disease (ESKD). Of new dialysis patients, 35% are diabetic and they have a very high burden of complications.

What we found

We adopted amputation in the first five years after starting dialysis as a measure of the quality of integrated diabetes care for these patients. Overall this is 12%, with wide centre variation. Delivering integrated diabetes care for dialysis patients is challenging as the professionals and agencies involved often span multiple divisions of primary and secondary care.

Infection in dialysis patients

Infection is common in dialysis patients, the commonest cause of admission and a common cause of death. We focused on bacteraemia in HD patients and peritonitis in PD patients.

What we found

There is wide centre variation in the rates of both bacteraemia and peritonitis, with many centres not meeting the national standards, but equally there are centres of excellence. Both infections require a systematic approach to quality improvement. The proven interventions are not complex.

Hospitalisation in patients on renal replacement therapy (RRT)

Linkage between UK Renal Registry (UKRR) data and Hospital Episode Statistics (HES) has provided GIRFT with a unique opportunity to analyse emergency hospitalisation in RRT patients. The high rates of hospitalisation represent a hidden burden of ESKD, both in terms of patient experience and cost.

What we found

Emergency hospitalisation is incredibly common in prevalent RRT patients, more so for dialysis patients, with wide centre variation. Likewise, there is considerable variation in length of stay (LoS) and readmission rates for newly transplanted patients. The underlying causes of this variation require more detailed analysis, but will inform future quality improvement opportunities.

Pharmacy and medicines optimisation

Medicines management is an important part of kidney care, both in the specialist setting of the renal centre and the general acute setting, especially AKI.

What we found

There is significant variation in the extent to which the pharmacy workforce has been developed in renal centres. We found examples where pharmacists in advanced roles are adding great value to care delivery. The work of repatriation and generic conversion of transplant immunosuppression has delivered huge safety and efficiency gains. It will be important to see this completed in all centres, and there are obvious future targets for generic conversion.

Registry data and informatics

Renal medicine is a data-rich discipline with registries held by both the Renal Association (RA) and NHSBT. Linkage with HES has increased their value. In addition there are valuable data sources on AKI, patient experience and rare diseases.

What we found

The ability of centres to provide timely and complete data to the relevant registries is variable, determined by unit culture, dataset design and complexity, information system compatibility and the need for informatics professionals in the team. A crucial data blind spot is the lack of information about patients with advanced CKD not yet on RRT. To make the most of the quality improvement opportunity that these datasets offer, they need improved timeliness and simplicity of design.

Procurement

Dialysis is an expensive therapy and the procurement of devices and consumables a major part of the cost. A significant amount of dialysis is procured in partnership with the independent sector.

What we found

Renal medicine has a strong track record of procurement at regional and national level. The greatest area of variation and potential efficiency gain is in the contracting of HD in the independent sector, although the NHS has no central intelligence on these costs.

Reducing the impact of litigation

Litigation is costly and reducing the burden of litigation in renal care is linked to improved patient safety.

What we found

Litigation represents less than 1% of total expenditure on specialised renal care, but it is growing and there is variation between trusts. Trusts with a transplant service typically have higher costs. Allocation of cases to renal care relies on the accuracy of clinical coding.

What happens next?

The completion of this renal GIRFT cycle coincides with the initiation of an ambitious Renal Service Transformation Programme (RSTP) by NHS England and NHS Improvement. We have worked closely with this emergent programme, and the 18 recommendations set out in this report are closely mapped to the ten high impact changes proposed and outlined by the RSTP. It is a regret that we could not cover every aspect of renal care and we have been petitioned by many stakeholders to do more. The RSTP differs from GIRFT in that it has a mandate for transformation across the whole healthcare system, rather than a provider focus. In the era of the NHS Long Term Plan (LTP) and the transition of commissioning to a whole system approach on an integrated care system (ICS) footprint, this will add further value to our recommendations. As a consequence, renal medicine has an unparalleled opportunity to improve care, address variation and inequality, and to gain efficiency.

Recommendations

Recommendation	Actions	Owners	Timescale
1. Establish NHS-funded, regional renal networks to ensure quality and efficiency of care, monitor service effectiveness, embed sustainable kidney care and accountability for service delivery.	**a** Renal network priorities to reflect the needs of the region and be guided by the RSTP and GIRFT recommendations.	NHS England Specialised Commissioning and accountable commissioners*, professional societies and GIRFT	Upon report publication, review annually
	b Commissioning and clinical leads within networks to set clear priorities for delivery (including sustainable kidney care) and commissioners to hold providers to account.	Accountable commissioners	Upon report publication, review annually
	c Network geographical footprint to take into account patient flows in all renal clinical pathways.	NHS England Specialised Commissioning, accountable commissioners, professional societies and GIRFT	Upon report publication
	d Multiprofessional renal QI to be embedded within networks and supported by project management, with leads in each renal centre, driven by timely access to data and focused on addressing regionally set priorities.	Accountable commissioners, professional societies and GIRFT	Upon report publication, to complete within 12 months
	e Regional renal networks to collaborate with related disciplines at network level to include imaging, critical care and vascular services.	Renal networks	Upon report publication, to complete within 12 months
	f UKRR/NHSBT to continue with support for national and regional renal QI networks and to deliver leadership training and project management.	UKRR and NHSBT	Upon report publication
	g Measures to address inequity of access to renal services, particularly in areas of high deprivation and/or ethnic diversity, to be implemented. (These measures are defined in the text of the relevant chapters throughout the report.)	NHS England Specialised Commissioning, accountable commissioners, professional societies and GIRFT	Upon report publication

*see page 28 for definition

Recommendation	Actions	Owners	Timescale
2. Ensure that patients predicted to reach ESKD within 18 months are fully assessed in advanced kidney care services and are offered all possible care options.	**a** A multiprofessional outpatient tariff or alternative effective commissioning approach to be developed to resource optimal advanced kidney care, encompassing comprehensive multiprofessional input that includes psychosocial care and SDM for all patients.	Accountable commissioners	Within 12 months of report publication
	b AKCCs to become a central focus of QI processes and monitoring to improve access to all modalities of renal care.	Renal centres	Within 12 months of report publication
	c Renal centres to incorporate trajectory monitoring of CKD to help optimise new patient nephrology referral service and ESKD preparation planning.	Renal centres	Within 12 months of report publication
	d All renal centres to adopt NICE NG107 which defines the minimum requirements for the AKCC pathway.	Renal centres and regional networks	Within 12 months of report publication
	e Renal centres to ensure that home therapy options are effectively communicated to those patients for whom a pre-emptive transplant (Transplant First) or a conservative approach is not appropriate.	Renal centres	Within 12 months of report publication
	f Metrics of access of patients with ESKD to renal transplantation and home therapies to be monitored quarterly in all renal centres.	Renal centres	Within 12 months of report publication
3. Ensure that access to a comprehensive renal conservative management pathway is available to all patients.	**a** NHS England and NHS Improvement to define what constitutes renal conservative management in order for UKRR to collect data on patients.	NHS England and NHS Improvement, UKRR	Within 12 months of report publication
	b Access to conservative management to be available for patients where appropriate. Patients will be identified by a comprehensive SDM process.	Trusts with a renal service	Within 12 months of report publication
	c Accountable commissioners to develop a year of care pathway tariff or equivalent commissioning tool for renal conservative management.	Accountable commissioners	Within 12 months of report publication
	d A multiprofessional conservative management service to be co-ordinated including a written pathway for identification and management of all potentially suitable patients. (Delivery to involve partnership with community and palliative care teams across ICSs.)	Trusts with a renal service, accountable commissioners, ICSs	Within 12 months of report publication

Recommendation	Actions	Owners	Timescale
4. Streamline renal transplant pathways to increase access and reduce unwarranted variation in deceased and living donor (DD and LD) transplantation.	**a** Discussions to be held in relation to options to improve the renal transplant commissioning pathway, as part of improved system-working. This should include equitable allocation of adequate resource for all steps in the recipient and LD pathways (assessment, surgery, follow-up) to all centres.	GIRFT/NHSE/I, NHSBT, RSTP, DHSC	Within 24 months of report publication
	b Renal National Service Specification (NSS) to require all providers to track patients with progressive CKD 4–5 using the Transplant First tool or local equivalent, to monitor timely work up of transplant candidates and their donors.	NHS England Specialised Commissioning	Within 24 months of report publication
	c Renal centres to have a dedicated specialist nurse transplant workforce.	Renal trusts	Within 12 months of report publication
	d Renal centres to ensure timely access to diagnostics and specialist opinions needed for transplant assessment.	Renal trusts	Within 12 months of report publication
	e Work up pathways of recipients and donors to the point of listing to be tracked using an 18-week timeline, which will require clinically appropriate 'clock rules'.	NHS England Specialised Commissioning and renal trusts	Within 12 months of report publication
	f Renal transplant NSS to require effective partnership within transplant networks, including local surgical assessment and representation of the referring team on the listing and LD MDTs.	NHS England Specialised Commissioning, RSTP and renal trusts	Within 12 months of report publication
	g NICE to develop a national guideline for suitability for transplant listing to be developed which is patient-centred and adopted in a consistent manner across all networks.	NICE, RA, British Transplantation Society (BTS), NHSBT, renal trusts, kidney patient groups	Approach NICE before April 2021
	h Access to transplant listing, organ allocation and LD transplants needs to be equal for patients of all ethnicities and socio-economic groups.	NHS England and NHS Improvement, RSTP, NHSBT	Ongoing

Recommendation	Actions	Owners	Timescale
5. Reduce variation in incident and prevalent definitive HD vascular access rates and deliver RA clinical practice guideline minimum thresholds.* ** 60% incident and 80% prevalent patients with AVF/G.*	**a** NHS England and NHS Improvement to review differential pricing, and the effectiveness of the existing HD BPT.	NHS England and NHS Improvement, accountable commissioners	Within 24 months of report publication
	b NHS England and NHS Improvement and professional societies to establish the surgical and IR capacity required to deliver an 80% prevalent definitive vascular access rate. (This will also require formal definition of the pathway urgency to be delivered by relevant teams.)	NHS England and NHS Improvement, professional societies	Within 24 months of report publication
	c Trusts with a renal service to ensure they have sufficient surgical and IR capacity to support their HD programmes.	Trusts with a renal service	Within 24 months of report publication
	d Trusts with a renal service to ensure their day case surgery rate for HD arteriovenous fistula/graft (AVF/G) formation is a minimum 70% of all cases.	Trusts with a renal service	Within 12 months of report publication
	e All renal centres to have a vascular access co-ordinator post or posts (depending on size).	Renal centres	Within 24 months of report publication
	f Accountable commissioners to explore network-based commissioning of HD vascular access, including commissioning of dedicated vascular access centres and IR support.	NHS England Specialised Commissioning, accountable commissioners, renal networks	Within 12 months of report publication
	g Renal centres to optimise skill mix and competencies of clinical staff in the needling and monitoring of HD vascular access.	Renal centres and KQuIP	Within 12 months of report publication
	h Collaboration with regional vascular access QI initiative to identify local actions needed to implement effective pathways, to be agreed at network level.	Renal centres, regional networks and ICSs	Upon report publication
	i Intervention (+/- transfer where relevant) of failing or thrombosed vascular access to be sufficiently rapid to avoid central venous access (usually 24–48 hours).	To be ratified by all relevant NHS England clinical reference groups (CRGs) (vascular, radiology and renal) and adopted in relevant NSSs	Within 12 months of report publication
	j A curriculum, training and qualification process to be developed for credentialling in vascular access intervention.	Royal College of Physicians (RCP), Royal College of Radiologists (RCR), Royal College of Surgeons (RCS), RA, Vascular Access Society of Britain & Ireland (VASBI), British Society of Interventional Radiology (BSIR), Health Education England (HEE)	Within 12 months of report publication

Recommendation	Actions	Owners	Timescale
6. Ensure home therapy is promoted and offered for all suitable dialysis patients and that a **minimum** prevalent rate of 20% is achieved in every renal centre.	**a** All centres to ensure adequate training facilities and staffing for home HD (HHD) and PD, sufficient to deliver the 20% target. (Centres to consult the staffing models outlined in the British Renal Society (BRS) workforce document[3].)	Renal centres	Within 12 months of report publication
	b The reduced risk of transmissible infection (e.g. COVID-19) for patients on a home therapy compared with in-centre HD (ICHD) to form part of the SDM process with patients.	Renal centres	Upon report publication
	c All centres to ensure they have a timely PD catheter insertion service. (Local resources will determine service design but a percutaneous method of insertion will become standard in most centres.)	Renal centres	Within 12 months of report publication
	d All centres to establish a late start PD service.	Renal centres	Upon report publication
	e All centres to ensure collaborative working within renal networks is in place to improve the resilience of services such as assisted automated PD (AAPD) and HHD, particularly for smaller services.	Renal centres and regional networks	Within 24 months of report publication
	f All centres to ensure that shared care HD becomes a feature of all ICHD facilities in the independent sector and the NHS.	Renal centres and independent sector HD providers	Within 24 months of report publication
	g Research to be undertaken to develop successful strategies to address inequities of access to home dialysis in deprived and black and minority ethnic (BAME) populations.	National Institute for Health Research (NIHR) and Kidney Research UK (KRUK)	Initiate within 12 months of report publication
7. Ensure that all acute trusts implement patient safety measures (as set out in NICE NG148) to deliver highly effective prevention, detection and management of AKI.	**a** All trusts to implement the recommendations set out in NICE NG148.	All trusts	Within 24 months of report publication
	b All trusts to ensure delivery of AKI care bundles as the first response to an AKI alert (shown to improve care quality and reduce length of stay (LoS)).	All trusts	Within 24 months of report publication
	c UKRR to report comorbidity and casemix-adjusted AKI incidence and mortality in all acute trusts and publish this data in Model Hospital and the UKRR annual report.	UKRR and GIRFT	Within 24 months of report publication

[3] *https://britishrenal.org/workforce/*

Recommendation	Actions	Owners	Timescale
8. Mandate clinically-approved AKI patient transfer to a renal centre within 24 hours of the decision by the receiving consultant nephrologist.	**a** NHS England AKI NSS to include the requirement for regional network working and to issue AKI patient transfer policy requiring transfer within 24 hours.	NHS England Specialised Commissioning, accountable commissioners, regional renal networks, ICSs	Within 12 months of report publication
	b Regional renal networks to monitor delayed transfer by means of exception reporting by referring or receiving centre.	Regional renal networks	Within 12 months of report publication
	c NHS England and NHS Improvement to develop a mandatory tariff or equivalent commissioning mechanism for AKI requiring HD which will support AKI service delivery and ensure accurate reporting of AKI HD.	NHS England and NHS Improvement, accountable commissioners	Within 24 months of report publication
	d Renal networks, acute trusts and ICSs to ensure urgent nephrostomy insertion (within 12 hours, 7 days per week as per NICE NG148) is achieved through network collaboration making best use of available IR resource; efficient inter-hospital transfer will be required.	Renal networks, acute trusts and ICSs	Within 12 months of report publication
9. Ensure that outpatient services are reformed in line with the NHS LTP to improve equity of access, patient experience and timeliness.	**a** Renal centres to provide a comprehensive e-referral and non-face-to-face new and follow-up outpatient service across all general nephrology and specialised clinics.	Renal centres	Upon report publication
	b Provision of remote blood and urine sampling, either in community hubs or by dry chemistry, to be established to facilitate non-face-to-face consultations.	ICSs and acute trusts	Upon report publication
	c Improvements to be made to ensure appropriate primary care referral to nephrology services and AKCC transfer through adoption of CKD progression prediction equations embedded in biochemistry laboratory and renal centre IT systems.	Renal services, including primary care and biochemistry laboratories	Within 24 months of report publication
	d Trusts to ensure equity of patient access to sub-specialty renal clinics[4] within each regional network through a hub and spoke model.	Renal centres	Within 24 months of report publication
	e Renal and transplant centres to transform post-transplant follow up, embedding remote consultation and blood sampling whenever suitable, and reduce default frequency for early post-transplant follow-ups to bi-weekly.	Renal and transplant centres	Within 24 months of report publication
	f Ensure sufficient pharmacy input to allow for safe and efficient hospital prescribing and supply of immunosuppressant therapies usually involving homecare services.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	g Ensure there is adequate workforce to support psychosocial and physical enablement needs in all outpatient settings.	Accountable commissioners, ICSs, renal centres	Within 24 months of report publication

[4] *Including renal genetics, renal/obstetrics, young person/transition, rare disease and immunological renal disease clinics.*

Recommendation	Actions	Owners	Timescale
10. Ensure that patient experience and SDM are central to the planning and delivery of renal services.	**a** Patient experience to be made a central component in assuring the quality of care, shaping local QI direction and optimising service delivery strategy.	Trusts with a renal service	Upon report publication
	b Effective, adequately resourced and culturally sensitive SDM, facilitated through clinician training, to be embedded into all aspects of renal care, especially in the AKCC.	Renal centres	Within 24 months of report publication
	c Data returns to the UKRR PREM portal to be mandated in the NSS.	NHS England Specialised Commissioning, RA/UKRR	Upon report publication
	d Sampling strategy for the UKRR PREM to be developed to facilitate inter-centre comparability.	UKRR, renal centres	Within 24 months of report publication
	e ICHD non-emergency patient transport to be incorporated in the HD tariff or equivalent and responsibility for the management of these contracts to be transferred to renal providers.	Accountable commissioners	Within 24 months of report publication
11. Reconfigure the multiprofessional renal workforce to reflect service requirements and provide optimal care, as defined throughout this GIRFT report, delivering the best outcomes and best patient experience.	**a** GIRFT benchmarked staffing data, GIRFT recommendations and the BRS workforce document[5] to inform how the workforce needs to adapt to match service need.	Trusts with a renal service	Upon report publication, to complete by 2023
	b Allocation of regional renal trainee numbers to be reviewed to support current need and address projected need.	Joint Royal Colleges of Physicians Training Board (JRCPTB)/RCP	Within 24 months of report publication
	c A national strategy to be developed aimed at increasing recruitment into renal medical training.	RCP/RA/specialty advisory committees (SACs)	Upon report publication
	d A comprehensive national renal nurse training curriculum and accessible online educational resources to be developed (through accredited university courses for NHS and independent sector renal providers).	HEE and the Association of Nephrology Nurses UK (ANN UK), regional renal networks	Within 24 months of report publication
	e The appropriate skill mix necessary to deliver future renal care to be developed, including expansion of multiprofessional ACP roles, physician associates (PAs) and non-medical consultant roles, in alignment with the multi-professional framework for advanced clinical practice	HEE, renal centre leads, professional societies	Upon report publication, to complete by 2023

[5] *https://britishrenal.org/workforce/*

Recommendation	Actions	Owners	Timescale
12. Reduce variation and co-ordinate improved provision of protocoled, holistic care for patients with diabetes and ESKD.	**a** Implement the multidisciplinary recommendations set out in the Joint British Diabetes Societies for Inpatient Care (JBDS-IP)/RA guidelines across primary and secondary care.	All acute trusts and primary care, co-ordinated by ICSs	Within 12 months of report publication
	b Renal centres to ensure that optimising the care of patients with ESKD and diabetes becomes an urgent focus for QI, with a lead in each centre responsible for co-ordination and quality of care.	Renal centres	Upon report publication
13. Ensure that all renal centres adopt a systematic QI approach to infection prevention and control (IPC), with HD bacteraemia and PD peritonitis given equal priority.	**a** Easily accessible national data to be published quarterly on renal service bacteraemia and peritonitis to drive QI by working with centres and Public Health England (PHE) to improve data reliability.	UKRR and PHE	Within 12 months of report publication
	b Renal centres to appoint a lead from any relevant professional background with responsibility for IPC and oversight into microbial stewardship[6].	Renal centres	Within 12 months of report publication
	c Relevant national and international practice standards to be comprehensively implemented for IPC in dialysis patients.	Renal centres	Upon report publication
	d Patient partnership and education to be at the centre of QI efforts in IPC for dialysis patients.	Renal centres, local and national patient representative groups	Upon report publication
14. Ensure that data on hospitalisation of RRT patients are available and adopted as a routine element of the quality assurance process in renal care.	**a** Linked data in prevalent patients with ESKD in the UKRR annual report to be used to report patterns of hospitalisation.	UKRR	Within 24 months of report publication
	b Monthly quality assurance review and regular access to healthcare professional support for all dialysis patients is an essential part of care that is required to reduce hospitalisation.	Renal centres	Upon report publication
	c NHSBT to incorporate hospitalisation patterns using data available from HES on incident renal transplant recipients in NHSBT annual reports on kidney transplantation.	NHSBT	Within 12 months of report publication
	d NIHR, KRUK and UKRR to promote research to better understand the factors that drive hospitalisation in renal care and to inform future QI initiatives aimed at reducing variation and hospitalisation overall.	NIHR, KRUK, UKRR	Within 24 months of report publication
	e All renal and transplant centres to incorporate analysis and tracking of hospitalisation data into local renal and transplant service quality assurance process.	All renal and transplant centres	Within 12 months of report publication

[6] *https://www.nice.org.uk/guidance/ng15*

Recommendation	Actions	Owners	Timescale
15. Ensure renal centres and ICSs deliver effective medicines optimisation in order to improve the safe care of patients with kidney disease and increase healthcare value.	**a** Renal centres and ICSs to increase the number and scope of work of the renal pharmacy workforce, guided by the recommendations of the pharmacy section of the BRS workforce report[7].	Renal centres and ICSs	Upon report publication
	b Advanced clinical practice pharmacy roles to be further developed and supported to achieve optimum renal centre care delivery.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	c Repatriation of transplant and other immunosuppression from primary to secondary/tertiary renal centre care to be completed with adequate pharmacy resource to ensure safety and supervise generic conversion wherever clinically appropriate.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	d Optimisation of CKD-mineral and bone disorder (MBD) medicines, especially generic conversion of calcimimetics, to be delivered in primary and secondary care.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	e All centres to ensure there is collaboration with the pharmacy department and adequate staffing to ensure home delivery of medications to support home therapies.	Renal centres	Within 12 months of report publication
16. Ensure that renal centres, commissioners and patients have timely access to contemporaneous, clinically relevant outcome data, in order to support quality assurance and quality improvement.	**a** UKRR, NHS England, NHS Digital and renal centres to revise the core renal dataset, including only essential items.	UKRR, NHS England, NHS Digital, renal centres	Within 12 months of report publication
	b UKRR and NHSBT to establish linked datasets with relevant NHS data streams to minimise centre manual data entry and provide new insights into care quality.	UKRR, NHSBT	Within 12 months of report publication
	c Mandated data returns to be developed and collected for patients with CKD 4–5[8].	GIRFT, NHS England, UKRR, NHS Digital	Within 24 months of report publication
	d All centres to have a data manager dedicated to renal informatics, with sufficient time to meet the requirements of mandated data returns.	Renal centres	Upon report publication
	e All renal centres and renal IT providers to return real time data to UKRR by the end of 2021, as mandated by NHS England.	Renal centres, renal IT providers, NHS England	Within 12 months of report publication
	f Expand the NHS England Renal Quality Dashboard to include key benchmarked metrics from the GIRFT dataset (available quarterly).	NHS England, GIRFT	Within 12 months of report publication
	g The correct currencies to be adopted for all aspects of the transplant pathway and used to report accurate activity and reference cost data.	Renal centres, NHS England and NHS Improvement	Within 12 months of report publication

[7] *https://britishrenal.org/workforce/*

[8] *Under renal follow-up but not on RRT, including those receiving conservative management.*

Recommendation	Actions	Owners	Timescale
17. Ensure that procurement of HD facilities and home therapies delivered in partnership with the independent sector offers consistent quality and cost-effectiveness across the NHS in England.	**a** Minimum specification contracts to be developed for independent sector HD and managed equipment service facilities, with scope for local flexibility. Contracts to include framework for price and clinical governance arrangements.	NHS England Specialised Commissioning, NHS Supply Chain	Within 12 months of report publication
	b A central register of procurement activity of dialysis facilities and services to be developed; price per therapy should be transparent in the NHS Spend Comparison Service (SCS) or an alternative NHS Digital mandatory contracts register.	NHS Digital, NHS Supply Chain	Within 12 months of report publication
	c NHS England and NHS Improvement to develop a catalogue of standard consumable, equipment and service codes that can be used in purchase orders, enabling benchmarking of costs and ensuring consistency across the system.	NHS England and NHS Improvement	Within 12 months of report publication
	d National contracts to be developed with the independent sector for home therapies which are patient-centred and include guarantees of geographical completeness.	NHS Supply Chain	Within 12 months of report publication
18. Reduce litigation costs through application of the GIRFT programme's five-point plan (actions a-e) in addition to actions f and g which are specific to renal medicine.	**a** Clinicians and trust management to assess their benchmarked position compared with the national average when reviewing the estimated litigation cost per activity. Trusts would have received this information in the GIRFT litigation data pack.	Clinicians, trust management	Upon report publication
	b Clinicians and trust management to discuss with the legal department or claims handler claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Trusts to inform NHS Resolution of any claims that are not coded correctly to the appropriate specialty via ***CNST.Helpline@resolution.nhs.uk***	Clinicians, trust management	Upon completion of 18a
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trust's panel firm should be able to provide support.	Clinicians, trust management	Upon completion of 18b
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (Sis); where a claim has not already been reviewed as an SI, this should be carried out to ensure no opportunity for learning is missed.	All trusts	Upon completion of 18c
	e Where trusts are outside the top quartile of trusts for litigation costs per activity, GIRFT will be asking national clinical leads and regional hubs to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trust examples of good practice where it would be of benefit.	GIRFT	For continual action throughout GIRFT programme
	f NHS Resolution, in collaboration with GIRFT, the renal providers and professionals, to define and publish the criteria by which they identify cases attributed to renal medicine, including all relevant surgical cases.	NHS Resolution and GIRFT	Upon report publication
	g Trusts to adopt these criteria when cases are referred to NHS Resolution and use them when reviewing claims as part of the GIRFT Programme's five-point plan.	All trusts	Within 12 months of report publication

What is renal medicine?

Renal medicine concerns the prevention, diagnosis and treatment of kidney diseases. It includes the management of CKD, AKI, and preparation/care of those needing RRT, including dialysis and renal transplant patients.

There are 52 adult renal centres in England, with an average catchment of one million. Most, but not all, of these centres have a group of referring hospitals, and each region has a number of referring renal centres that refer suitable patients to renal transplant centres. There are 19 adult renal transplant centres in England, with an average catchment of 2.8 million.

Kidney disease can occur suddenly ('acute') or over months and years ('chronic'). AKI, which is often – but not always – reversible, occurs when there is a sudden loss of kidney function. Some patients with severe AKI will need dialysis temporarily until their renal function improves, although a small proportion will never recover renal function. AKI occurs more frequently in the context of pre-existing CKD and other serious illnesses such as sepsis, heart disease, liver disease and diabetes or medicines that may damage the kidneys. It is estimated that up to one in five patients admitted to hospital as an emergency is affected by AKI.

CKD 3-5 affects around 6% of the UK's adult population, or roughly 2.6 million people. Most patients are elderly, and experience mild to moderate impairment of the renal function. CKD is often associated with other diseases, most frequently diabetes, hypertension and cardiovascular disease. It is estimated that there are around 40-45,000 premature deaths each year in patients with CKD.

A report published by KRUK in 2018[9] highlights some significant inequalities in kidney health, including:

- People from south Asian and black backgrounds are three to five times more likely to start dialysis than people from white backgrounds.
- More women have kidney disease, yet more men start dialysis.
- People from socially disadvantaged backgrounds have a higher burden of kidney disease and are more likely to start dialysis.
- Dialysis patients from south Asian, black and socially disadvantaged backgrounds are less likely to receive a kidney transplant.

The causes of such inequalities are complex. Nevertheless, the GIRFT programme is committed to working towards the goal of reducing and eliminating inequities in access to treatment.

Treatment of established kidney failure

RRT encompasses the three treatments used in patients with established kidney failure:

1. kidney transplantation;
2. HD; and
3. PD.

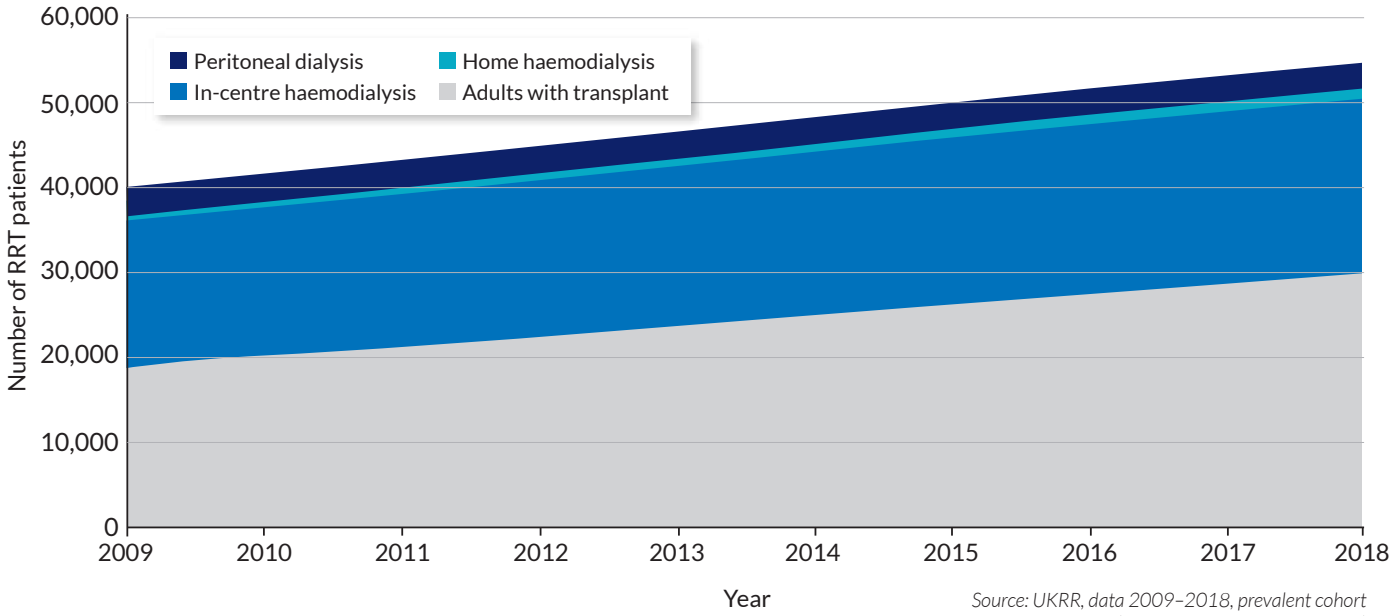
Around 56,200 patients (1,227 per million population) are currently receiving RRT in England, and the number has grown by 3% over the last year (see **Figure 1**).

Kidney transplantation – from either an LD or DD, following brain stem (DBD) or circulatory death (DCD) – is the preferred treatment option for patients who are considered suitable. Around half of all patients on RRT fall into this category. Over the past ten years there has been a steady annual increase in the number of patients receiving a transplant in the UK, from 2,694 in 2009/10 to 3,597 in 2018/19[10].

[9] *https://kidneyresearchuk.org/wp-content/uploads/2019/02/Health_Inequalities_Report_Complete_FINAL_Web_20181017.pdf*

[10] *https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17289/kidney-annual-report-2018-19-november19.pdf*

Figure 1: Growth in numbers of prevalent adult RRT patients by treatment modality at year end 2009–2018



Source: UKRR, data 2009–2018, prevalent cohort (data from one centre is missing)

Transplantation is associated with improved patient quality of life, increased longevity and substantially reduced healthcare costs. On average a kidney transplant from an LD functions effectively for 15 years and from a DD for 11 years, with patients subsequently returning to dialysis or being considered for a further transplant. For many patients transitions between RRT therapies are necessary over their lifetime. Other complications related to CKD – including anaemia and abnormal mineral bone metabolism – will require additional treatments.

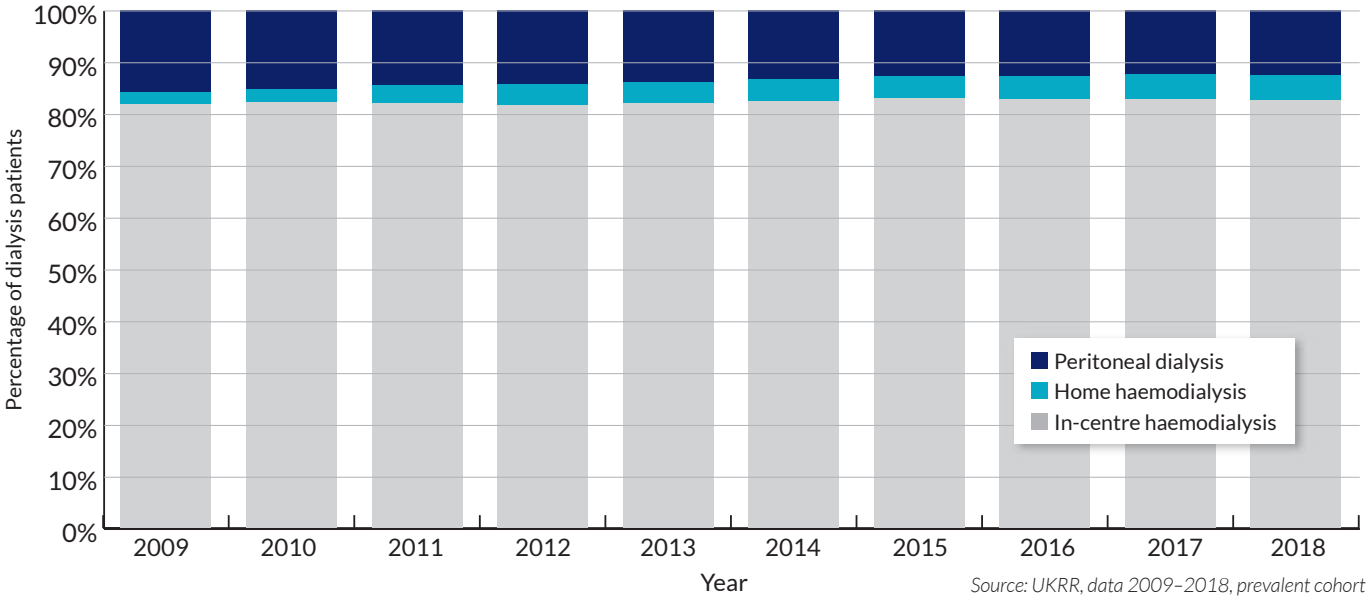
Both forms of dialysis work by removing excess fluid and waste products from the blood. Over the past ten years, the number of patients receiving HD – where a machine is used to filter and clean the blood – has increased. HD may be delivered in a hospital centre, at a satellite dialysis unit or within the patient's home.

At the same time, the number of patients on PD – where the lining of the patient's abdomen is used to filter and clean the blood – is falling. PD is carried out in the patient's home. There are several different types of PD, including:

- continuous ambulatory PD (CAPD), a machine-free technique where dialysis is carried out while the patient goes about their daily activities;
- automated PD (APD), where a machine is used to carry out dialysis overnight while the patient sleeps; and
- assisted APD (AAPD), where the patient is supported by a health assistant to carry out dialysis.

Dialysis at home – whether HD or PD – has the potential to deliver significant benefits in terms of patient experience and outcomes. Data for the ten years to 2018 shows an increase in the number of patients receiving HD at home. However, this is largely cancelled out by a fall in the number of patients receiving home PD. As a result, the number receiving home therapies has remained stable, as shown in **Figure 2**.

Figure 2: Prevalent dialysis patients, by year and modality



Source: UKRR, data 2009–2018, prevalent cohort (data from one centre is missing)

Some patients with advanced CKD choose not to have dialysis or transplantation. For these patients, there is a need for high quality conservative care. This will require active combined management by primary care services, kidney specialists and palliative care specialists.

The renal workforce

The delivery of renal services depends on integrated working with MDTs, including physicians, transplant and vascular access surgeons, interventional radiologists, nurses, dieticians, pharmacists, renal technologists, psychologists and social workers. There are also strong links with many other specialties including diabetes, cardiology and vascular surgery. In transplant centres, there will be interplay between renal physicians and transplant surgeons, and pre-transplant assessment and post-transplant follow-up will often include both medical and surgical care. Much assessment and preparation for transplantation and post-transplant care is delivered by non-transplanting/referring renal centres. Recruitment of Band 5 nurses into the renal workforce is particularly problematic in some areas.

Nephrology is one of many medical specialties with recruitment challenges – according to the RCP, in 2017 only 4 out of 5 consultant posts advertised were filled. The situation improved somewhat in 2018 with a fill rate of 1.0, but recruitment remains a major issue in ensuring quality care delivery going forward.

Modernising the renal workforce, in particular through the appointment of ACPs from among the multidisciplinary workforce and where relevant, PAs, must be a priority if the recommendations set out in this report are to be implemented.

During the first wave of the COVID-19 pandemic, almost 11% of the ICHD population and around 3% of those on home dialysis therapies were infected, with mortality rates of around one quarter. A forthcoming RA survey of the renal workforce points to high levels of stress and attrition which we as a community must address in further waves.

Commissioning renal services

There are two main sources of funding for renal medicine. At the time of the deep dives, both chronic dialysis treatment and renal transplantation were funded by NHS England Specialised Commissioning. Dialysis commissioning is set to move to NHS regions but will remain under the auspices of NHS England Specialised Commissioning. This change should allow commissioners to address regional network priorities. It remains unclear whether NHS England Specialised Commissioning funding will be devolved to ICSs in the future. For dialysis, national tariffs apply, including a BPT for HD with and without definitive access.

Funding of transplant services is not standardised. There is no mandatory national tariff for either the transplant itself, or for the assessment/follow-up phase. Currently, prices are agreed at a local level. There are shadow tariffs, but these have not as yet been adopted. One barrier to agreement of a national tariff is that centres have not universally adopted the correct currencies (HRGs) for this work or have not provided accurate reference costs.

Nephrology inpatient and outpatient care is funded by CCGs. There are national tariffs for nephrology outpatient work, including a multiprofessional team tariff, but some centres are contracted on a block payment by CCGs and so do not receive the appropriate tariff. Intercurrent admissions or procedures in dialysis/transplant patients are funded by CCGs. This includes vascular and PD access surgery, even though it is integral to dialysis. NHS England Specialised Commissioning sets the NSS for AKI and RRT preparation, but the actual funding comes from CCGs. There is a currency for HD in AKI, but no agreed payment structure.

This means that while the transplant itself – and up to the first three months' follow-up – is always funded by NHS England Specialised Commissioning (with prices set by local negotiation), in many centres follow-up past the three month stage is recorded as nephrology activity and therefore funded by CCGs.

Resolving this inconsistency is a significant challenge to be addressed once a mandatory national tariff has been set. NHS England Specialised Commissioning also funds an agreed list of high cost drugs for dialysis and transplantation, via a 'pass through' payment system.

Since the start of the COVID-19 pandemic, all renal dialysis, transplant and outpatient activity has moved to a block contract. This has been an enabler for the rapid introduction of innovative practice and has given provider renal centres greater responsibility for developing and ensuring quality outpatient services, including AKCCs (see page 37). Building on this, it is anticipated that future commissioning arrangements will be on a local or regional footprint, for example, at the level of an ICS. Commissioning priorities will be informed by population health need, aiming to address the whole pathway. There will be scope for blended payments to incentivise local or regional health priorities and to address over or under performance, congruent with NHS LTP commitments to move to a blended payment model[11].

Where commissoners are included in the ownership list for recommendations in this report, we have adoped the term 'accountable commissioners', reflecting the fact that the future renal commissioning landscape remains fluid. Where national oversight will still be needed (e.g. for NSSs) our proposals for ownership include national commissioning structures.

The scope of this report

The GIRFT review looks only at renal services for adults in England. It covers aspects of renal medicine where there is significant potential to deliver better outcomes for patients, for example access to transplantation, access to dialysis therapy at home, the organisation of treatment of advanced AKI, and availability of definitive vascular access. It also looks at those aspects of care that have a significant impact on quality of life, such as patient transport, SDM and AV fistula needling. It focuses on areas such as medicines management that offer scope for significant efficiency gains and cost savings, and explores how the specialty as a whole can deal effectively with resourcing challenges, for example by supporting a regional network model. It also looks at ways in which trusts can work together to embed and deliver overall quality improvement, including by providing robust and timely data and supporting the multiprofessional workforce.

Data is used throughout to illustrate differences, and more notably, unwarranted variation. Case studies are used to bring key themes to life by providing practical examples of good practice and areas that are in need of improvement.

[11] *NHS Long Term Plan (2019), p.101. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf*

Our deep-dive visits all took place before the COVID-19 pandemic. We acknowledge that it has had a major impact on all healthcare provision and renal services are no exception. We have summarised this impact on patterns of service delivery in the relevant sections of the report.

After the deep dives but prior to writing this report, we conducted a series of virtual meetings with key opinion leaders, both professionals and lay people, to discuss topics including access to transplantation, advanced kidney care and conservative care, AKI, home therapies, informatics, medicines management, patient experience, vascular access and workforce. These meetings proved invaluable in shaping the themes and recommendations in the report.

About our analysis

Analyses follow the established GIRFT methodology. The first step was to compile all the relevant data. The data pack includes equity of access, outcomes and pathways in nephrology, dialysis and transplantation and draws on data from a wide range of sources including:

- UKRR;
- NHSBT;
- HES;
- NHS England Quality Dashboard data;
- the Office of National Statistics (ONS);
- renal GIRFT surveys completed by clinical directors of renal centres; and
- the Define pharmacy database.

Data provided by UKRR was linked with HES data.

We also conducted our own supplementary data collection through an extensive questionnaire to providers. Where the data allowed, we benchmarked providers on key measures and identified where there was variation.

Deep-dive meetings with providers were a vital part of the GIRFT process. At these meetings we reviewed data at trust level, working with clinicians and managers to review performance and gather opinions and insights, focusing particularly on variations in clinical data. In the course of compiling this report, we visited 52 English trusts providing adult renal care.

While QI is not embedded in most services, we have been struck by the enthusiasm most people have for improvement and the strong ethos of good MDT working. There are areas where almost all services would agree that change is needed. There are significant opportunities to bring about improvements for patient care; changes that would also result in cost savings.

It should also be noted that there is major potential for linking this GIRFT review with ongoing work being undertaken by the NHS England RSTP. This represents an excellent timely opportunity for major service redesign and implementation of the GIRFT recommendations and is the greatest chance there has been to improve renal services for a considerable time.

In addition, the outcomes of the NHSBT Strategy Review, the work of the Intensive Care Society, RightCare, NICE, the NHS England Renal Dialysis and Transplant CRG and QI structures such as the specialty-led KQuIP are highly pertinent to consider alongside this report.

Regional renal clinical networks and quality improvement (QI) implementation

The renal community has a strong track record of innovation in service delivery and improving the quality of patient care. During our deep-dive visits we observed effective leadership, constructive joint clinical working across medical and MPTs and a strong commitment to service improvement. Dedicated, motivated renal staff are working hard to deliver high quality care using the resources available to them in what are often challenging circumstances.

We also found evidence of widespread variation in key patient outcomes (and processes) across centres in all modalities of kidney care. We believe that, in many cases, this variation is unwarranted. This is not a new observation: but there has been little evidence of improvement over time despite the impact of this variation on both healthcare value and patient outcomes. Annual UKRR and NHSBT audit reports highlight inequities in access to care: in particular renal transplantation, home dialysis, definitive HD vascular access and key patient experience measures. Implementation of the recommendations set out in this report depends on renal services adopting a regional network approach. It is our view that the resulting improvements in care quality and healthcare value will easily offset the relatively modest investment required.

There has never been greater potential opportunity for service improvement through joint work between commissioners, informed by the recommendations of GIRFT, the RSTP, the NHS LTP and supported by the clinical community and underpinned by QI structures. The *Kidney health: delivering excellence* report represents the combined ambitions of the renal community (including patient representatives)[12].

Key elements for delivering quality improvement

To deliver evidence-based practice improvement, better clinical outcomes and greater healthcare value, the following elements must be in place[13]:

- An agreed strategy and service transformation plan that meets regional population needs, combined with evidenced-based clinical practice guidelines.
- Adequately resourced healthcare with QI-enabled clinical leadership (both multiprofessional and medical).
- Investment in funded regional multiprofessional renal QI networks and a strategic commissioner-led board incorporating existing regional operational delivery networks.
- Access to real-time patient outcome data. Data should be timely, accessible and transparent and, wherever possible, take advantage of all linked NHS data sources.
- Structured and resourced QI processes which are embedded into day-to-day practice. This requires project management support from the centre business team, clinician accountability and training in QI methodology and leadership for clinicians focusing on the multiprofessional workforce.
- Accountable commissioners and clinicians (both medical and multiprofessional) enabling one another. The recommendations set out in this report require delivery by a combination of commissioner-led, supported transformation and clinically-led iterative QI structures.

The RA, BTS, NICE and others deliver comprehensive clinical practice guidance to the community. By comparison with other medical specialties, renal services are rich in outcome data and analysis. UKRR and NHSBT annual reports provide for service assurance. However, although there were islands of good practice, QI was not systematically embedded in many renal services. This shortfall must be addressed in order for the renal community to be able to implement many of the recommendations in this report.

The NHS England Renal Service Transformation Programme (RSTP) and National Service Specifications (NSSs)

The GIRFT process and recommendations coincide with a second key NHS England and NHS Improvement initiative, the RSTP, led by the chair of the Renal Dialysis and Transplant CRG. GIRFT and the RSTP have been working in collaboration, with GIRFT contributing to regional renal RSTP consultation events at the beginning of 2020. The key messages arising from the RSTP data review and consultations are consistent with those of GIRFT, and the actions required to implement

[12] *https://www.britishrenal.org/wp-content/uploads/2016/10/KIDNEY-HEALTH-DELIVERING-EXCELLENCE.pdf*

[13] *Backhouse, A., Ogunlayi, F. (2020) Quality improvement into practice. BMJ, 368: m865. https://www.bmj.com/content/368/bmj.m865*

many of the recommendations in this report complement those of the RSTP. The renal NSSs are currently being updated which is a major opportunity to support change including, where necessary, review of the renal tariff and increased collaboration with primary care.

The NHS LTP sets out the imperative for secondary/tertiary and community healthcare services collaboration at the level of the ICS. This underpins delivery of GIRFT recommendations.

Current status of quality improvement (QI) in renal centres

Taking considered action to change healthcare for the better is not new, but QI as a distinct approach to improving healthcare is a relatively recent development. There are well established tools and approaches for QI, including Plan, Do, Study, Act (PDSA) cycles, the NHS Change Model and Lean methodology.[14] Underpinned by measurement and with a skilled and supported workforce, QI can enable clinical teams to improve the healthcare that is provided at a service level.

During our deep dives, clinical directors were asked: 'Does your centre have an identified, structured, adequately resourced QI process which also engages the multiprofessional team?' Although services have made progress, the answer in most cases was 'no'. Common reasons for this included:

- failure to empower those on the front line;
- failure to invest in QI training and leadership; and
- lack of available time for project management.

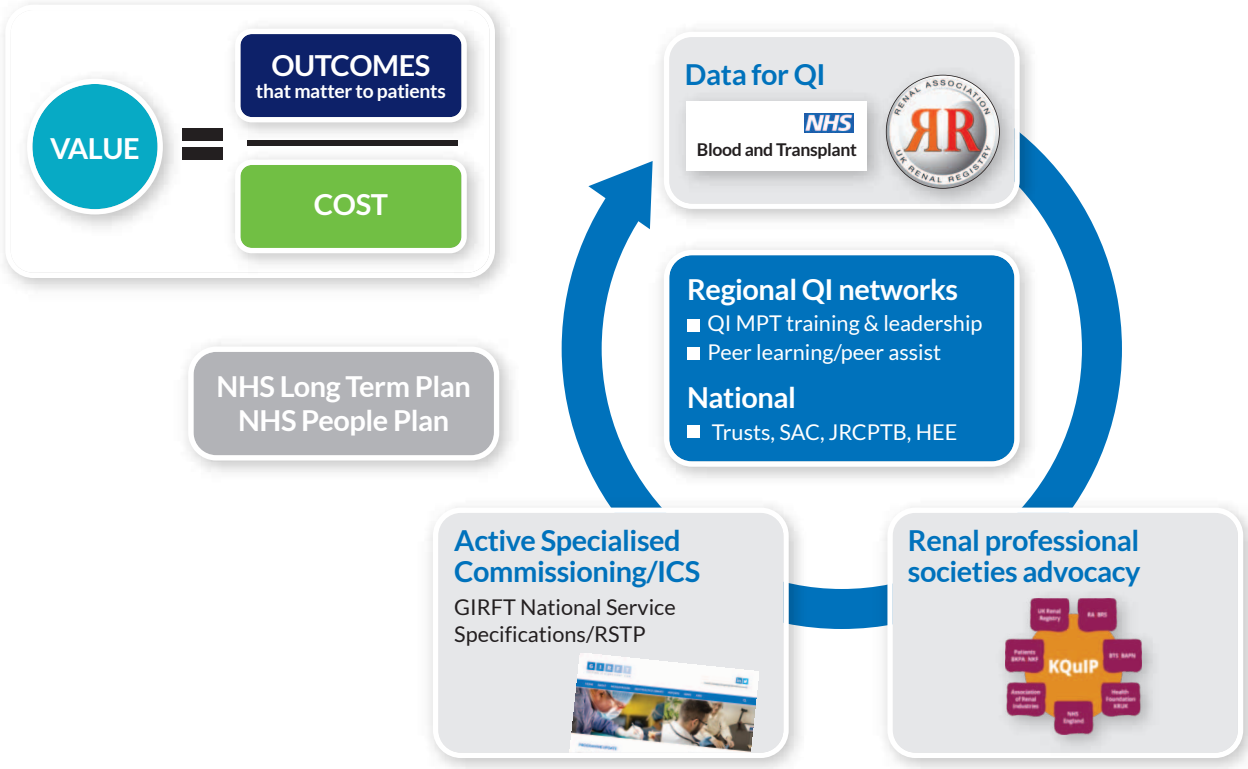
Despite widespread recognition of their importance, quality and patient safety improvement processes involving the multiprofessional workforce are not fully embedded in daily clinical practice in renal services.

How a regional renal network structure can support service and quality improvement (QI)

Renal medicine delivers detailed patient monitoring and interventional procedures and treatment across a highly complex regional pathway. A regional approach to service transformation, QI co-ordination, project management, training and leadership is particularly important for delivery of the recommendations in this report. This is illustrated in **Figure 3**. The crucial elements to service improvement are clinical engagement, support for regional QI collaborative networks and support for training and QI project management at renal centre level.

[14] *ibid.*

Figure 3: The virtuous regional quality improvement circle



1. Lessons learned from the COVID-19 pandemic

Patients with kidney disease suffered high rates of infection and mortality in the first wave of the COVID-19 pandemic in 2020. This required urgent, major reorganisation of chronic and acute dialysis services to sustain operational delivery, infection prevention and control, outpatient reconfiguration and AKI support in intensive care units. These pressures led NHS England and NHS Improvement to rapidly introduce regional managed clinical networks, appointing clinical leads, linking renal centre clinical directors and co-ordinating between renal services and critical care operational delivery networks. These have been highly effective in managing capacity, co-ordination, procurement and instituting best practice guidance. Regional renal network collaboration will support the implementation of GIRFT recommendations. Patients must be key contributors to the COVID-19 response and a coalition of patient charities called Patient Voices has articulated five key principles for adoption[15].

2. The transplant pathway is regional

Renal services have traditionally collaborated regionally where one or more transplant centres deliver transplantation surgery for a number of non-transplanting referring centres. This inter-relationship requires close collaboration, co-ordinated patient flows and joint clinical policies. Regional renal network footprints need to reflect this transplant pathway. Regional networks should appoint regional transplant leads to assist in optimisation of recipient and LD pathways and work with lead transplant clinicians identified in each renal centre. This should be undertaken in close collaboration with commissioners who will have oversight of the outcomes of this work.

[15] *https://www.nationalvoices.org.uk/publications/our-publications/nothing-about-us-without-us*

3. Audit

The regional approach lends itself to comparative renal centre audit involving the multiprofessional workforce. Some regional audit continues, but the loss of NHS England funding for strategic clinical renal networks meant that a substantial amount of regional audit stopped from around 2013 onwards.

4. Peer assist and support

Renal centres face similar challenges and a regional peer assist programme and repository of good practice would support improvement. GIRFT is currently developing a library of exemplary unit practice.

5. Professional development opportunities

These are substantially improved when co-ordinated and shared across a region. High quality education is fundamental to the delivery of GIRFT recommendations, and we note the loss of renal nurse training courses. There is scope for regions, in collaboration with universities and HEE, to develop comprehensive renal multiprofessional training to improve care.

6. Interaction with primary care

Regions will contain a number of ICSs. Close collaboration with primary care will be needed to deliver certain services, for example, virtual renal clinics and remote forms of consultation. This can be co-ordinated and supported at regional level with horizontal working between providers. Another important function of networks will be to integrate primary care work in disease identification and prevention. This offers considerable scope for improving both quality and efficiency of care. The NHS Diabetes Prevention Programme (NDPP) and NICE NG136 on hypertension in adults have the potential to reduce the flow of patients on to kidney care pathways.

7. Acute kidney injury (AKI) regional network groups allow interaction with critical care operational development networks

Renal centres service large geographical areas for delivery of intrinsic AKI and dialysis-dependent AKI. Creation of regional AKI networks would facilitate delivery of the GIRFT recommendations allowing interaction between trusts and between renal and intensive care networks as evidenced in the recent COVID-19 crisis.

8. Sub-specialised renal care

Equitable patient access to areas of renal sub-specialisation, a key GIRFT recommendation, is facilitated by regional co-ordination and will improve care quality and healthcare value.

9. Quality improvement

This is best co-ordinated regionally.

10. Capacity planning

Strategic service decision-making by commissioners, guided by public health and renal professionals, is facilitated across a region involving all providers and ICSs.

The Kidney Quality Improvement Partnership (KQuIP)

The renal community has supported several effective QI projects and reflected on learning from these. In 2016, the renal professional societies, kidney patient charities and research bodies, linked with NHS England and NHS Improvement, set up KQuIP[16] with the aim of developing a lean, inclusive clinically-led national QI structure. The partnership's core aims are to support the embedding of QI into daily practice, to identify and reduce unwarranted variation in care, and to spread and share good practice. KQuIP has strict governance structures: UKRR provides project management and employs a core team of regional programme managers working with clinical leadership that has developed at a local, regional and national level.

It is funded by the RA and Kidney Care UK along with industry partners. These are the core delivery elements:

- **National clinical QI projects** addressing key areas of unwarranted variation in addition to building QI capability and capacity. Each has clinical and project management leadership.
  - **Transplant First**[17]: Improving access to renal transplantation.
  - **Managing Access by Generating Improvements in Cannulation (MAGIC)**[18]: Improving maintenance of HD vascular access.
  - **DAYlife**[19]: Improving access to home dialysis therapies.

  KQuIP is also involved in scaling up other QI projects for sustainability and COVID-19-related practice learning[20,21].
- Regional sustainable QI infrastructure across 9 of 11 English regions. This means that KQuIP now covers 80% of the UK population.
- Training in QI leadership and capability.
- Accountability. Each renal service has nominated medical and multiprofessional QI leadership. In addition, renal centres identify responsible leads for national projects.
- The KQuIP hub. An online repository of QI resources.

Clinicians have confidence in professional society-led work recognising that in general these may be more permanent structures than the ever changing NHS. A collaboration between NHS England and NHS Improvement and professional societies is likely to be well received.

Sustainable kidney care

In response to the climate emergency and in light of the future substantial adverse impact of climate change on health outcomes, the NHS' chief executive officer, Sir Simon Stevens, has committed NHS England and NHS Improvement to delivering a carbon 'net zero' NHS by 2045, including an 80% reduction in carbon emissions by 2036[22]. This is particularly relevant to this report, as the Centre for Sustainable Healthcare identifies kidney care as creating a disproportionately high water and carbon footprint. Each HD session consumes approximately 400 litres of water and annual carbon emissions are equivalent to 7.1 tonnes of CO2 per dialysis patient.

The Centre estimates that adoption of 20 trialled 'green nephrology network'[23] initiatives across English renal centres could save 470 million litres of water and 11,000 tonnes of CO2 emissions per annum as well as reducing costs[24]. Implementation of many of the recommendations in this GIRFT report would also result in reduced carbon emissions by renal centres. Renal services have a national and moral duty to set sustainable kidney care as a key objective and the establishment of regional renal networks and implementation of QI processes recommended in this report can act as a mechanism by which this could be assessed and implemented. It should also be noted that the RA and other professional societies intend to develop clinician-led structures to support and work closely with commissioners on initiatives around sustainability.

[16] *https://www.thinkkidneys.nhs.uk/kquip/about-us/*
[17] *https://www.thinkkidneys.nhs.uk/kquip/transplant-first/*
[18] *https://www.thinkkidneys.nhs.uk/kquip/magic/*
[19] *https://www.thinkkidneys.nhs.uk/kquip/daylife/*
[20] *https://www.thinkkidneys.nhs.uk/kquip/wp-content/uploads/sites/5/2020/06/COVID-19-Learning-Haemodialysis-FINAL-130620-1.pdf*
[21] *https://www.thinkkidneys.nhs.uk/kquip/hub/kidney-services-improving-at-scale-qi-learning-report/*
[22] *https://www.england.nhs.uk/greenernhs/wp-content/uploads/sites/51/2020/10/delivering-a-net-zero-national-health-service.pdf*
[23] *https://www.networks.sustainablehealthcare.org.uk/network/green-nephrology*
[24] *Limb, M. NHS could save £1bn by adopting green strategies used in kidney units (2013) BMJ;346:f588. https://www.bmj.com/content/346/bmj.f588*

The impact of commissioning recommendations

Active regional commissioning which is outcome data driven is particularly important to influence and support improved renal service quality. Elements of the renal pathway are currently divided between CCG commissioners and NHS England Specialised Commissioning, with little co-ordination between the two in most regions.

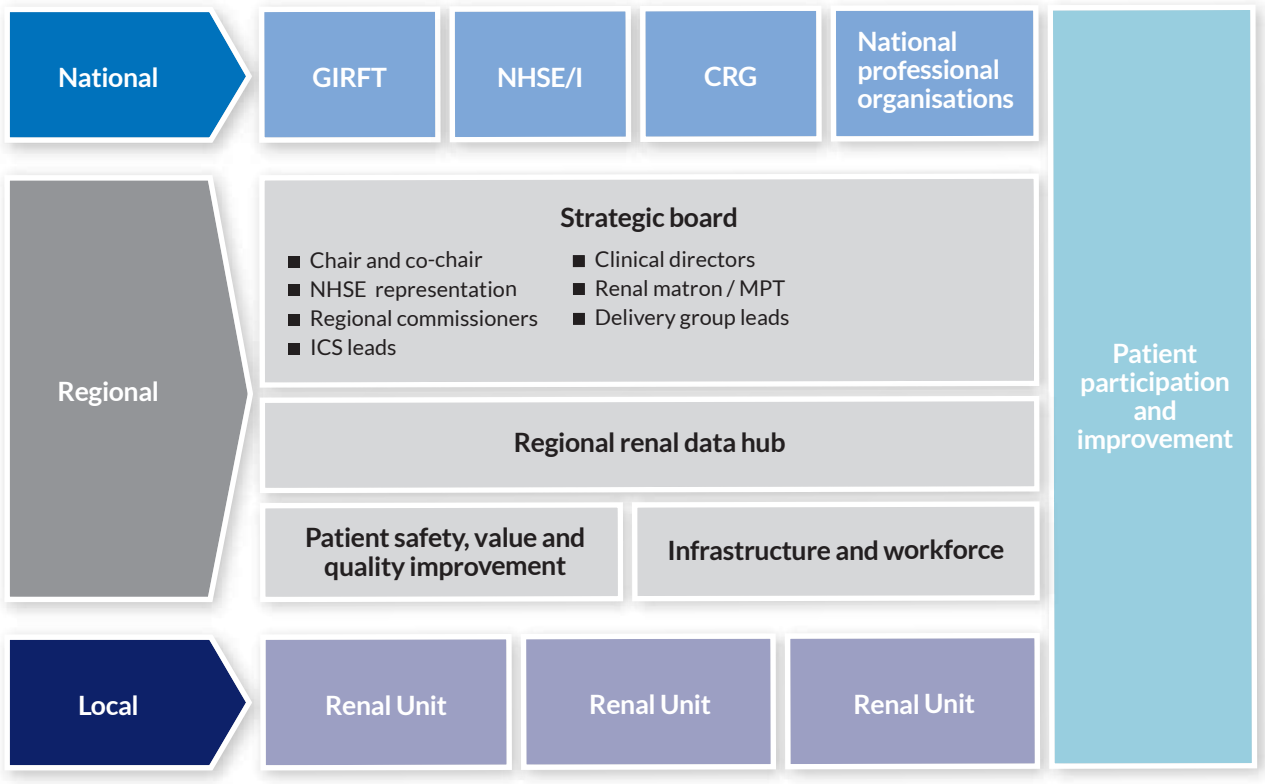
GIRFT supports the following commissioning improvements:

- **Revision of renal NSSs.** Updating the NSSs is imminent. Since these represent a blueprint for the specialised renal pathway, it is crucial that they take into account the recommendations of the GIRFT report and the RSTP.
- **Integration of Specialised Commissioning and CCG elements of the pathway.** This is a task well suited to the newly formed ICSs working with a regional renal network.
- **Sustainable funding of regional QI networks.** The professional societies are able to support clinically-led QI with the UKRR acting as co-ordinating body. It is essential that NHS England provides central resource for project management of these QI structures within each region. Without this, these QI projects are not sustainable into the medium term.
- **Active commissioning.** QI structures should be agreed and mandated, and accountability established, at both regional and national level. This is an essential role for commissioners. Objectives can be agreed by commissioners and clinicians at a regional level. Priorities should be based on GIRFT, RSTP and NHS LTP priorities as set out in NSSs.

Proposed network structures

The case for regional structures to support delivery of GIRFT recommendations and implementation of the RSTP is set out above. **Figure 4** shows one possible structure, with a regional strategic commissioning board setting direction and priorities for each region, guided by GIRFT and the RSTP. A second linked QI co-ordinating group is required with representation from each renal service and supported by KQuIP project management overseen by the UKRR, reporting to the strategy board. A data hub reporting outcomes to centres and back to the strategic group would enable regions and services to monitor overall progress against targets.

Figure 4: Potential draft composition of a regional clinical quality improvement renal board



Source: KQuIP Board, 2020

Recommendation

Recommendation	Actions	Owners	Timescale
1. Establish NHS-funded, regional renal networks to ensure quality and efficiency of care, monitor service effectiveness, embed sustainable kidney care and accountability for service delivery.	**a** Renal network priorities to reflect the needs of the region and be guided by the RSTP and GIRFT recommendations.	NHS England Specialised Commissioning and accountable commissioners, professional societies and GIRFT	Upon report publication, review annually
	b Commissioning and clinical leads within networks to set clear priorities for delivery (including sustainable kidney care) and commissioners to hold providers to account.	Accountable commissioners	Upon report publication, review annually
	c Network geographical footprint to take into account patient flows in all renal clinical pathways.	NHS England Specialised Commissioning, accountable commissioners, professional societies and GIRFT	Upon report publication
	d Multiprofessional renal QI to be embedded within networks and supported by project management, with leads in each renal centre, driven by timely access to data and focused on addressing regionally set priorities.	Accountable commissioners, professional societies and GIRFT	Upon report publication, to complete within 12 months
	e Regional renal networks to collaborate with related disciplines at network level to include imaging, critical care and vascular services.	Renal networks	Upon report publication, to complete within 12 months
	f UKRR/NHSBT to continue with support for national and regional renal QI networks and to deliver leadership training and project management.	UKRR and NHSBT	Upon report publication
	g Measures to address inequity of access to renal services, particularly in areas of high deprivation and/or ethnic diversity, to be implemented. (These measures are defined in the text of the relevant chapters throughout the report.)	NHS England Specialised Commissioning, accountable commissioners, professional societies and GIRFT	Upon report publication

Preparation for renal replacement therapy (RRT) and conservative management

RRT preparation, usually delivered in an AKCC, is the most important aspect of the specialised renal service because it sets the scene for the subsequent health and quality of life of kidney patients.

The AKCC is the focal point of the CKD patient pathway. If adequately resourced and enabled, it can deliver improved access to renal transplantation, home dialysis therapies and, where chosen, conservative management. NICE NG107[25] provides a detailed description of the principles that underpin preparation for RRT and conservative management, including:

- timeliness – ensuring preparation is started sufficiently early;
- multidisciplinary care – ensuring the team includes all the necessary professionals;
- shared decision-making – ensuring patients make informed choices about their modality of renal care; and
- equity – ensuring patients have access to all clinically appropriate treatments including transplantation, home dialysis therapies and conservative management.

NG107 states that renal services should be designing structured care pathways for patients with advanced CKD. The guidelines recommend that patients have at least a year to allow adequate preparation. Some patients may need longer than this, while those whose kidney disease is progressing rapidly will need an accelerated pathway. Adverse outcomes associated with a failure to deliver these pathways include:

- suitable patients who do not get an early assessment for transplantation being denied the chance of a pre-emptive (before dialysis) kidney transplant (see *Access to kidney transplantation*, page 43);
- patients commencing HD doing so without definitive vascular access (see *Vascular access for haemodialysis*, page 52);
- patients whose preferred choice is a home dialysis therapy may start hospital HD instead (see *Home therapies*, page 62); and
- patients with frailty and/or comorbidity may not have sufficient information to make an informed choice regarding conservative management versus dialysis.

Failure to address conservative care needs and supportive care in existing dialysis populations is resulting in some patients – many of them elderly – receiving invasive and expensive therapy from which they are unlikely to benefit in terms of either longevity or quality of life.

Advanced kidney care clinics (AKCCs)

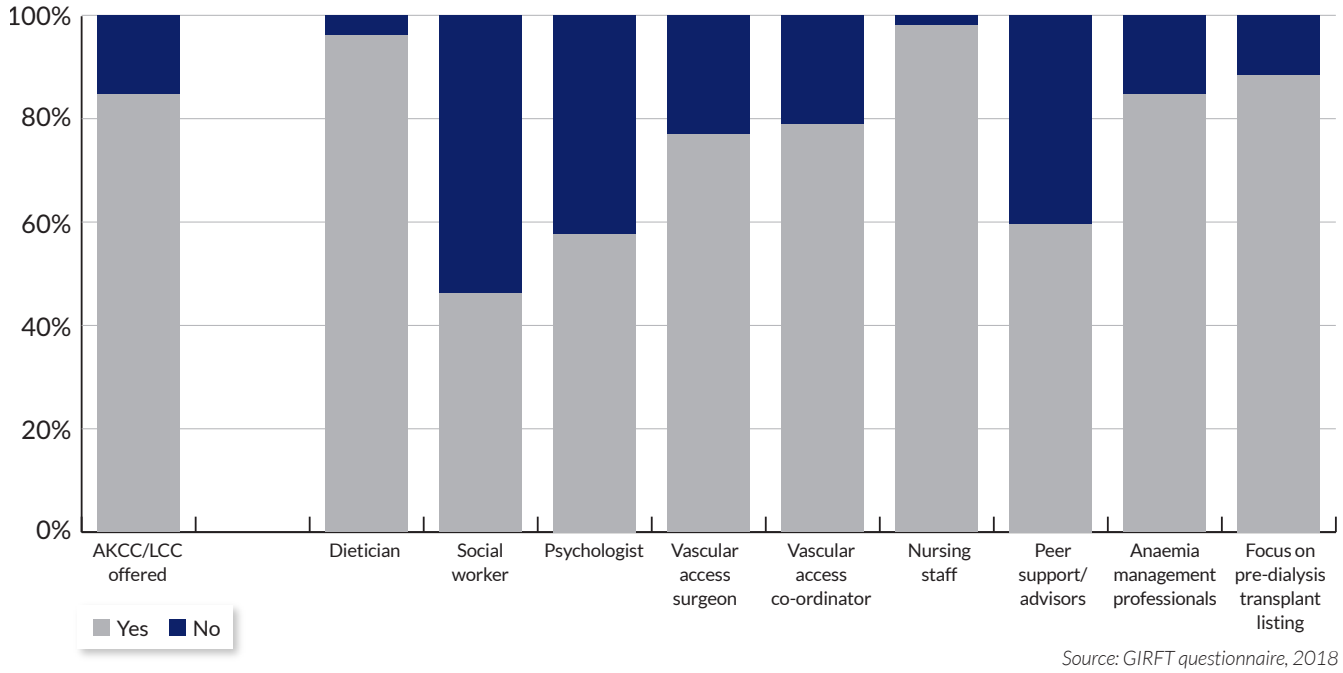
The NSS mandates that patients with progressive CKD 4–5 have access to AKCCs, which are also referred to as RRT preparation or low clearance clinics. These should offer comprehensive access to multiprofessional support for patients above and beyond what can be provided by a general nephrology clinic and have links to conservative management and palliative care support. This process is pivotal to the overall success of specialist renal services, as illustrated in a published NHS RightCare case scenario which compares a sub-optimal clinical scenario with an ideal pathway[26].

There is significant unwarranted variation in the completeness of staffing resources in AKCCs within renal centres across England, as illustrated in **Figure 5**. In particular, provision of psychosocial support services is often limited and this must be addressed.

[25] *https://www.nice.org.uk/guidance/ng107*

[26] *https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2018/02/abduls-story-progressive-chronic-kidney-disease-full-narrative-1.pdf*

Figure 5: Multiprofessional input to advanced kidney care clinics in England



Source: GIRFT questionnaire, 2018

There is evidence of a link between the availability of relevant professionals and how effective a renal centre is in preparing patients for RRT. For example, more LD co-ordinator resource is associated with higher levels of LD transplantation (see *Access to kidney transplantation*, page 43). It should be noted that every member of the AKCC team and peer support should play a role in promoting transplantation and home therapies.

It was clear at deep dives that there is significant under-investment in resources in many AKCCs, and clinicians described this as a significant factor contributing to low incident home therapy and pre-emptive transplant listing rates. The relative value of the NHS England and NHS Improvement multiprofessional tariff for this type of nephrology clinic has diminished over the past five years and is now only 20% higher than a standard new nephrology assessment[27]. Some centres on a block contract do not benefit from this enhanced tariff at all and as a consequence do not record the activity or report reference costs. There is a need for commissioners to review the commissioning arrangements relating to AKCCs and for trusts to make sure that their true cost is reflected in reference cost returns. This would help to facilitate adequate multiprofessional input and optimise patient outcomes.

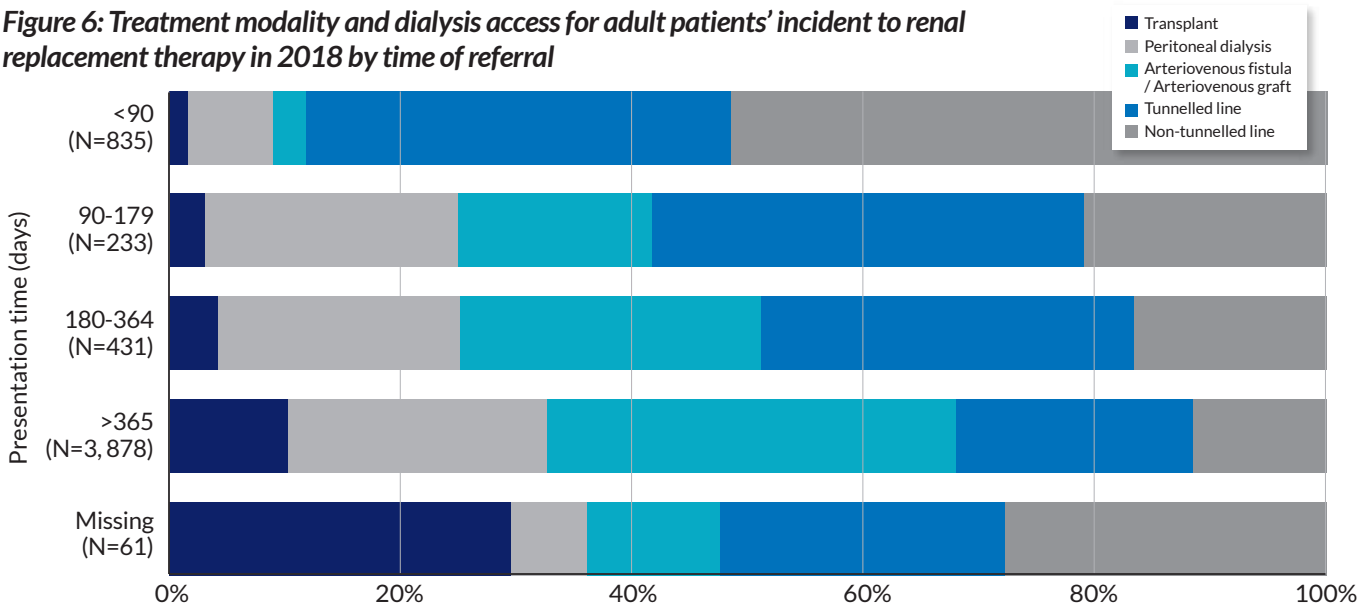
As previously mentioned, the ideal timing of referral to AKCC is a difficult clinical decision, because not all patients progress at the same rate. Improved prediction of ESKD timing could substantially improve resource planning. At present, it is judged empirically on known clinical risk factors for progression, which is imprecise. The use of fixed glomerular filtration rate (GFR) criteria for referral to AKCC and for vascular access or renal transplant listing is sub-optimal. Patients, particularly those who are elderly or who do not exhibit proteinuria, may have a slow progression rate, and some may never progress from advanced CKD to ESKD. International practice pattern studies indicate that many patients who undergo AVF formation may never require dialysis[28]. A recent Scottish study found that 63% of incident patients started HD with an AVF or AVG, although 92% had undergone access surgery identifying the need to allow time for more than one access procedure in many patients prior to starting HD[29]. The importance of timely referral into the AKCC is demonstrated by **Figure 6**.

[27] *https://improvement.nhs.uk/resources/national-tariff/#h2-tariff-documents*

[28] *Allon M. (2018) Lessons From International Differences in Vascular Access Practices and Outcomes. Am.J. Kidney Dis., 71(4): 452–4.*

[29] *Murray, E., Eid, M., Traynor, J.P. et al. (2018) The first 365 days on haemodialysis: variation in the haemodialysis access journey and its associated burden. Nephrol.Dial.Transplant, 33(7): 1244–1250. https://pubmed.ncbi.nlm.nih.gov/29401294/*

Figure 6: Treatment modality and dialysis access for adult patients' incident to renal replacement therapy in 2018 by time of referral



Source: UKRR 2018 Multisite Dialysis Access Audit (with permission)

Some centres have looked to address these challenges by adopting risk prediction equations for ESKD into electronic patient software such as the Kidney Failure Risk Equation[30] or alternative prediction methods. This requires further validation but, if confirmed, should be recommended as standard practice.

Clinicians in some centres that do not have an AKCC (15% of respondents) report that they place a higher value on continuity of consultant-led care and prefer not to cohort these patients in a specialist clinic. Nevertheless, all renal centres need to demonstrate that patients with advanced CKD have rapid access to as comprehensive an RRT preparation service as possible.

Conservative management for end stage kidney disease (ESKD)

Conservative management for ESKD involves all aspects of care of advanced CKD without resort to dialysis. It includes measures to slow CKD progression, symptom control and advanced care planning, involves a holistic approach that includes medical, emotional, social, spiritual and practical aspects of care, and is underpinned by SDM.

Although many elderly patients may benefit from dialysis, observational evidence suggests that dialysis in more elderly and comorbid patients may not improve survival and can be associated with reduced quality of life, increased hospital admissions, intrusive interventions, reduced access to hospice care and a lower likelihood of dying in their chosen setting[31].

Conservative management decisions are typically made during advanced kidney care and are crucial in setting priorities for the future. Many patients with advanced CKD are frail and suffer from several chronic disease processes. NICE recommends that decisions about future conservative management versus dialysis be based on factors including predicted quality of life, predicted life expectancy and co-existing conditions, but that ultimately informed patient choice should be the guide[32].

Renal conservative management is not just relevant to decisions about future RRT; it affects all stages of kidney disease including symptom control in less advanced CKD, dialysis withdrawal and palliative care[33]. Underlining this, the UKRR identifies withdrawal of dialysis to be the cause of death in around 21% of patients over the age of 65 treated by RRT[34].

[30] *https://kidneyfailurerisk.com/*

[31] *O'Riordan, J., Noble, H., Kane, P.M., Smyth, A. (2019) Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study [published online ahead of print, 2019 Jun 25]. BMJ Support.Palliat.Care, bmjspcare-2018-001759. https://pubmed.ncbi.nlm.nih.gov/31239255/*

[32] *https://www.nice.org.uk/guidance/ng107/resources/renal-replacement-therapy-and-conservative-management-pdf-66141542991301*

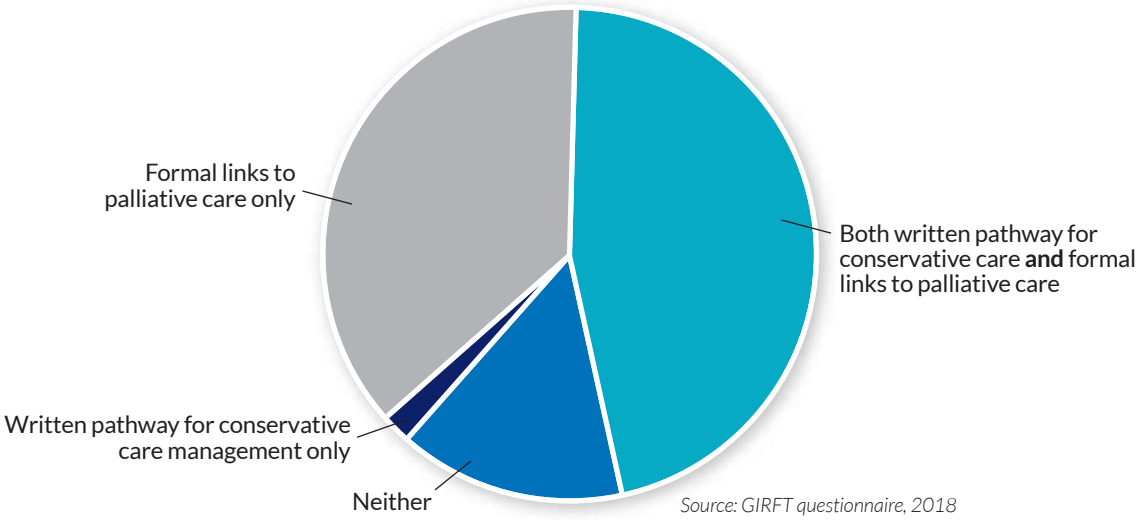
[33] *Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care (2015) Kidney Int.Sep., 88(3): 447–59. https://www.pubmed.ncbi.nlm.nih.gov/25923985/*

[34] *https://www.renalreg.org/reports/data_to_end_2017/*

GIRFT found both adequacy of provision and organisation of delivery of conservative management to be highly variable across English renal centres, as illustrated by **Figure 7**. Only around half of centres have a written pathway for renal conservative management, and 15% have neither a written pathway nor any formal links to local palliative care services.

This is consistent with a previous UK national survey of practice patterns[35] and suggests that provision of this important service remains under-developed[36]. Currently some centres provide the whole care pathway, while most work in partnership with palliative care and community teams, in accordance with NICE NG142 on End of Life Care for Adults[37].

Figure 7: Provision of conservative management for end-stage kidney disease



Source: GIRFT questionnaire, 2018

There is currently no agreed definition of conservative management, which makes it very difficult to measure and audit provision. There is no systematic data collection to give a picture of patient numbers, cost or indeed quality of care[38]. However, estimates suggest that 21% of patients in AKCCs in south London are aged over 80. In a national survey between 10% and 90% of those aged over 75 opted for conservative care[39]. One renal centre estimated the cost of conservative management at £4,764 per year per patient, but it is clear that this varies immensely[40]. There are no clearly identified commissioning arrangements for this pathway, which is not directly funded by NHS England Specialised Commissioning.

Provision of conservative management does not currently appear to be adequate in terms of definition, resourcing, recording and provision, and highly variable in delivery. There is a need for an agreed definition, national data collection, development of patient assessment tools and for staff training to be routinely incorporated in AKCCs. All centres need to develop written pathways and the infrastructure to deliver them, including links to primary and palliative care, and to define ownership in order to offer an effective service. A successful KQuIP collaboration in South London is described in the case study below and illustrates the challenges and integration of services at a network level that is required to improve care.

The renal professional societies have established a special interest group focused on improving delivery of conservative care. The RA commentary on NICE CG107 also provides direction for development of these services[41]. It should be noted that there is a NICE patient decision aid to assist with preference-sensitive decisions about RRT and conservative management[42].

[35] *Okamoto, I., Tonkin-Crine, S., Rayner, H., et al. (2015) Conservative care for ESRD in the UK: a national survey. CJASN, 10 (1): 120–126. https://www.cjasn.asnjournals.org/content/10/1/120*

[36] *O'Riordan, J., Noble, H., Kane, P.M., Smyth, A. (2019) Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study [published online ahead of print, 2019 Jun 25]. BMJ Support.Palliat.Care, bmjspcare-2018-001759. https://www.pure.qub.ac.uk/en/publications/advance-care-plan-barriers-in-older-patients-with-end-stage-renal*

[37] *https://www.nice.org.uk/guidance/ng142*

[38] *https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Chronic-Kidney-Disease-in-England-The-Human-and-Financial-Cost.pdf*

[39] *Okamoto, I., Tonkin-Crine, S., Rayner, H., et al. (2015) Conservative care for ESRD in the UK: a national survey. CJASN, 10 (1): 120–126. https://www.cjasn.asnjournals.org/content/10/1/120*

[40] *Conway, B., Webster, A., Ramsay, G., et al. (2009) Predicting mortality and uptake of renal replacement therapy in patients with stage 4 chronic kidney disease. Nephrol.Dial.Transplant, 24: 1930–7. https://www.pubmed.ncbi.nlm.nih.gov/19181760/*

[41] *https://www.renal.org/sites/renal.org/files/Commentary-on-the-NICE-Guideline-on-RRT-and-conservative-management.pdf*

[42] *https://www.nice.org.uk/guidance/ng107/documents/evidence-review-12*

CASE STUDY

Conservative care in South London

The south London Supportive Care KQuIP project

The national pilot Supportive Care KQuIP project[43] is now running in south London, developing pathways across the renal centres at Guy's and St Thomas' Hospital, King's College Hospital, St George's University Hospital and Epsom and St Helier's University Hospital. The project spans both patients in the AKCC (where up to 20% of the population are following a conservative care pathway) and those on dialysis for whom quality of life and later life planning are the main care priorities. Key elements include the development of educational material to facilitate patient choice, and a staff communications training programme.

The systematic introduction of clinical frailty scoring (and cognitive assessment where relevant) together with the introduction of advanced care planning is taking place across both the AKCC and the dialysis population.

The creation of networks to allow referral to frailty, memory or physiotherapy services are in development with the aim of developing more holistic care either instead of or in parallel with patient-tailored dialysis. The group is also trialling a standardised dataset to understand this population and allow quality improvement in this area.

[43] *https://renal.org/kquip/projects/supportive-care*

Recommendation

Recommendation	Actions	Owners	Timescale
2. Ensure that patients predicted to reach ESKD within 18 months are fully assessed in advanced kidney care services and are offered all possible care options.	**a** A multiprofessional outpatient tariff or alternative effective commissioning approach to be developed to resource optimal advanced kidney care, encompassing comprehensive multiprofessional input that includes psychosocial care and SDM for all patients.	Accountable commissioners	Within 12 months of report publication
	b AKCCs to become a central focus of QI processes and monitoring to improve access to all modalities of renal care.	Renal centres	Within 12 months of report publication
	c Renal centres to incorporate trajectory monitoring of CKD to help optimise new patient nephrology referral service and ESKD preparation planning.	Renal centres	Within 12 months of report publication
	d All renal centres to adopt NICE NG107 which defines the minimum requirements for the AKCC pathway.	Renal centres and regional networks	Within 12 months of report publication
	e Renal centres to ensure that home therapy options are effectively communicated to those patients for whom a pre-emptive transplant (Transplant First) or a conservative approach is not appropriate.	Renal centres	Within 12 months of report publication
	f Metrics of access of patients with ESKD to renal transplantation and home therapies to be monitored quarterly in all renal centres.	Renal centres	Within 12 months of report publication
3. Ensure that access to a comprehensive renal conservative management pathway is available to all patients.	**a** NHS England and NHS Improvement to define what constitutes renal conservative management in order for UKRR to collect data on patients.	NHS England and NHS Improvement, UKRR	Within 12 months of report publication
	b Access to conservative management to be available for patients where appropriate. Patients will be identified by a comprehensive SDM process.	Trusts with a renal service	Within 12 months of report publication
	c Accountable commissioners to develop a year of care pathway tariff or equivalent commissioning tool for renal conservative management.	Accountable commissioners	Within 12 months of report publication
	d A multiprofessional conservative management service to be co-ordinated including a written pathway for identification and management of all potentially suitable patients. (Delivery to involve partnership with community and palliative care teams across ICSs.)	Trusts with a renal service, accountable commissioners, ICSs	Within 12 months of report publication

Access to kidney transplantation

Kidney transplantation improves patient outcomes and quality of life, and has significant economic benefits compared with dialysis. Not all patients are suitable for transplantation but there are more prevalent RRT patients with a transplant than on dialysis. A successful transplant means a return to better health and avoids the need for dialysis treatment.

Patients may receive a transplant from a living donor (LD) or deceased donor (DD). LD transplantation – which accounts for around 30% of transplants in the UK – has a number of advantages, including improved graft survival and the ability to plan a kidney transplant 'pre-emptively', before the need for dialysis treatment. This delivers benefits in terms of better outcomes and cost savings[44]; pre-emptive transplantation avoids both the preparation associated with dialysis (e.g. vascular access surgery) as well as dialysis.

UK LD transplantation numbers more than doubled between 2004/05 and 2013/14 but fell slightly in 2014/15 and have plateaued since. Within the four health systems of the UK there are very wide variations in LD transplant rates (33.2 per million population in Northern Ireland, 19.6 in Scotland, 14.4 in Wales and 14.1 in England in 2018-19)[45]. Even within England the rate varies from 19.3 per million population in the North East to 8.6 in the East Midlands.

Not all patients have a suitable LD and some patients choose not to pursue this option. DD transplantation remains a good treatment for patients with ESKD and numbers have grown by about two-thirds in the past decade. There is concern about the increase in the median age of DDs which has an impact on organ quality.

UKRR data from patients commencing RRT in 2012-14 showed that patients who were primarily managed in a non-transplant centre were 32% less likely to be listed for a DD transplant and 35% less likely to receive an LD transplant[46]. Once listed, their chances of receiving a DD transplant were broadly equivalent. Ethnicity did not impact on the likelihood of DD renal transplant listing. However, once listed, BAME patients were less likely to receive a DD or LD transplant. Improving equity of transplant opportunity for patients of all ethnicities is an area that is subject to work by NHSBT, with successive revisions of the National Organ Allocation Scheme. It is predicted that the latest iteration of the scheme, implemented in 2019, will equalise waiting time for patients of all ethnicities in four years[47].

Access to Transplantation and Transplant Outcome Measures (ATTOM), a UK prospective observational study, has improved our understanding of factors associated with the likelihood of receiving a transplant[48]. Key findings include:

- Organisation of transplant assessment varies from centre to centre.
- There are a number of patient-level factors associated with a lower rate of transplant listing, including measures of social deprivation and health literacy.
- Transplantation is associated with improved quality of life, although no specific advantage of LD transplantation over DD transplantation was demonstrated in this domain.
- A more complete understanding of the broader health economic advantages of transplantation over dialysis, especially reduced hospitalisation.

Centre variation in transplantation

Centre variation is apparent at all levels of the pathway and activity metrics have been published for many years by NHSBT (all subsequent NHSBT data are from this report unless stated)[49]. Most of the data have been published at transplant centre level, often without any adjustment for the size of the population served. A large amount of pre- and post-transplant care is delivered in non-transplanting renal centres. In the past two years, NHSBT has produced valuable metrics at renal centre level and has indexed these to the catchment population of that centre[50]. However, pre-emptively transplanted patients may be inappropriately attributed to the transplanting centre even though they were referred by a local renal service. Furthermore, the size of the catchment population does not accurately define demand. Areas of the country with a high incident ESKD rate, often urban populations with high levels of deprivation and ethnic diversity, will have much higher demand for transplantation.

[44] *https://www.bts.org.uk/wp-content/uploads/2018/07/FINAL_LDKT-guidelines_June-2018.pdf*

[45] *https://www.nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17289/kidney-annual-report-2018-19-november19.pdf*

[46] *https://www.renalreg.org/wp-content/uploads/2019/05/21st_UKRR_Annual_Report_Ch6.pdf*

[47] *https://www.odt.nhs.uk/odt-structures-and-standards/odt-hub-programme/kidney-offering-scheme/*

[48] *Oniscu, G.C., Ravanan, R., Wu, D. et al. on behalf of the ATTOM investigators. (2016) Access to Transplantation and Transplant Outcome Measures (ATTOM): study protocol of a UK-wide, in-depth, prospective cohort analysis. BMJ Open, 6: e010377. https://www.bmjopen.bmj.com/content/6/2/e010377*

[49] *https://www.nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17289/kidney-annual-report-2018-19-november19.pdf*

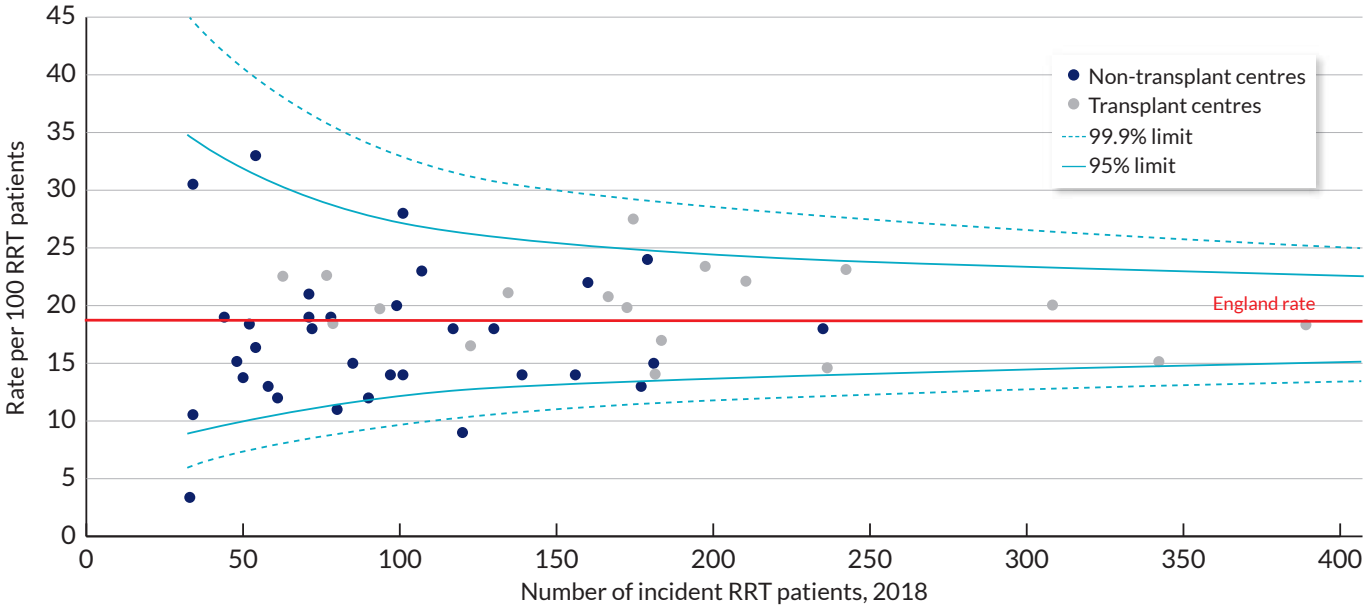
[50] *https://www.nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17587/kidney-transplantation-annual-renal-unit-report-2017-2018.pdf*

GIRFT has produced metrics relative to the number of incident RRT patients in a centre (as a measure of need), rather than the size of the catchment population. Analyses are adjusted for age, sex, and primary renal disease. While social deprivation and ethnicity are relevant we have not adjusted for these because poorer access in BAME or deprived populations is neither acceptable nor inevitable. Pre-emptively transplanted patients have been allocated to the parent renal centre on the basis of postcode. In conurbations with overlapping catchments and multiple transplant centres, postcode adjustment is unlikely to be perfect and a degree of error can still be demonstrated when the metrics are compared with network audits of activity.

Pre-emptive transplant listing and living donor (LD) transplantation

Pre-emptive listing for renal transplantation varies considerably (see **Figure 8**). We have included pre-emptive LD transplantation in this metric as not all such patients are listed for a DD transplant. Some 18% of RRT starters are listed or receive an LD transplant before starting dialysis, but the range is wide, from 3% to 33%. Patients in a transplant centre were 18% more likely to be pre-emptively listed (odds ratio 1.18 (1.03–1.35). There are high performing non-transplanting centres, suggesting that the national trend can be challenged. Within some transplant networks there is evidence of equity, but in some networks the disparity with the referring centres remains. For example, one transplant centre with a rate of 21% has rates of 3%, 12% and 18% in its three referring centres.

Figure 8: Adjusted rate of pre-emptive deceased donor listing or living donor transplant

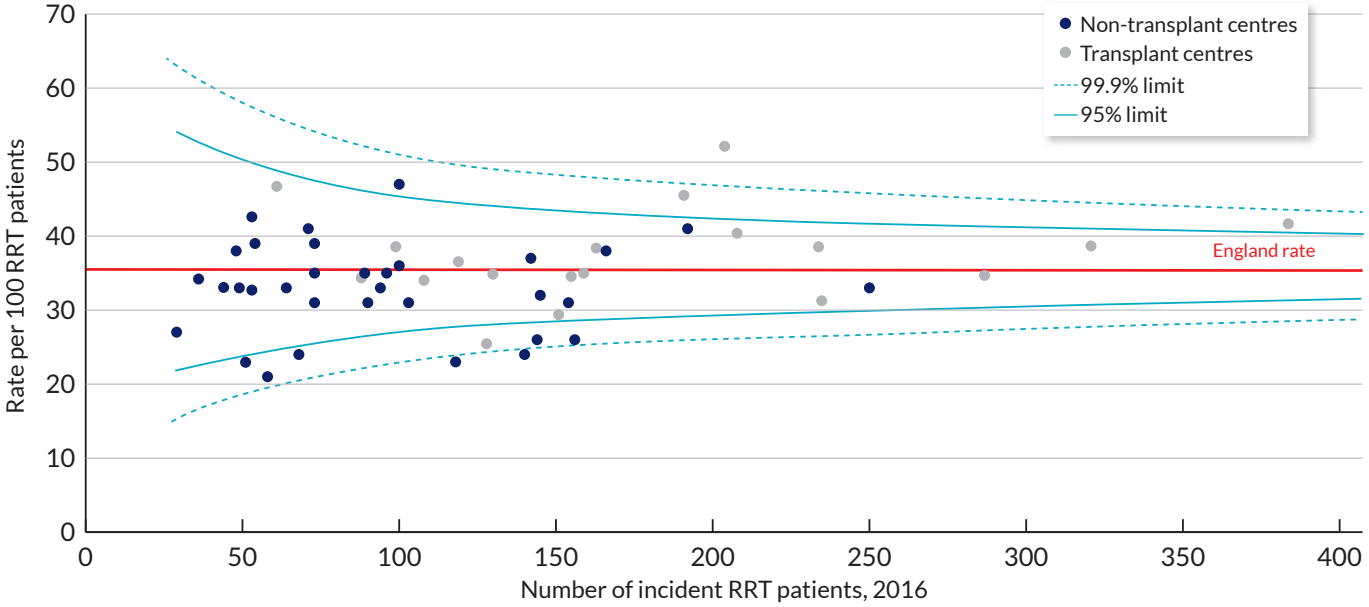


Source: UKRR-NHSBT linked database, incident RRT patients 2018, adjusted for age, sex, and primary renal disease

Transplant listing and living donor (LD) transplantation two years after start of renal replacement therapy (RRT)

The picture is similar when analysed two years after the start of RRT (see **Figure 9**). On average, 36% of patients are listed by this point. Patients in transplant centres are 34% more likely to have been listed (odds ratio 1.34 (1.19–1.52)). One transplant centre in England lists patients at a much higher rate than the national average (52%) but, again, there are non-transplanting centres that challenge the national trend, including one above the 95% control line (47%). It is unlikely to be a coincidence that these two centres are in the same transplant network.

Figure 9: Adjusted rate of listing or living donor transplantation within two years from start of renal replacement therapy



Source: UKRR–NHSBT linked database, incident RRT patients 2016, adjusted for age, sex, and primary renal disease

Living donor (LD) transplantation two years after the start of renal replacement therapy (RRT)

The most significant finding in this contemporary, adjusted analysis is the fact that the differential access between transplanting and non-transplanting centres is no longer apparent (see **Figure 10**, page 47). Patients in transplanting centres were not more likely to receive an LD transplant, by contrast with older analyses (odds ratio 1.07 (0.88–1.29)). In England, 8% of RRT starters receive an LD transplant by two years but there is still wide variation, with two renal centres below the 99.9% control line. There are high performing non-transplanting centres, including one above the 95% control line. This centre is located in an area with high levels of social deprivation and is an excellent example of how a high quality service can tackle such potential inequities in access to healthcare.

CASE STUDY

Achieving high living donor rates in an area of high deprivation

South Tees Hospitals NHS Foundation Trust

South Tees is an area affected by socioeconomic factors associated with reduced access to kidney transplantation (and in particular LD transplantation), including high levels of deprivation and below-average literacy. The trust set out to establish a 'transplant first' culture, providing a service that would be accessible to all, and giving all eligible patients the opportunity to receive a pre-emptive kidney transplant with as much care as possible delivered locally. There is a strong emphasis on robust audit and quality improvement.

Priority areas

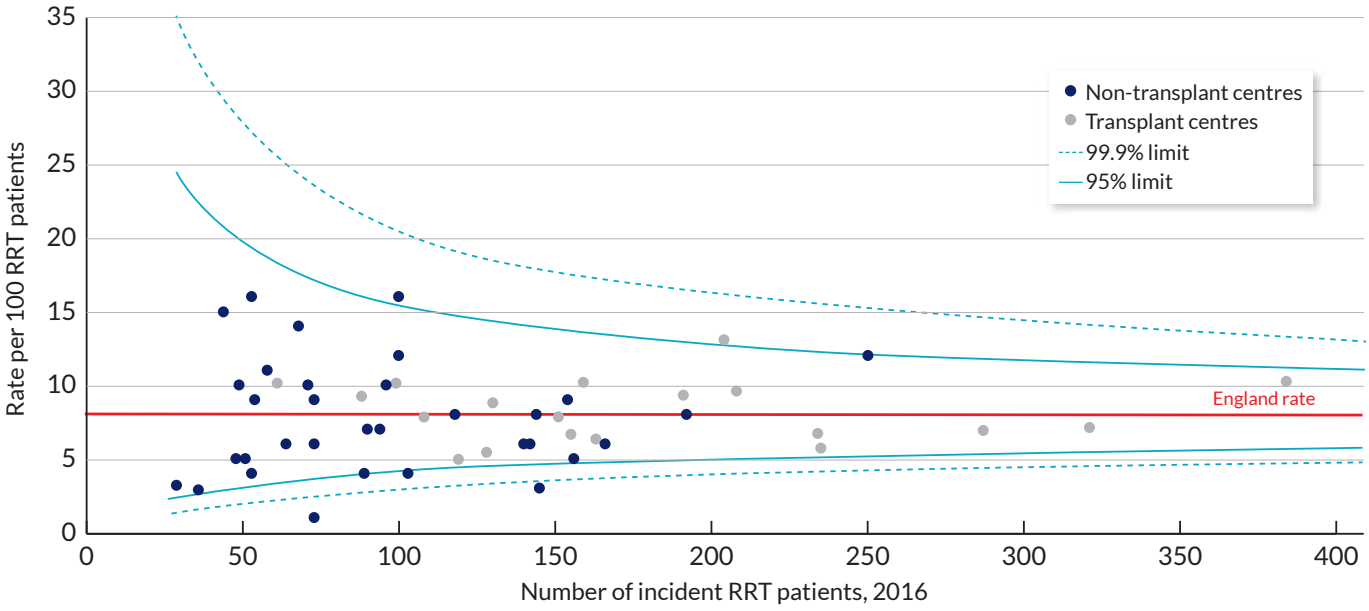
The work has focused on the following areas:

- Strengthening leadership: Nursing and clinical staff have been empowered to engage in service evaluation and improvement through development, mentorship and support, with dedicated job planned time. A specialist nurse for DD was appointed in 2006 and for LD in 2011, along with a clinical lead for LD.
- Building a cohesive team culture: Guidance and training has helped the whole team feel confident in starting the conversation about pre-emptive donation with patients.
- Patient focused pathways: Defined simple pathways reduce waiting time for tests, offer tests locally and allow several tests to be combined into one visit. A standardised pathway also creates a framework for regular audit and allows comparison between units, facilitating further quality improvement.
- Patient involvement: Donors and recipients have had input into the development of new pathways, most notably in the establishment of a 'one stop' clinic in 2012.
- Peer education and public awareness: Advanced kidney care patients are invited to an open day where they can access information on topics including dialysis and transplant. Peer support is offered to potential donors and recipients, and donor and recipient stories are shared through a range of channels including the unit website and hospital magazine.
- Cross specialty engagement and local collaboration: Involving other services, e.g. cardiology and urology, has been crucial in creating pathways that are well designed, flexible and sustainable.
- Partnership with the local transplant team and donor surgeons:
- Good communication between the referral centre (James Cook) and transplant centre (Freeman Newcastle) is facilitated through regional transplant meetings and makes the transition for the donor and recipient easier.

Results

- Mean time to be activated on the transplant waiting list is 148 days (compared with a UK mean of 437 days).
- The unit is in the top 5% for incident transplants/year.
- LD rate up from 16 to 24 per million population, with growth >25% above national average.
- The number of hospital visits required by donors has fallen by 50%.
- 95% of donors rated their experience 'excellent' or 'very good'.

Figure 10: Adjusted rate of living donor transplantation by two years from start of renal replacement therapy



Source: UKRR–NHSBT linked database, incident RRT patients 2016, adjusted for age, sex, and primary renal disease

Variation in deceased donor (DD) transplantation in transplant centres

There is variation in the DD transplant rate between the 19 transplant centres when expressed as per million population as reported by NHSBT. Once listed, variation in DD transplantation rates and wait time are determined by organ supply and the practice pattern in the transplant centre. Review of these factors was beyond the scope of renal GIRFT deep dives as the team did not include a surgical clinical lead, but it contributes to variation in access and is briefly discussed below. Transplant centre capacity and resilience was also beyond the scope of renal GIRFT but is an area of active work by the BTS[51].

The median wait for a DD kidney transplant in the UK is 675 days (for patients listed 2012–16)[52]. Risk-adjusted median waiting time in the 19 English centres varies widely, from 394 to 985 days, and many centres are significant outliers. However, waiting times in the UK have been falling progressively and the degree of variation has diminished. Many factors influence waiting time, including the offer decline rate. For a standard criteria DBD organ, this varies from 25% to 56%, with a UK average of 46% (2016–19)[53].

Quality improvement opportunities in access to kidney transplantation

Renal GIRFT deep dives identified a range of factors that contribute to the variation in access to kidney transplantation. Many of these have been previously described by initiatives such as ATTOM and Transplant First, as well as highlighted in NICE NG107[54]. Transplant First is an established quality improvement methodology hosted by KQuIP[55] which offers training and tools to deliver improved access to all forms of kidney transplantation. It includes a tracking tool that enables real time monitoring of performance.

[51] *https://www.bts.org.uk/wp-content/uploads/2018/09/Summary-of-Sustainability-summit.pdf*

[52] *https://www.nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17289/kidney-annual-report-2018-19-november19.pdf*

[53] *ibid.*

[54] *https://www.nice.org.uk/guidance/ng107*

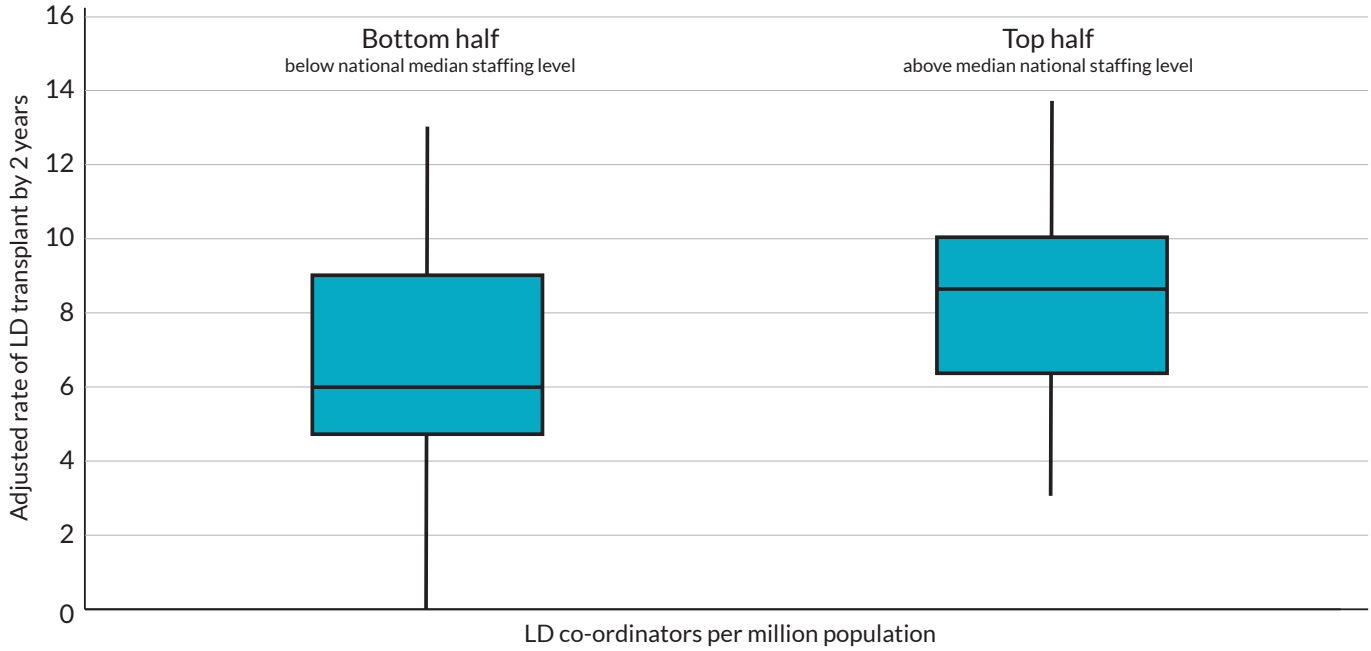
[55] *https://www.thinkkidneys.nhs.uk/kquip/transplant-first/*

Many of the sources of variation identified by GIRFT are recognised as themes by Transplant First, especially issues of funding, culture and working relationships within a network. Specific barriers identified across the two programmes include:

- lack of systems to ensure timely identification of patients with progressive CKD and early discussion of transplantation and living donation (typically in the AKCC, but in many centres even earlier than this);
- absence of a culture that makes transplant preparation a key 'clinical focus' of the AKCC;
- lack of staff and clinic capacity for transplant assessment, especially in non-transplanting centres;
- lack of a clear funding mechanism for transplant assessment, especially in non-transplanting centres;
- poor working relationships within transplant networks;
- lack of consistent criteria for transplant listing and assessment, nationally and within a network;
- bidirectional delays in handover and communication between referring and transplanting centres in 'two step' pathways;
- complexity of pathways with multiple visits;
- inconsistency in assessment processes and lack of evidence base for some of the tests 'required' by transplant centres (e.g. dental assessments); and
- local delays in specialist tests (e.g. cardiac imaging) and specialist opinions (e.g. cardiology, urology).

Accurate assessment of staffing levels for transplant assessment work proved difficult, because in smaller non-transplanting centres this work is often just one element of the specialist nurse for advanced kidney care role. Many non-transplanting centres reported insufficient specialist nurses to ensure an efficient pathway. We were able to demonstrate a weak association between inadequate co-ordinator staffing and lower levels of LD transplantation (see **Figure 11**). A workforce planning tool for LD co-ordinators is available from NHSBT[56].

Figure 11: Living donor (LD) co-ordinator workforce and LD transplant rate (well resourced vs. less well resourced centres)



Source: GIRFT questionnaire and UKRR-NHSBT linked database, incident RRT patients 2015 (LD transplant rate adjusted for age, sex and primary renal disease)

[56] *https://www.odt.nhs.uk/living-donation/tools-and-resources/*

There must be willingness to work proactively to recruit LDs, and to tackle what may be a sensitive subject with patients and families. There must also be resources available to carry out this assessment and co-ordination work. Of the 52 trusts surveyed in the GIRFT questionnaire, 19 had less than one full-time equivalent LD co-ordinator. LD co-ordinator resource is often concentrated in the transplant centres. It was evident at deep dives that non-transplanting centres with co-ordinators were more effective at identifying donors and that, all else being equal, this could contribute to better living donation rates.

There is no national tariff for the assessment or follow-up elements of the transplant pathway. It is within the remit of Specialised Commissioning, unlike the nephrology workload which is CCG funded. The work required is beyond the scope of the funding for AKCCs, even though the process is often initiated there. Some centres receive very little funding for this work which can have high unmet costs (e.g. staff costs, costs of histocompatibility testing). Transplant centres are rewarded financially for the surgical procedure and so it is the non-transplanting centres that are more disadvantaged.

Transplant centres recognise the principle that they are equal partners in a transplant network with the referring centres, where much of the work is undertaken. However, the extent to which they are invested in this philosophy varies and perceptions in the renal and transplant centres were sometimes contradictory. It was not uncommon for renal centres to report sub-optimal engagement even when the transplant centre felt it was delivering its network obligations. Conversely, some transplant centres felt that LD numbers might be improved with better local assessment of donors. Many transplant centres undertake local assessment of patients through outreach and while there is no hard evidence that this has an impact, it reinforces the philosophy of shared responsibility and a patient-centred approach.

NHSBT has a published policy, *Patient Selection for Deceased Donor Kidney Only Transplantation*[57], based on a 2008 revision of the RA guidelines which has subsequently been archived[58]. The policy sets out important principles for determining listing suitability but is not always didactic. For example, the NHSBT policy recommends case-by-case assessment of patients where BMI is greater than 30kg/m^2, but this translates into variation in the readiness of individual centres to list and transplant obese patients. Most renal centres reported that a local listing policy was available, but that it was not always applied consistently. The wide variation in listing rates suggests that there is a need for a consistently adopted national set of criteria.

National policy drivers and initiatives in kidney transplantation

There are a number of important national policy drivers that have been successful in promoting kidney transplantation:

- The **Living Donation Strategy 2020**[59] was published in 2015 after a decade of growth in living donation. It aimed to build on that growth with the goal of achieving an LD rate of 26 per million population, but this has proven difficult to deliver. A second important aim was improved equity of access, and the data presented above suggest that progress has been made in equalising opportunities of patients in transplanting and non-transplanting centres. The establishment of a UK-wide living donor network has been a significant achievement. NHSBT currently funds the LD national network but this is felt to be unsustainable. Finally, it aimed to maximise the opportunities offered by the UK Living Kidney Sharing Scheme (UKLKSS) (see page 50), an area of great success and growth where the UK leads the field internationally.
- **Saving More Lives With More Living Kidney Donors** is a patient-centred commentary document hosted by the All Party Parliamentary Kidney Group, published in 2017[60]. It makes a number of recommendations aimed at tackling the failure to deliver a donation rate of 26 per million population.
- **Taking Organ Transplantation to 2020**[61], which has delivered continuation of the growth in deceased donation with improved support for trusts and consent to donation. As a measure of the success of this and previous organ donation strategies, numbers on the active kidney transplant list fell by 31% between 2010 and 2019.
- **Taking Organ Utilisation to 2020**[62] aims to optimise the use of kidneys and minimise the organ discard rate.
- **The National Kidney Offering Scheme**[63] was revised and implemented in 2019, aimed specifically at improving equity of access for those patient groups that experience extended waiting times and those patients difficult to match for human leukocyte antigens (HLA) or who are highly sensitised. This will indirectly help to address inequality of access for patients from the BAME population.
- **'Opt out' legislation** for organ donation is now operational in England.

[57] *https://www.nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/18170/pol184.pdf*
[58] *https://www.renal.org/wp-content/uploads/2017/06/Module_4_-_Assessment_for_Transplantation_-_4th_Edition.pdf*
[59] *https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/living-donor-transplantation-strategy-2020/*
[60] *https://www.kidney.org.uk/Handlers/Download.ashx?IDMF=ad2135be-1bab-42c4-9ec3-447ad4799b33*
[61] *https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/taking-organ-transplantation-to-2020/*
[62] *https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/taking-organ-utilisation-to-2020/*
[63] *https://www.nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16915/kidney-allocation-policy-pol186.pdf*

NHSBT is currently developing a strategy for the next decade. It is anticipated that the net impact of initiatives in organ donation and utilisation, including the 'opt out' legislation, will yield an additional 500–600 kidney transplants per annum in the next five years. This has important implications for the capacity of the service nationally. Among the stated aims is a further commitment to improve equity of access across barriers of social deprivation and ethnicity.

The UK Living Kidney Sharing Scheme

The UKLKSS is an umbrella term for the schemes in which kidneys from LDs are 'shared' across the UK to optimise compatibility. These include paired/pooled donation and altruistic donor chains initiated by non-directed altruistic donors. The scheme has been fantastically successful and is the envy of other national transplant organisations[64]. GIRFT data demonstrated centre variation in utilisation of the scheme, although adoption was in evolution during the period of data capture. One consequence of this success has been a dramatic reduction in higher risk antibody incompatible transplantation, with only 34 blood group incompatible and 7 HLA incompatible transplants performed in the UK in 2018–19, compared with 208 in the UKLKSS.

[64] *https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16883/annual-report-on-living-donor-kidney-transplantation-2018_19.pdf*

Recommendation

Recommendation	Actions	Owners	Timescale
4. Streamline renal transplant pathways to increase access and reduce unwarranted variation in deceased and living donor (DD and LD) transplantation.	**a** Discussions to be held in relation to options to improve the renal transplant commissioning pathway, as part of improved system-working. This should include equitable allocation of adequate resource for all steps in the recipient and LD pathways (assessment, surgery, follow-up) to all centres.	GIRFT/NHSE/I, NHSBT, RSTP, DHSC	Within 24 months of report publication
	b Renal National Service Specification (NSS) to require all providers to track patients with progressive CKD 4–5 using the Transplant First tool or local equivalent, to monitor timely work up of transplant candidates and their donors.	NHS England Specialised Commissioning	Within 24 months of report publication
	c Renal centres to have a dedicated specialist nurse transplant workforce.	Renal trusts	Within 12 months of report publication
	d Renal centres to ensure timely access to diagnostics and specialist opinions needed for transplant assessment.	Renal trusts	Within 12 months of report publication
	e Work up pathways of recipients and donors to the point of listing to be tracked using an 18-week timeline, which will require clinically appropriate 'clock rules'.	NHS England Specialised Commissioning and renal trusts	Within 12 months of report publication
	f Renal transplant NSS to require effective partnership within transplant networks, including local surgical assessment and representation of the referring team on the listing and LD MDTs.	NHS England Specialised Commissioning, RSTP and renal trusts	Within 12 months of report publication
	g NICE to develop a national guideline for suitability for transplant listing to be developed which is patient-centred and adopted in a consistent manner across all networks.	NICE, RA, British Transplantation Society (BTS), NHSBT, renal trusts, kidney patient groups	Approach NICE before April 2021
	h Access to transplant listing, organ allocation and LD transplants needs to be equal for patients of all ethnicities and socio-economic groups.	NHS England and NHS Improvement, RSTP, NHSBT	Ongoing

Vascular access for haemodialysis (HD)

The pre-assessment, formation process, AVF rate, monitoring and care of HD vascular access are key areas of concern due to the unwarranted variation in how this is undertaken in different renal centres. This is highlighted by both UKRR data and evidence provided by clinicians and patients during deep dives. Capacity and organisational process issues are resulting in suboptimal clinical outcomes and unnecessary healthcare costs. Improving outcomes will require system change and concerted action by commissioners, regional networks, educators and clinicians.

HD involves the circulation and 'cleaning' of the patient's blood through a dialysis machine at a rate of over 350ml/min, and this requires secure vascular access. The successful creation, safe and effective use, maintenance and longevity of HD vascular access is critical to care quality delivery in HD. For most patients, this will involve the skills and expertise of a dialysis nurse, needling a surgically created AVF or, less commonly, AVG three times every week. Some patients involved in shared HD care can be successfully trained to self needle. This should be encouraged. Where AV access is not available (patient choice, surgically unsuitable or urgency awaiting creation), access to the circulation by a tunnelled central venous catheter (CVC) is required.

Epidemiological data shows that AVF HD access is associated with lower hospitalisation, blood stream infections, healthcare costs and reduced mortality when compared with CVCs[65,66]. The international Standardised Outcomes in Nephrology (SONG-HD) study identified management of vascular access as a core outcome critical to patients and caregivers[67]. The RA UKRR PREM report also identified vascular access-related patient experience as a source of significant variation at renal centre level. This has remained unchanged over the past three years[68].

Existing guidance on access for haemodialysis (HD)

Based on effectiveness, patient choice and complication rates, the RA's clinical practice and international guidelines[69] identify a hierarchy of preferred HD access. UK and international guidelines note that, where chosen by patients, AVF is favoured over AVG and CVC is considered the least preferred option[70,71]. The RA audit standard recommends a rate of incident AVF of 60% and 80% in the prevalent HD population. Most renal centres are unable to meet these standards for a variety of reasons, as discussed in more detail below.

NICE NG107[72] recommends that when HD is planned via AVF, clinicians should aim to create the fistula around six months before the anticipated start of dialysis to allow for maturation. Clinicians are advised to take into account the possibility of the first fistula failing or needing further interventions before use. Multiple procedures are required, both to create and to maintain vascular access. In a UK single centre study, 0.92 vascular access procedures per patient were carried out pre-dialysis, but only 58% of patients started HD on an AVF and this rate actually fell in the first two months[73]. A national study from Scotland showed that on average, HD patients require 0.48 procedures per year to maintain AVF patency[74]. GIRFT data confirms that multiple procedures are required: 59% of patients have reintervention in the year before starting dialysis; and 47% in the year after starting[75]. Access for dialysis should be created in time to ensure people can use their preferred dialysis modality and access route. Timing of surgery must be balanced so as to minimise the risk of creating access too early, as some people may never require dialysis.

How services are organised

Access assessment, formation, use and optimal care requires a formally organised complex interrelated multidisciplinary service involving nephrologists, access surgeons, vascular acess co-ordinators, dialysis nurses, radiologists and patient input. Assessment, monitoring of access function and expert needling technique reduces complications and extends the lifespan of the AV access, facilitating optimum dialysis delivery. Poor technique can lead to complications including AVF stenosis, aneurysm development, site infections, haematoma, pseudoaneurysm, bleeding and pain.

[65] *Woo, K., Lok, C.E. (2016) New Insights into Dialysis Vascular Access: What Is the Optimal Vascular Access Type and Timing of Access Creation in CKD and Dialysis Patients? Clin.J.Am.Soc.Nephrol., 11(8): 1487-94. https://www.pubmed.ncbi.nlm.nih.gov/27401524/*

[66] *Almasri, J., Alsawas, M., Mainou, M., et al. (2016) Outcomes of vascular access for hemodialysis: A systematic review and metaanalysis. J.Vasc.Surg., 64(1): 236-43. https://www.pubmed.ncbi.nlm.nih.gov/27345510/*

[67] *https://www.songinitiative.org/projects/song-hd/*

[68] *https://www.renalreg.org/wp-content/uploads/2017/05/PREM-report-2019-final-web-copy.pdf*

[69] *https://www.renal.org/wp-content/uploads/2019/10/FINAL-HD-Guideline.pdf*

[70] *https://www.renal.org/wp-content/uploads/2017/06/vascular-access.pdf*

[71] *Lok, C.E., Huber, T.S., Lee, T. et al. KDOQI Vascular Access Guideline Work Group. (2020) KDOQI clinical practice guideline for vascular access: 2019 update. Am.J.Kidney Dis., 75(4)(suppl 2): S1-S164. https://www.ajkd.org/article/S0272-6386(19)31137-0/fulltext*

[72] *https://www.nice.org.uk/guidance/ng107/chapter/Recommendations*

[73] *Murray, E., Eid, M., Traynor, J.P. et al. (2018) The first 365 days on haemodialysis: variation in the haemodialysis access journey and its associated burden. Nephrol.Dial. Transplant, 33(7): 1244–1250. https://www.pubmed.ncbi.nlm.nih.gov/29401294/*

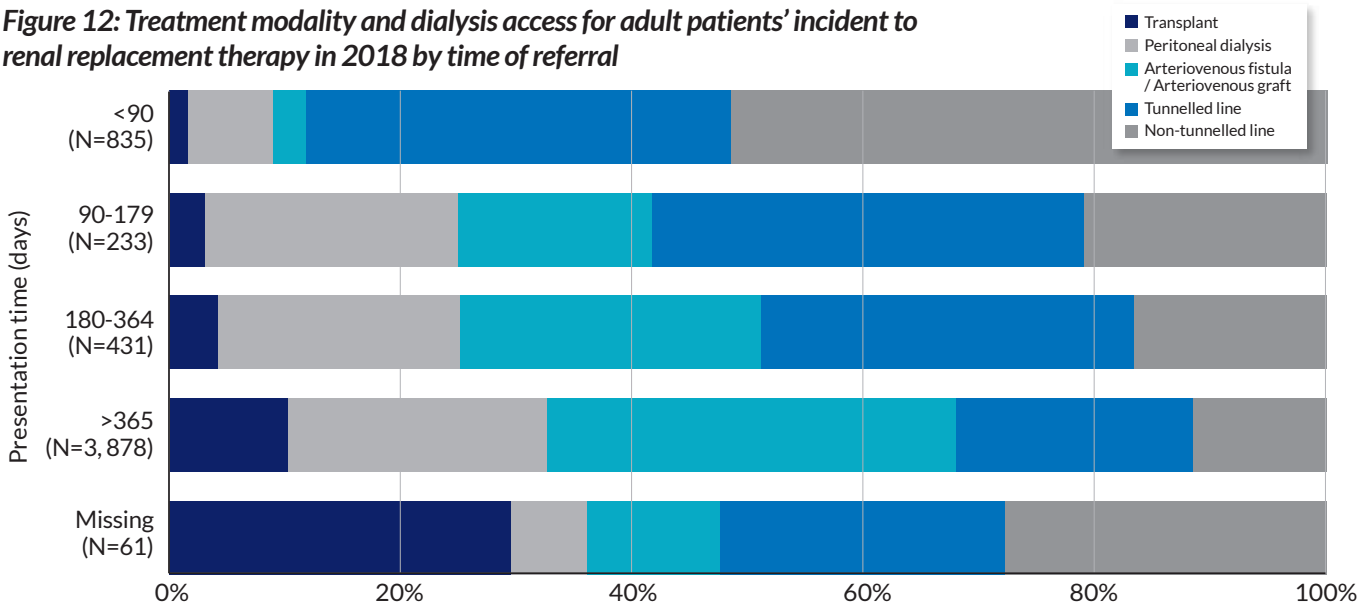
[74] *Stoumpos, S., Traynor, J.P., Metcalfe, W., et al. (2019) A national study of autogenous arteriovenous access use and patency in a contemporary hemodialysis population. J.Vasc.Surg., 69(6): 1889-1898. HES–UKRR, incident dialysis 2014–15. https://www.pubmed.ncbi.nlm.nih.gov/30583903/*

[75] *HES–UKRR, incident dialysis 2014–15.*

Dialysis access audit in incident dialysis patients

The RA UKRR Multisite Dialysis Access Audit[76] identifies factors associated with a higher chance of AVF/G use at first HD start. The factors with the greatest impact on definitive vascular access appear to be the referral time to renal services or vascular access surgical referral prior to dialysis start. Only 3% of patients known to renal services for less than 90 days started HD with an AVF/G and this increased to 22%, 34% and 52% in those referred to a nephrologist 3–6 months, 6–12 months and over one year respectively (see **Figure 12** below). Age, ethnicity, primary renal diagnosis (apart from autosomal dominant polycystic kidney disease (ADPKD)) and BMI had little association.

Figure 12: Treatment modality and dialysis access for adult patients' incident to renal replacement therapy in 2018 by time of referral

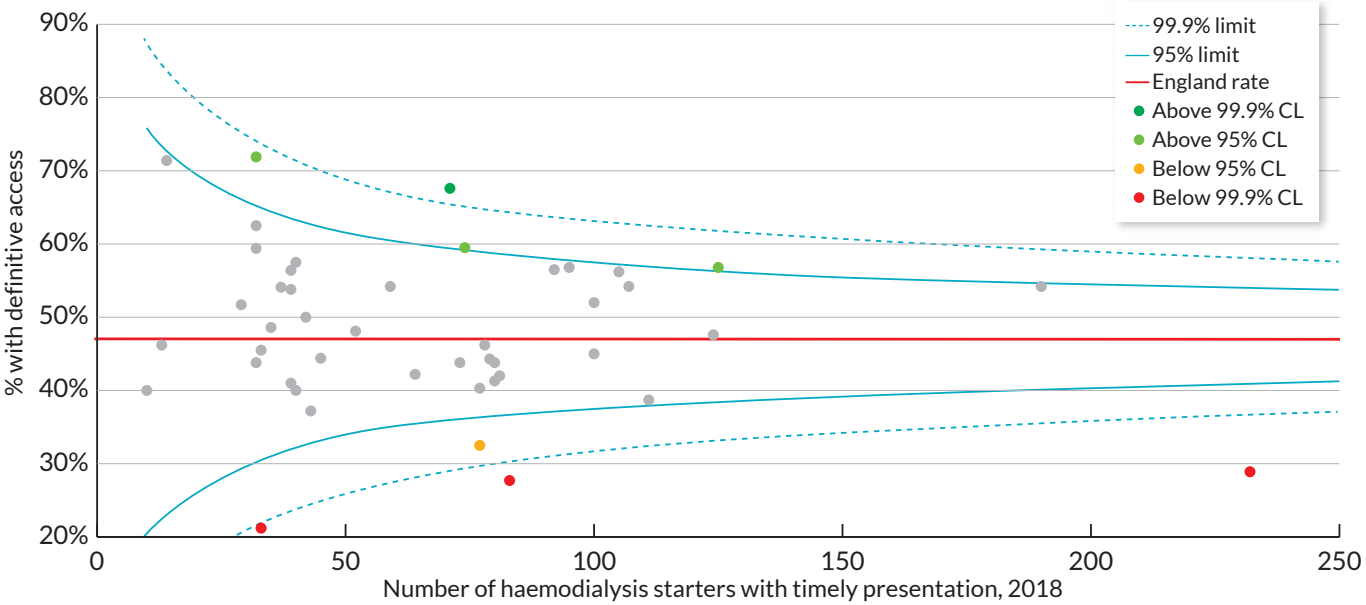


Source: UKRR 2018 Multisite Dialysis Access Audit (with permission)

While the timing of referral is important, centres vary widely in their ability to deliver a 60% definitive VA rate even for incident HD patients that present in a timely manner (see **Figure 13**, page 54). The national average in 2018 was 47%, with only four centres reporting rates above 60% and a reported range of 21%–72%.

[76] *www.renalreg.org/wp-content/uploads/2017/09/C12-Dialysis-access-Plain-English-Summary-19th-report.pdf*

Figure 13: Definitive vascular access rate by centre for patients starting haemodialysis after timely presentation in England

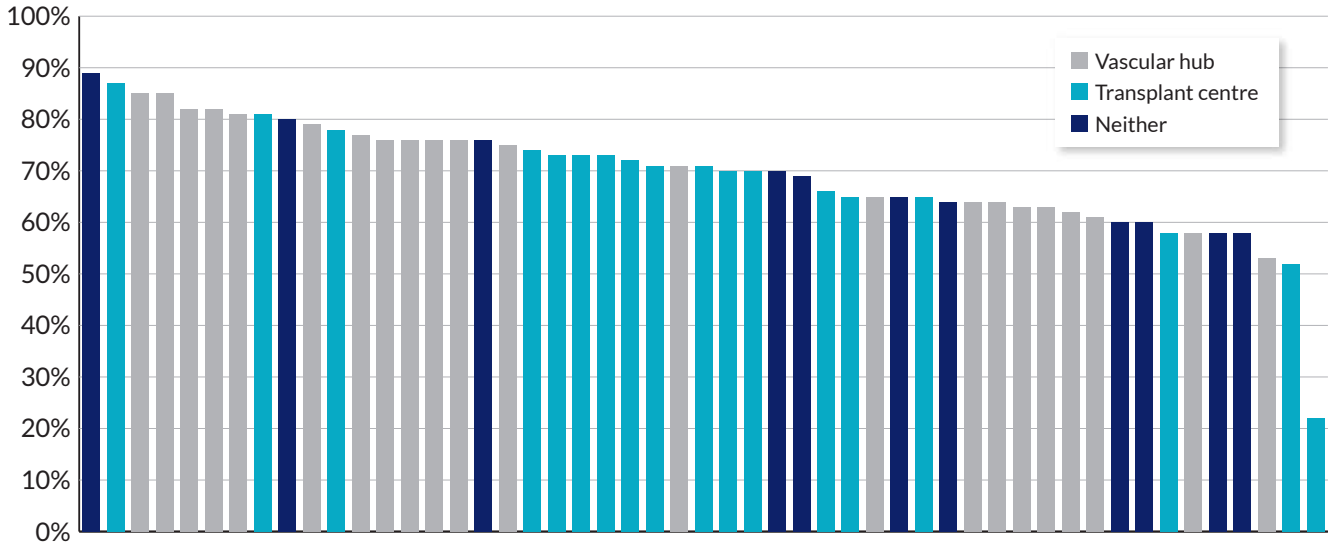


Source: UKRR 2018 Multisite Dialysis Access Audit

Prevalent arteriovenous fistula/graft (AVF/AVG) rates in English renal centres

Prevalent rates of HD AVF/G access rates also demonstrate wide unwarranted variation (see **Figure 14**). The English mean is 66% with an extremely wide range, from 22% to 89%. Only nine centres achieved the 80% standard in 2017–18. Whether a renal centre is co-located with a transplant or vascular surgery hub does not seem to be the sole determinant of good performance, although the reorganisation of vascular services has undoubtedly had an impact on renal care. This is discussed further below.

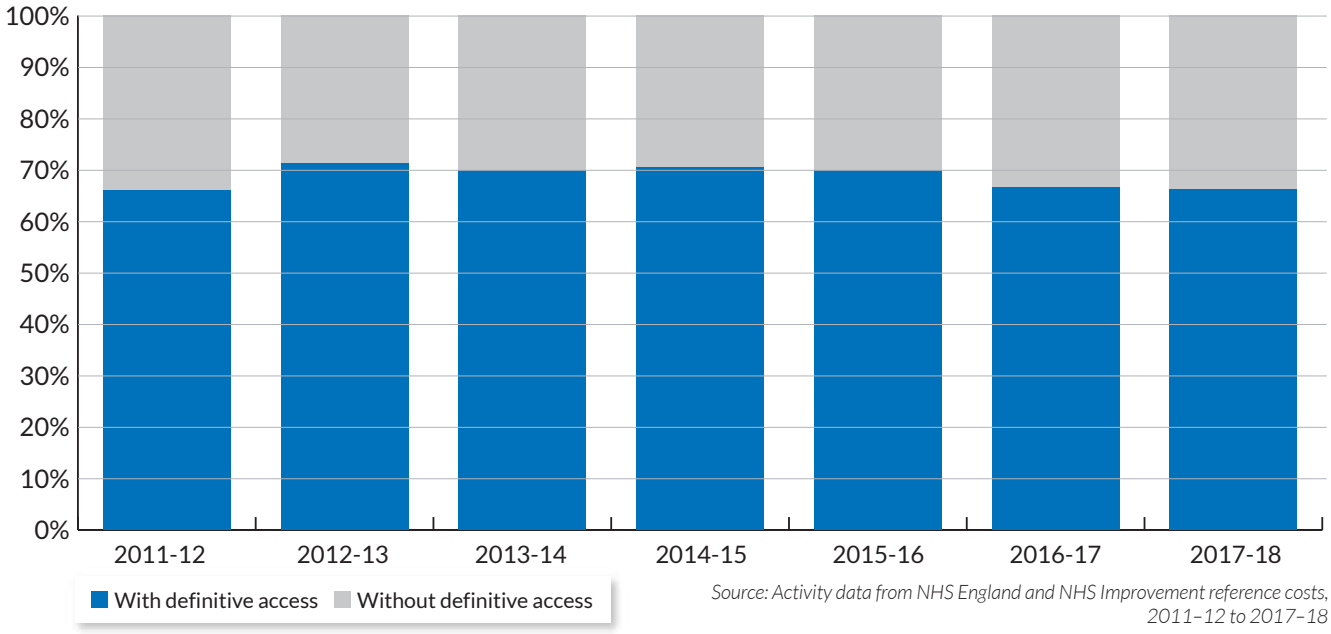
Figure 14: Prevalent haemodialysis patients with definitive access by renal centre type (vascular hub/transplant centre/neither)



Source: Activity data from NHS England and NHS Improvement reference costs, 2017–18

Despite recognition of the clinical and patient benefits and notwithstanding the introduction of the BPT in 2012 (which created a strong financial incentive for AVF/G access for HD over tunnelled CVC access), prevalent AVF/G rates in English renal centres have remained low for over ten years, as shown in **Figure 15**. This has led to unnecessary adverse patient outcomes. For a typical ICHD patient, the BPT incentive for definitive vascular access is large, at just under £5,000 per patient per annum.

Figure 15: Prevalent haemodialysis definitive access rate over time (since introduction of best practice tariff)



Source: Activity data from NHS England and NHS Improvement reference costs, 2011–12 to 2017–18

When the BPT was introduced, it was modelled so that the quantum of renal centre income remained unchanged if the AVF/G target of 80% was reached. Since this target has not been reached, the impact overall has been to reduce the quantum of income paid to renal services in the tariff. Based on current tariff and the gap between the target and achieved rate, we estimate this reduction to be in the region of £13m per annum. The reasons for the failure to increase definitive AVF/G rates were discussed with each renal service at the deep dives and are various and multifactorial but include centre culture, surgical and IR resource capacity constraints, service organisation, probable variation in access monitoring and recanalisation rates. The failure of the BPT to have the desired impact here is in line with other complex interventions where a financially advantageous BPT has been ineffective in changing clinical behaviour.

There is a requirement to review the BPT which could include adjusting the 80% threshold, introducing an alternative approach to review the differential tariff, or even progressively retiring the tariff. An alternative approach would be to redirect financial tariff incentives to address other areas of variation in this report including more effective SDM in AKCCs and pre-dialysis renal transplant listing.

Features common to high performing centres

It is clear from the individual deep-dive visits that the reasons for variation in incident/prevalent vascular access rates between centres are complex and the same approach will not be appropriate for all. Patient choice is sometimes cited as a limiting factor and it is certainly the case that all centres have patients who choose not to have definitive access. However, to some extent, patient choice reflects the quality of the information provided in the SDM process regarding the advantages of definitive vascular access as well as the proficiency of the team in managing the AVF/G. Each centre must focus on this key area of practice using QI methodology including process mapping and careful audit involving the multiprofessional workforce, nephrology, surgery and radiology. Each centre must review the process from the AKCC to creation and surveillance of AVF/G, including intervention for dysfunction or thrombosis of existing definitive access.

Deep dives identified a number of common elements in centres that were performing effectively:

- lower untimely presentation rates to ESKD and 'late start' focus;
- AKCC organisation and culture;
- risk-based timing of AVF formation;
- vascular access co-ordination;
- predominance of day case surgery;
- adequate surgical and operating theatre capacity with dedicated theatre lists for vascular access;
- vascular access monitoring and maintenance; and
- urgent intervention (IR and surgery) for failing vascular access.

These are explored in more detail below.

Lower untimely presentation rates to end stage kidney disease (ESKD) and 'late start' focus

Centres with a high untimely start rate for ESKD (largely those with high urban deprivation and ethnic diversity) are less able to plan timely vascular access preparation. However, a number do focus on those patients starting in an untimely fashion, the majority of whom receive and remain on HD.

Advanced kidney care clinic (AKCC) organisation and culture

When this is working well it includes supportive clinical leadership, a 'fistula first' culture, and vascular access co-ordinator input for an organised AKCC MDT with capacity for case management. Anecdotally, having ESKD prediction software embedded into routine AKCC practice assists timely AVF/G formation. A strong supportive surgical culture with clear leadership appears to have a significant positive impact. Real-time audit and embedded QI process structure allows close AVF/G rate monitoring and adjustment of service where required.

Risk-based timing of arteriovenous fistula (AVF) formation

NICE guidance recommends formation of AVF six months before dialysis starts. In practice, renal centres struggle to achieve this as ESKD prediction is clinically imperfect. A combination of prediction software including GFR slope and progression estimates can assist in supporting planning and identifying groups with advanced CKD unlikely to reach ESKD. As such, valuable surgical resource is directed to those with greatest need, reducing AVF formation in those who will not require dialysis[77,78].

Vascular access co-ordination

High performing centres typically have a vascular access co-ordinator, usually a specialist nurse, acting as the key link between the patient, the nephrologists and the vascular surgery/IR teams. A recurring theme in high achieving centres was a multiprofessional approach to listing and prioritisation of cases and surgical leadership in driving the service.

[77] *Tangri, N., Grams, M.E., Levey, A.S., et al. (2016) Multinational Assessment of Accuracy of Equations for Predicting Risk of Kidney Failure: A Meta-analysis. JAMA, 315: 164–174. https://www.jamanetwork.com/journals/jama/fullarticle/2481005*

[78] *Major, R.W., Shepherd, D., Medcalf, J.F., Xu, G., Gray, L.J., Brunskill, N.J. (2019) The Kidney Failure Risk Equation for prediction of end stage renal disease in UK primary care: An external validation and clinical impact projection cohort study. PLoS Med., 16(11): e1002955. https://www.journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002955*

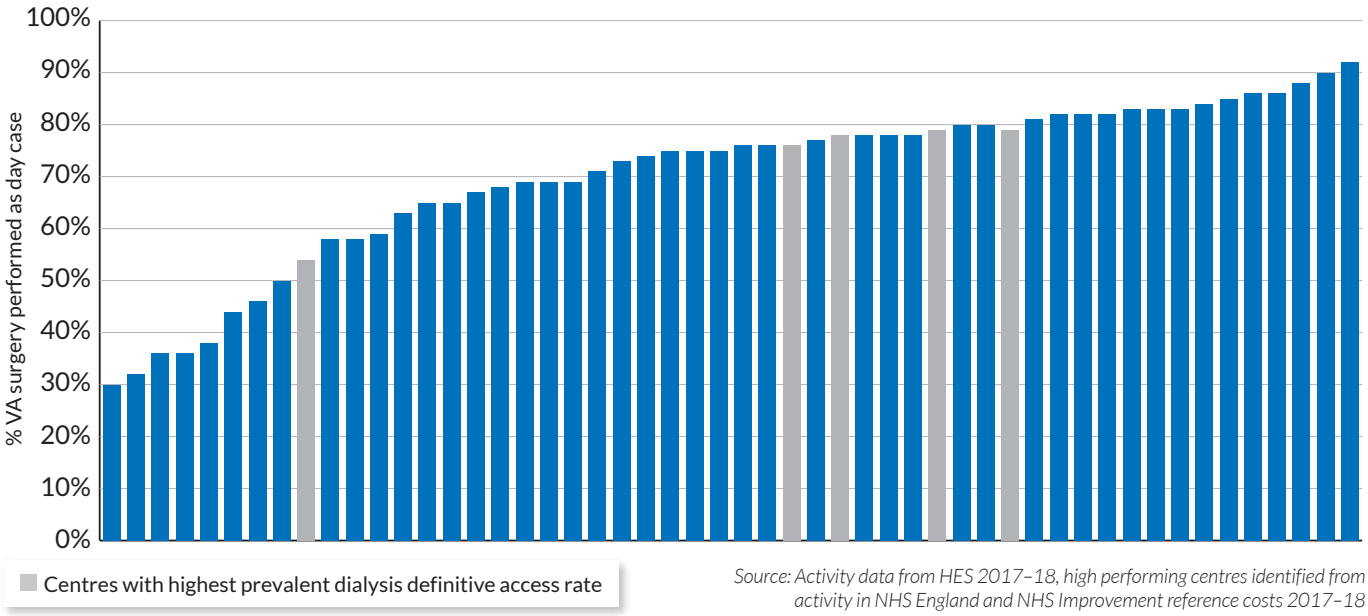
Predominance of day case surgery

Vascular access surgery and IR intervention can be delivered safely and effectively in the majority of cases as a day case. This facilitates shorter waiting times, improves access to theatre and reduces the likelihood of late cancellation.

A repeated concern among clinicians was that overnight bed capacity restrictions lead to high cancellation rates for access procedures. Predominant day case procedures (facilitated by local or regional anaesthetic) were a common feature of centres with higher prevalent and incident AVF rates. Rates of day case procedures vary from 30% to over 90% across the UK (see **Figure 16**). Some centres stated that their anaesthetists declined in those with ESKD for day care, citing high ASA scores as justification for deeming the patient unfit for surgery.

Figure 16: Inconsistency in day case rates for vascular access procedures across England*

* Includes day case admissions and elective admissions with an LoS of zero



Source: Activity data from HES 2017–18, high performing centres identified from activity in NHS England and NHS Improvement reference costs 2017–18

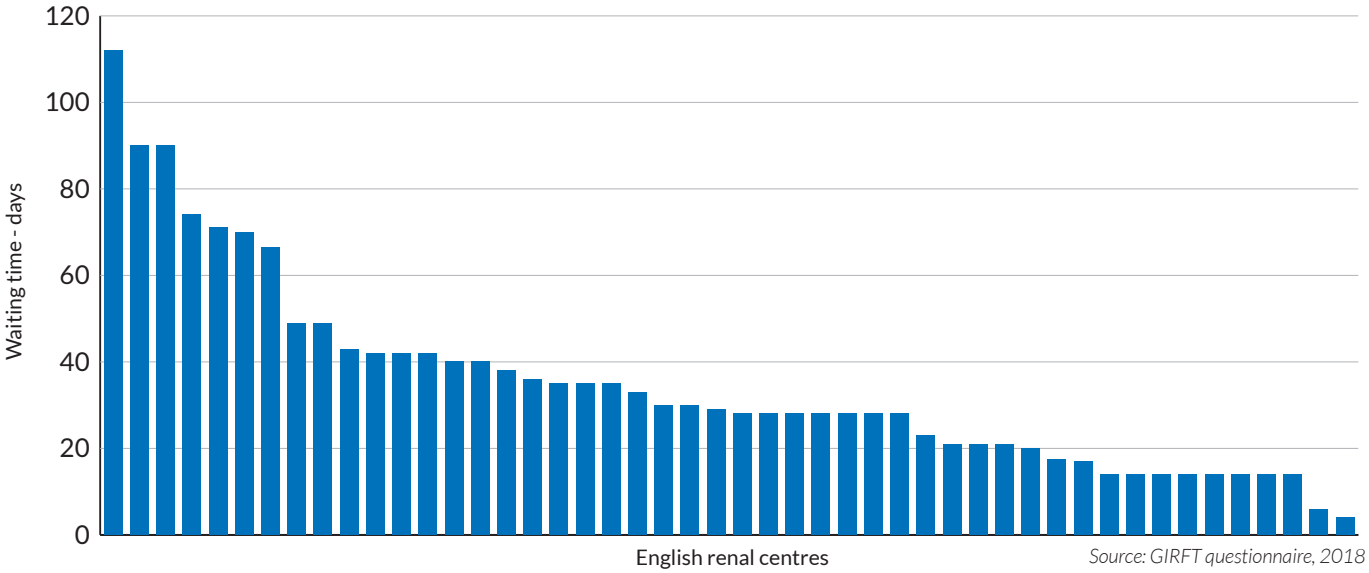
The British Association of Day Case Surgery (BADS) guidance notes that many trusts have successfully transformed their surgical pathways by increasing day case surgery, which ensures patients are treated safely and efficiently while managing costs. Since 2006 BADS has produced lists of procedures considered appropriate for day surgery. Its 2019 guidance[79] lists 204 procedures across 12 surgical specialties, including vascular surgery. The GIRFT anaesthesia and perioperative medicine report, due to be published in 2021, will include a recommendation on day case surgery. BADS recommends selection of patients for day case surgery to be based on functional status rather than ASA scoring.

Adequate surgical and operating theatre capacity with dedicated theatre and outpatient capacity for vascular access

There is widespread evidence that surgical, theatre and outpatient capacity is insufficient for many centres to deliver the national standard set for rates of definitive surgical vascular access for HD. Many of the renal centres visited by GIRFT identified this as the main reason preventing them from delivering the 80% standard. This is despite the fact that the BPT provides a strong economic incentive to deliver the 80% target. In theory, this commissioning model should make the business case to build sufficient vascular access capacity straightforward. The fact that the BPT has not achieved this strongly implies an absolute shortage of theatre/surgical capacity rather than funding resource. This is illustrated by the wide variation in waiting time for vascular access day case surgery reported by centres (see **Figure 17**).

[79] *https://www.daysurgeryuk.net/media/322269/guidelines_for_day_case_surgery_2019.pdf*

Figure 17: Waiting time (days) for day case surgery across England



Source: GIRFT questionnaire, 2018

Most transplant centres deliver vascular access surgery by transplant surgeons with variable vascular surgical colleague support. In non-transplanting centres, vascular surgical support predominates. Vascular access work is delivered on a 'grace and favour' basis by vascular surgery in a few centres, without any dedicated renal outpatient or theatre lists.

It is undoubtedly the case that the establishment of hub and spoke vascular networks[80] has had a significant impact on the provision of vascular access surgery and IR support to renal vascular access services in some English regions. The rationalisation and reorganisation of vascular services has meant that renal centres which may previously have had a vascular surgical support on site 24/7 no longer do so, or are offering more limited services at night or weekends. This has been raised with the GIRFT vascular surgery workstream team. However, our evidence does not point to a straightforward link between lack of on-site vascular surgery provision and attainment of vascular access target rates, indicating that surgical delivery organisation is not the only relevant factor.

Vascular access monitoring and maintenance

Expert vascular access needling, monitoring and maintenance appears key to ensuring persistent high prevalent rates of functioning access and is optimised by a multiprofessional workforce approach. This is essential to increase access survival and reduce complications including infiltration, stenosis, aneurysm formation and infective complications. The BRS vascular access monitoring group with VASBI have produced detailed clinical practice recommendations on access needling, including physical inspection and monitoring of AV access, which can inform practice and training development[81].

RA clinical practice guidelines recommend that all patients on long-term HD should have their vascular access monitored and maintained to minimise failure, allow timely planning for subsequent replacement with definitive vascular access (or peritoneal access) and avoid the need for emergency access[82]. In addition, the guidelines suggest that systematic observation and advanced surveillance should be employed to predict and prevent access failure. Clinical and dialysis parameters should be regularly reviewed and, where indicated, radiological imaging of access anatomy should be systematically employed. The evidence base and cost effectiveness of this approach merits further research.

MAGIC, a UK national QI programme with substantial supportive resources, has been established under KQuIP and adopted in a number of regions[83]. Professional society support and resources provided at regional network level enables substantial opportunities to improve practice and should be encouraged.

[80] *GIRFT national report for vascular surgery (2018) https://www.gettingitrightfirsttime.co.uk/vascular-surgery-report/*

[81] *https://www.thinkkidneys.nhs.uk/kquip/wp-content/uploads/sites/5/2018/10/Clinical-Practice-Recommendations-for-Needling-of-Arteriovenous-Fistulae-and-Grafts-for-Haemodialysis.pdf*

[82] *https://www.renal.org/sites/renal.org/files/vascular-access.pdf*

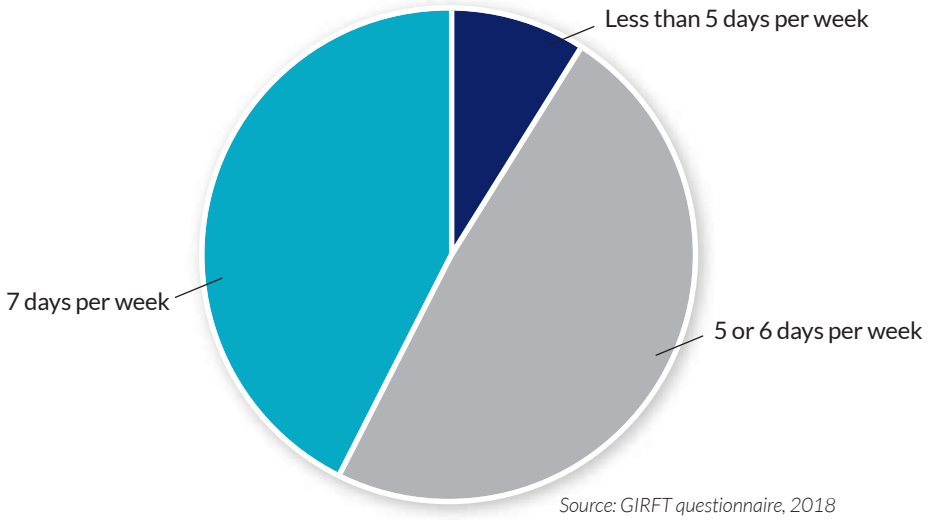
[83] *https://www.thinkkidneys.nhs.uk/kquip/magic/*

Urgent intervention for failing vascular access and interventional radiology support

Failing or acutely thrombosed vascular access is typically due to underlying vessel stenosis. Severe bleeding from vascular access is a surgical emergency and has been the focus of a National Patient Safety Alert[84]. There are numerous techniques for vascular access rescue, both by surgery and IR. Over the past decade there have been advances in IR techniques and in many centres this is the predominant form of intervention for stenosis and thrombosis. The NHS England NSS states clearly that: 'There should be 24/7 and urgent on-site cover available from vascular surgeons, interventional radiologists'[85]. It was clear on deep dives that failing vascular access is not given sufficiently urgent level of priority for transfer and intervention by supporting specialties in every renal centre. This is a particular challenge where surgical/IR support is no longer co-located with the renal centre. While vascular access salvage is sometimes only effective in the medium term, it provides a time window to plan new definitive vascular access without the requirement for a tunnelled CVC or possibly prolonged admission to hospital.

Imaging and IR support is also essential to planning surgical and some central venous access procedures. IR provides pre-emptive intervention to improve access function and prevent impending thrombosis. Currently, there is insufficient provision in many renal services across England (see **Figure 18**). Only half of centres currently have access to seven-day IR support, suggesting that half are unable to fulfil the current requirements of the NSS. Shortages in the IR workforce impacts the delivery of the renal service and GIRFT supports growth in this area.

Figure 18: Availability of interventional radiology by days per week in English renal centres for urgent vascular access procedure



Source: GIRFT questionnaire, 2018

Indeed, the RCR workforce consensus[86] notes that even though the whole time equivalent (WTE) consultant clinical radiology workforce has grown by 4% per year over the last four years, there is still a major shortfall against the numbers required to meet demand for IR. Assuming that demand continues to grow, and workforce issues are not addressed, it predicts a national shortfall of 1,900 clinical radiologists by 2023. This is discussed further in the GIRFT national report for radiology[87].

There is no easy immediate solution to this problem. Regional network arrangements should be explored to develop workable seven-day service provision. Trusts must be able to ensure the efficient, timely transfer of patients and put in place robust patient pathways.

[84] *https://www.improvement.nhs.uk/documents/3478/Patient_Safety_Alert_-_Bleeds_from_arteriovenous_fistulae_and_grafts.pdf*

[85] *https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/a06-serv-spec-haemodialysis-ichd.pdf*

[86] *https://www.rcr.ac.uk/clinical-radiology/service-delivery/rcr-radiology-workforce-census*

[87] *https://www.gettingitrightfirsttime.co.uk/clinical-work-stream/radiology/*

In combination with the RCR and the BSIR, the renal community should explore the development of the sub-specialty focus of interventional nephrology with appropriate credentialling and training. This may be the only realistic solution to support appropriately trained nephrologists to be competent in basic imaging and low risk access intervention, releasing IR consultants to deliver more complex interventions. This strategy is being developed successfully in a few renal centres, but lacks any formal training curriculum and accreditation process in the UK. This might be developed with the JRCPTB. The RCR has legitimate concerns regarding the breadth of competence and safety of interventional radiology work in vascular access. Any credentialling process would require full collaboration with the RCR and BSIR.

New models of care and commissioning

Commissioning arrangements for the vascular access service lack clarity and there has been very little commissioner intervention despite the fact that most centres in England fail to meet the standards for incident and prevalent patients. The required surgical and IR capacity to deliver an 80% prevalent definitive access rate has never been defined, nor has the urgency of this pathway. Even planned vascular access surgery is relatively urgent, given the profound impact of definitive access on outcomes.

ICHD falls within the remit of NHS England Specialised Commissioning and the 80% prevalent definitive access rate is a specified standard in the NSS. However, NHS England Specialised Commissioning has not intervened in the lack of provision of vascular access and the procedures themselves are largely funded by CCGs. Because this is seen as part of a specialised pathway, CCGs have not seen it as a priority. The current model fails to deliver the target required for definitive vascular access in the majority of renal centres and delivery has not improved since the introduction of the BPT, strongly suggesting capacity limitation. A radical review and revision of vascular access provision is required in some regions to deliver first-class care. This will require direct intervention by commissioners. We believe that, logically, the responsibility for this should more clearly sit with NHS England Specialised Commissioning, supported by the renal and vascular CRGs.

Across Europe and the US, health systems have developed cost-effective vascular access centres which support multiple renal centres, often involving independent sector partnerships capable of delivering the IR, surgery and monitoring required to deliver an acceptable service. With COVID-19 further limiting capacity, these options should be explored, ideally to provide service to more than one renal centre. This is most achievable in large conurbations.

Recommendation

Recommendation	Actions	Owners	Timescale
5. Reduce variation in incident and prevalent definitive HD vascular access rates and deliver RA clinical practice guideline minimum thresholds.* ** 60% incident and 80% prevalent patients with AVF/G.*	**a** NHS England and NHS Improvement to review differential pricing, and the effectiveness of the existing HD BPT.	NHS England and NHS Improvement, accountable commissioners	Within 24 months of report publication
	b NHS England and NHS Improvement and professional societies to establish the surgical and IR capacity required to deliver an 80% prevalent definitive vascular access rate. (This will also require formal definition of the pathway urgency to be delivered by relevant teams.)	NHS England and NHS Improvement, professional societies	Within 24 months of report publication
	c Trusts with a renal service to ensure they have sufficient surgical and IR capacity to support their HD programmes.	Trusts with a renal service	Within 24 months of report publication
	d Trusts with a renal service to ensure their day case surgery rate for HD arteriovenous fistula/graft (AVF/G) formation is a minimum 70% of all cases.	Trusts with a renal service	Within 12 months of report publication
	e All renal centres to have a vascular access co-ordinator post or posts (depending on size).	Renal centres	Within 24 months of report publication
	f Accountable commissioners to explore network-based commissioning of HD vascular access, including commissioning of dedicated vascular access centres and IR support.	NHS England Specialised Commissioning, accountable commissioners, renal networks	Within 12 months of report publication
	g Renal centres to optimise skill mix and competencies of clinical staff in the needling and monitoring of HD vascular access.	Renal centres and KQuIP	Within 12 months of report publication
	h Collaboration with regional vascular access QI initiative to identify local actions needed to implement effective pathways, to be agreed at network level.	Renal centres, regional networks and ICSs	Upon report publication
	i Intervention (+/- transfer where relevant) of failing or thrombosed vascular access to be sufficiently rapid to avoid central venous access (usually 24–48 hours).	To be ratified by all relevant NHS England clinical reference groups (CRGs) (vascular, radiology and renal) and adopted in relevant NSSs	Within 12 months of report publication
	j A curriculum, training and qualification process to be developed for credentialling in vascular access intervention.	Royal College of Physicians (RCP), Royal College of Radiologists (RCR), Royal College of Surgeons (RCS), RA, Vascular Access Society of Britain & Ireland (VASBI), British Society of Interventional Radiology (BSIR), Health Education England (HEE)	Within 12 months of report publication

Home therapies

Home dialysis therapy offers clear benefits in terms of patient experience and quality of life, eliminating the need for patients to travel to hospital several times a week[88]. Given the choice, many would prefer to dialyse at home[89]. These factors provide a strong rationale for improving access to home therapy. Dialysis modality choice is closely related to the information given in the AKCC (see *Preparation for renal replacement therapy (RRT) and conservative management*, page 37).

Home dialysis therapy may be delivered by PD or HHD. PD is available in a variety of formats: CAPD; APD; and AAPD. APD uses a cycling machine to perform the dialysis, usually overnight; in AAPD this treatment is supported by a community healthcare worker. HHD may also take a variety of forms, with newer technologies requiring less complex home adaptation and reduced training time. Most but not all HHD patients are supported by a carer – often a family member – and only a few centres offer assisted HHD.

There is variation in the adoption of home therapies by centre for patients starting RRT. On average, 21% of new RRT patients start on home therapy but there is a wide range (11%–42%), with large and small centres above and below the expected degree of variation (see **Figure 19a**, page 63). Incident home dialysis patients are mainly on PD; very few start on HHD directly. The variation in the proportion of prevalent dialysis patients on home dialysis is similarly wide, and the centres with high or low rates are generally the same as for incident RRT (also shown in **Figure 19b**, page 63). The prevalent home dialysis rate by centre ranges from 10%–40% with a national average of 17%. There are 33 centres below 20%.

The underlying causes of lower home therapy rates include issues of clinical culture, leadership and capacity: how committed clinicians in a particular trust are to the idea of promoting home therapies, and how much resource they have to do so. Some centres face capacity issues in terms of having sufficient nurses available to support home therapies. There is also a shortage of healthcare professionals in the community to facilitate home dialysis. GIRFT found significant variation in self-reported staffing levels in home therapy nursing teams. Where the team was combined (PD and HHD) the median staff to patient ratio was 12:1, with a range from 3:1 to 27:1. For PD teams the median was 17:1 (range 2:1 to 25:1) and for HHD teams 12:1 (range 2:1 to 25:1). Some centres have also diverted funding from PD programmes (traditionally the more common form of home dialysis) to HHD services, to the detriment of the original service.

There is variation in access to home therapy by ethnicity and social deprivation[90]. Levels of adoption are lower among BAME patients, who make up 28% of prevalent ICHD, 22% of PD and 13% of HHD. The proportion of prevalent patients on each dialysis modality also varies by level of social deprivation, with 16.3% and 9.8% of the least and most deprived quintiles of deprivation using PD, respectively. The difference for HHD is less marked (5.6% and 4.6% for the same quintiles). One centre found that the use of peer educators increased engagement by Asian patients and families in RRT preparation discussions[91]. This centre challenges the national picture, having an above-average rate of patients on home therapies in the context of an ethnically diverse catchment population with above-average deprivation.

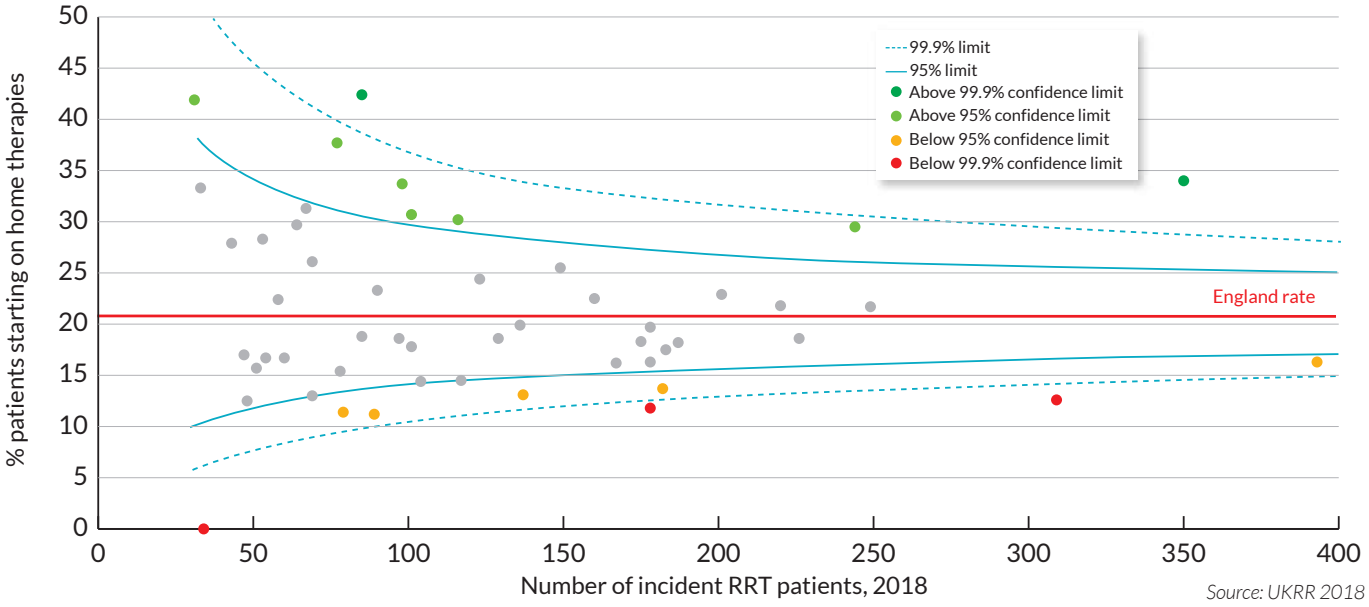
[88] *https://www.nice.org.uk/guidance/ng107*

[89] *Devoe, D.J., Wong, B., James, M.T., et al. (2016) Patient Education and Peritoneal Dialysis Modality Selection: A Systematic Review and Meta-analysis. Am.J. Kidney Dis., 68(3): 422-433. https://www.pubmed.ncbi.nlm.nih.gov/27125246/*

[90] *Tabinor, M., Casula, A., Wilkie, M., Davies, S., Caskey, F., Lambie, M. (2017) UK Renal Registry 19th Annual Report: Chapter 13 Home Therapies in 2015: National and Centre-specific Analyses. Nephron., 137 Suppl. 1: 297-326. https://www.karger.com/Article/Abstract/481376*

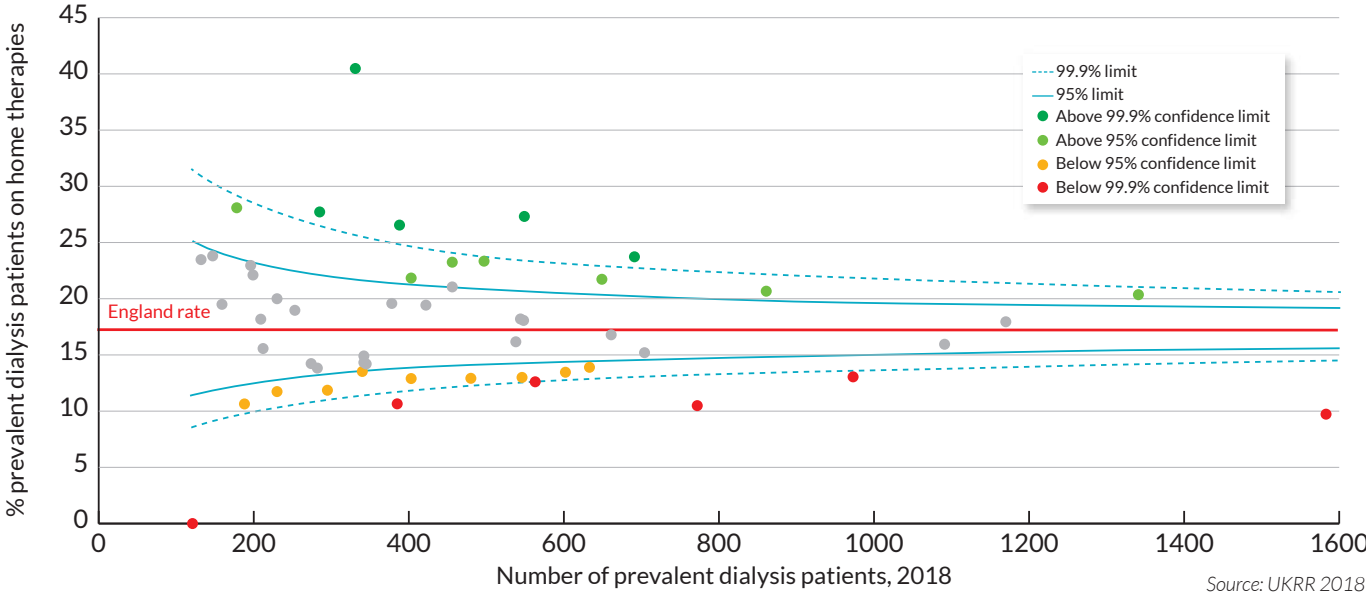
[91] *Jain, N., Baharani, J., Dodds, A., Lumsdon, A., Khawaja, S.S. (2019) Acceptance, choice and empowerment (ACE) for pre-dialysis patients: a peer educator-based community project that aims to improve choice and quality of life for patients with kidney failure. Future Health J., 6 (Suppl. 1): 9. https://www.pubmed.ncbi.nlm.nih.gov/31363534/*

Figure 19a: Proportion of patients starting renal replacement therapy on a home dialysis therapy*



Source: UKRR 2018

Figure 19b: Proportion of prevalent dialysis patients on home dialysis therapy*



Source: UKRR 2018

*The centre with a zero value does refer patients to a neighbouring centre for home therapy and since this data was gathered the two have merged.

PD has been the dominant home dialysis therapy in the UK for decades, but various factors have led to a significant growth in HHD for the past ten years and more. This was initiated by a 2002 NICE Technology Appraisal which found that, based on UKRR figures, up to 15% of the dialysis population would opt for HHD[92]. This has since been updated by NICE CG107. Subsequent commissioning incentives and technological advances have increased the availability of HHD, supported by an improved understanding of the benefits for patient experience and overall health. It is important to note however that the growth in HHD has been balanced by a decline in PD. The overall proportion of prevalent dialysis patients on a home therapy has therefore not changed over the past decade (see **Figure 1**, page 26).

This lack of growth prompted KQuIP to support DAYLife, a QI project aimed at promoting culture change and strengthening leadership within renal centres such that home therapy becomes the first option considered for dialysis[93]. This is a good example of network collaboration, with ten centres in the East and West Midlands involved. The 2013/17 Kidney Alliance report and update *Kidney Health: Delivering Excellence*[94] identified expansion of home therapy as a goal, and the All-Party Parliamentary Kidney Group's *A Home Dialysis Manifesto*, published in 2013, recommended that NHS England Specialised Commissioning set a national minimum target for home therapies[95]. Clearly, there is no shortage of support for this change in the delivery of dialysis care from multidisciplinary professional bodies, patients and carers.

The COVID-19 pandemic has highlighted an additional advantage of home therapy that has not previously formed a significant part of the SDM process, but will in the future. ICHD patients are very vulnerable to transmissible respiratory viral infections. This is not just the case for COVID-19; it is evident each year during the influenza season. By 3 June 2020, 10.6% of ICHD patients in England had been infected with COVID-19, and 2.7% had died. For patients on a home therapy, the equivalent statistics are 2.7% and 1.1%[96]. Although ICHD patients are more frail and the data are not casemix adjusted, the difference is stark. These data provide evidence that home dialysis patients are less exposed to respiratory viral infections and that thrice-weekly hospital attendance for ICHD had very serious consequences during the COVID-19 pandemic.

Peritoneal dialysis (PD)

The design, culture and clinical leadership of the AKCC is an important factor in determining access to PD. Healthcare professionals in low adoption centres may have misconceptions about suitability for PD and a tendency to consider patients unsuitable based on their medical or surgical history and social circumstances. There may also be a lack of balanced education available for patients, their families and carers as to the practicalities and potential benefits of PD. The ideal model of care for SDM is discussed in the NICE guidelines[97] and elsewhere in this report (see *Preparation for renal replacement therapy (RRT) and conservative management*, page 37).

There is centre variation in access to AAPD – a highly desirable option for frail patients or for new PD starters requiring a bridge to full independence. This service relies on healthcare assistants travelling to patients' homes to help them connect to their machine. Much of this work has been contracted out to independent sector providers. Often, the scope of the service is limited: e.g. providers are less likely to operate in rural areas. One-third of centres reported limitations in access to AAPD, usually related to independent sector provision. This is an area where there is clear potential for collaboration at network level, as smaller centres struggle to maintain in-house AAPD provision.

GIRFT data and deep dives have identified two additional features of dialysis practice in centres that have a bearing on PD uptake:

- a 'late start' PD programme that can recruit unplanned dialysis starters; and
- timely availability of PD catheter insertion, typically percutaneous.

Patients presenting less than 90 days before going on to dialysis are less likely to go on to PD[98], and in many centres HD is the default therapy in this patient group. On deep dives, centres with high PD uptake described agile assessment and education that enabled them to make PD available for late presenting RRT patients – a 'late start' programme. This observation is supported by GIRFT questionnaire data which shows a modest trend towards higher PD uptake in such centres (see **Figure 20**), which account for 58% of the total. In a few centres even patients presenting as true AKI can be managed by PD.

[92] *https://www.nice.org.uk/guidance/TA48*

[93] *https://www.thinkkidneys.nhs.uk/kquip/daylife/*

[94] *https://www.kidneycareuk.org/news-and-campaigns/news/kidney-health-delivering-excellence/*

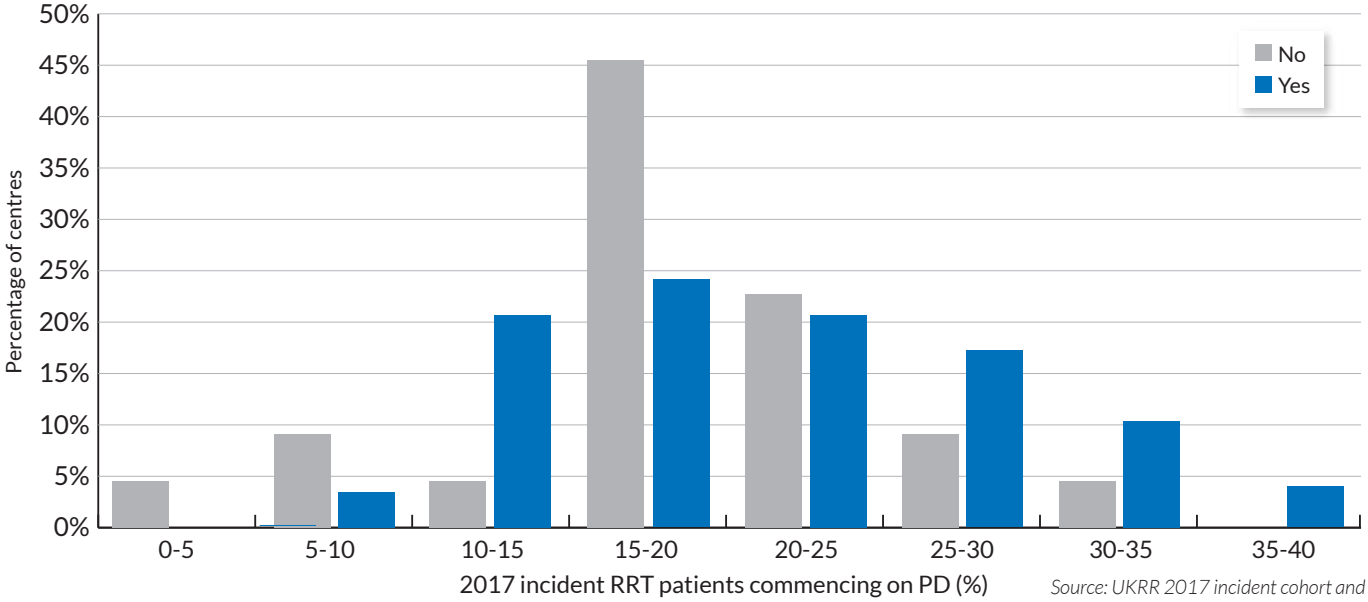
[95] *https://www.kidney.org.uk/Handlers/Download.ashx?IDMF=ffca233b-27c8-4bbd-ae3d-1d3cad97cd6c*

[96] *https://www.renal.org/covid-19/*

[97] *https://www.nice.org.uk/guidance/ng107*

[98] *https://www.renalreg.org/wp-content/uploads/2019/05/21st_UKRR_Annual_Report_Ch1.pdf*

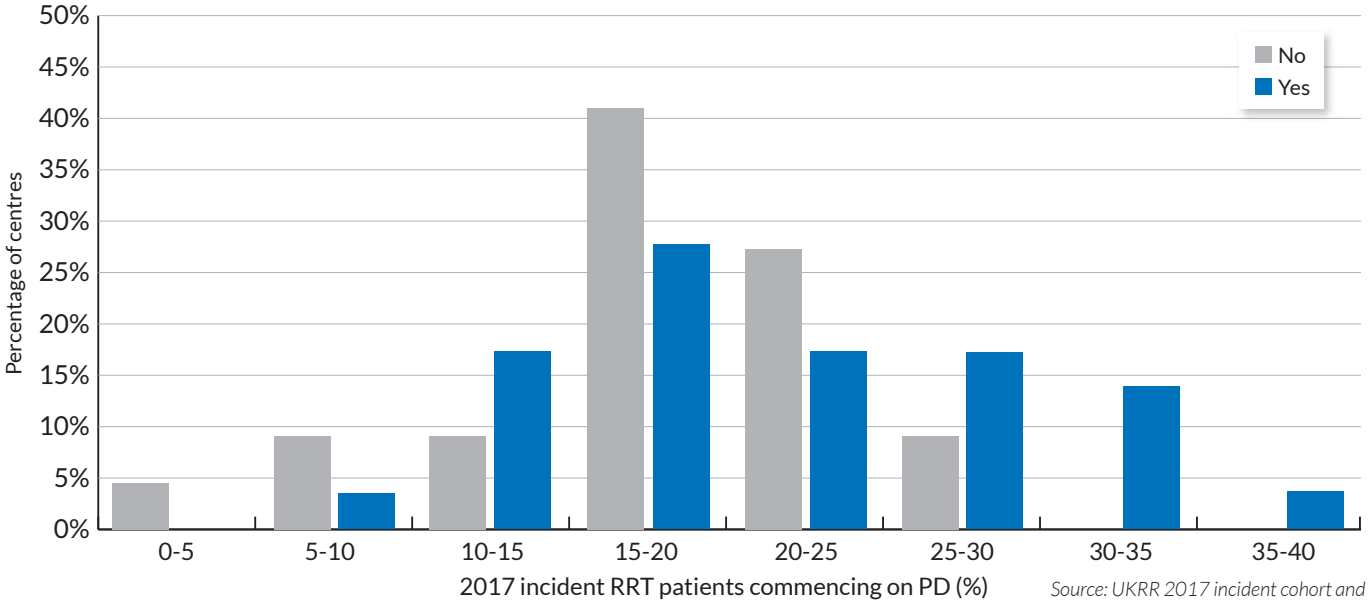
Figure 20: Relationship between peritoneal dialysis adoption by incident renal replacement therapy patients and presence of a late start peritoneal dialysis programme



Source: UKRR 2017 incident cohort and GIRFT questionnaire data

The NHS England NSS for PD expects a 14-day turnaround for routine catheter insertion and 48 hours for urgent catheter insertion. Despite this being a commissioner requirement, only 63% of centres reported that they could meet the routine insertion target and 56% the urgent insertion target. A timely catheter service was more likely in the 58% of centres that had established percutaneous catheter insertion, typically delivered by physicians or advanced nurse practitioners (ANPs). Again, there was a modest trend towards higher PD uptake in centres that had established percutaneous PD catheter insertion (see **Figure 21**). This observation is supported by UKRR data; among centres that used the percutaneous approach, 25.9% of incident RRT patients started PD, compared with 21.0% overall[99].

Figure 21: Relationship between peritoneal dialysis adoption by incident renal replacement therapy patients and percutaneous catheter insertion



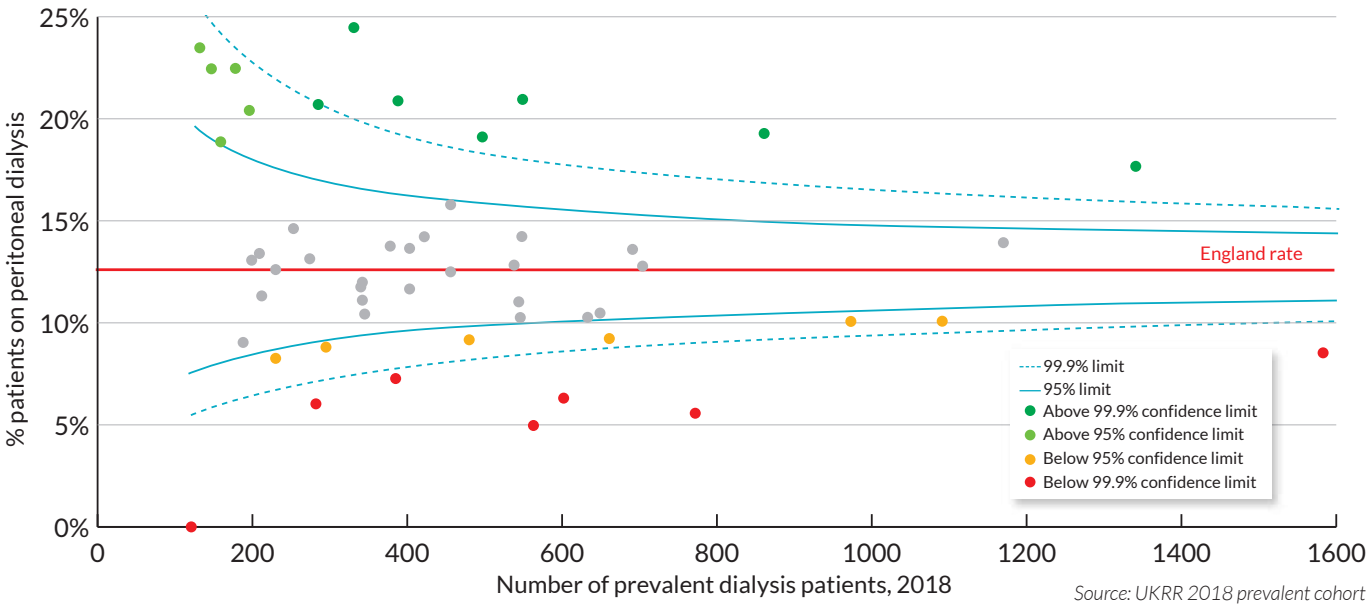
Source: UKRR 2017 incident cohort and GIRFT questionnaire data

[99] *Hole, B., Caskey, F., Evans, K. et al. (2017) UK Renal Registry 19th Annual Report: Chapter 12 Multisite Dialysis Access Audit in England, Northern Ireland and Wales in 2015 and 2014 PD One Year Follow-up: National and Centre-specific Analyses, Nephron.137 Suppl 1: 269-96. https://www.karger.com/Article/Abstract/481374*

GIRFT has provided insight into two important features of a PD catheter insertion service that affect patterns of care, but there are many other aspects of quality that are less well understood. For example, UK data on primary catheter patency rates and infection early after catheter insertion are limited. From linked HES-UKRR data we have found that 32% of catheter insertions are followed by a further catheter intervention (replacement or repositioning) within 12 months. The UK Catheter Study, which is due to report later in 2021, will describe in detail the characteristics and outcomes of PD access services[100] and recommendations from this study will define future QI priorities.

The proportion of a prevalent dialysis programme treated by PD is determined in part by the use of this therapy in incident patients, but also by the balance of patient flow between other modalities. Peritonitis is the commonest cause of technique failure (see *Infection in dialysis patients*, page 99) leading to transfer to ICHD; some patients transfer from ICHD to PD through choice; while some patients are transplanted. Patients on PD are often transplant candidates and the transplant rate in a given centre is likely to influence the prevalent PD population. The variation in the prevalent PD population by centre is akin to that seen for incident home therapy, with the same centres showing above and below average rates. The average proportion of the prevalent dialysis population on PD is 13%, with wide variation from 5%–24% (see **Figure 22**).

Figure 22: Variation in proportion of prevalent dialysis patients on peritoneal dialysis*



Source: UKRR 2018 prevalent cohort

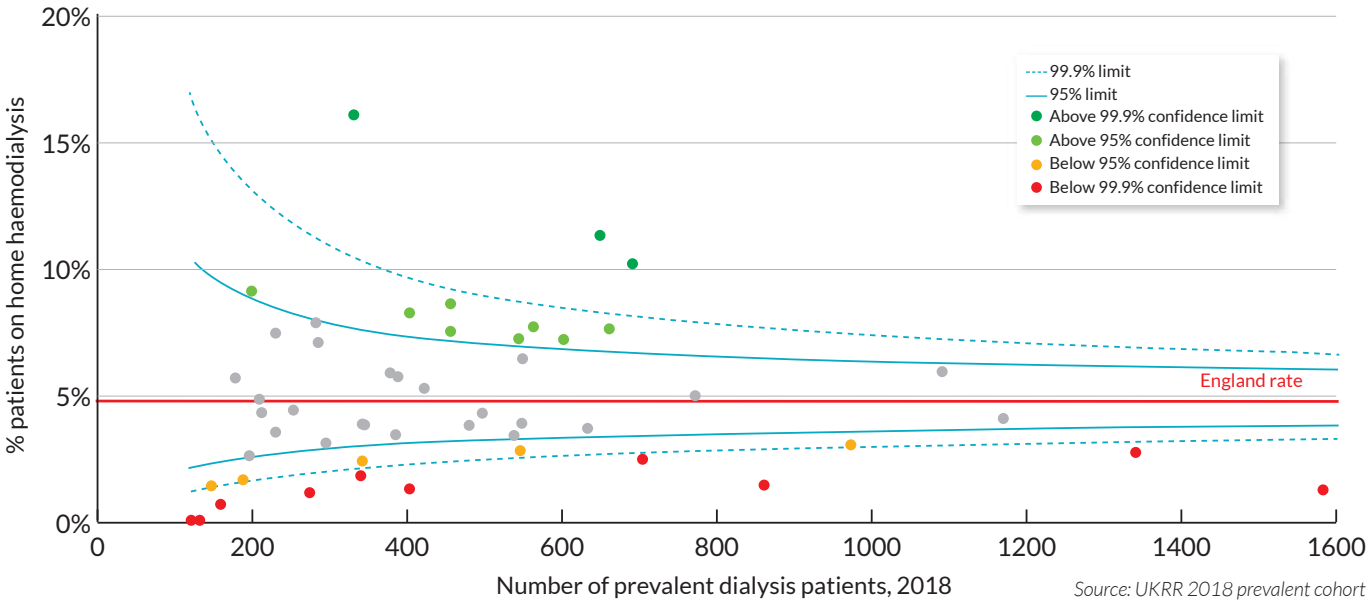
*The centre with a zero value does refer patients to a neighbouring centre for home therapy and since this data was gathered the two trusts have merged.

[100] *Briggs, V., Solis-Trapala, I., Wailloo, A,. et al. (2018) United Kingdom Catheter Study – Protocol Synopsis. Perit Dial Int., 38(2): 113-118. https://www.pubmed.ncbi.nlm.nih.gov/29563275/*

Home haemodialysis (HHD)

The prevalent rate of HHD rose from 2% to 5% of dialysis patients between 2009 and 2018 (see **Figure 1**, page 26). Once again, there is wide variation from 0% to 16% and a significant number of outliers (see **Figure 23**).

Figure 23: Variation in proportion of prevalent dialysis patients on home haemodialysis*



Source: UKRR 2018 prevalent cohort

*The centre with a zero value does refer patients to a neighbouring centre for home therapy and since this data was gathered the two trusts have merged.

Commonly cited barriers to HHD growth reported on deep dives included:

- lack of available training facilities, leadership and staff for training;
- financial barriers to adoption of HHD, including newer technologies;
- competing interests with PD and transplantation; and
- patient choice.

A successful HHD programme requires significant investment in training facilities and staff and a local or regional 'champion' who is prepared to manage the risks associated with HHD growth.

There is no longer an absolute requirement for large scale capital investment because HHD can be procured on a per session basis from independent sector partners; indeed this is the norm for the newer technologies, which also have reduced home conversion costs. A per therapy payment structure will typically mean a higher cost per dialysis session, but avoids the upfront costs and offers greater flexibility for growth. The NHS England and NHS Improvement tariff for HHD was introduced at a payment level designed to incentivise growth, and per therapy costs for HHD are affordable for providers within this tariff. HHD is included in the scope of the forthcoming national procurement framework and this should be an enabler for centres that have struggled to finance HHD growth. See *Procurement*, page 118, for more information.

Arguably it is more important that home therapy is a central facet of the dialysis strategy in all centres than whether PD or HHD is the dominant form. However, while with PD competing interests play a part, it is very difficult to justify the fact that one centre has 16% of patients for whom HHD is the better home dialysis option while another has none. The argument that transplantation competes for potential home therapies patients is also often cited. While this is undoubtedly true, the centre with the shortest wait for transplantation in England also has a rapidly growing HHD service, twice the prevalent rate of the national average.

On deep dives two main factors were cited by centres as instrumental in the successful growth of HHD programmes:

- adoption of shared care HD; and
- adoption of new HHD technologies with lower set-up costs and quicker training.

Shared care haemodialysis (HD)

Shared care HD is a powerful driver for HHD, and is seen in many centres as a key initiator on the HHD pathway. Not all patients who participate in shared care will progress to HHD, but some will – and all stand to benefit from greater engagement in their care. ShareHD[101] is a multicentre QI project aimed at promoting shared HD care. Patients progress to varying degrees along a shared care pathway, starting with simple tasks such as measuring their own blood pressure and carrying out their own skin preparation, before moving on to setting up their own HD machines and, in some cases, needling their own fistulas. From here, it is a relatively short step to dialysing at home. A short video on the ShareHD website provides a powerful description of the benefits of this programme in the eyes of patients, including how it acts as a gateway to HHD for some[102]. See also the case study from Sheffield Teaching Hospitals NHS Foundation Trust on page 90.

We have found some barriers to accessing shared care HD. For example, some independent sector facilities do not include shared care in their contracts, as establishing shared care requires a significant commitment of time and resource. The benefit of shared care is a constant theme throughout the whole of chronic disease care. Patient activation measures are a strong indicator of better outcomes: the more engaged patients are with their own care, the better their health will be[103].

Health economics of home dialysis therapy

The health economics of home dialysis versus in-centre dialysis are complex. Factors that contribute to this complexity are discussed in the evidence review that supports NICE CG108[104]. They include:

- the relative unreliability of NHS England reference costs for dialysis, especially for HHD;
- variation in the casemix of patients treated by each modality;
- the fact that the overall cost of a dialysis modality includes transport, hospitalisation and high cost medicines as well as the cost of the therapy itself; and
- incidental costs incurred by patients on home dialysis.

The NICE evidence review does not develop a new economic analysis but it does provide a comparison between the costs of PD and ICHD based on a summary of a Canadian study considered sufficiently robust to translate into UK costs[105]. The equivalent aggregated three-year cost of PD and all associated indirect care including hospitalisation was £33,252, whereas for ICHD it was £99,656. By comparison, NHS England's one-year reference costs (dialysis therapy expenditure and transport only) were £26,857 for PD, £9,588 for HHD and £27,420 for ICHD.

Incidental costs incurred by home dialysis patients are often cited as a disincentive to adoption. This is especially true for HHD where energy and water costs can be significant. The NHS does have mechanisms that allow patients to claim back incidental costs but patient experience data gathered by KQuIP suggest that the delay and uncertainty around this process does have an impact on patient choice. This has also been demonstrated in Australia where modest patient grants to negate this disincentive have been proposed[106].

Reference costs for dialysis, especially HHD, are unreliable, so we have used the NHS England and NHS Improvement tariff[107] with the addition of the NICE estimate of annual transport costs for ICHD in our financial impact statement (page 126). The financial impact is based on the current spread of dialysis activity by each HRG and modelled on a future minimum 20% prevalent home therapy rate. The multiple HRGs cover centre HD, satellite HD, HHD, PD, APD and AAPD. For centre and satellite HD there are separate HRGs for therapy with and without definitive access (the BPT, see *Vascular access for haemodialysis*, page 52) and with and without blood-borne virus infection.

On balance, home therapies do offer a health economic advantage, and this is addressed in our financial impact statement (page 126).

[101] *Wilkie, M. and Barnes, T. (2019) Shared Hemodialysis Care: Increasing Patient Involvement in Center-Based Dialysis. Clin.J.Am.Soc.Nephrol., 14(9): 1402–1404. https://www.pubmed.ncbi.nlm.nih.gov/31350275/*

[102] *https://www.shareddialysis-care.org.uk/sharehd*

[103] *https://www.england.nhs.uk/publication/patient-activation-measures-uk-renal-registry-case-study/*

[104] *https://www.nice.org.uk/guidance/ng107/evidence*

[105] *Chui, B.K., Manns, B., Pannu, N., et al. (2013) Health care costs of peritoneal dialysis technique failure and dialysis modality switching. Am J Kidney Dis., 61(1): 104-111. https://www.pubmed.ncbi.nlm.nih.gov/22901772/*

[106] *Walker, R.C., Howard, K., Tong, A., Palmer, S.C., Marshall, M.R., Morton, R.L. (2016) The economic considerations of patients and caregivers in choice of dialysis modality. Hemodial Int.,20(4): 634-642. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5324572/*

[107] *https://www.improvement.nhs.uk/resources/national-tariff/*

CASE STUDY

Home haemodialysis and peritoneal dialysis

University Hospitals of Derby and Burton NHS Foundation Trust

Within the trust's renal centre, each member of the renal team has experienced the benefits of home therapies. These experiences are discussed among various team members – including consultants and nursing staff – and evidenced with data. The data is discussed every month at an MDT meeting.

The evidence of success helps at the time of educational sessions for low clearance patients, building their confidence. Patient selection and subsequent home visits for home therapy are essential and are a stepping stone for successful home therapy. The opportunity to meet and chat informally with other home therapy patients increases the prospective patient's confidence. Utilising the enthusiasm, knowledge and skillsets of the nursing teams, vascular surgeons and interventional radiologists who are available to support patients are of utmost importance. The team at UHDB have ensured the skills of placing PD catheter under local anaesthetic are passed on to new consultants. This has helped UHDB to place PD catheters at short notice ensuring patient choice always comes first.

Recommendation

Recommendation	Actions	Owners	Timescale
6. Ensure home therapy is promoted and offered for all suitable dialysis patients and that a minimum prevalent rate of 20% is achieved in every renal centre.	**a** All centres to ensure adequate training facilities and staffing for home HD (HHD) and PD, sufficient to deliver the 20% target. (Centres to consult the staffing models outlined in the British Renal Society (BRS) workforce document[108].)	Renal centres	Within 12 months of report publication
	b The reduced risk of transmissible infection (e.g. COVID-19) for patients on a home therapy compared with in-centre HD (ICHD) to form part of the SDM process with patients.	Renal centres	Upon report publication
	c All centres to ensure they have a timely PD catheter insertion service. (Local resources will determine service design but a percutaneous method of insertion will become standard in most centres.)	Renal centres	Within 12 months of report publication
	d All centres to establish a late start PD service.	Renal centres	Upon report publication
	e All centres to ensure collaborative working within renal networks is in place to improve the resilience of services such as assisted automated PD (AAPD) and HHD, particularly for smaller services.	Renal centres and regional networks	Within 24 months of report publication
	f All centres to ensure that shared care HD becomes a feature of all ICHD facilities in the independent sector and the NHS.	Renal centres and independent sector HD providers	Within 24 months of report publication
	g Research to be undertaken to develop successful strategies to address inequities of access to home dialysis in deprived and black and minority ethnic (BAME) populations.	National Institute for Health Research (NIHR) and Kidney Research UK (KRUK)	Initiate within 12 months of report publication

[108] *https://www.britishrenal.org/workforce/*

Acute kidney injury (AKI)

Acute kidney injury (AKI) is a sudden, potentially reversible, loss of kidney function. Affecting up to one in five emergency hospital admissions, and 7.6% of admissions overall,[109] it is associated with a marked increase in short term morbidity and mortality, increased subsequent risk of CKD and higher healthcare utilisation and costs.[110, 111] For patients admitted in England in 2017, 32% of AKI developed in hospital, while 68% arose in the community or soon after admission.[112]

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report *Acute Kidney Injury: Adding Insult to Injury* raised the profile of AKI and provided the impetus for national efforts to improve care.[113] Clinical experts reviewing cases of AKI in hospital where the patient died concluded that AKI could have been prevented in 15% of cases and that only 50% of patients received a standard of care that was considered 'good'. Using clinical coding in hospital notes, it even proved difficult to accurately identify those who had AKI, with only 65% of the cases reviewed fulfilling the criteria.

In a recent UK analysis of AKI in hospital and community settings, 69.5% of patients with AKI peak at AKI stage 1, while 17.3% peak at AKI2 and 13.2% peak at AKI3 (see below for classification).[114] Patients with pre-existing CKD and those who present with sepsis or undergo major surgical procedures such as coronary artery bypass surgery and abdominal aortic aneurysm repair carry a significant risk of AKI. This risk increases with advancing patient age and comorbidities.

AKI is associated with a high mortality. In England, 18% of patients with AKI in all care settings (hospital and community) die within 30 days, increasing to up to 33% for those with AKI3.[115] Given the high number of patients involved, the complexity of care required and the protracted length of stay, the cost to the NHS is substantial. Recent estimates put it at between £434 million and £620 million per year,[116] more than the costs associated with breast, lung and skin cancer combined.

Those patients with more severe AKI may require dialysis support for anywhere between a few days and a few weeks until their renal function recovers, although for a small proportion it will never return. There is good evidence that repeated cycles of AKI in comorbid patients contribute to substantial increased long term risk of CKD, which in a proportion will eventually lead to RRT.[117]

Staging of AKI

AKI is staged by KDIGO classification (1–3) according to the patient's level of serum creatinine and/or reduced urine output. A 2014 NHS England Patient Safety Alert[118] mandated reporting of AKI stages through an algorithm in the laboratory information management system (LIMS) in order to generate automatic warning reports for AKI stages. More than 90% of English laboratories now report these and outputs are collected in a master patient index (MPI) by the UKRR. Linkage of the MPI to HES data has enabled GIRFT to derive trust-specific rates for all stages of AKI for the first time.

[109] *Selby, N.M., Casula, A., Lamming, L. et al. (2019) An Organizational-Level Program of Intervention for AKI: A Pragmatic Stepped Wedge Cluster Randomized Trial. J.Am.Soc.Nephrol., 30(3): 505–515. https://www.jasn.asnjournals.org/content/30/3/505*

[110] *Lameire, N.H., Bagga, A., Cruz, D. et al. (2013) Acute kidney injury: an increasing global concern. Lancet, 382(9887): 170–179. https://www.jpubmed.ncbi.nlm.nih.gov/23727171/*

[111] *Selby, N.M., Fluck, R.J., Kolhe, N.V. et al. (2016) International Criteria for Acute Kidney Injury: Advantages and Remaining Challenges. PLoS Med., 13(9): e1002122. https://www.journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002122*

[112] *https://www.renal.org/resource/aki-report*

[113] *https://www.ncepod.org.uk/2009akitoolkit.html*

[114] *https://www.renal.org/resource/aki-report*

[115] *ibid.*

[116] *https://www.nice.org.uk/guidance/ng148*

[117] *See E.J., Jayasinghe K., Glassford N. et al. (2019) Long-term risk of adverse outcomes after acute kidney injury: a systematic review and meta-analysis of cohort studies using consensus definitions of exposure. Kidney Int, 95: 160–172. https://www.pubmed.ncbi.nlm.nih.gov/30473140/*

[118] *Selby, N.M., Hill, R., Fluck, R.J. (2015) NHS England "Think Kidneys" AKI Programme. Standardizing the Early Identification of Acute Kidney Injury: The NHS England National Patient Safety Alert. Nephron., 131(2): 113–117. https://www.pubmed.ncbi.nlm.nih.gov/26351847/*

National patient safety electronic alerts based on a laboratory algorithm have helped to highlight AKI. There are robust NICE[119] and RA[120] clinical practice guidelines covering the prevention, detection and optimal management of AKI. There is also increasing evidence that the organisation of acute care has an impact on AKI outcomes. Recent high quality evidence indicates that the introduction of a combination of AKI e-alerts, care bundles and education can lead to improved detection, reduced length of stay and enhanced quality of care, albeit without delivering any reductions to mortality[121].

Most cases of AKI1 and 2, where the cause is known, will be managed by healthcare professionals practising in acute specialties other than nephrology. Renal services will be involved in cases where a patient with severe AKI3 is likely to require dialysis, where AKI is due to intrinsic kidney disease or where the cause of AKI is unknown and requires specialist input. Patients with multiple organ failure are cared for in critical care with some needing ongoing nephrology care post-discharge, sometimes with short or long term dialysis.

Although most patients with AKI are not managed by renal teams, renal services play a significant role in reviewing and supporting their care by developing protocols for optimal care of patients by other medical or surgical specialties. Acute trusts without a renal service currently manage some patients with severe single organ AKI on a critical care unit where timely transfer to a nearby renal service is not achievable. The formality, governance and staffing of such AKI networks is highly variable, with dedicated renal AKI outreach teams a feature of more progressive renal centres.

The GIRFT renal medicine team did not visit all acute trusts and in the context of AKI we focused mainly on the involvement of renal services at the more severe end of the disease spectrum including AKI HD, cases requiring inter-hospital transfer and step-down to renal from critical care. Nevertheless, our findings on AKI will be relevant to all acute trusts and the learning points will be supplemented by the findings in the forthcoming GIRFT national reports for acute and general medicine and adult critical care. It is important to note that AKI incidence and outcomes when corrected for casemix and comorbidity are likely to reflect the overall safety profile of all acute trusts, and high quality data is important for quality assurance.

Variation in the incidence of acute kidney injury (AKI)

Linking the AKI MPI to HES has enabled GIRFT to determine the incidence of AKI to the 41 of the 52 individual trusts containing renal centres and to 86 acute trusts overall (including two specialist paediatric trusts).

The incidence of all levels of AKI in elective (**Figure 24**) and emergency admissions (**Figure 25**, page 72) to acute trusts is highly varied[122]. The data below are not casemix adjusted, and the scope of the services offered will inevitably have an impact. For example, an acute trust with a large cardiothoracic centre or vascular centre would be predicted to have a higher incidence of AKI. For this reason, the graphs do not include control lines. **Figure 26** (page 73) specifically shows the variation in the incidence of AKI3 in renal trusts, a significant proportion of which will be managed by renal services because these are the patients with the most severe level of injury and some will require dialysis.

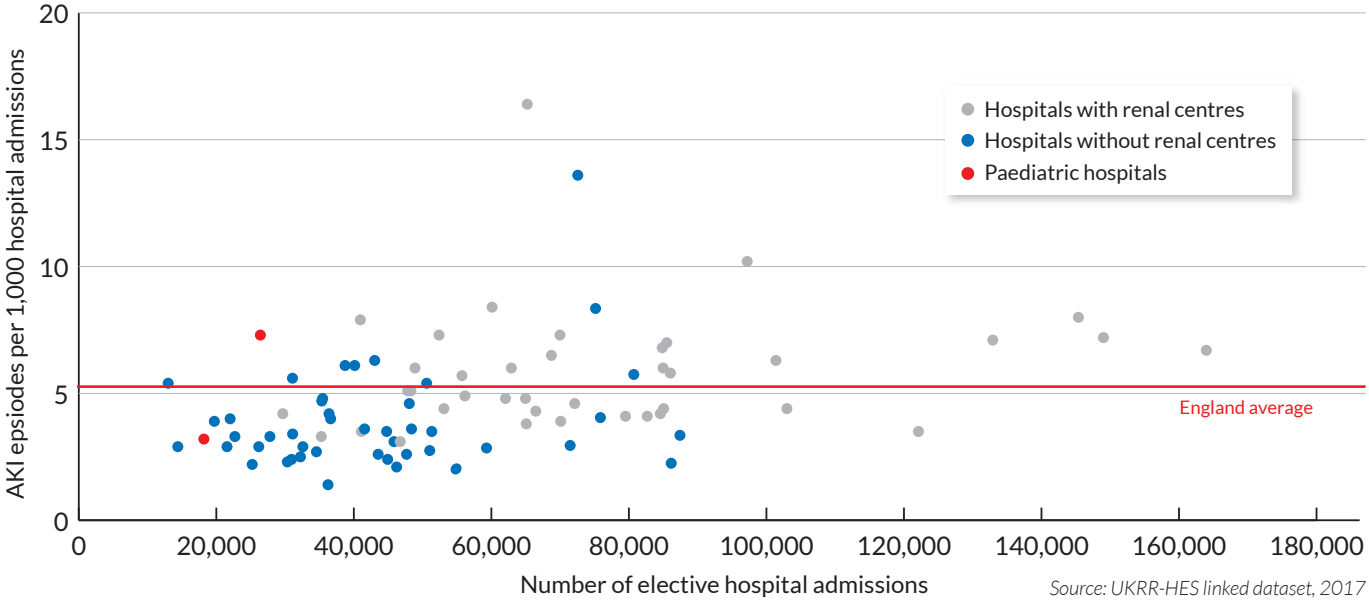
[119] *https://www.nice.org.uk/guidance/ng148*

[120] *https://www.renal.org/wp-content/uploads/2017/07/FINAL-AKI-Guideline.pdf*

[121] *Selby, N.M., Casula, A., Lamming, L. et al. (2019) An Organizational-Level Program of Intervention for AKI: A Pragmatic Stepped Wedge Cluster Randomized Trial. J.Am.Soc.Nephrol., 30(3): 505–515 https://www.jasn.asnjournals.org/content/30/3/505*

[122] *Figures from https://www.renal.org/wp-content/uploads/2020/07/AKI_report_FINAL.pdf (with permission).*

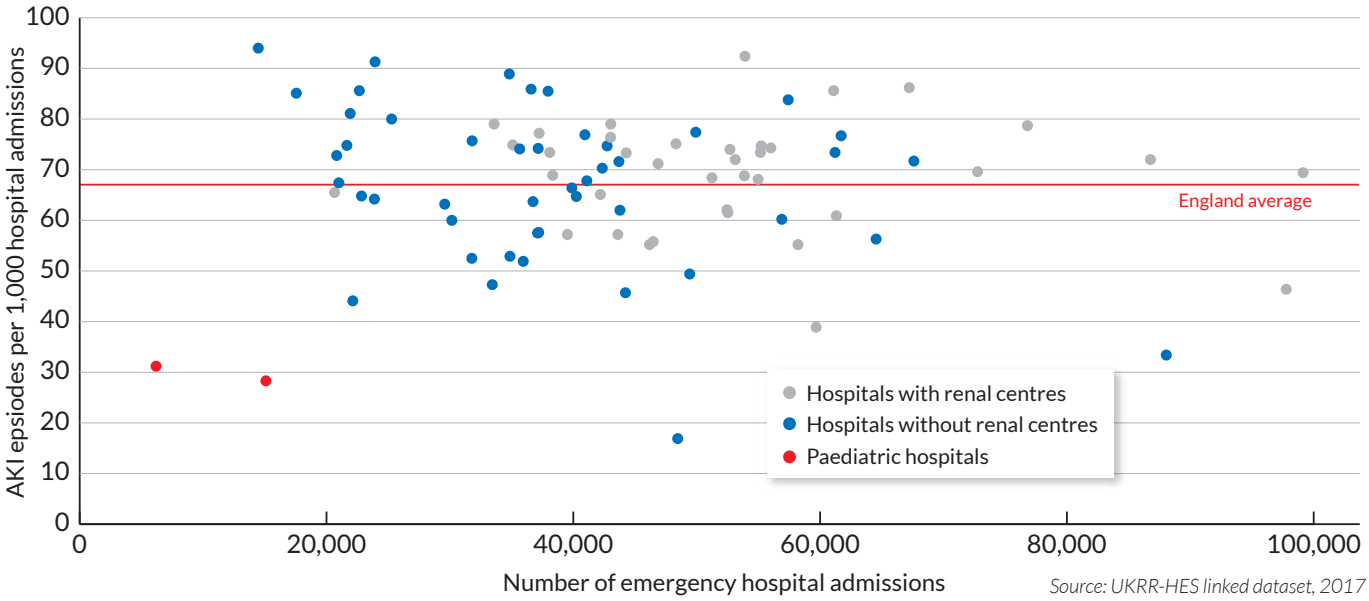
Figure 24: Incidence of acute kidney injury in elective admissions to acute trusts*



Source: UKRR-HES linked dataset, 2017

* Numerator: Hospital-acquired and admitted community-acquired AKI. Denominator: all elective admissions including day cases. Unadjusted.

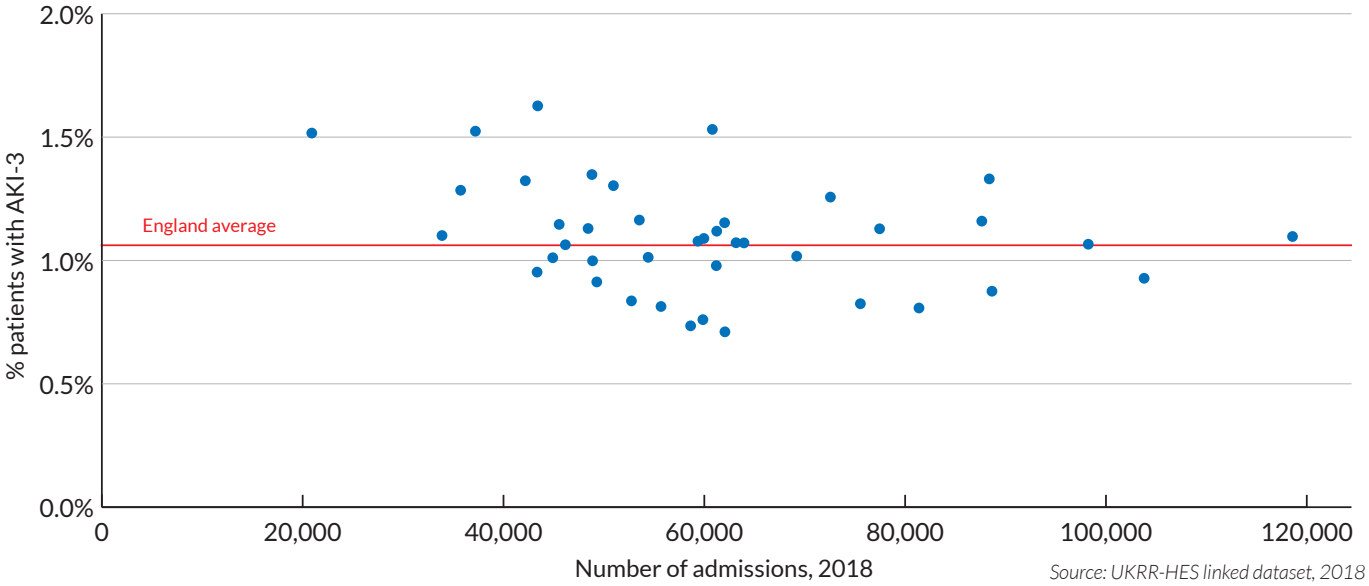
Figure 25: Incidence of acute kidney injury in emergency admissions to acute trusts*



Source: UKRR-HES linked dataset, 2017

*Numerator: Hospital-acquired and admitted community-acquired AKI. Denominator: all emergency admissions. Unadjusted.

Figure 26: Percentage of all admissions to trusts with a renal service complicated by AKI3



Source: UKRR-HES linked dataset, 2018

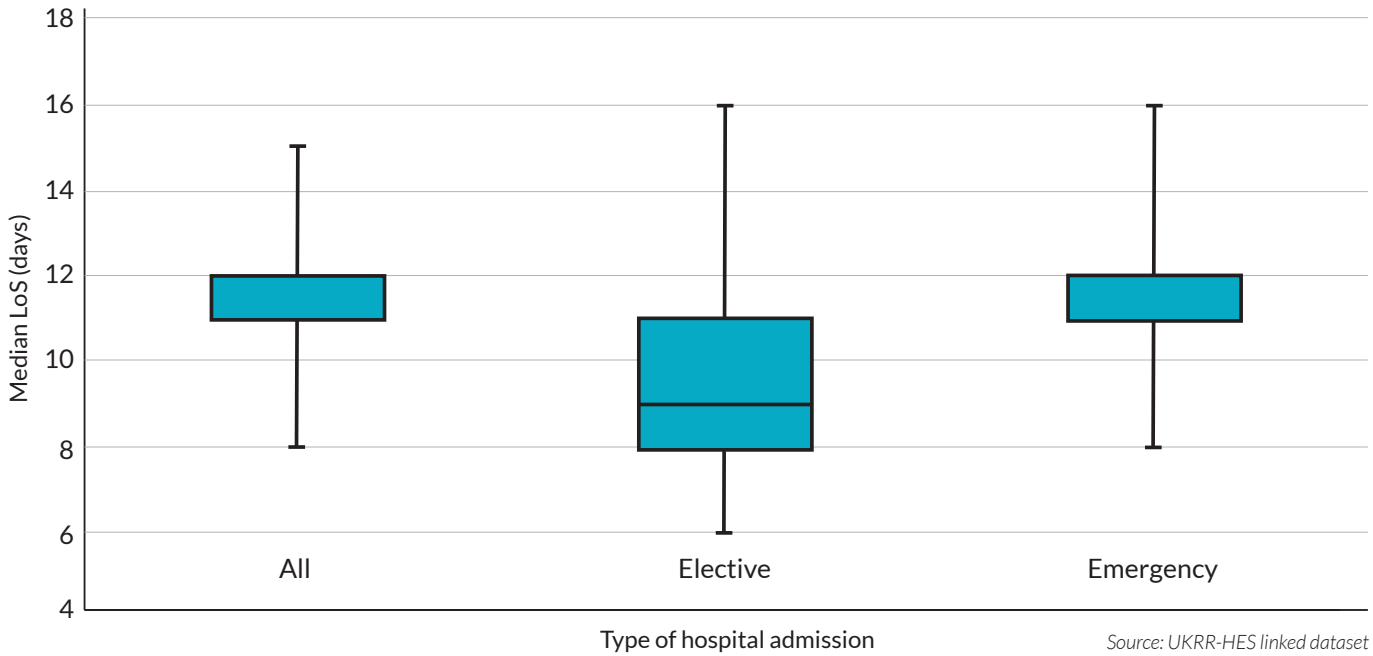
*Numerator: Hospital-acquired and admitted community-acquired AKI3. Denominator: all emergency admissions and elective admissions excluding day cases. Unadjusted.

In addition to casemix, there are a number of possible explanations for these variations, including variable levels of investment in staff training to identify, prevent and care for patients with AKI or at risk of developing AKI.

Length of stay (LoS) in hospitalised acute kidney injury (AKI)

Hospitalised AKI is associated with prolonged hospitalisation, with a median LoS of 12 days overall, 10 days in elective admissions and 12 days in emergencies[123] (see **Figure 27**). There is marked centre variation of between 6 and 18 days for elective admissions and 8 to 16 days for emergency admissions. Given how common AKI is, even a modest reduction in LoS across the NHS would have a significant impact on patient experience and use of resources.

Figure 27: Median length of stay in admitted AKI to acute trusts in England*



Source: UKRR-HES linked dataset

* Hospital-acquired and admitted community-acquired AKI. The box shows the median and interquartile range (IQR) and the whiskers are the minimum and maximum values. The median and third quartiles for the "All" and "Emergency" admissions boxplots coincide.

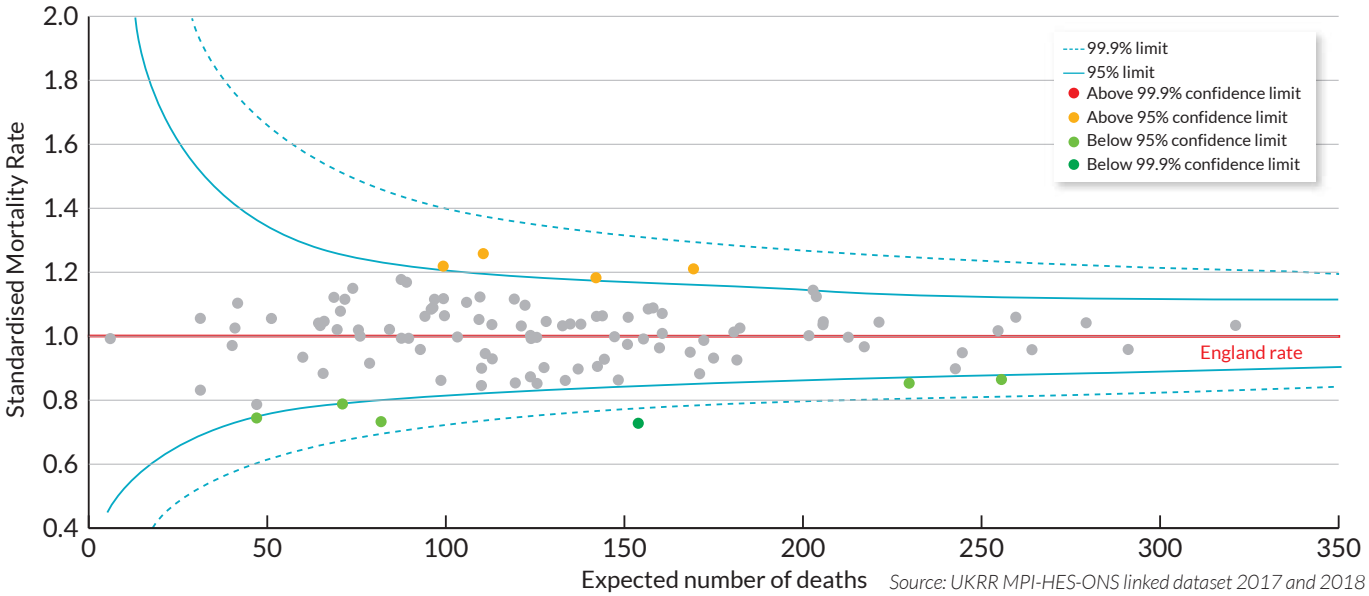
[123] *Figures from https://www.renal.org/resource/aki-report*

Mortality in hospital-acquired acute kidney injury (AKI)

Comparison of mortality between different acute hospitals requires careful casemix adjustment. A variety of methods exist. Linkage of the HES dataset with the UKRR MPI has enabled us to develop an adjusted mortality rate after hospital-acquired AKI for 106 acute adult trusts in England which have complete data returns to the MPI in 2017 and/or 2018. UKRR has adapted the SHMI[124] methodology that reports a standardised mortality rate (SMR) for hospital-acquired AKI. Importantly, AKI is identified using the internationally agreed biochemical criteria rather than by clinical coding.

AKI is a feature of all acute hospitals, not just those with a renal service, and in this metric we report on outcomes for renal and non-renal trusts. Mortality in hospital or within 30 days of discharge was 26.3%, 39.8% and 43.0% for AKI1, AKI2 and AKI3 respectively. **Figure 28** shows the degree of centre variation in the standardised mortality rate for AKI2/3 combined (0.73 to 1.26). No trust had an SMR above the 99.9% confidence limit but one had a significantly low SMR and a number of trusts sit above and below the 95% confidence limit.

Figure 28: Standardised mortality* in hospital-acquired AKI2/3 in 106 acute trusts



Source: UKRR MPI-HES-ONS linked dataset 2017 and 2018

* Mortality defined as death in hospital or within 30 days of discharge following the first hospital-acquired AKI warning alert. Adjusted for age, sex, month of admission, AKI stage, primary diagnosis, comorbidity score and admission method and interactions between age and AKI stage, age and comorbidity, and primary diagnosis and comorbidity.

Clinical coding of acute kidney injury (AKI)

AKI is recorded by clinical coders as 'N17 Acute Renal Failure', a legacy term that is still used in International Statistical Classification of Diseases Version 10 (ICD10). GIRFT/UKRR analysis[125] of HES data from 2017 shows generally poor coding accuracy, which improves with ascending AKI stage. When AKI alerts are compared with clinical coding practice in English trusts, 81% of AKI3 cases have an N17 code (range 57% –98%), 69% of AKI2 (range 43%–97%) and 47% of AKI1 (range 19%–94%). There is no evidence that trusts with a renal centre code with any greater accuracy. An NHS England Commissioning for Quality and Innovation (CQUIN) promoted reporting of AKI in discharge summaries. It is likely that this has led to improvement of AKI coding[126].

How care for patients with acute kidney injury (AKI) is organised

There is variation in the extent to which those at risk of developing AKI are being identified, and in whether actions are undertaken in a timely preventative manner (including optimal fluid and medicines management to avoid or prevent AKI progression). GIRFT questionnaire data shows that even in trusts with a renal service, only 87% had a written AKI protocol.

[124] *https://www.digital.nhs.uk/SHMI*

[125] *https://www.renal.org/resource/aki-report*

[126] *https://www.england.nhs.uk/wp-content/uploads/2015/03/9-cquin-guid-2015-16.pdf*

An NCEPOD review[127] of cases involving patients with AKI who died rated care as good in only half of cases. It also found significant delays in the identification of AKI. In one-fifth of cases, the AKI episode was preventable. In response to this and other evidence, 35% of trusts with a renal service have established an AKI specialist nursing team to work with nephrologists and intensivists to improve patient care both in centre and in some cases through outreach to neighbouring acute hospitals in their network. AKI care has a large degree of overlap with the general principles of managing the deteriorating patient and in many trusts the critical care outreach team meets this need.

However, variation remains in the extent and effectiveness of outreach and development of AKI care bundles[128] – a structured set of practices designed to improve care delivery and ensure better patient outcomes – in respect both to other local specialties and surrounding hospitals that do not have a renal service. Many renal services provide onsite inpatient AKI support to surrounding hospitals (usually covering weekday periods) whereas others provide a referral and advice telephone arrangement. An innovative approach to AKI care in non-renal acute trusts has been the creation of hybrid posts, jointly appointed with a renal trust. Appointment of consultant physicians in non-renal trusts who are dually accredited in acute medicine and renal medicine can add to the quality of AKI care and improve the collaboration within an AKI network.

The importance of medicines management in AKI, and variation in pharmacy input, is discussed in *Pharmacy and medicines optimisation* (page 109).

Patient education has an important role in AKI prevention and therapy, both in primary and secondary care. This is embraced in NICE NG148 and further resource is available from Kidney Care UK and the RA[129].

Reporting of dialysis-dependent acute kidney injury (AKI)

Clinicians report that the lack of a mandatory tariff for patients with AKI requiring HD has had an adverse impact on the funding of AKI services and on AKI-HD reporting. The RA has described the current situation, in which renal centres provide HD for AKI unfunded, as 'unsustainable'[130].

As a result, many centres were using the chronic HD tariffs for patients with AKI receiving dialysis, rather than the relevant HRG. This results in inaccurate information and reporting of the ESKD metric. Likewise, very few centres are reporting AKI HD activity to the UKRR. Reference cost data clearly demonstrates that patients with dialysis dependent AKI consume significantly more healthcare resource per dialysis than a stable patient with ESKD.

Delays in transfer of patients with severe acute kidney injury (AKI)

As AKI is a medical emergency, patients who develop single organ AKI3 and do not respond to initial medical intervention should be referred to a nephrologist or, in the case of multiple organ failure, to critical care services. Those patients who develop advanced AKI or whose AKI is caused by intrinsic renal disease and who are in a hospital without acute renal services will need urgent transfer to a hospital with a renal centre.

GIRFT has identified significant delays in the transfer of patients with advanced AKI from referring hospitals to renal centres: 73% of renal centres report delays in transfer of more than 24 hours and of these, 100% reported adverse patient outcomes as a consequence of the delay. These outcomes included deterioration in the patient's condition and having to admit patients to critical care solely to enable continuous RRT, thus using unnecessary critical care resources.

HES data supports this view. There is significant variation in the time from admission to first dialysis in AKI: 4.3 days for those patients admitted directly to a hospital with a renal centre compared with an average 9.2 days for patients initially admitted to a referring hospital (see **Figure 29**). In some cases this may be clinically appropriate, for example where a patient needs critical care to stabilise them before transfer, but the variation taken together with the clinical survey indicates otherwise.

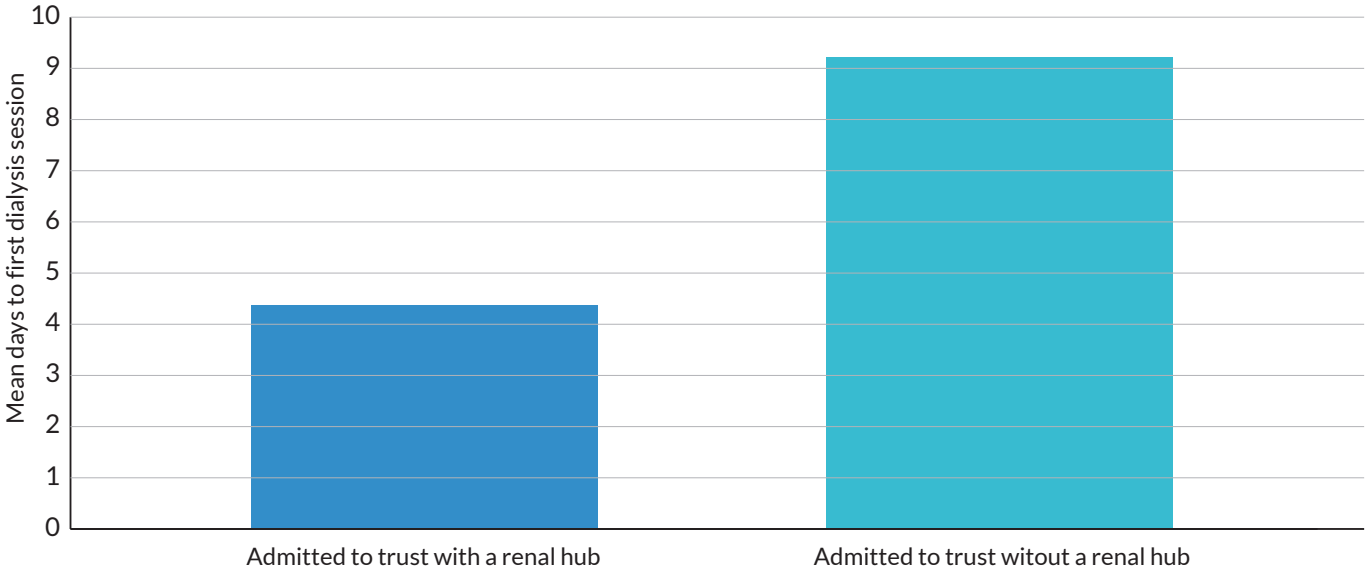
[127] *https://www.ncepod.org.uk/2009report1/Downloads/AKI_report.pdf*

[128] *https://www.thinkkidneys.nhs.uk/aki/wp-content/uploads/sites/2/2020/03/AKI-care-bundle-2020.pdf*

[129] *https://www.renal.org/wp-content/uploads/2017/06/KCUK-AKI_web.pdf*

[130] *Proposed Renal Tariffs 2017–2019 Compared with Past 2 Years: Renal Association Response to NHS Improvement.*

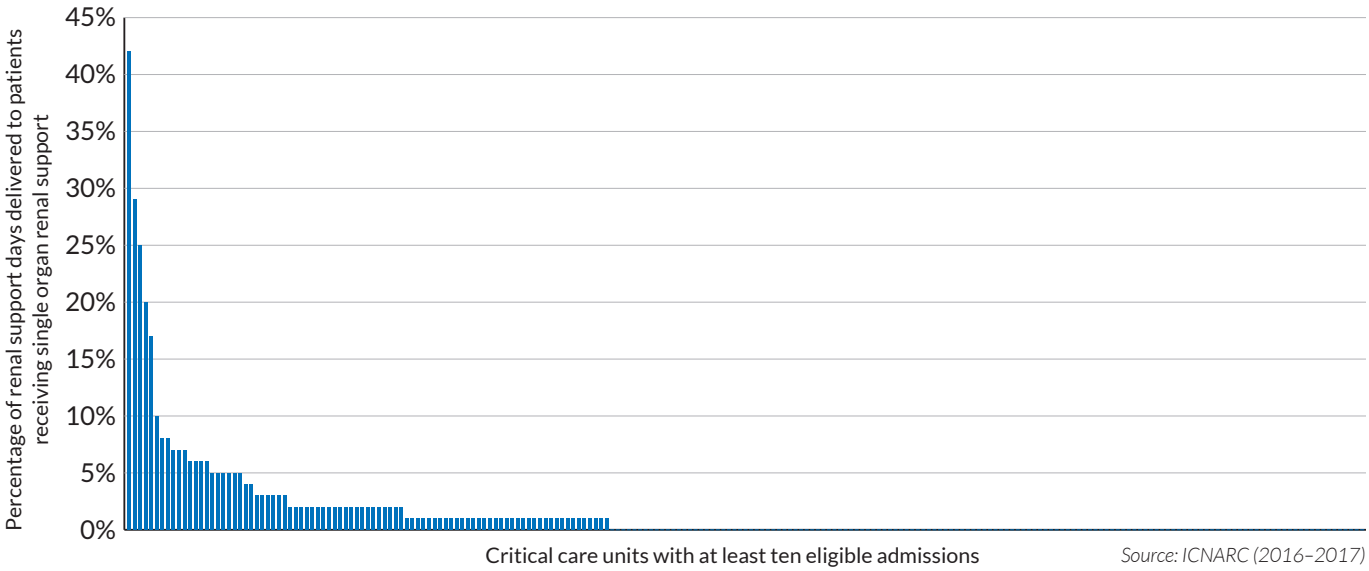
Figure 29: Difference in time to first dialysis for acute kidney injury patients in different settings (renal centres vs non-renal centres)



Source: HES (July 2018–June 2019)

Factors contributing to inappropriate delay include lack of bed access in trusts with renal centres and lack of an agreed inter-hospital transfer standard: only 58% of renal centres reported a written transfer protocol. Those patients stepping down from critical care with ongoing single organ kidney failure still requiring RRT are another group with similar limited access to renal services. This results in sub-optimal clinical care with adverse clinical outcomes. The health economic consequences are substantial: the National Critical Care database shows that in some critical care facilities a disproportionately high number of bed days are taken up by patients with single organ kidney failure (see **Figure 30**).

Figure 30: Percentage of renal support days delivered to patients in critical care with single organ renal support



Source: ICNARC (2016–2017)

Access to nephrostomy in patients with acute kidney injury (AKI)

Bilateral ureteric obstruction or ureteric obstruction in a single kidney is a remediable cause of AKI requiring urgent management, usually best treated by insertion of nephrostomy (or nephrostomies) by an interventional radiologist.

The GIRFT questionnaire found that only half of renal centres currently offer seven-day access to nephrostomy whether on- or off-site, even though this is a requirement set out in both the NSS[131] and NICE NG148 on the prevention, detection and management of AKI.[132] Indeed, NG148 sets a challenging target of intervention within 12 hours. It was identified at the deep dives that there is significant lack of capacity in the IR workforce across many trusts and there is no imminent likelihood of resolving this issue. GIRFT and the renal services involved considered the current situation to be unacceptable from both a clinical and service perspective.

Those trusts not currently able to meet the requirements of NICE and the NSS will need to collaborate on a regional network basis with providers that do offer seven-day IR cover to ensure that in urgent cases, patients undergo inter-hospital transfer to enable access to nephrostomy within six hours.

Resilience of acute kidney injury (AKI) services in critical care during the COVID-19 pandemic

The GIRFT visits took place before the COVID-19 pandemic but AKI was a common feature in patients admitted to critical care with COVID-19 infection. Continuous RRT (CRRT) rather than HD or PD is the standard form of renal replacement in UK critical care facilities. At the first peak of the pandemic when demand was exceptionally high, capacity for CRRT was overwhelmed, mainly due to lack of CRRT consumable supplies and, in a few facilities, insufficient CRRT machines. RRT of some form was required for 26% of COVID-19 patients admitted to critical care and 61% of these patients died.[133] Renal services provided essential support to critical care by delivering HD and in some centres acute PD, usually in critical care units co-located with a renal hub. This required great flexibility on the part of renal MDTs, including technical staff. Critical care services wish to maintain this resilience to treat patients with AKI using all modalities of RRT in the longer term and will collaborate with renal services to achieve this.

CASE STUDY

Nurse-led AKI care

Portsmouth Hospitals University NHS Trust

Wessex Kidney Centre has been delivering a nurse-led AKI service since 2016.

The AKI team comprises a consultant nephrologist lead, two renal ANPs and one clinical specialist nurse. The team is able to support inpatient AKIs trust-wide, by providing quick inpatient reviews in 'real time' via the electronic alert system provided by VitalPAC® clinical. This is helping to foster excellent working relationships across the trust, and supporting the effective identification, treatment, management and education of AKIs by experienced nephrology nurses.

Through this, the aim is to provide a service that continues to focus on improving patient experience and outcomes, as well as being committed to service improvement projects to track and manage AKI alerts and AKI deteriorations and ultimately, to be advocates for good kidney health for all.

[131] *https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/a06-spec-acu-kidney-inj-ad.pdf*

[132] *https://www.nice.org.uk/guidance/ng148*

[133] *ICNARC report on COVID-19 in critical care 12 June 2020. https://www.icnarc.org/Our-Audit/Audits/Cmp/Reports*

Recommendations

Recommendation	Actions	Owners	Timescale
7. Ensure that all acute trusts implement patient safety measures (as set out in NICE NG148) to deliver highly effective prevention, detection and management of AKI.	**a** All trusts to implement the recommendations set out in NICE NG148.	All trusts	Within 24 months of report publication
	b All trusts to ensure delivery of AKI care bundles as the first response to an AKI alert (shown to improve care quality and reduce length of stay (LoS)).	All trusts	Within 24 months of report publication
	c UKRR to report comorbidity and casemix-adjusted AKI incidence and mortality in all acute trusts and publish this data in Model Hospital and the UKRR annual report.	UKRR and GIRFT	Within 24 months of report publication
8. Mandate clinically-approved AKI patient transfer to a renal centre within 24 hours of the decision by the receiving consultant nephrologist.	**a** NHS England AKI NSS to include the requirement for regional network working and to issue AKI patient transfer policy requiring transfer within 24 hours.	NHS England Specialised Commissioning, accountable commissioners, regional renal networks, ICSs	Within 12 months of report publication
	b Regional renal networks to monitor delayed transfer by means of exception reporting by referring or receiving centre.	Regional renal networks	Within 12 months of report publication
	c NHS England and NHS Improvement to develop a mandatory tariff or equivalent commissioning mechanism for AKI requiring HD which will support AKI service delivery and ensure accurate reporting of AKI HD.	NHS England and NHS Improvement, accountable commissioners	Within 24 months of report publication
	d Renal networks, acute trusts and ICSs to ensure urgent nephrostomy insertion (within 12 hours, 7 days per week as per NICE NG148) is achieved through network collaboration making best use of available IR resource; efficient inter-hospital transfer will be required.	Renal networks, acute trusts and ICSs	Within 12 months of report publication

Outpatients

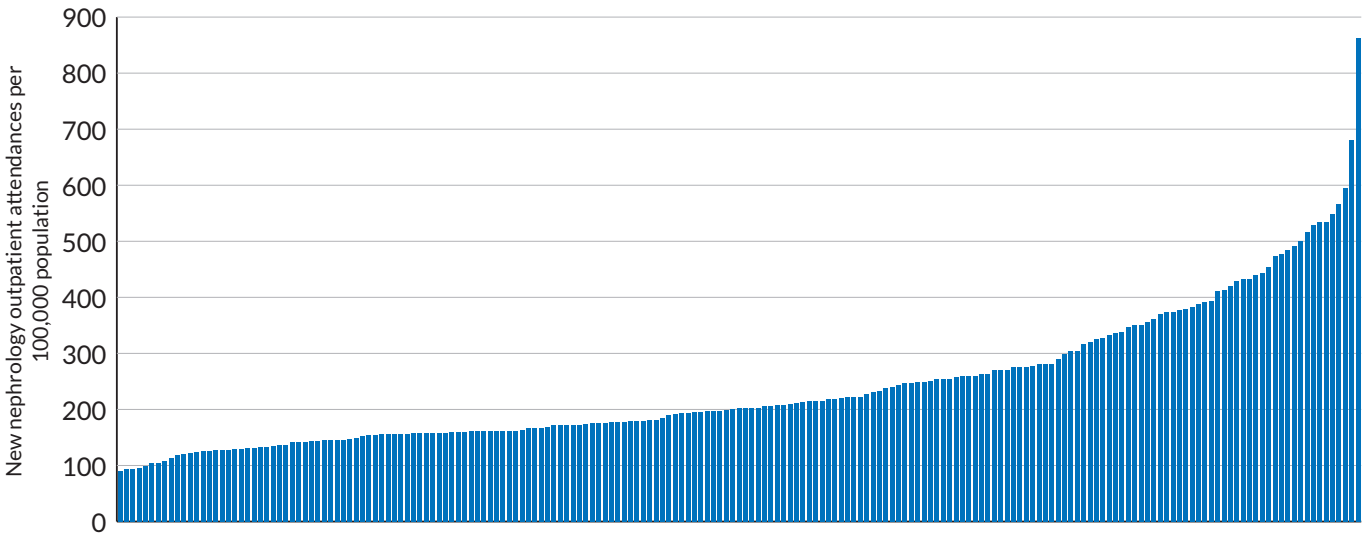
A substantial proportion of nephrology activity is outpatient based. Demand per 1,000 of the population has risen by 30% since 2014/15. Improvements in renal outpatient delivery would have a major beneficial impact on patient care and trust and primary care resource. Within the NHS LTP, the linked Outpatient Transformation Programme[134] targets a reduction of up to one-third in face-to-face consultations which should be a minimum target for renal services. This requires co-ordinated care and planning across an ICS and should be enabled and supported through ICSs and the Virtual CKD special interest group of the RA and BRS. The latter is actively exploring QI approaches to implement both virtual and remote outpatient models.

GIRFT identified considerable variation in new nephrology outpatient rates and models of outpatient care, including in levels of access to subspecialty renal clinics. Access to and maturity of remote or virtual clinic development was also highly variable.

There is significant geographical variation in both the predicted prevalence of CKD and the likelihood of patients with CKD being identified in primary care. Predicted prevalence of CKD within a given CCG is derived from an epidemiological model and can be compared with the recorded prevalence in primary care[135]. The disparity between the predicted and observed prevalence indicates that primary care facilities in some CCGs have inadequate systems for identifying CKD patients and placing them on their CKD register.

In addition to these epidemiological factors, there is large variation in practice between CCGs in nephrology outpatient referral, as shown in **Figure 31**.

Figure 31: New outpatient appointments per 100,000 population by clinical commissioning group*



* Denominator adjusted for age and sex.

Source: NHS RightCare 2017–18

This may be a consequence of differing thresholds for referral from primary care and/or acceptance of referral by secondary care. The NICE guidelines on CKD (CG182)[136] define thresholds for referral to secondary care but these should be viewed with caution: many patients with CKD who are not at high risk of progression do not require secondary care review. The use of prediction equations may make it easier to define thresholds for referral, and the Kidney Failure Risk Equation has recently been validated in a UK setting[137].

Psychosocial and physical enablement resource is lacking in many renal outpatient centres (general and specialised) as well as outpatient dialysis settings, as evidenced in the AKCC survey presented on page 38. This represents a major lost opportunity for quality care and promotion of the concept of 'living well with kidney disease'[138].

[134] *https://www.england.nhs.uk/outpatient-transformation-programme/*

[135] *https://www.fingertips.phe.org.uk/profile-group/cardiovascular-disease-diabetes-kidney-disease*

[136] *https://www.nice.org.uk/guidance/cg182*

[137] *Major, R.W., Shepherd, D., Medcalf, J.F., Xu, G., Gray, L.J., Brunskill, N.J. (2019) The Kidney Failure Risk Equation for prediction of end stage renal disease in UK primary care: An external validation and clinical impact projection cohort study. PLoS Med., 16(11): e1002955. https://www.journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002955*

[138] *Fraser, S., Taal, M. (2020). British Journal of Hospital Medicine, 81 (6). https://www.magonlinelibrary.com/doi/abs/10.12968/hmed.2020.0069*

Nephrology outpatients and new ways of working

The traditional outpatients model has remained unchanged for decades, but is no longer adequate for the delivery of optimal modern care. The advent of digital health records and IT solutions are creating opportunities to improve this approach for the benefit of patients in both primary and secondary care.

Potential new methods of delivering outpatient care include remote interrogation of primary care IT with virtual specialist input, and consultation either by phone or video, with blood tests performed in advance in the community. Both offer significant benefits for patients in terms of reduced time commitment – including less time spent travelling – as well as reducing pressure on secondary care outpatient capacity.

The NHS LTP[139] highlights the Tower Hamlets Chronic Kidney Disease e-Clinics project as an example of how virtual clinics can help improve the management of both CKD and ESKD. There are multiple benefits, including GPs being provided with more timely input from specialists which in turn benefits patients who can then access further specialist care or be cared for appropriately in the community.[140]

However, the commissioning model must evolve to accommodate these new approaches. This will mean acknowledging that while a move to virtual consultations might not offer savings in terms of nephrologist time, it will reduce the overall cost to the NHS once costs such as estates and transport are factored in. To date, those trusts that have introduced alternatives to face-to-face appointments have done so by making financial arrangements at a local level, or without formal funding.

It is unlikely that there will be a 'one size fits all' solution as the clinical and IT environment is so varied across England. Although the Advice and Guidance facility within the NHS England e-referral system has now been rolled out nationally, it does not have sufficient functionality to meet the needs of CKD patients and the clinicians looking after them. The professional renal societies have developed a special interest group focused on supporting the future development of outpatient services, including virtual appointments. This will be embedded into regional QI structures. This is closely linked to KQuIP for regional support in implementation.

Impact of the COVID-19 pandemic on renal outpatient care

The impact of COVID-19 has dramatically expedited implementation of outpatient remote models across all trusts which should be further refined and supported. Non-face-to-face consultation became the norm during the pandemic and is a good example of a change that will be retained as renal services recover activity. Virtual renal clinics are only possible with good facilities for blood and urine testing and blood pressure (BP) measurement in the community. Again, the response to COVID-19 led to rapid development of community blood testing hubs in some regions.[141] Furthermore, some centres have made home testing available via a range of technologies, including BP and self testing of urine, to vulnerable patients.

[139] *https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf*

[140] *Hull, S.A., Rajabzadeh, V., Thomas, N. et al. (2020) Do virtual renal clinics improve access to kidney care? A preliminary impact evaluation of a virtual clinic in East London. BMC Nephrol., 21(1): 10. https://www.bmcnephrol.biomedcentral.com/articles/10.1186/s12882-020-1682-6*

[141] *https://www.thinkkidneys.nhs.uk/kquip/blog/drive-through-phlebotomy-service-developed-by-sheffield-teaching-hospitals-nhs-foundation-trust-during-the-covid-19-pandemic/*

CASE STUDY

New approaches to delivering outpatient services

East London Community Kidney Service

The East London Community Kidney Service was launched in November 2014 in response to three specific challenges:

- patient and staff experience of out-patient nephrology care was often poor;
- GPs were waiting for long periods for advice; and
- high levels of late presenting ESKD with untimely start among the local population.

Key workstreams

Four CCGs, the GP Care Groups in these boroughs, Barts Health NHS Trust and the east London Clinical Effectiveness Group, a GP-led quality improvement initiative, combined to build the service, which comprises four key workstreams:

1. **Virtual CKD consultations:** Barts nephrologists draw on patients' primary care history to provide written advice in the primary care record, easily accessible to GPs, within five to ten days of referral. This compares with waits of 64 days for a first attendance appointment in the year prior to service launch. Only those patients who nephrologists feel they need to see are then offered a clinic appointment – currently around 12% of all referred cases are brought to a 'hot diagnostic clinic' or a new patient appointment for consultant review. Consultants also offer education, advice and support to GPs.
2. **Specialist nurse support:** A CKD specialist nurse provides group or 1:1 education sessions and counselling for patients.
3. **CKD dashboards:** Each practice has a CKD dashboard to drive improvements in CKD coding, with the aim of reducing medication errors and increasing statin use and blood pressure control to mitigate the cardiovascular consequences associated with CKD. Practice facilitators work with primary care teams to share best practice, and comparative outcomes data drives improvement over time.
4. **eGFR trigger tool:** A declining eGFR tool is run on all kidney function tests in practices belonging to the service, ensuring that any patients with declining function can be referred for review either by a GP, or through referral for advice.

Results

The service was rapidly scaled up across four inner London boroughs – a catchment area of some 1.1 million people. Now in its sixth year, it has seen more than 8,000 patients virtually. The number of referrals made to nephrology has increased three-fold, reflecting the level of previously unmet need. Coding across east London is significantly improved (as high as 90% in some CCGs), and GP satisfaction with the service is high. It is too early to confirm any impact on unknown-to-service incident ESRD, but it seems likely that easy referral and the use of the trigger tool is leading to earlier diagnosis of progressive CKD.

See page 37 for information on advanced kidney care clinics (AKCCs).

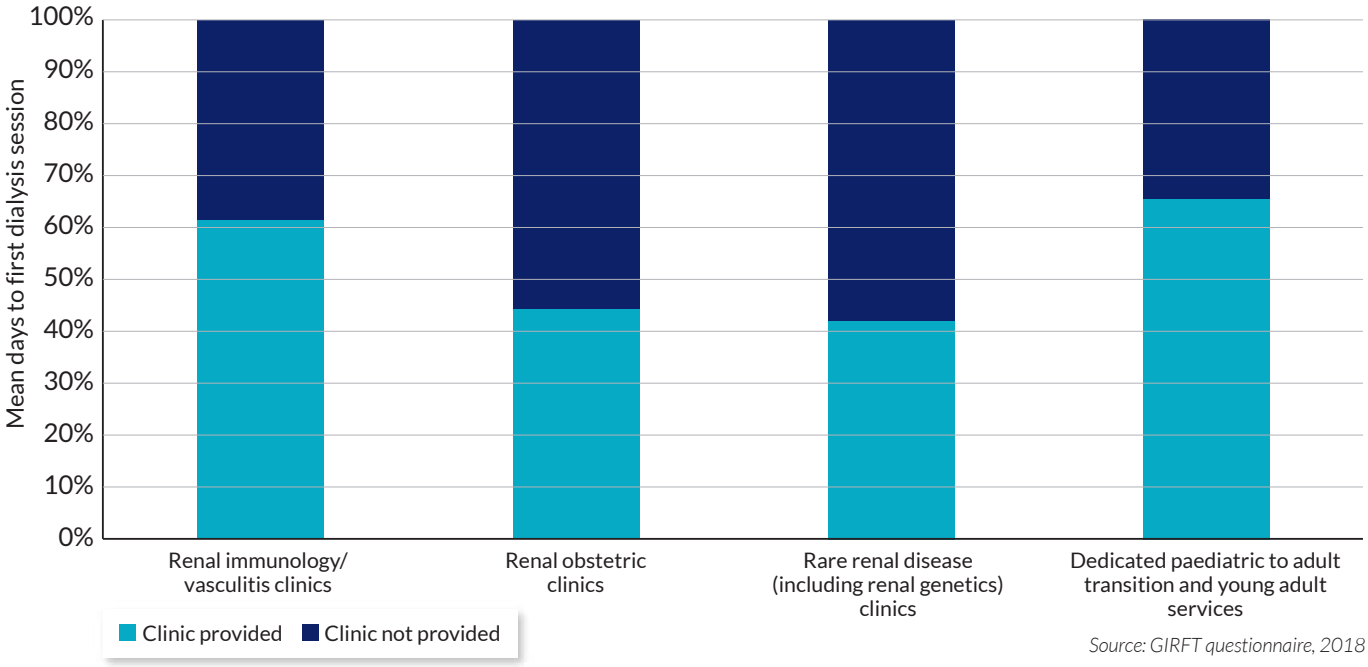
Access to sub-specialty clinics

The GIRFT questionnaire looked at provision of four categories of sub-specialist clinic:

- renal immunology/vasculitis clinics;
- renal obstetric clinics;
- rare renal disease (including renal genetics) clinics; and
- dedicated paediatric to adult transition and young adult services.

The results are summarised in **Figure 32**. Responses also showed that transplant centres are more likely to offer specialist clinic provision than non-transplant centres. All 19 transplant centre respondents offered a young adult/transition clinic – as mandated in the NSS – compared with 45% of non-transplant centres. It should be noted though that for some smaller centres, the annual number of patients under 25 may be too low to justify setting up and running a comprehensive service. These centres could look to work in collaboration with other specialties (e.g. rheumatology, diabetology, cardiology) or to adopt a regional approach. The overarching principles of an effective service are described in NICE NG43 on transition from childrens' to adults' services[142].

Figure 32: Provision of specialist clinics in English renal centres



Source: GIRFT questionnaire, 2018

For the other sub-specialisations, there is considerable variation, even among transplant centres. It is unrealistic to expect all centres to provide specialist support in all four areas by themselves – but there must be equity of patient access to specialisations at a regional level. Ensuring this should be an important function of the regional renal networks.

One area that is changing rapidly is the diagnosis and treatment of genetic renal disease. Once seen as a highly specialised area of care and considered the preserve of large teaching centres, genetic diagnosis is playing an increasingly important role in the investigation of many kidney diseases, and in screening potential live kidney donors where there may be a familial element.

Genomics England recognises the need to expand access to genetic testing by specialists in the near future, opening up an important opportunity for renal services. Current service models, where individual patients have access to a clinical geneticist and support from a counsellor, will no longer be practicable as demand increases. Genomic testing for specified conditions is now available to nephrologists, a substantial shift in access that represents a major diagnostic opportunity[143]. There is also a significant training deficit to make up, as most nephrologists are not formally trained in consenting patients for genetic tests and need support from genetic experts to interpret results.

[142] *https://www.nice.org.uk/guidance/ng43*

[143] *https://www.england.nhs.uk/publication/national-genomic-test-directories/*

Currently, the care of adult patients with rare diseases that affect the kidneys is subject to significant variation across England and within regions. Such conditions are best managed through specialist centres where expertise is concentrated and which can offer access to specialist therapies, co-ordinated monitoring and research opportunities[144]. Each region should signpost patients with rare kidney diseases to appropriate expertise within their geography. The principles of rare disease care apply equally to patients with immune mediated renal disease and women with kidney disease in pregnancy. Looking ahead, a network approach will be key to ensuring equitable access to both renal genetics and rare disease clinics.

Transplant outpatient follow-up

Both the RA/BTS Guidelines[145] and the NSS[146] state that transplant patients should be seen two to three times a week in clinic in the first weeks post-surgery. The frequency will decrease over time as patients become more stable, typically to one appointment every three to four months after the first year.

The two to three times weekly review standard reflects an era when acute rejection was a common event after transplantation, compared with around 10% incidence with modern anti-rejection therapy. Some centres are seeing patients less often and some have adopted a standard of twice-weekly review in the early post-transplant follow up period (although this has been subject to criticism by the NHS England Quality Surveillance Team). A small number of centres are delivering transplant patient review remotely while still ensuring timely access to blood test results, achieving good levels of patient satisfaction and reducing travelling time and costs. Remote follow-up for this highly vulnerable group has been encouraged during the COVID-19 pandemic, as has offsite patient blood sampling. The fact that this has proved popular with many patients and clinicians should support ongoing service redesign.

Comparative data on post-transplant follow-up has not previously been available to the renal community. The current mean frequency of transplant outpatient follow-up in the first six months varies from 19 to 35 visits. Despite this, there is no evidence from HES data that centres with less frequent early follow-up have higher readmission rates or poorer patient outcomes. Scope remains for more frequent follow-up in very complex patients. We believe that the value of more frequent overall post-transplant follow-up is unproven and the default frequency of early post-transplant review can therefore be reduced, and remote consultations increased where appropriate.

Clinicians reported inadequate medical transplant outpatient capacity, as a result of the welcome growth in renal transplantation rates. Some centres have responded to this – and also sought to improve standards of care – by integrating expanded allied health professional support including advanced clinical practitioners and multiprofessional consultant support. Transplant pharmacist input was highlighted as playing a particularly important part in delivering more effective care in transplanting centres. Advanced pharmacist input is also required for transplant patient follow-up in non-transplant centres. As in nephrology care, growth in innovative methods of transplant outpatient follow-up should be encouraged and supported by realistic commissioning arrangements.

[144] *https://www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/781472/2019-update-to-the-rare-diseases-implementation-plan-for-england.pdf*

[145] *https://www.renal.org/wp-content/uploads/2017/06/FINAL-Post-Operative-Care-Guideline-1.pdf*

[146] *https://www.england.nhs.uk/wp-content/uploads/2017/05/service-spec-adult-kidney-transplant-service.pdf*

Recommendation

Recommendation	Actions	Owners	Timescale
9. Ensure that outpatient services are reformed in line with the NHS LTP to improve equity of access, patient experience and timeliness.	**a** Renal centres to provide a comprehensive e-referral and non-face-to-face new and follow-up outpatient service across all general nephrology and specialised clinics.	Renal centres	Upon report publication
	b Provision of remote blood and urine sampling, either in community hubs or by dry chemistry, to be established to facilitate non-face-to-face consultations.	ICSs and acute trusts	Upon report publication
	c Improvements to be made to ensure appropriate primary care referral to nephrology services and AKCC transfer through adoption of CKD progression prediction equations embedded in biochemistry laboratory and renal centre IT systems.	Renal services, including primary care and biochemistry laboratories	Within 24 months of report publication
	d Trusts to ensure equity of patient access to sub-specialty renal clinics[147] within each regional network through a hub and spoke model.	Renal centres	Within 24 months of report publication
	e Renal and transplant centres to transform post-transplant follow up, embedding remote consultation and blood sampling whenever suitable, and reduce default frequency for early post-transplant follow-ups to bi-weekly.	Renal and transplant centres	Within 24 months of report publication
	f Ensure sufficient pharmacy input to allow for safe and efficient hospital prescribing and supply of immunosuppressant therapies usually involving homecare services.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	g Ensure there is adequate workforce to support psychosocial and physical enablement needs in all outpatient settings.	Accountable commissioners, ICSs, renal centres	Within 24 months of report publication

[147] *Including renal genetics, renal/obstetrics, young person/transition, rare disease and immunological renal disease clinics.*

Patient experience

Renal medicine was one of the first services to enable patients to access their own information online via the UKRR's PatientView portal. It was also one of the first specialties to introduce large scale PREMs reporting in patients with ESKD across 13 domains.

The renal PREM programme has undergone significant development and validation by UKRR since it was introduced. Data returns to the PREM are not mandated in the NHS England NSS and the mechanism of PREM return is not standardised. For example, there is no random sampling method and no adjustment for the fact that PREM returns from different centres have widely varied levels of inclusion. PREM returns are dominated by HD patients but in some centres a significant number of transplant patients are included. Further work by UKRR is required to develop a more robust sampling strategy. Developing Patient Reported Outcome Measures (PROMs) for renal outpatient care should be a future aim for UKRR. Donor Reported Outcome Measures (DROM) and Experience Measures (DREM) were introduced by NHSBT in January 2019 and January 2020 respectively.

The lessons learned from the PREM are important to national and local policy decisions regarding the organisation of care. Around 16,469 people took part in the PREM survey in 2019. Overall, the patient experience is a positive one, with a score of 6.3 out of 7[148]. This was borne out by GIRFT deep dives, in which patients spoke of committed staff providing an excellent service.

There are, however, three key areas where there is significant variation in patient satisfaction between renal centres which should be addressed:

- HD non-emergency patient transport (NEPT);
- needling of HD arteriovenous vascular access; and
- SDM.

Non-emergency patient transport

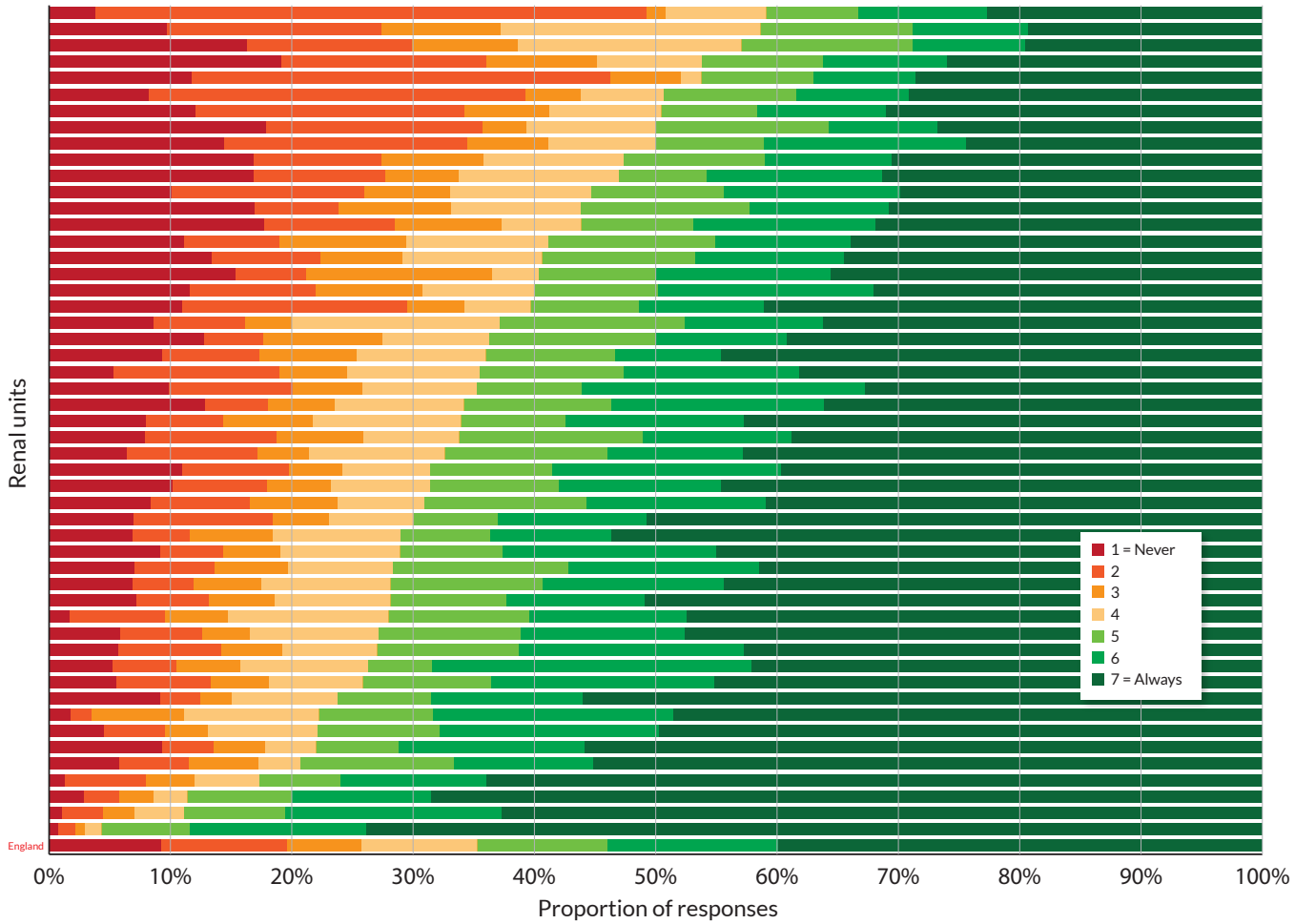
Almost 21,000 people receive ICHD in England[149]. Most of these patients receive three HD sessions every week which equates to an average of 312 back and forth journeys per year per patient. The median patient age is 68, many are frail with multiple comorbidities and patients are often at their weakest at the end of the four-hour dialysis treatment. GIRFT identified that the average direct journey out and back is 12km but the actual journey is longer as multiple patients are often picked up and dropped off along the way using shared vehicles.

For most patients receiving HD, NEPT is an integral part of their episode of care. Despite this, patient satisfaction with HD NEPT is consistently the lowest scoring section with the greatest variance in the PREM survey (see **Figure 33**, page 86). This is backed up by feedback from deep dives where poor quality dialysis transport was consistently high on the agenda for public and patient voice representatives and staff.

[148] *https://www.renal.org/wp-content/uploads/2017/05/PREM-report-2019-final-web-copy.pdf*

[149] *https://www.renalreg.org/reports/data_to_end_2017/*

Figure 33: Responses to PREM questions on transport, by centre: 'Once your visit to the renal centre is finished and you are ready to leave, are you able to leave within less than 30 minutes? Is the time it takes to travel between your home and the renal centre acceptable to you?'



Source: Patient Reported Experience of Kidney Care in the UK 2019, Renal Association and Kidney Care UK (combined scores from two questions)

A recent national report commissioned by Kidney Care UK, the National Kidney Federation and the UK professional renal societies identified significant variation in the proportion of patients on HD in trusts accessing NEPT. There was also wide variation in service quality and organisation, including eligibility criteria and commissioning arrangements[150]. Addressing the problem of transport would arguably lead to the single most significant improvement in the quality of patients' experience.

Since that report was published, the COVID-19 pandemic has highlighted the infection, prevention and control risks of shared dialysis transport. NEPT for dialysis changed radically during the first peak of the pandemic, with a temporary move to a single patient per vehicle in most areas. Patients were also strongly encouraged to seek transport provision from household members/carers. This was successful in some facilities, and has potential to improve patient experience, but is not sustainable for many patients in the longer term. Nevertheless, it has led to suggestions by NEPT providers that patient-initiated transport options could be more actively explored when patients start HD. This would require straightforward and timely reimbursement for patients/carers, e.g. via Personalised Healthcare Budgets, which have been piloted in a few centres.

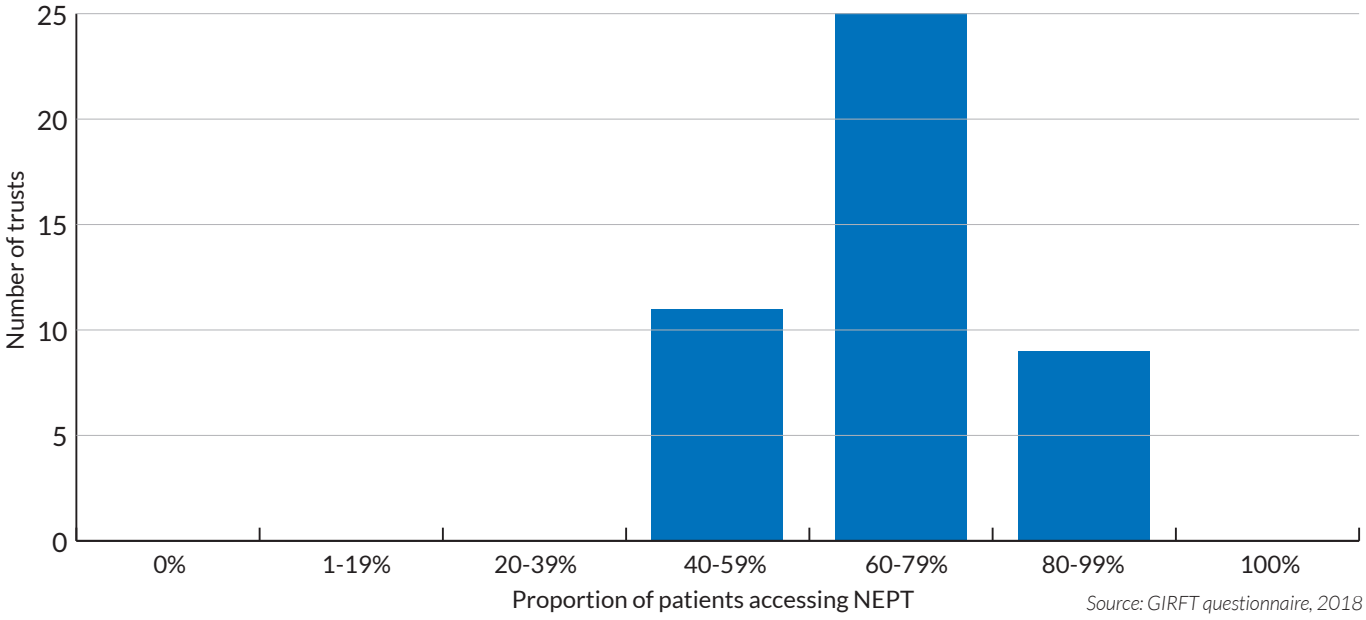
NHS England and NHS Improvement does not collate any central data on the cost or volume of NEPT. Only estimates are available. The majority of patients on ICHD, estimated at 78% by NICE[151], receive NEPT to and from dialysis. This was consistent with the findings of the GIRFT questionnaire, as shown in **Figure 34**. These journeys in total are considered to be around 50% of all NEPT[152].

[150] *Loud, F., Jenkins, K., Cockwell, P., et al. (2019) Dialysis Transport: Finding a Way Together https://www.thinkkidneys.nhs.uk/ckd/news/comprehensive-kidney-patient-transport-guidance-launched/*

[151] *https://www.nice.org.uk/guidance/ng107/evidence/b-modalities-of-rrt-pdf-6542344047*

[152] *Loud, F., Jenkins, K., Cockwell, P., et al. (2019) Dialysis Transport: Finding a Way Together https://www.thinkkidneys.nhs.uk/ckd/news/comprehensive-kidney-patient-transport-guidance-launched/*

Figure 34: Percentage of in-centre haemodialysis patients who access non-emergency patient transport



Source: GIRFT questionnaire, 2018

NICE estimates that the average annual cost of NEPT for an ICHD patient is £4,058, an aggregated figure which allows for the wide range of quoted journey costs and the fact that not all patients use funded transport. Given the size of the HD population this equates to an annual spend of around £85 million in England in 2017, although according to Kidney Care UK this is likely to be a significant underestimate[153].

GIRFT questionnaires identified commissioning as a key factor limiting improvement in provision of NEPT for ICHD patients, and this was confirmed during the deep dives. In most trusts, NEPT is commissioned by CCGs while the HD service itself falls under Specialised Commissioning. Trusts have little opportunity to contribute to the setting of key performance indicators and – often – minimal input into monitoring of the contract. This is unsatisfactory and underlies an inefficient and costly service. Moreover, for those patients arranging their own transport, there is a range of different centre policies for reimbursement[154].

GIRFT supports the findings and principle recommendations of the national dialysis transport review[155]. NEPT for ICHD should be considered an integral part of the episode of care. Patients should have influence over their transport arrangements. Clinical services, commissioners and providers should work together to ensure high quality and cost efficient services and contract key performance indicators should be embedded and reviewed. This has important implications for future commissioning. The cost of transport is specifically excluded for HD tariff and reference costs. Sir Simon Stevens, chief executive of the NHS, announced a national review of non-emergency patient transport in 2019, providing an opportunity to deliver the above recommendations[156].

Needling of haemodialysis vascular access

The successful creation, effective use, maintenance and longevity of HD vascular access is critical to HD delivery. For most patients this will involve the skills and expertise of a dialysis nurse needling an AV fistula or, less commonly, AV graft access three times per week. The substantial inter-centre variation in incident and prevalent AVF/G rates is discussed in *Vascular access for haemodialysis* (HD), page 52.

Assessment, monitoring and good needling technique reduces complications and extends the lifespan of the AV access, facilitating optimum dialysis delivery. Poor technique can lead to complications including AVF stenosis, aneurysm development, site infections, haematoma, pseudoaneurysm, bleeding and pain.

A report from the Standardised Outcomes in Nephrology (SONG) study identified management of vascular access as a core outcome critical to patients and caregivers[157]. While it should be noted that the majority of patients are satisfied with the standard of care they receive, the 2019 PREM survey shows significant variation in quality outcomes between centres (see **Figure 35**, page 88).

[153] *ibid.*

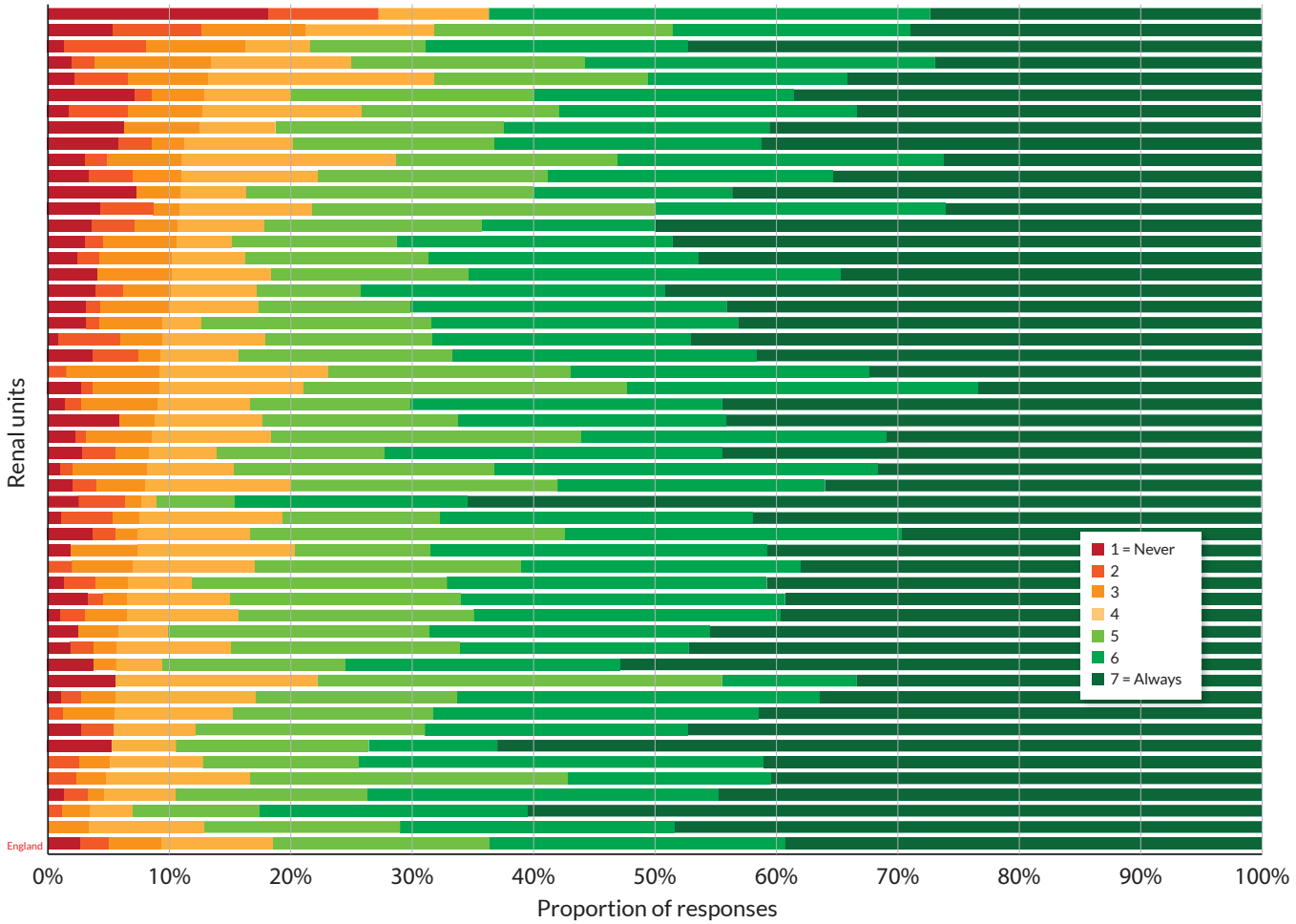
[154] *ibid.*

[155] *ibid.*

[156] *https://www.england.nhs.uk/nepts-review/*

[157] *Viecelli, A.K., Howell, M., Tong, A., et al. (2020) Identifying critically important vascular access outcomes for trials in haemodialysis: an international survey with patients, caregivers and health professionals. Nephrol.Dial. Transplant, 35(4): 657-668. https://www.pubmed.ncbi.nlm.nih.gov/31369099/*

Figure 35: Responses to PREM question for in-centre haemodialysis patients on needling, by centre: 'How often do the renal team insert your needles with as little pain as possible?'



Source: Patient Reported Experience of Kidney Care in the UK 2019, Renal Association and Kidney Care UK

Respondents raised specific concerns, including regarding poor needling technique and high staff turnover leading to a lack of continuity in their care. Patients often experience anxiety and pain during needling. Lead dialysis nurses and vascular access surgeons at the deep dives described the need for increased training to improve access to needling and monitoring.

It was clearly expressed to the GIRFT leads during deep dives and following discussions with professional associations that limited professional development opportunities for HD nurses contributes to this nationally. GIRFT supports the use of the excellent resources created by the BRS/VASBI expert working group on needling AV access[158] as a priority for adoption through adequate training.

GIRFT also welcomes the work being carried out by the MAGIC national quality improvement programme[159]. This is supported by KQuIP and comprises a structure to support local improvement with national oversight. The programme includes education, principles and practical support materials and metrics to improve practice and has regional project management support.

[158] *https://vo2k0qci4747qecahf07gktt-wpengine.netdna-ssl.com/wp-content/uploads/2018/09/Clinical-Practice-Recommendations-for-Needling-of-Arteriovenous-Fistulae-and-Grafts-for-Haemodialysis.pdf*

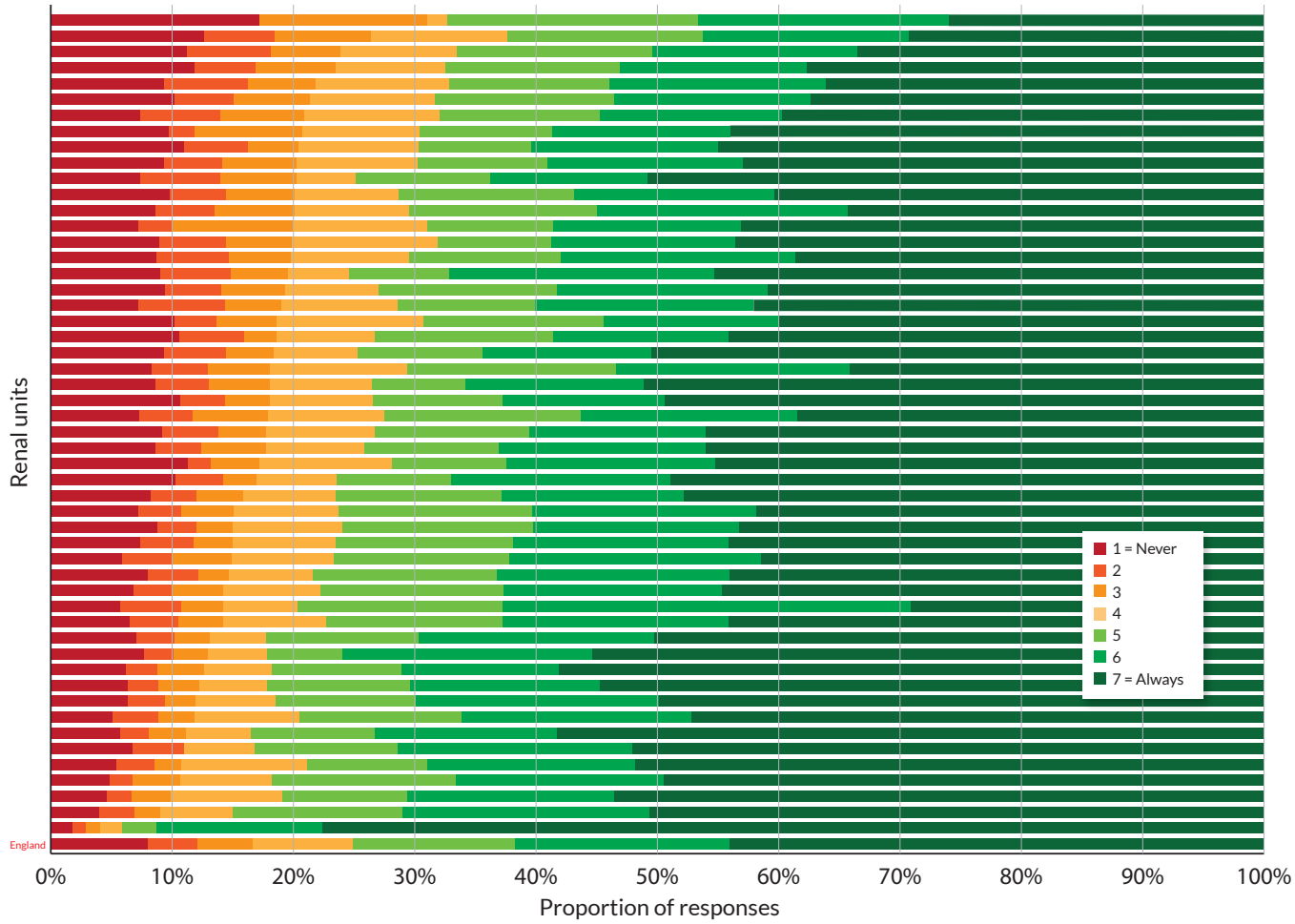
[159] *https://www.thinkkidneys.nhs.uk/kquip/magic/*

Shared decision-making (SDM) and patient activation

There are challenges too relating to behavioural and cultural aspects of care. Joint patient and professional involvement is a fundamental principle in decision-making, and underlies the delivery of high quality renal healthcare. Too often in the past patients have been passive recipients of care, largely uninvolved in decisions about their own treatment.

Currently, SDM is the joint lowest-scoring area in the PREM survey (with patient transport) with significant variation between centres (see **Figure 36**).

Figure 36: Responses to PREM questions on sharing decisions, by centre:
'Does the renal team talk to you about taking a more active role in managing your own kidney care?'
'Does the renal team enable you to participate in decisions about your kidney care as much as you want?'
'Does the renal team talk with you about your treatment and life goals?'



Source: Patient Reported Experience of Kidney Care in the UK 2019, Renal Association and Kidney Care UK (combined scores from three questions, equally weighted)

Respondents referred to discussions about care as a 'one way conversation' and expressed their wish for greater involvement in and engagement with their own care. In cases where this is already happening, the response is positive.

Effective SDM is critical to informed patient choice in areas including access to transplantation, home dialysis, mode of vascular access and conservative care. There is evidence to show that engaging people in their own care not only helps them to feel more in control, it can actually improve outcomes. Low health literacy in dialysis patients is associated with lower survival rates.

Adoption of SDM and shaping services based on patient experience measures are key components of healthcare delivery and we have drawn attention to them in many specific areas of this report. However, fully capitalising on the benefits of SDM and PREM data requires an attitudinal shift across all aspects of a service, as well as further refinement of patient experience data. Delivery of effective SDM requires adequate training for healthcare professionals[160]. This has not received sufficent attention to date and requires particular focus. We believe renal care has progressed further than many other specialties in this domain, but there is still significant work required.

CASE STUDY

ShareHD in Sheffield

Sheffield Teaching Hospitals NHS Foundation Trust

The trust has taken the lead in ShareHD, a national programme of shared HD care, where patients who dialyse at centres are consistently given the opportunity and choice when they attend for dialysis to participate in treatment-related tasks. Individuals select what they would like to do from a list of approximately 14 tasks, ranging from performing basic observations to more complex tasks such as preparting the dialysis machine, inserting needles or managing alarms.

Results

The value of this approach is that it systematically engages the service user in learning and performing aspects of their own care to a level determined by the individual themselves. From an initial position of feeling nervous and overwhelmed by the treatment, service users describe gradually gaining expertise and confidence and gaining a greater understanding of their treatment and its management, giving a better sense of confidence and control. This contributes to SDM since as the individual gains expertise at their own pace, they are then better able to make a high quality decision about where and how they would like to have their dialysis treatment – for example, choosing to dialyse at home.

[160] *https://www.england.nhs.uk/personalisedcare/*

Recommendation

Recommendation	Actions	Owners	Timescale
10. Ensure that patient experience and SDM are central to the planning and delivery of renal services.	**a** Patient experience to be made a central component in assuring the quality of care, shaping local QI direction and optimising service delivery strategy.	Trusts with a renal service	Upon report publication
	b Effective, adequately resourced and culturally sensitive SDM, facilitated through clinician training, to be embedded into all aspects of renal care, especially in the AKCC.	Renal centres	Within 24 months of report publication
	c Data returns to the UKRR PREM portal to be mandated in the NSS.	NHS England Specialised Commissioning, RA/UKRR	Upon report publication
	d Sampling strategy for the UKRR PREM to be developed to facilitate inter-centre comparability.	UKRR, renal centres	Within 24 months of report publication
	e ICHD non-emergency patient transport to be incorporated in the HD tariff or equivalent and responsibility for the management of these contracts to be transferred to renal providers.	Accountable commissioners	Within 24 months of report publication

Workforce: building the renal centre of the future

The workload in renal centres continues to increase. The incidence and prevalence of RRT in England has risen by 11% and 30% respectively over the last decade, along with increases in patient age[161]. Up to 1 in 12 of the population is identified as having CKD, and AKI impacts on 1 in 5 of acute hospital admissions. Despite this, no new renal centres have been established over the last decade. Instead, renal services rely on an expanding 'hub and spoke' model, with a centre surrounded by an expanding number of satellite haemodialysis units. Nephrologists employed by a central trust provide outpatient care and, for most centres, in-reach services to surrounding hospitals, often over large geographical footprints.

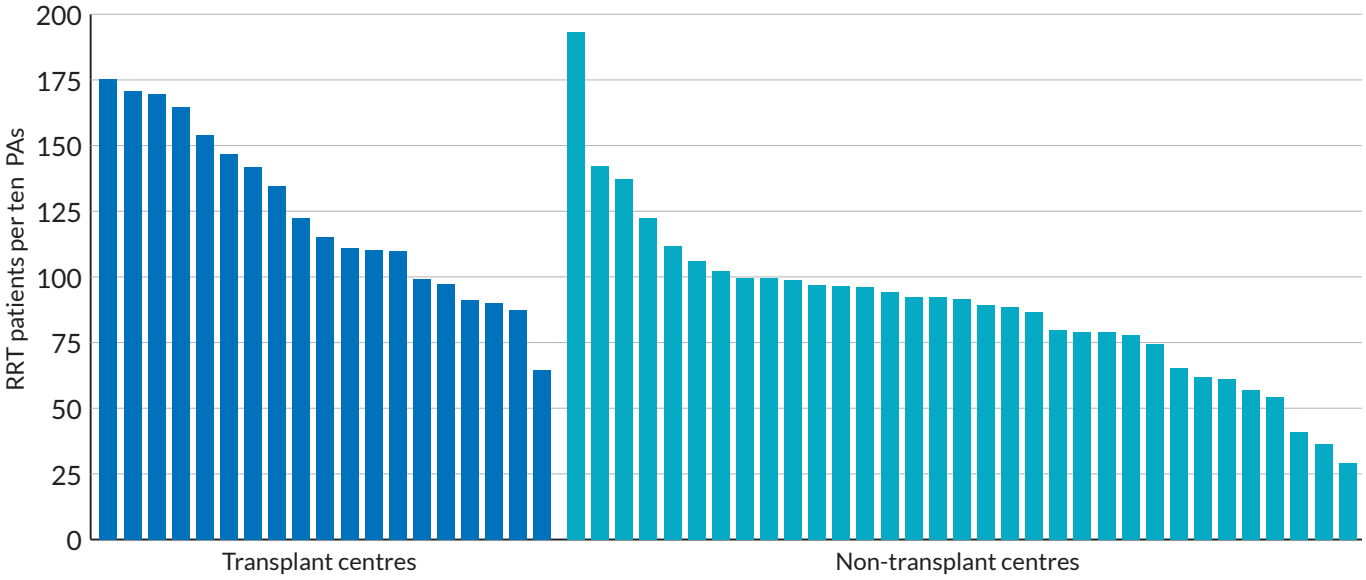
It cannot be over-stated that while renal patients have suffered substantial morbidity and mortality as a result of the first wave of the COVID-19 pandemic, the renal workforce has also been adversely impacted. This is having an impact on care in subsequent waves. A forthcoming RA survey of the UK renal workforce indicates high levels of emotional exhaustion and significant disruption to training, access to CPD and research opportunities.

The medical workforce

At the deep dives, many nephrologists reported constraints in regard to capacity. Around 30% are delivering general internal medicine (GIM) in addition to renal care, and some reported tension between these two areas of responsibility, in part due to the tendency of medical directors to prioritise acute medicine. It should be noted that where nephrologists are undertaking GIM duties, they are often highly valued members of the team.

In England, consultant nephrologist numbers are increasing and currently stand at 526 WTE (10PA renal activity) and 616 in total, of which 30% are female and 14% work less than full time. Academic contracts are held by 17% of consultants. However, UK nephrologist numbers per million population remain one of the lowest in western Europe[162]. GIRFT also identified marked inter-centre variation in 10PA WTE consultant nephrologist posts corrected for centre RRT population (as shown in **Figure 37**), unlikely to be fully explained by service organisation or staffing models.

Figure 37: Number of RRT patients per ten renal consultant programmed activities



Source: Renal Association Workforce Survey, 2018

[161] *https://www.enalreg.org/wp-content/uploads/2018/06/01-Chap01-1.pdf*

[162] *https://www.rcplondon.ac.uk/projects/outputs/focus-physicians-2018-19-census-uk consultants-and-higher-specialty-trainees*

The perception of renal medicine as a specialty where work-life balance can be challenging is widespread among junior doctors. National training number (NTN) recruitment has been incomplete in recent years. Important ongoing work by the Renal Specialist Advisory Committee of the JRCPTB and the RA aimed at addressing this issue is essential to the future of the specialty.

Specialist trainee numbers – which currently stand at 327 – have remained static over the last decade, reflecting the ongoing transition to predominantly consultant-delivered services. The 2018 RCP Census reports significant regional variation in population numbers per trainee from 120,000 to 570,000. Current geographical distribution of trainees does not reflect population need.

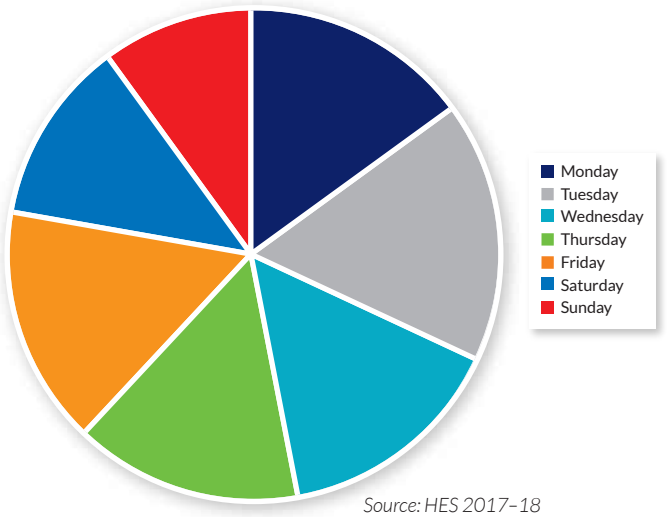
It is unlikely that renal specialist trainee numbers will increase. There is therefore a need to plan for and modernise the future renal centre workforce, focusing on opportunities to engage extended workforce roles in line with the NHS People Plan[163].

Although GIRFT did not specifically include review of either area, it was clear that there are significant concerns regarding the sustainability of both the renal transplant surgical workforce in light of rising transplantation rates and organisation of organ offering[164], and of the vascular access surgical workforce, in particular interventional radiologists. The former is an ongoing area of focus for the BTS and NHSBT, while the latter has been raised with the GIRFT clinical lead for vascular surgery.

Seven-day working

Seven-day working is a stated aim of NHS England and NHS Improvement[165] and offers significant benefits, including better access to services, earlier diagnosis, fewer admissions and shorter stays, and a reduction in weekend mortality. Renal medicine has a strong tradition of delivering seven-day working for inpatient care as evidenced by the emergency admission and discharge patterns shown in **Figures 38** and **39**.

Figure 38: Emergency inpatients by day of admission



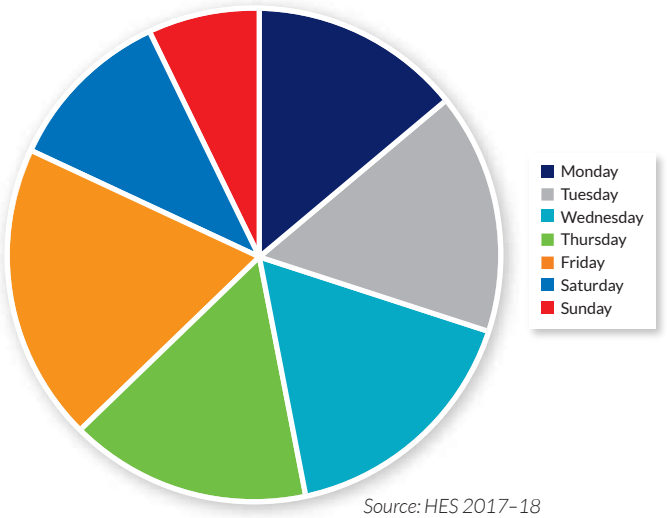
Source: HES 2017–18

[163] *https://www.england.nhs.uk/ournhspeople*

[164] *https://www.bts.org.uk/wp-content/uploads/2018/09/Summary-of-Sustainability-summit.pdf*

[165] *https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Equality-for-all-Delivering-safe-care-seven-days-a-week.pdf*

Figure 39: Emergency inpatients by day of discharge



Source: HES 2017–18

Dialysis care and transplantation are seven-day per week activities. Some centres are now providing weekend outpatient services in transplantation and nephrology. However, there are significant challenges to delivery including both workforce and financial resources. For example, lack of pharmacy and therapist resource may limit weekend discharges. The key to providing a consistent seven-day service across the country for highly specialised renal services (e.g. emergency nephrostomy) may be collaboration with neighbouring providers (see *Acute kidney injury*, page 70).

The dialysis nurse workforce

There is a shortage of Band 5 nurses across the NHS and this impacts significantly on dialysis nurse workforce recruitment. GIRFT identified a mean of 11% unfilled nursing posts (with a range from 0% to 35%) across English renal centres, representing a significant risk to service delivery. There are variations in hospital and satellite unit staffing ratios, including for dialysis assistant roles. There is a need to agree the appropriate staff skill mix and share innovative staffing solutions, including with independent sector dialysis providers.

Dialysis nurse training has been identified as a key quality issue, impacting on recruitment and quality outcomes, notably in the area of needling (see *Patient experience*, page 85). The previous postgraduate renal nurse training course, ENB 136, accredited by the Nursing and Midwifery Council, ceased several years ago. There is currently no national curriculum. Some universities have collaborated with trusts to develop renal nursing modules at degree or masters level, but these are variable in quality and content. Renal matrons reported major challenges in accessing funds to support renal nurse postgraduate training, including attendance at regional and national CPD meetings.

We believe that the current situation is unsatisfactory and that this deficit in nurse training represents one of the greatest threats to high quality renal patient care over the next five years. ANN UK[166] is currently working to develop a national online modular renal nurse education course, subject to securing funding. GIRFT supports this move. GIRFT welcomes the anticipated and agreed 50,000 nurse expansion planned by NHS England and NHS Improvement (https://www.nao.org.uk/wp-content/uploads/2020/03/The-NHS-nursing-workforce.pdf). We are hopeful that this will have an impact on the challenging dialysis workforce recruitment.

The multiprofessional workforce: advanced practitioners and multiprofessional consultants

The variation in access to multiprofessional teams is highlighted throughout this report (see *Access to kidney transplantation* (page 43), *Home therapies* (page 62), *Preparation for renal replacement therapy (RRT) and conservative management* (page 37) and *Pharmacy and medicines optimisation* (page 109). *The BRS workforce document 2020*[167] discusses this variation in detail.

[166] *https://britishrenal.org/ann-uk/*

[167] *https://britishrenal.org/workforce/*

It is clear that the multiprofessional workforce has not expanded in line with the growth in RRT patient numbers, a shortfall that could potentially compromise the ability to deliver a quality service. The shortfall is particularly marked for psychosocial support. GIRFT supports the society's forthcoming recommendations.

Renal centres have traditionally adopted joint medical and multiprofessional working, with many deploying embedded extended practitioner roles. As delivery of care by nephrology trainees has reduced, inpatient, outpatient and sub-specialty development all continue to require high quality support. There are major opportunities for renal centres to embrace ACP, multiprofessional consultant and PA roles. We note, however, that the PA role is currently restricted by the absence of prescribing rights or ability to request diagnostics involving ionising radiation.

There are many examples demonstrating the effectiveness of ACP roles across English renal centres, but there remains much variation in uptake and application. Development of these roles is critical to delivering better, and more holistic, patient care. The opportunities arising from the NHS People Plan[168] should help to enable this. Recent guidance has identified particular opportunities for appointment of nurse and pharmacist consultants and ACPs across the whole MPT within the renal team[169]. We believe that greater inclusion of advanced pharmacy roles in the workforce in particular will provide support for patient-facing roles (both inpatient and outpatient) and there are excellent examples of this across England (see case study on page 112).

The Council of Deans of Health in collaboration with Health Education England have set the direction on advanced clinical practice. The *Multi-professional framework for advanced clinical practice in England*[170] sets out the four pillars that underpin advanced clinical practice:

1. Clinical practice.
2. Leadership and management.
3. Education.
4. Research.

It is essential that trusts use national professional societies guidance in providing opportunities for development of the extended practioner and PA roles which are critical to the future quality of renal patient care. These practitioners must also work to share best practice and lessons learned, and to encourage innovative approaches to developing these roles across services.

The BRS workforce document[171] provides a blueprint for a multiprofessional renal workforce development and includes opportunities for modernisation to deliver high quality renal services going forward.

[168] *https://www.england.nhs.uk/ournhspeople/*

[169] *https://www.hee.nhs.uk/sites/default/files/documents/Consultant%20Pharmacist%20Guidance%20Final%20Jan2020.pdf*

[170] *https://www.hee.nhs.uk/sites/default/files/documents/Multiprofessional%20framework%20for%20advanced%20clinical%20practice%20in%20England.pdf*

[171] *ibid.*

Recommendation

Recommendation	Actions	Owners	Timescale
11. Reconfigure the multiprofessional renal workforce to reflect service requirements and provide optimal care, as defined throughout this GIRFT report, delivering the best outcomes and best patient experience.	**a** GIRFT benchmarked staffing data, GIRFT recommendations and the BRS workforce document[172] to inform how the workforce needs to adapt to match service need.	Trusts with a renal service	Upon report publication, to complete by 2023
	b Allocation of regional renal trainee numbers to be reviewed to support current need and address projected need.	Joint Royal Colleges of Physicians Training Board (JRCPTB)/RCP	Within 24 months of report publication
	c A national strategy to be developed aimed at increasing recruitment into renal medical training.	RCP/RA/specialty advisory committees (SACs)	Upon report publication
	d A comprehensive national renal nurse training curriculum and accessible online educational resources to be developed (through accredited university courses for NHS and independent sector renal providers).	HEE and the Association of Nephrology Nurses UK (ANN UK), regional renal networks	Within 24 months of report publication
	e The appropriate skill mix necessary to deliver future renal care to be developed, including expansion of multiprofessional ACP roles, physician associates (PAs) and non-medical consultant roles, in alignment with the multi-professional framework for advanced clinical practice.	HEE, renal centre leads, professional societies	Upon report publication, to complete by 2023

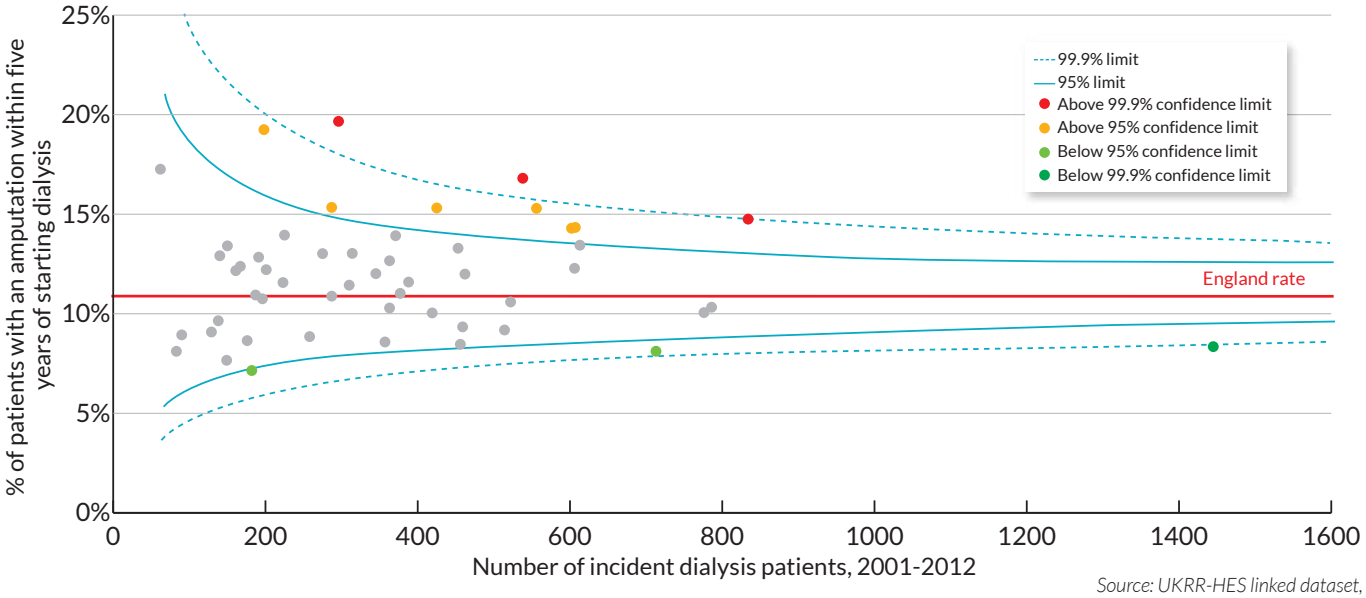
[172] *https://www.britishrenal.org/workforce/*

Diabetes care in patients with end stage kidney disease (ESKD)

Diabetes is the commonest identified cause of ESKD. UKRR data covering the period 2001–12 shows that 25% of incident patients receiving dialysis had diabetes as a primary renal disease and a further 10% had diabetes as a reported comorbidity. Patients from diverse ethnic backgrounds are over-represented in this group. There is substantial variation in the nature and standard of diabetes care received by patients with ESKD. Sub-optimal care carries with it a risk of serious secondary complications, including blindness, foot ulcers and amputations.

Around 12% of patients with diabetes will undergo an amputation within five years of starting dialysis. There is considerable variation in amputation rates between trusts; unsurprising given the very high degree of variation in amputation rates for patients with diabetes when analysed by CCG in England[173]. In a GIRFT casemix-adjusted analysis, the range after five years in patients with diabetes on dialysis is from 7% to 20%, as shown in **Figure 40**.

Figure 40: Adjusted five-year amputation rate for incident dialysis patients who have diabetes*



* Adjusted for age, sex, ethnicity, deprivation and year of dialysis start. Diabetes as a primary renal disease or comorbidity.

Source: UKRR-HES linked dataset, incident cohort 2001-12

There is evidence[174] that treating these patients as high risk with increased monitoring is a cost-effective approach. There is also evidence that structured care from an MPT can reduce amputation rates[175]. This is borne out by the findings of the GIRFT national report for diabetes[176].

Improving diabetes care for dialysis patients requires access to and closer working with multi-disciplinary teams, including renal medical, specialist diabetes and dialysis nurses, podiatrists and dedicated multi-disciplinary diabetes footcare services. Access is a particular challenge for patients receiving dialysis in satellite HD units, and requires effective co-ordination.

[173] *https://www.app.box.com/s/pmdl91gf2d6pscttb9avqwan6mcbs296/file/432108631907*

[174] *Kerr, M., Barron, E., Chadwick, P., et al. (2019) The cost of diabetic foot ulcers and amputations to the National Health Service in England. Diabetic Medicine, 36(8): 995–1002. https://www.pubmed.ncbi.nlm.nih.gov/31004370/*

[175] *Krishnan, S., Nash, F., Baker, N., Fowler, D., Rayman, G. (2008) Reduction in diabetic amputations over 11 years in a defined UK population: benefits of multidisciplinary team work and continuous prospective audit. Diabetes Care, 31(1): 99–101. https://www.pubmed.ncbi.nlm.nih.gov/17934144/*

[176] *https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2020/11/GIRFT-diabetes-report.pdf*

Guidelines published by the JBDS-IP and the RA include a recommendation that each unit develops appropriately trained link nurses for diabetes care such that every patient is reviewed regularly, and that the link nurse liaises with a named diabetes specialist nurse[177]. The RA has recently published a new set of guidelines on managing hyperglycaemia in people with diabetes and CKD[178]. Newer technologies including continuous glucose monitoring and the 'artificial pancreas' may have an important future role in optimising the care of these patients. Evidence clearly demonstrates a J-shaped curve relationship between glycaemic control and all cause and cardiovascular mortality in ESKD. The importance of avoiding periodic hypoglycaemia especially during the dialysis session is clear, and lower as well as higher glycaemic markers are also associated with higher mortality[179].

The ideal model for multidisciplinary footcare services is described in the GIRFT national report for diabetes[180] and relevant standards are set by NICE in NG19[181]. For haemodialysis, JBDS-IP and the RA have recently set standards for optimal care of patients with diabetes[182].

Post-transplant diabetes is common, affecting greater than 40% of patients in some series and guidelines for the care of this patient group have also recently been published by ABCD/RA[183].

Recommendation

Recommendation	Actions	Owners	Timescale
12. Reduce variation and co-ordinate improved provision of protocoled, holistic care for patients with diabetes and ESKD.	**a** Implement the multidisciplinary recommendations set out in the Joint British Diabetes Societies for Inpatient Care (JBDS-IP)/RA guidelines across primary and secondary care.	All acute trusts and primary care, co-ordinated by ICSs	Within 12 months of report publication
	b Renal centres to ensure that optimising the care of patients with ESKD and diabetes becomes an urgent focus for QI, with a lead in each centre responsible for co-ordination and quality of care.	Renal centres	Upon report publication

[177] *Frankel, A.H., Kazempour-Ardebili, S., Bedi, R., et al. (2018) Management of adults with diabetes on the haemodialysis unit: summary of guidance from the Joint British Diabetes Societies and the Renal Association. Diabetic Medicine, 35(8): 1018–26. https://www.pubmed.ncbi.nlm.nih.gov/30152585/*

[178] *https://www.bjd-abcd.com/index.php/bjd/article/view/351/515*

[179] *Ricks, J., Molnar, M.Z., Kovesdy, C.P. et al. (2012) Glycemic control and cardiovascular mortality in hemodialysis patients with diabetes: a 6-year cohort study. Diabetes 61(3):708-15. https://www.pubmed.ncbi.nlm.nih.gov/22315308/*

[180] *https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2020/11/GIRFT-diabetes-report.pdf*

[181] *https://www.nice.org.uk/guidance/ng19/*

[182] *Frankel, A.H., Kazempour-Ardebili, S., Bedi, R., et al. (2018) Management of adults with diabetes on the haemodialysis unit: summary of guidance from the Joint British Diabetes Societies and the Renal Association. Diabetic Medicine, 35(8): 1018–26. https://www.pubmed.ncbi.nlm.nih.gov/30152585/*

[183] *https://www.renal.org/health-professionals/guidelines/association-british-clinical-diabetologist-and-renal-association*

Infection in dialysis patients

Infection is a significant cause of morbidity and mortality for dialysis patients and a common reason for emergency hospital admission. Dialysis patients are prone to a broad range of infections, but this section of the report focuses on the two most important, bacteraemia in HD and peritonitis in PD.

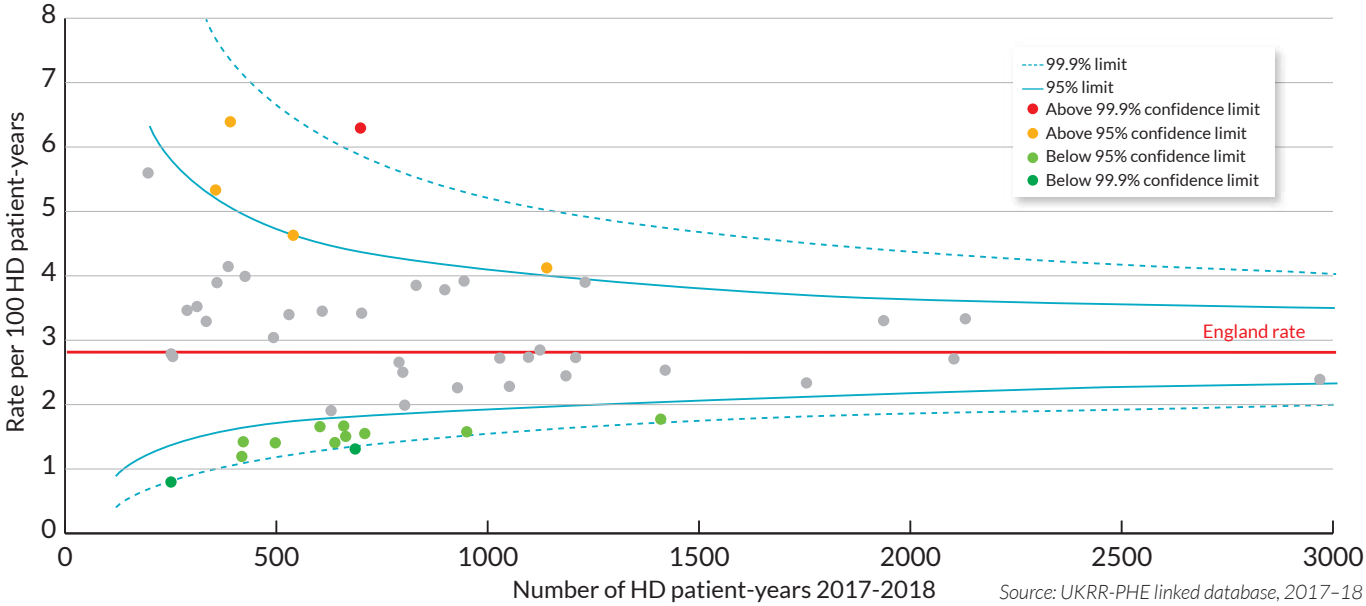
Bacteraemia in in-centre haemodialysis (ICHD)

Infection is the cause of death in around 20% of patients treated by ICHD[184]. HD patients are very prone to bloodstream infection because of the absolute requirement to access the circulation three times per week for dialysis treatment. As well as mortality, bacteraemia leads to poor patient experience, prolonged hospitalisation and metastatic infection of the joints and heart.

After a decade of improvement, rates of bloodstream infection with MRSA or MSSA reported by PHE have remained stable over the past four years, standing at 2.83 per 100 HD patient years in 2017–18. Within this, there is significant variation in centres – from 0.8 to 6.4 – and 63% of centres failed to meet the RA standard[185] of 2.5 (see **Figure 41**). Infection remains the second most common cause of death in ICHD patients up to the age of 65.

Bloodstream infection has long been associated with use of central venous catheter access for ICHD. Using contemporary data, GIRFT did not find that the prevalence of catheter HD in any one centre was closely correlated with rates of MSSA/MRSA bacteraemia. While definitive HD access is undoubtedly a crucial element of quality HD provision that contributes to preventing bacteraemia (see *Vascular access for haemodialysis*, page 52), it follows that infection control measures – beyond simply avoiding catheter dialysis – are also important.

Figure 41: MRSA+MSSA bacteraemia per 100 haemodialysis patient-years by centre



Source: UKRR-PHE linked database, 2017–18

[184] *https://www.renalreg.org/wp-content/uploads/2019/05/21st_UKRR_Annual_Report.pdf*

[185] *https://www.renal.org/wp-content/uploads/2017/06/vascular-access.pdf*

It is often the case that simple, inexpensive and technically undemanding interventions are effective in delivering low bacteraemia rates. During GIRFT visits, centres with low rates typically reported having made significant investment in training the workforce to adhere to mandatory use of aseptic technique when accessing all forms of HD access, as defined in guideline 7.2 of the RA standards[186].

Patient education is a crucial component of this, and the principles of shared care HD are highly relevant (see *Home therapies*, page 62, and *Patient experience*, page 85). Patient education and engagement covers a range of topics from the basics of good hand/arm hygiene to advanced techniques such as self-needling for physically able patients. It should be noted that shared care HD is not about reducing staffing levels or costs; it is about using staff to empower patients so they can work together to deliver the best possible care.

Root cause analysis (RCA) has become a mandated feature of the response to MRSA bacteraemia in the NHS, and successful renal centres have also applied this approach rigorously to bacteraemia caused by MSSA and other organisms. A systematic QI methodology[187] including improved vascular access management[188], the use of RCA to investigate bacteraemia and the appointment of IPC champions within a renal service have typically driven falling bacteraemia rates in successful centres.

To support this QI, data on bacteraemia are available quarterly on the NHS England Quality Dashboard, but they may not be sufficiently visible or reliable (see *Registry data and informatics*, page 114). They are self-reported and discrepancies can arise with PHE-derived data. In the future, it would be preferable to derive the quarterly data from PHE linkage.

CASE STUDY

Achieving low rates of bacteraemia

The Royal Wolverhampton NHS Trust (New Cross Hospital)

In 2005 the renal service in Wolverhampton had a high infection rate of over three episodes per 1,000 patient days.

At this time a number of interventions were implemented including: use of a catheter care bundle; change of line dressing to chlorhexidine gluconate (CHG); introduction of antimicrobial locking solution; strict compliance with hand hygiene; IPC training; and a review of patient and staff education. Use of non-tunnelled catheters is minimal and levels of vigilance at removal are high.

The service also introduced screening and management of staphylococcus aureus in dialysis patients. A World Health Organisation checklist is used, which includes assessment of the medical staff asepsis technique by the assisting nurse during CVC line insertion. It is reported every month. Vancomycin is administered post-line insertion.

An MDT root cause analysis is completed for every device-related bacteraemia, and discussed at the monthly renal governance meeting. HD is delivered exclusively by qualified nurses, who are assessed annually for competence in aseptic non-touch technique and care of a dialysis catheter. Every quarter, 12 random spot checks are carried out.

Since 2013, overall catheter-related infection rates have consistently remained below 0.1 bacteraemia episodes per patient year with an MRSA / MSSA rate of below 0.01 per patient year. There has been no MRSA bacteraemia in an HD patient since 2008. Vascular access rates are consistently above 82%.

[186] *https://www.renal.org/wp-content/uploads/2017/06/vascular-access.pdf*

[187] *Wells, S., Tamir, O., Gray, J., et al. (2018) Are quality improvement collaboratives effective? A systematic review. BMJ Qual.Saf., 27(3): 226–240. https://www.qualitysafety.bmj.com/content/27/3/226*

[188] *https://www.thinkkidneys.nhs.uk/kquip/magic/*

Peritoneal dialysis (PD) peritonitis

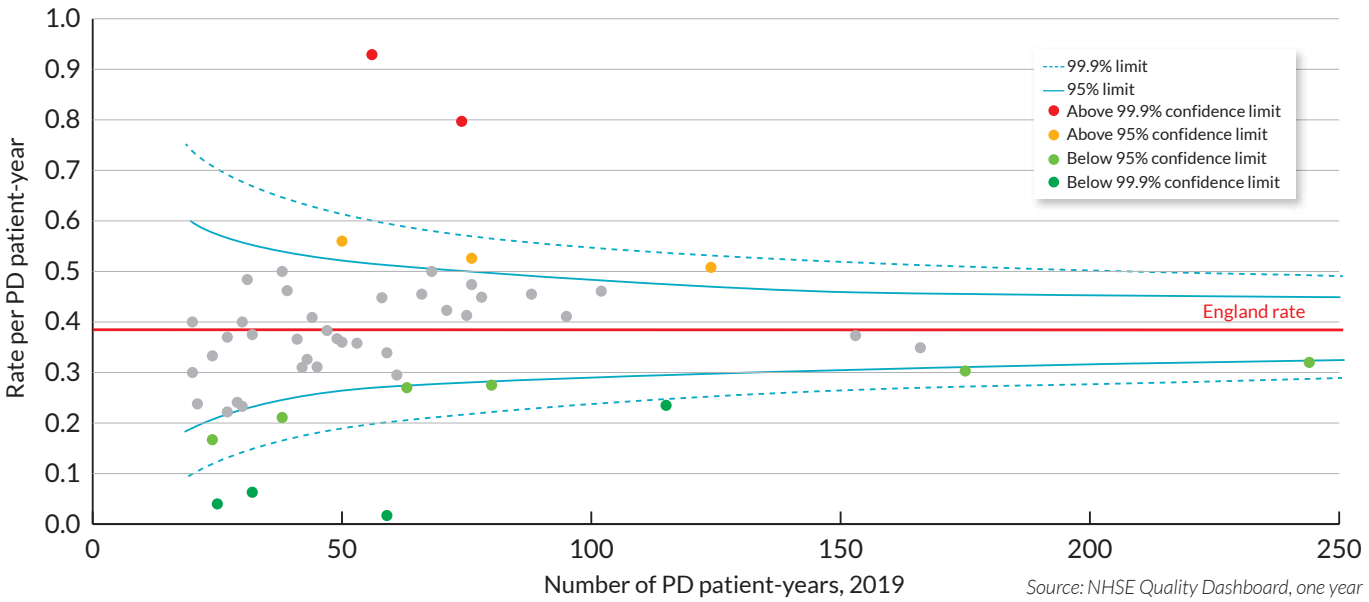
Peritonitis is the complication most feared by patients on PD and a common reason for technique failure and subsequent transfer to HD. Rates of peritonitis in patients receiving PD varies very significantly by centre (see **Figure 42**).

There are seven centres with a rate above 0.5 per patient per year, the maximum set in the international standard[189]. Of these, five sit beyond the 99.9% confidence limit when English centres are analysed, suggesting unwarranted variation. It should be noted that some centres do have rates below the 99.9% confidence limit, so clearly excellence is achievable. The international standard is not a stretch target and many centres do much better.

Data from a PD research collaborative, the Peritoneal Dialysis Outcomes and Practice Patterns Study (PDOPPS), allows us to look at this data in an international context. Overall in PDOPPS, the UK average rate of infection is above the international average: country-specific peritonitis rates range from 0.26 to 0.29 episodes/patient year in the US, Japan and Canada, and from 0.35 to 0.40 episodes/patient year in Australia/New Zealand, the UK and Thailand[190]. It is not surprising that the rate of transfer from PD to HD is also higher in the UK than international comparators.

There are well established international guidelines on the prevention and treatment of peritonitis, but the extent to which UK centres have adopted these also varies considerably[191]. For example, using prophylactic topical mupirocin at the PD catheter exit site is an evidence-based recommendation, but only 47% of UK centres have adopted this practice according to PDOPPS.

Figure 42: Peritonitis per peritoneal dialysis patient-year by centre



Source: NHSE Quality Dashboard, one year rolling average end 2019

It was apparent from GIRFT visits that, while there are some centres of excellence, PD peritonitis is not always given the same level of priority as bacteraemia in HD. This is a missed opportunity: reducing peritonitis rates improves patient experience and reduces the risk of both hospitalisation and technique failure and subsequent transfer to ICHD.

Strategies for reducing peritonitis are well established and they are very often low cost and technically straightforward. As for bacteraemia, a systematic QI approach is required for successful implementation of these interventions. Similarly, patient education and shared care are key elements. Our questionnaire data confirmed that 90% of centres re-train patients after an episode of peritonitis. We did not gather formal data on the use of RCA after peritonitis, but it was not commonly reported on visits. There is enthusiasm within the UK PD community to develop a national QI initiative in this field, but it is not yet operational.

[189] *Li, P., Szeto, C., Piraino, B., et al. (2016) ISPD Peritonitis Recommendations: 2016 Update on Prevention and Treatment. Perit Dial Int, 36(5): 481–508. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5033625/*

[190] *Perl, J., Fuller, D.S., Bieber, B.A., et al. (2020) Peritoneal Dialysis-Related Infection Rates and Outcomes: Results From the Peritoneal Dialysis Outcomes and Practice Patterns Study (PDOPPS). Am.J.Kidney Dis., 76(1): 42–53. https://www.pubmed.ncbi.nlm.nih.gov/31932094/*

[191] *Boudville, N., Johnson, D., Zhao, J., et al. (2019) Regional Variation in the Treatment and Prevention of Peritoneal Dialysis-Related Infections in the Peritoneal Dialysis Outcomes and Practice Patterns Study. Nephrol. Dial.Transplant, 34: 2118–26. https://www.pubmed.ncbi.nlm.nih.gov/30053214/*

Resilience of in-centre haemodialysis (ICHD) provision during the COVID-19 pandemic

The GIRFT visits took place before the COVID-19 pandemic but it is critical not to lose sight of the lessons learned. The resilience of centres to provide ICHD has been severely tested and staff infection rates were significant in some centres[192]. Practice recommendations for ICHD in the context of pandemic respiratory viral infection have been summarised by NICE and are not discussed further in this report[193].

Recommendation

Recommendation	Actions	Owners	Timescale
13. Ensure that all renal centres adopt a systematic QI approach to infection prevention and control (IPC), with HD bacteraemia and PD peritonitis given equal priority.	**a** Easily accessible national data to be published quarterly on renal service bacteraemia and peritonitis to drive QI by working with centres and Public Health England (PHE) to improve data reliability.	UKRR and PHE	Within 12 months of report publication
	b Renal centres to appoint a lead from any relevant professional background with responsibility for IPC and oversight into microbial stewardship[194].	Renal centres	Within 12 months of report publication
	c Relevant national and international practice standards to be comprehensively implemented for IPC in dialysis patients.	Renal centres	Upon report publication
	d Patient partnership and education to be at the centre of QI efforts in IPC for dialysis patients.	Renal centres, local and national patient representative groups	Upon report publication

[192] *Corbett RW, Blakey S, Nitsch D, Loucaidou M, McLean A, Duncan N, Ashby DR; West London Renal and Transplant Centre. Epidemiology of COVID-19 in an Urban Dialysis Center. J Am Soc Nephrol. 2020 Aug;31(8):1815-1823. https://www.pubmed.ncbi.nlm.nih.gov/32561681/*

[193] *https://www.nice.org.uk/guidance/ng160*

[194] *https://www.nice.org.uk/guidance/ng15*

Hospitalisation in patients on renal replacement therapy (RRT)

The GIRFT review process has enabled us to investigate in depth the hospitalisation of patients on RRT, and to build up a more detailed picture than has previously been available. The data show considerable variation in hospital admissions for both transplant and dialysis patients. These data are derived from HES, either directly or by means of linkage with the UKRR dataset.

Emergency admission in prevalent RRT patients

Linking UKRR data with HES has facilitated analysis of emergency hospitalisation in prevalent RRT patients, a novel metric in renal care. These data are shown in this report as emergency inpatient days per patient-year. This method of expressing emergency hospitalisation allows centre comparison, but it hides some of the detail.

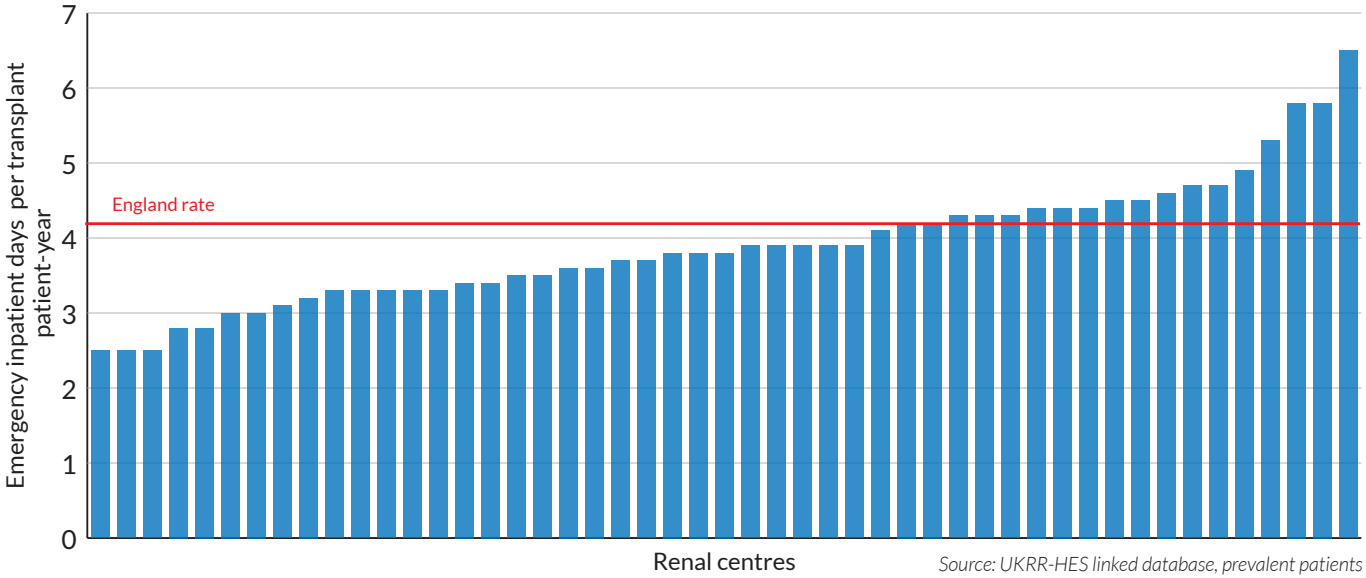
Two factors drive the metric: LoS and frequency of emergency admission. Both of these factors show variation when analysed separately. In any one year, not all RRT patients are admitted, some experience multiple admissions and a few experience very long admissions. Furthermore, admissions may be under any specialty and are not necessarily under the renal team.

The burden of emergency hospitalisation in dialysis patients is about three times that for transplant patients, reflecting the fundamental differences between the modalities, as well as the greater comorbidity and age of dialysis patients. Nationally, emergency inpatient days per patient-year are 4 for transplant patients, 11 for PD patients and 13 for ICHD patients (see **Figures 43–45**.

For all modalities, there is considerable variation between centres. For transplant patients the range is from three to seven days. For PD patients the variation is from four to as high as 28 days and for ICHD patients from 8 to 20 days. These data are unadjusted for age, comorbidity and other patient factors likely to influence emergency hospitalisation. We have not censored very long admissions which may skew the analysis, especially if a number have occurred in smaller centres.

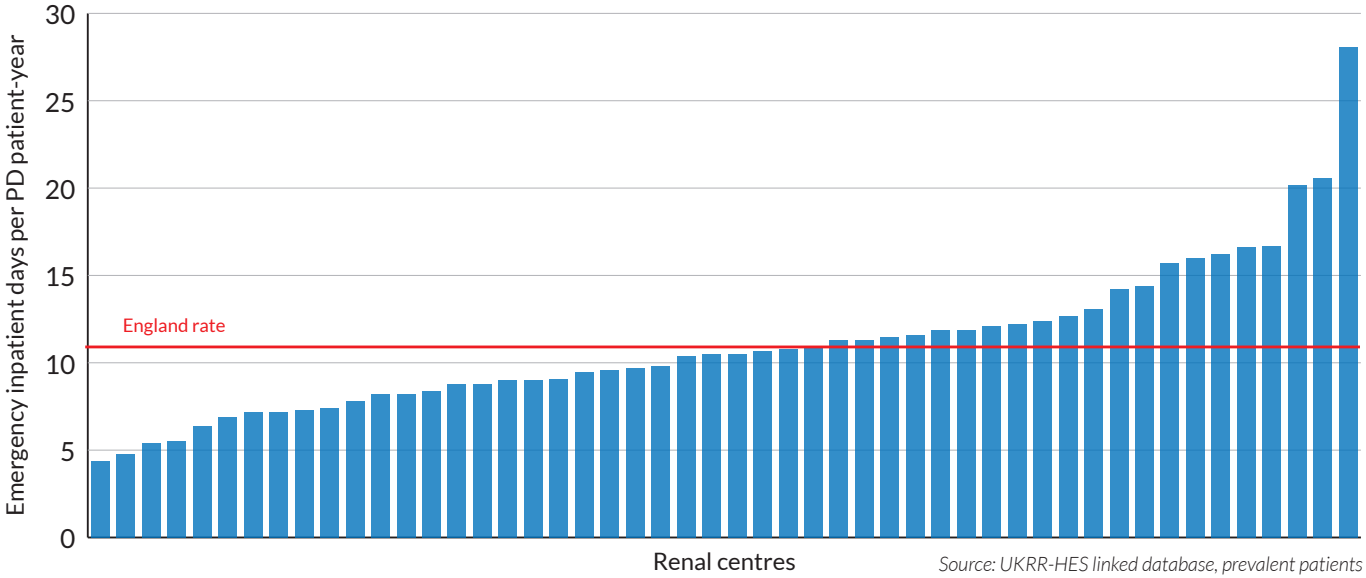
Nevertheless, it is unlikely that variation on this scale can be fully explained by patient-level factors; it seems likely that centre-level factors are also at play. Centres typically had consistent performance across all hospitalisation metrics. It is recognised that delayed discharge has a powerful effect on LoS and delayed transfer of care may often be an issue for a trust as a whole, rather than just for the renal service. This problem may be amplified for regional services that span multiple CCGs, where transfer of care beyond the local CCG is often logistically more challenging. Delayed discharge beyond the local CCG was commonly reported during GIRFT visits.

Figure 43: Emergency inpatient days per transplant patient-year



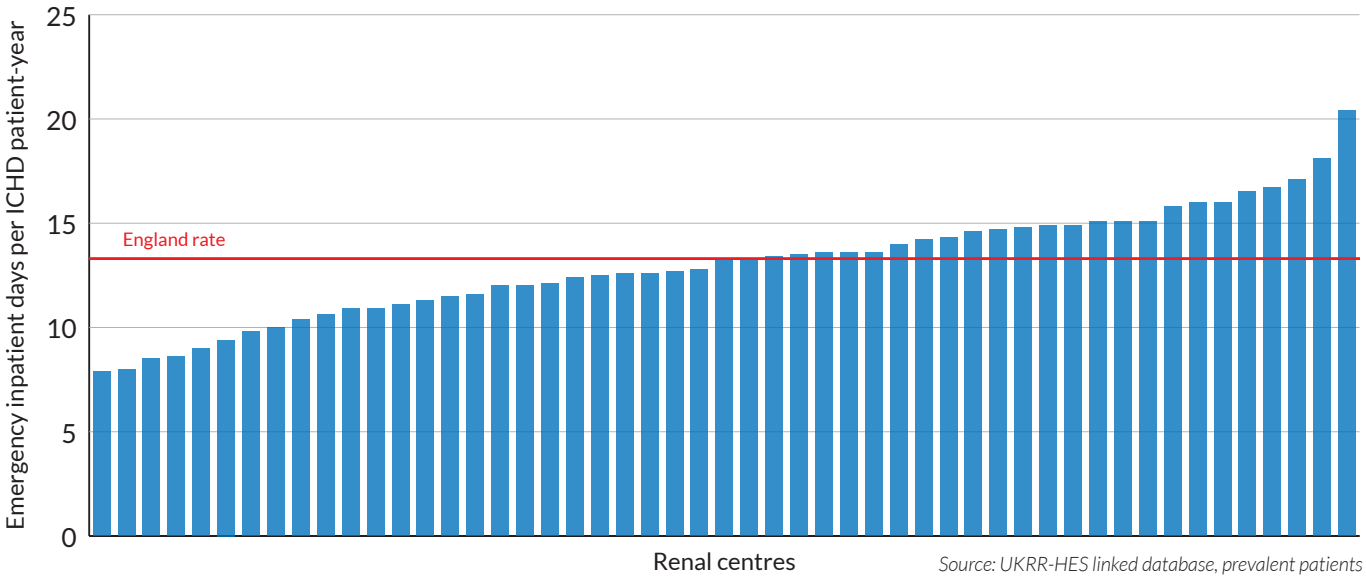
Source: UKRR-HES linked database, prevalent patients (1 January 2018)

Figure 44: Emergency inpatient days per peritoneal dialysis patient-year



Source: UKRR-HES linked database, prevalent patients (1 January 2018)

Figure 45: Emergency inpatient days per in-centre haemodialysis patient-year



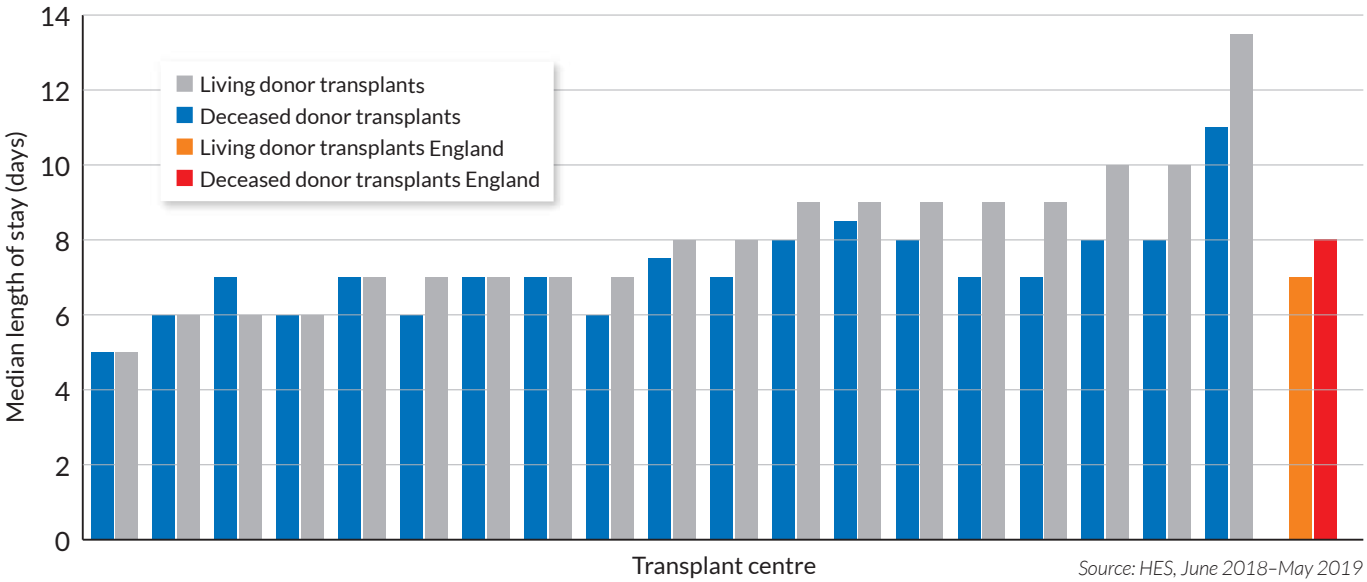
Source: UKRR-HES linked database, prevalent patients (1 January 2018)

Incident renal transplant recipients

There is considerable variation in the amount of time that incident transplant patients spend in hospital after surgery. Median LoS after transplant surgery in the 19 transplant centres is anything from 5 to 11 days for LD transplants, and from 5 to 14 days for DD transplants (see **Figure 46**). Nationally, the median LoS is seven for LD and eight for DD, and there is generally correlation between DD and LD LoS in each centre.

Contemporary surgical, anaesthetic and immunosuppression practice has greatly reduced the requirement for inpatient care after transplantation. One centre has introduced the principles of Enhanced Recovery after transplant surgery, resulting in meaningful reductions in LoS[195]. Critics of shorter LoS after transplantation point to the possibility that this will translate into higher readmission rates. It is certainly true that there is wide variation in rates of readmission after transplant surgery, as detailed below, but we could not find any relationship between a high readmission rate and a shorter initial LoS. Interestingly, there is also no correlation between having more frequent outpatient follow-up appointments and a reduced risk of readmission (see *Outpatients*, page 79).

Figure 46: Median length of stay after transplantation in England

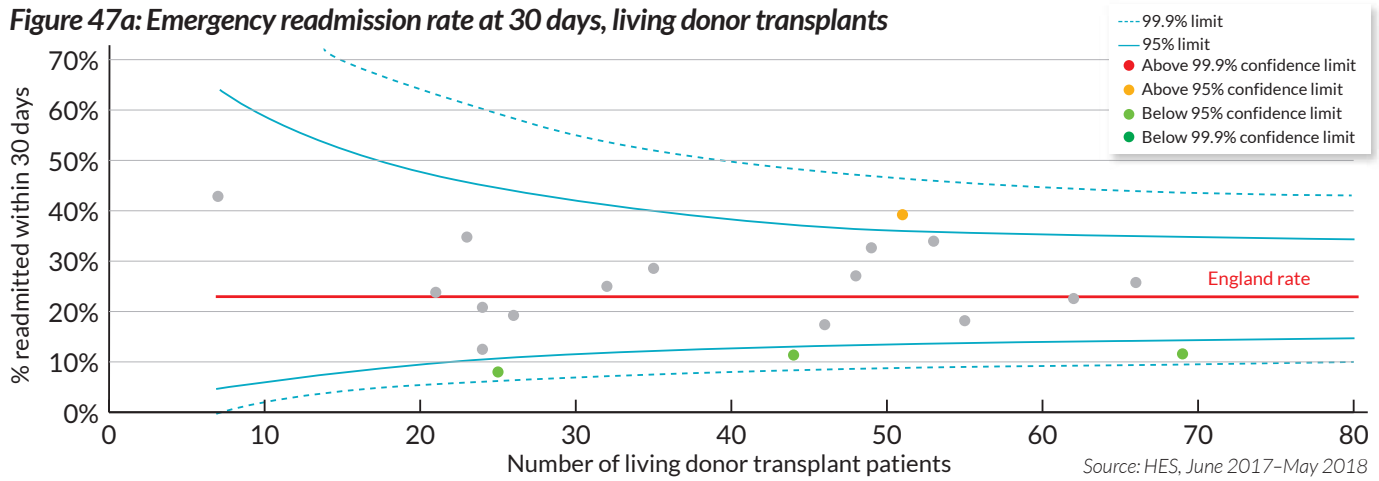


Source: HES, June 2018–May 2019

HES-derived data show that emergency readmission rates of patients following LD or DD renal transplantation vary widely (see **Figure 47**). Between 8% and 43% of those receiving LD transplants can expect to be readmitted to hospital within 30 days. The equivalent figures for DD transplants are between 17% and 52%. For readmissions within one year, percentages range from 30% to 71% for LD transplants and from 44% to 76% for DD transplants. These analyses exclude planned admissions such as those for routine stent removal or protocol biopsy.

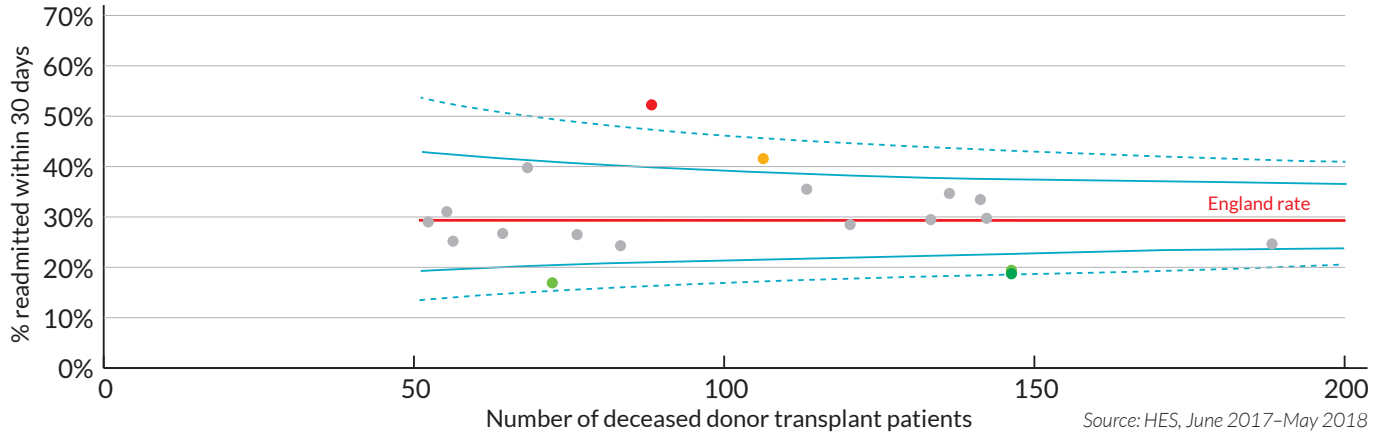
[195] *Halawa, A., Rowe, S., Roberts, F., et al. (2018) A Better Journey for Patients, a Better Deal for the NHS: The Successful Implementation of an Enhanced Recovery Program After Renal Transplant Surgery). Exp.Clin. Transplant, 16(2): 127–32. https://www.europepmc.org/article/med/28836932*

Figure 47a: Emergency readmission rate at 30 days, living donor transplants



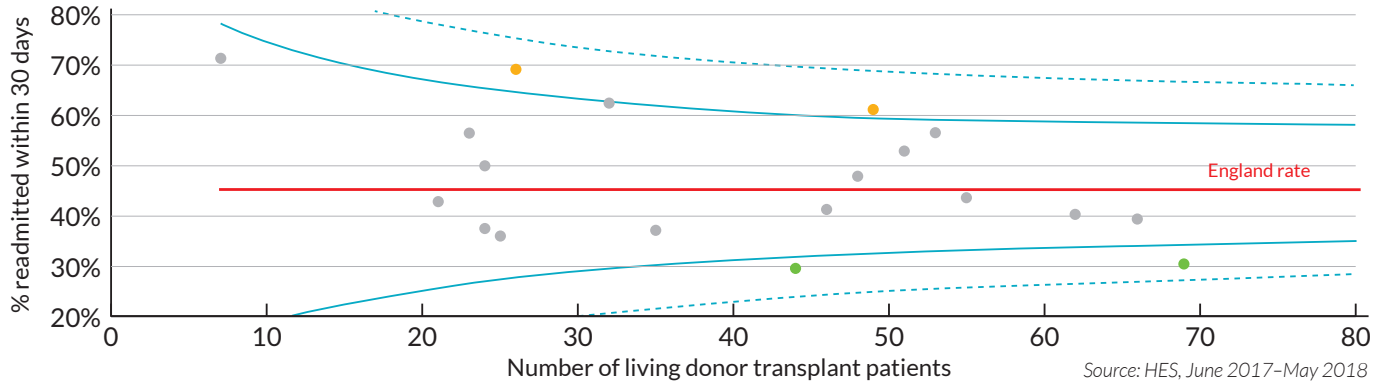
Source: HES, June 2017–May 2018

Figure 47b: Emergency readmission rate at 30 days, deceased donor transplants



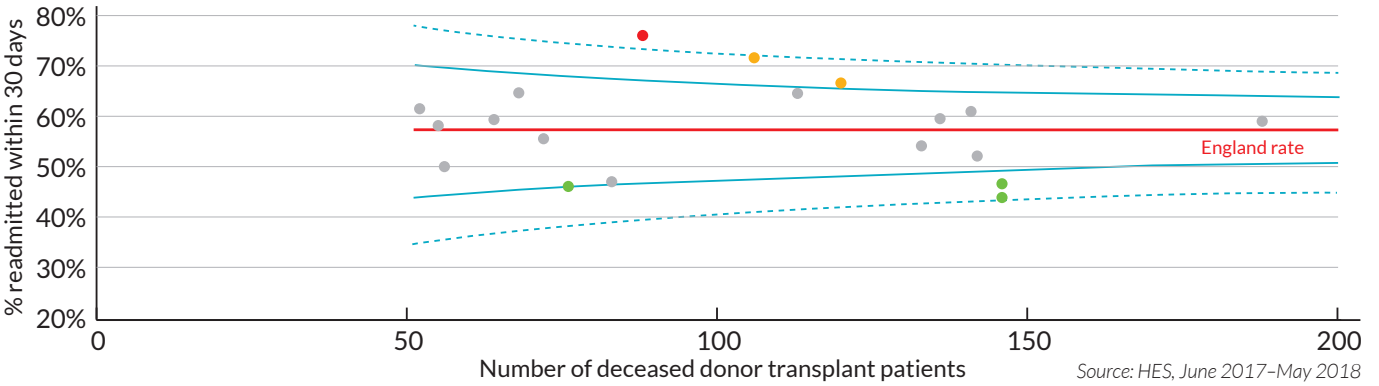
Source: HES, June 2017–May 2018

Figure 47c: Emergency readmission rate at 365 days, living donor transplants



Source: HES, June 2017–May 2018

Figure 47d: Emergency readmission rate at 365 days, deceased donor transplants



Source: HES, June 2017–May 2018

We found no simple explanation as to why some trusts should have such high readmission rates in these unadjusted analyses. The top ten primary diagnoses derived from HES for these readmissions are dominated by ICD10 codes that indicate infection or kidney dysfunction, with urinary tract infection the most common. None of the centres visited reported that analysis of readmission was part of their routine governance or quality assurance process, but wider availability of these data should prompt this in the future.

Future analysis of variation in hospitalisation of renal replacement therapy (RRT) patients

Hospitalisation data on prevalent RRT and incident transplant patients give useful insight into the level of support needed to maintain a dialysis and transplant programme. The economic impact of RRT provision is often reported solely in terms of the direct cost of RRT, but the very high rate of emergency admission to hospital is a major contributor to the global cost of care for these patients and has a major impact on quality of life.

However, the factors driving variation have not been explored in any detail. No obvious correlations with other features of renal service provision were apparent. For example, we might have expected a link between high bacteraemia rates or low prevalent definitive access rates and emergency hospitalisation in any one centre, but this was not the case.

Furthermore, we have not systematically analysed the diagnostic or procedure codes that are driving these admissions, except for incident transplantation where we know that infection is a dominant feature. One centre proposed that closer outpatient assessment and increased contact time with senior decision-makers for ICHD patients may be undervalued in UK renal services. This is an aspect of dialysis care that is known to affect quality but is not accurately measured, nor is it monitored by commissioners. More frequent outpatient review has been shown to improve outcomes in other chronic conditions[196], but tracking outpatient review of dialysis patients in HES is not reliable and we were not able to carry out this analysis. Finally, correlating these data with available patient experience measures would be valuable.

To date, these data have not formed part of the quality assurance process for renal services, despite the fact that hospitalisation is extremely important both economically and in terms of patient experience. It is difficult to make specific recommendations as to how trusts might reduce hospitalisation without a clear picture of the factors determining risk. We are confident that as UKRR makes these data more routinely available they will generate research to explain the variation and develop QI initiatives to reduce hospitalisation.

[196] *Johnson, C., Butler, S.M., Konstan, M.W., Morgan, W. and Wohl, M.E. (2003) Factors influencing outcomes in cystic fibrosis: a center-based analysis. Chest., 123(1): 20–27. https://www.pubmed.ncbi.nlm.nih.gov/12527598/*

Recommendation

Recommendation	Actions	Owners	Timescale
14. Ensure that data on hospitalisation of RRT patients are available and adopted as a routine element of the quality assurance process in renal care.	**a** Linked data in prevalent patients with ESKD in the UKRR annual report to be used to report patterns of hospitalisation.	UKRR	Within 24 months of report publication
	b Monthly quality assurance review and regular access to healthcare professional support for all dialysis patients is an essential part of care that is required to reduce hospitalisation.	Renal centres	Upon report publication
	c NHSBT to incorporate hospitalisation patterns using data available from HES on incident renal transplant recipients in NHSBT annual reports on kidney transplantation.	NHSBT	Within 12 months of report publication
	d NIHR, KRUK and UKRR to promote research to better understand the factors that drive hospitalisation in renal care and to inform future QI initiatives aimed at reducing variation and hospitalisation overall.	NIHR, KRUK, UKRR	Within 24 months of report publication
	e All renal and transplant centres to incorporate analysis and tracking of hospitalisation data into local renal and transplant service quality assurance process.	All renal and transplant centres	Within 12 months of report publication

Pharmacy and medicines optimisation

Prescribing and medicines optimisation in renal medicine is complex and the embedded renal pharmacy workforce is an essential element in ensuring the safe, effective and high value care of patients with acute and chronic kidney disease.

The existing pharmacy workforce across the system (ICS/STP) should be utilised effectively to implement integrated medicines optimisation across primary and secondary care to ensure best clinical management and outcomes for patients with kidney disease. The medicines optimisation strategies for patients with renal disease should improve patient pathways through greater integration of the pharmacy workforce in clinical care in addition to supporting development of formularies and prescribing guidelines with expert input from specialist renal networks. The development of clinical renal networks with commissioner input at regional level will provide oversight, strategic direction and quality improvement opportunities.

The pharmacy service in acute care provides effective pharmaceutical care and promotes and delivers medicines optimisation within secondary care. AKI affects one in five patients admitted as an emergency and develops in a significant proportion of patients in hospital. Mortality approaches one in three. Most cases are not seen by renal physicians but all require medicines review to reduce AKI progression and adjust therapy according to altered pharmacokinetics. Medicines review is a key element of the AKI care bundle (see section on *Acute kidney injury (AKI)*, page 70). For further information, medicines optimisation to prevent and treat AKI is described on the Think Kidneys website[197].

Within renal services, renal MPTs support patients to achieve the best healthcare outcomes from their medicines. Specialist renal pharmacists are essential to providing safe, cost-effective and optimal clinical care. Prescribing and medicines optimisation at ward level are a critical element of the multidisciplinary inpatient team as well as outpatient nephrology care and in-centre and home-based dialysis and transplant care. GIRFT noted pockets of excellence in the uptake of specialist pharmacist roles in renal centres, including consultant pharmacists, pharmacist independent prescribers and specialist renal pharmacists. Where consultant or advanced clinical pharmacy roles have developed, this was associated with improved patient care and safety. It was clear to the GIRFT reviewers that there is a significant opportunity for improved service which is currently being missed. Accredited pharmacy technicians are also integral members of many renal pharmacy teams and have numerous and varied supporting roles. Pharmacy assistants may also be highly effective in the MPT, particularly to assist with management of homecare services[198].

Outside specialist renal wards, non-renal specialist pharmacists are routinely trained and are fully able to modify therapeutic doses based on renal function in chronic and acute kidney disease. They are a key part of the clinical team to identify and mitigate preventable drug-drug interactions and adverse drug reactions associated with inappropriate doses for medicines that require renal-based dose adjustments across the system and to prevent AKI associated with medicines.

However, data from UK Renal Pharmacy Group (UKRPG) member surveys in 2009 and 2012, and in the latest BRS workforce document[199] show a countrywide variation in renal pharmacy service skill mix and staffing levels, with few centres achieving adequate provision. The reasons are multifactorial, often based on historical, local funding arrangements, failure to expand with enlarging renal centre size, insufficient multiprofessional skill mix and direct patient need. Specialist surgical transplant centres were generally found to have highest pharmacy staffing levels.

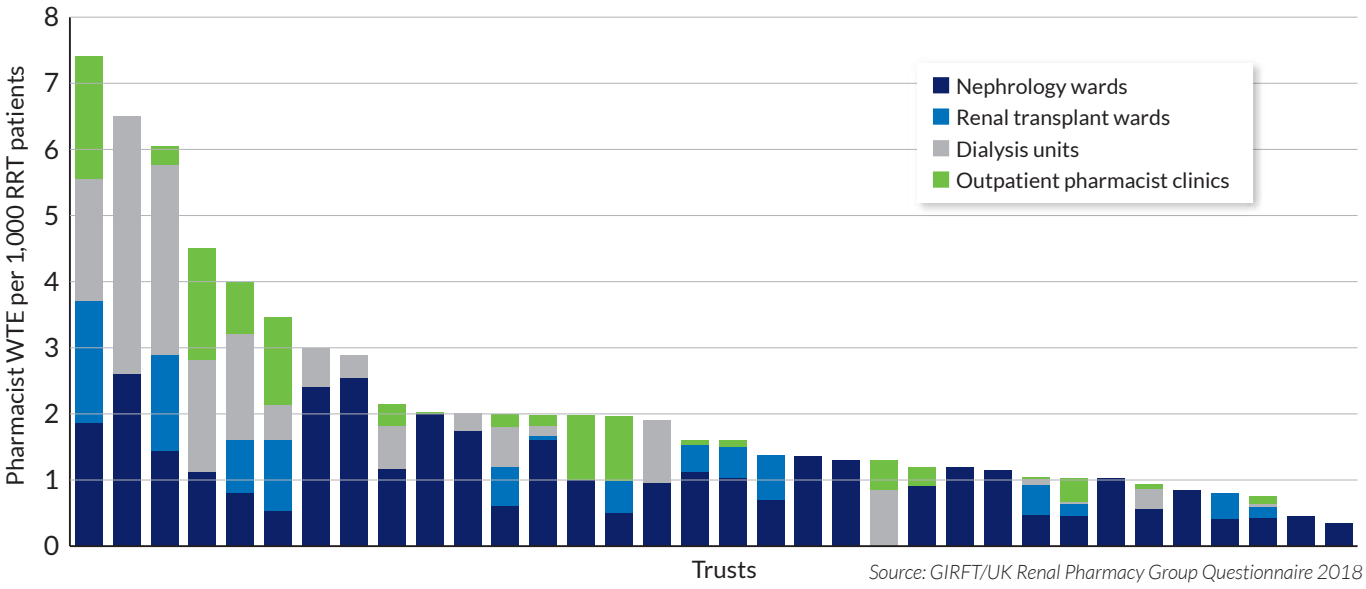
The renal GIRFT /UKRPG survey also found that the extent to which pharmacy workforce has been deployed varies significantly by centre (see **Figures 48** and **49**).

[197] *https://www.thinkkidneys.nhs.uk/aki/medicines-optimisation-for-aki/*

[198] *https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Professional%20standards/Professional%20standards%20for%20Homecare%20services/towards-a-vision-for-the-future-taking-forward-the-recommendations.pdf*

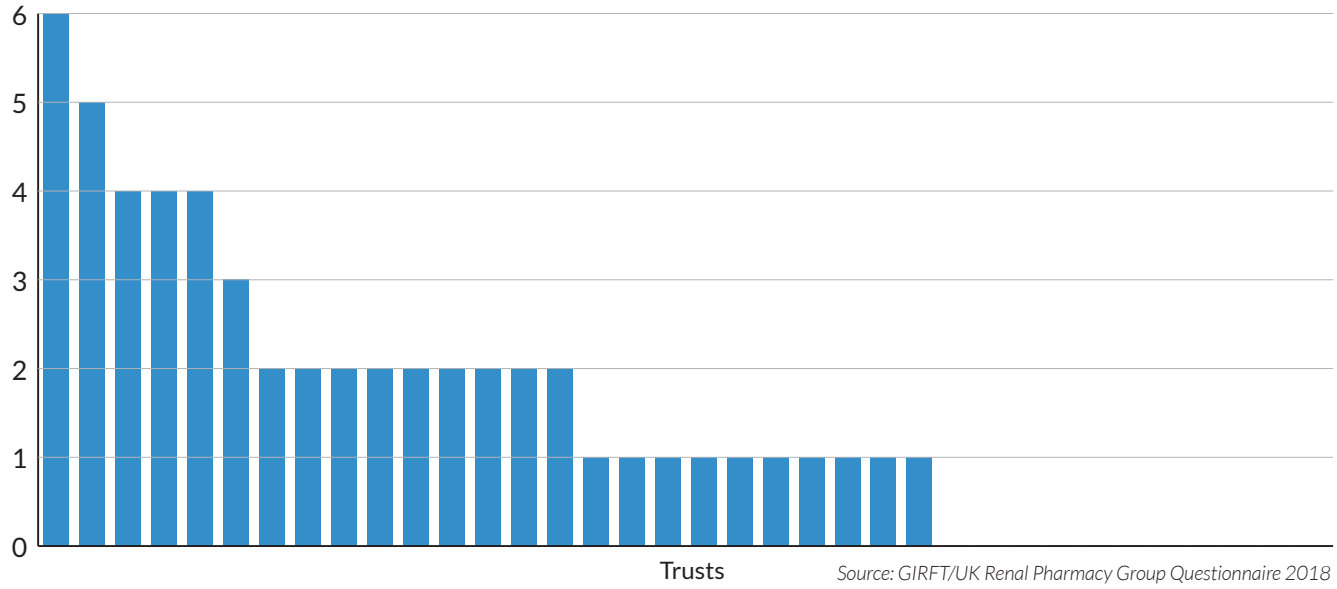
[199] *https://www.britishrenal.org/workforce/*

Figure 48: Pharmacist staffing levels and deployment in English renal centres



Source: GIRFT/UK Renal Pharmacy Group Questionnaire 2018

Figure 49: Number of pharmacist independent prescribers in English renal centres



Source: GIRFT/UK Renal Pharmacy Group Questionnaire 2018

The renal centre pharmacist establishment, as for other services, should be based on unit size, organisation, and local patient case-mix, taking into consideration acuity, dependency and patient complexity as well as using a system by default approach for provision of integrated care. Integrated renal services across systems can include primary care community pharmacists, GP pharmacists and technicians, and general practice and community nurses to provide care in a community setting.

Consideration should be given to the recommendations of the UKRPG in the BRS workforce report 2020[200], as shown in **Table 1**. Although this table makes no specific recommendations based on centre size, granular detail to estimate staffing requirements is included within the report.

Table 1: UKRPG expert panel recommendations for minimum staffing for essential and core adult renal pharmacy service (direct and indirect patient care)

Location of deployment	Recommended staffing level
Nephrology ward	1–2 WTE pharmacist
Transplant ward (transplant centres only)	1–2 WTE pharmacist
Renal dialysis unit	0.5–1.5 WTE pharmacist
Cross service	1–1.5 WTE pharmacy technician

GIRFT supports the further development of advanced pharmacy practice. Pharmacist outpatient activity, as advanced pharmacy practice, is specifically not included in the table above as it is not a core service. Examples of advanced practice are cited within the BRS workforce document[201] as local service developments and an exemplar is given in the case study below. Where this is established or planned, additional pharmacy staff with appropriate qualifications and experience will be required. This is illustrated by **Table 2**, based on a survey from the Shelford Group[202] of ten large teaching hospitals which reported the following level of staffing in their renal services:

Table 2: Renal pharmacy staffing levels in Shelford Group hospitals (2018)

Renal pharmacy team WTE staffing	Mean	Median	Range
Pharmacist – nephrology ward	1.2	1.0	0.5–2.0
Pharmacist – renal transplant ward	1.19	1.0	0.2–2.0
Pharmacist – renal dialysis unit	0.41	0.05	0.0–1.3
Pharmacist – outpatient clinic	0.7	0.4	0.0–2.5
Pharmacy technicians	0.8	1.0	0.0–2.0
No. of pharmacist non-medical prescribers within team	2.0	2.0	0.0–6.0

[200] *https://www.britishrenal.org/workforce/*

[201] *ibid.*

[202] *https://www.shelfordgroup.org/*

CASE STUDY

Advanced renal pharmacy practice

University Hospitals of Leicester NHS Trust

A strong commitment to multi-professional leadership resulted in the appointment of a consultant pharmacist in Renal and Transplant Services in 2015.

The role delivers non-medical advanced clinical practice (including prescribing) in the area of transplantation. The consultant pharmacist is an established and credible clinical expert, operating with a high level of autonomy to support the management of complex cases, often across specialties, to improve patient care. This includes a medicines optimisation programme integrated in transplant work-up to facilitate equitable access to, and ensure the success of, transplantation. The post has brought further benefits to patients through driving research, innovation and introducing new healthcare models to deliver high quality care and support public health agendas. An example of this is leading the flu vaccination programme for the HD population. In addition to the strategic component, the consultant pharmacist contributes to the development of individuals in the wider renal team through education, training and role modelling the right values and behaviours.

The consultant pharmacist role has been a critical workforce development, which is fully integrated and strengthens the senior multi-professional leadership team to deliver better outcomes for patients.

Repatriation of immunosuppression and conversion to generic preparations

Repatriation of transplant immunosuppression from primary care to specialised renal centres was mandated by NHS England Specialised Commissioning in 2014 but GIRFT identified in 2018 that this had still not been realised in 40% of English renal centres.

The repatriation of transplant immunosuppression prescribing back to specialist centres was based on three key principles:

1. Safety – to ensure that the correct formulation was prescribed and dispensed to maintain graft and avoid graft rejection as per MHRA alert[203].
2. Monitoring – to maintain access to specialist centres where formularies are more tightly controlled for immunosuppressant medicines with specialist multidisciplinary input, where renal patients can be monitored effectively, especially where there is an intentional medicine/brand change.
3. Improved healthcare value.

Branded to generic immediate release tacrolimus switch

Multidisciplinary input to medicines optimisation for renal patients has enabled cost-effective care. The best example of this is the transition from branded to generic prescribing of immunosuppression that has taken place over the past ten years. An average of 92% tacrolimus immediate release (IR) was generic in 2019 calendar year for hospital renal services, delivering a saving of £19.4m. Cumulative savings from 2010 calendar year to June 2020 (part calendar year) stand at £103m.

Tacrolimus IR continues to be prescribed in primary care at around 46% generic and 54% branded, compared with 92% generic and 8% branded in acute care renal speciality for calendar year 2019. While primary tacrolimus IR prescribing is not exclusively related to renal care, the majority is, since more than 70% of organ transplants under follow-up in the UK are kidney transplants. Further work is required to complete repatriation to specialist renal centres as a first step to ensure safety and access, and then generic conversion of tacrolimus IR under specialist care. This will require collaboration between commissioners and renal centres to ensure a sufficient pharmacy workforce to safely manage repatriation and ongoing clinical monitoring, dose adjustment and dispensing. Where centres have already achieved this, the investment required has been more than repaid by overall cost savings to the NHS, while the quality of care has also improved.

[203] *https://www.gov.uk/drug-safety-update/oral-tacrolimus-products-reminder-to-prescribe-and-dispense-by-brand-name-only*

Chronic kidney disease – mineral and bone disorder (CKD-MBD)

A generic version of cinacalcet preparations, the main calcimimetic drug used to treat renal hyperparathyroidism, was made available in 2020. The 12-month spend in primary care (up to April 2020) was £9,299,386 and cinacalcet combined volume (all brand preparations) was 1,098,851 Defined Daily Doses (DDDs). Going forward there is potential for huge cost savings once primary care services start to use the 'cost effective' preparation where appropriate. For secondary care the potential savings from a 100% switch to generic preparations for cinacalcet could amount to £1.4m based on 12 months volume (July 2019 to June 2020) for various branded cinacalcet preparations. Potential savings from complete generic conversion across primary and secondary care are significant. This will require effective utilisation of medicines optimisation principles and formulary management drawing on multidisciplinary input for integrated renal service provision.

Non-calcium-containing phosphate binders (sevelamer hydrochloride/carbonate and lanthanum carbonate) are another important high cost medicine group in renal care. Where generic preparations are available, the drug with lowest acquisition cost should be prescribed in order to offer best value healthcare. We found very wide variation in the prescribing patterns for these drugs on deep dives, even though current guidelines make few specific recommendations about their use[204].

Recommendation

Recommendation	Actions	Owners	Timescale
15. Ensure renal centres and ICSs deliver effective medicines optimisation in order to improve the safe care of patients with kidney disease and increase healthcare value.	**a** Renal centres and ICSs to increase the number and scope of work of the renal pharmacy workforce, guided by the recommendations of the pharmacy section of the BRS workforce report[205].	Renal centres and ICSs	Upon report publication
	b Advanced clinical practice pharmacy roles to be further developed and supported to achieve optimum renal centre care delivery.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	c Repatriation of transplant and other immunosuppression from primary to secondary/tertiary renal centre care to be completed with adequate pharmacy resource to ensure safety and supervise generic conversion wherever clinically appropriate.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	d Optimisation of CKD-mineral and bone disorder (MBD) medicines, especially generic conversion of calcimimetics, to be delivered in primary and secondary care.	Renal centres, ICSs, accountable commissioners	Within 12 months of report publication
	e All centres to ensure there is collaboration with the pharmacy department and adequate staffing to ensure home delivery of medications to support home therapies.	Renal centres	Within 12 months of report publication

[204] *https://www.renal.org/wp-content/uploads/2018/06/FINAL-KDIGO-CKD-MBD-commentary-Final-for-publication.pdf*

[205] *https://www.britishrenal.org/workforce/*

Registry data and informatics

Compared with other specialties, the renal community is well served by accurate, validated activity and outcome data from the UKRR and NHSBT. UKRR provides good visibility of biomedical outcomes in dialysis and renal transplant populations. The UKRR annual report on ESKD provides a data portal allowing benchmarking and outcome comparisons between units. NHSBT reports activity and outcomes at both transplant centre and more recently, individual renal centre level. The latter is essential, as much transplant activity is delivered outside transplant surgical units. UKRR data returns are mandated by the NHS England NSSs and is funded through a capitation system on each patient with ESKD, in turn funded through renal centre tariff income. NHSBT Registry is funded directly from the centre.

GIRFT notes the agility of both UKRR and NHSBT in developing registries collecting data in the COVID-19 pandemic. These have been critical in monitoring rates and outcomes of COVID-19 infection as well as informing service planning.

UK Renal Registry

- **PatientView**

  UKRR provides renal patients with access to their laboratory results, clinic letters and notification of renal transplant list status through a secure online portal, PatientView. The portal has well over 30,000 registrants and reports indicate a high level of patient satisfaction with the programme and system use. Patients report a high level of comfort with the PatientView App, including biometric logins. This reduces the work of renal centre administrative staff. Patient portal access is a rapidly developing area and some trust EPR systems include a portal. The UKRR should ensure continuity of the patient portal, with regular reviews to maintain optimal delivery. GIRFT acknowledges the intended transition from PatientView to the Patient Knows Best platform, which will improve opportunities for patient education.

- **The Rare Renal Databases (RADAR)**

  This UKRR database covers 32 rare kidney disease groups and gives patients access to information and collected outcome data on these conditions, in addition to supporting research. The groups themselves run regular patient information days. Nevertheless, major opportunities remain to improve data collection and clinical care through guidelines, improved patient information and in particular, research output.

- **PREMs**

  The UKRR has reported validated PREM across 13 domains for the past three years, providing valuable insights into service delivery (see *Patient experience*, page 85). These proved to be a highly valued resource during our deep-dive visits. Other GIRFT clinical leads confirmed that information on PREMs was not systematically available in other specialties.

- **AKI Master Patient Index**

  A serum creatinine-based algorithm within trusts' laboratory information management systems identifies patients developing AKI (stages 1–3) in hospital or in the community and all but two UK laboratories now report this electronically to the AKI Master Patient Index held by UKRR. Limited data on some patients receiving acute dialysis for severe AKI is also recorded. The incidence of AKI is now reported at CCG level in an annual report.

- **KQuIP**

  UKRR provides a 'using data to improve care' approach by supporting and providing project management to KQuiP (see *Regional renal clinical networks and quality improvement (QI) implementation*, page 30).

- **Research**

  The Registry has also collaborated to develop and deliver substantial epidemiologic and clinical research.

The NHS Blood and Transplant (NHSBT) Registry

The NHSBT Registry provides an annual report on all solid organ transplant activity and outcomes including graft survival rates within transplanting centres[206]. Over the past two years, NHSBT has also produced reports at renal centre level, highlighting the critical role of centres in referring patients for deceased donor transplant listing, live kidney donor assessment and long-term post-operative care following repatriation from the surgical centre. NHSBT shares data with UKRR (and vice versa) on transplant listing, transplant episodes and outcomes.

NHS England Quality Dashboards

There are currently five renal metrics in the NHS England Renal dashboard covering access to transplantation, bloodstream and peritonitis infection in dialysis patients and the uptake and use of PatientView by renal patients[207]. These data are largely self-reported without independent validation and are collated by UKRR. This information is anonymised and is only accessible to clinical directors. A similar transplant dashboard, covering around 20 metrics, exists, although it is not currently updated.

During the deep dives, clinicians reported frustration with limited access to the data. The outputs are currently not reported into the public domain, unlike all other registry data. We feel this is a missed opportunity to support QI. In addition, bacteraemia rates are reported by UKRR annually in its report from linkage to PHE, which takes the data direct from laboratories. It demonstrates that the self-reported data does not accurately reflect the validated data collected by PHE.

Areas for improvement in data for renal services

Data linkage opportunities

GIRFT has highlighted new insights into clinical practice from linkage of NHS data sources with NHSBT and UKRR data sets, identifying hitherto unrecognised clinical issues. Progress is being made with data linkage but bureaucracy and the inter-departmental NHS costs involved limit progress. This must be addressed promptly.

Renal dataset and report timeliness

Timely and complete registry data returns are key to the value of registries, and we welcome the recent development of the UKRR Data Portal which will enable real time benchmarking of collected data. We also recognise that this will entail considerable work in data collection, validation and analysis. However, despite improvements in the last two years in the timeliness of UKRR reports, the lag between year end and publication of the report reduces its value to the community.

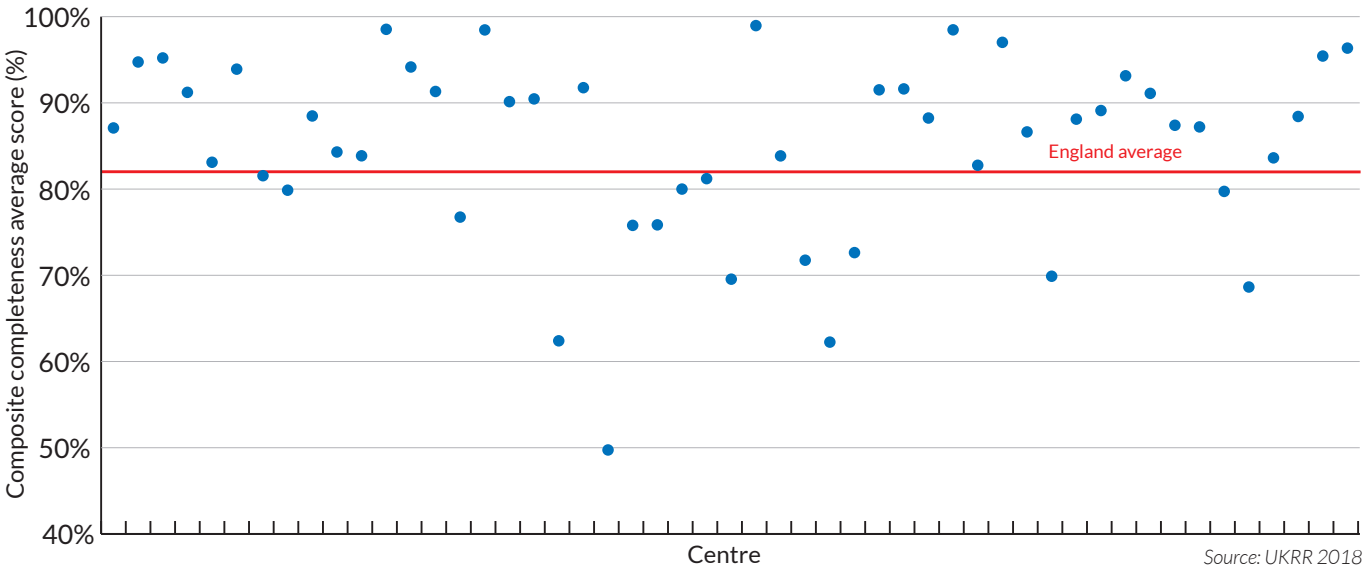
Renal dataset 4.2

The UKRR-mandated renal dataset 4.2 is felt by many centres to be unnecessarily large. The accuracy and completeness of data collected is variable, as shown by **Figure 50**. Centre resource and IT system limitations preclude full collection and cause delay in electronic transfer and validation of data, delaying publication. There are significant opportunities to increase data completeness, improve accessibility and speed up reporting. It is our view that the renal dataset should be reviewed and reduced. Opportunities for data linkage should be adopted to reduce manual entry. During GIRFT visits, it was clear that attitudes and approaches to the importance of data collection and data use vary. Centres with a data manager in post generally achieved better data returns.

[206] *https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/*

[207] *https://www.england.nhs.uk/commissioning/spec-services/npc-crg/spec-dashboards/*

*Figure 50: Completeness of UKRR data returns by centre**



Source: UKRR 2018

* A composite completeness score based on a limited subset of the data items considered essential for quality assurance.

IT compatibility issues

The delay in UKRR annual report publication in part reflects delays in centres submitting data in an enabling format. The UKRR has invested considerable resource in the development of the UK Renal Data Collaboration (RDC), with the aim of enabling real-time download from trust IT systems. Currently, IT compatibility issues preclude direct download to the RDC. The technical issues and costs of solutions should be explored.

Those centres that look to change IT systems should be mandated to involve the UKRR so that compatibility issues are included. Such technical issues are beyond the scope of this report, and we recommend that NHS England and NHS Digital work with UKRR to address them.

Lack of outcome data for patients with advanced chronic kidney disease

There is a lack of outcome data for patients in the critically important pre-dialysis stages of CKD (stages 4–5, pre-ESKD), including those receiving conservative management. A legal agreement would need to be reached with NHS Digital to collect these data. Decisions regarding the care of these patients will have a very significant impact on key outcomes which this report seeks to address. Systematic data collection on this pathway will inform QI.

Transplant reference costs

Few renal centres use the relevant currencies for the transplant pathway and, as a consequence, most do not return reference costs. The intention is to introduce mandatory tariffs related to transplantation. As more centres do not return than do return, it has been challenging to develop the tariff. A transplant tariff for LD assessment would address one factor limiting LD transplant work up in referring centres to a transplant centre (see *Access to kidney transplantation*, page 43).

Recommendation

Recommendation	Actions	Owners	Timescale
16. Ensure that renal centres, commissioners and patients have timely access to contemporaneous, clinically relevant outcome data, in order to support quality assurance and quality improvement.	**a** UKRR, NHS England, NHS Digital and renal centres to revise the core renal dataset, including only essential items.	UKRR, NHS England, NHS Digital, renal centres	Within 12 months of report publication
	b UKRR and NHSBT to establish linked datasets with relevant NHS data streams to minimise centre manual data entry and provide new insights into care quality.	UKRR, NHSBT	Within 12 months of report publication
	c Mandated data returns to be developed and collected for patients with CKD 4–5[8].	GIRFT, NHS England, UKRR, NHS Digital	Within 24 months of report publication
	d All centres to have a data manager dedicated to renal informatics, with sufficient time to meet the requirements of mandated data returns.	Renal centres	Upon report publication
	e All renal centres and renal IT providers to return real time data to UKRR by the end of 2021, as mandated by NHS England.	Renal centres, renal IT providers, NHS England	Within 12 months of report publication
	f Expand the NHS England Renal Quality Dashboard to include key benchmarked metrics from the GIRFT dataset (available quarterly).	NHS England, GIRFT	Within 12 months of report publication
	g The correct currencies to be adopted for all aspects of the transplant pathway and used to report accurate activity and reference cost data.	Renal centres, NHS England and NHS Improvement	Within 12 months of report publication

Procurement

The delivery of renal care to patients with ESKD is expensive and an important component of that cost lies in the procurement of equipment, supplies, medicines and contracted-out services. Dialysis requires large-scale procurement of high cost facilities, equipment and consumables. Solely for dialysis (excluding hospitalisation, the outpatient tariff, high cost drugs and transport) the annual tariff value in England ranges from £17,155 to £32,850 per annum, with the commonest modality costing £24,024[209]. AKESO[210], a consultancy company contracted to NHS Supply Chain, estimates that 75% of HD cost is non-pay, so efficient procurement is an important element in the cost-effective delivery of renal care.

There are many areas of procurement in renal care but the most important are:

- consumables for HD;
- equipment for HD;
- provision of NHS centre HD services by the independent sector;
- provision of NHS home dialysis therapies by the independent sector; and
- high cost drugs (see *Pharmacy and medicines optimisation*, page 109).

In general, renal services have taken a well-organised approach to procurement, often running large tenders at regional or national level: for example, the north of England has run a very successful HD consumables framework for 20 years. For this reason, we did not anticipate the very large differential procurement costs that are described in other published GIRFT national reports such as orthopaedics[211].

There is a remarkable lack of central intelligence on non-drug dialysis procurement costs provided by the NHS Spend Comparison Service (SCS)[212]. Spend is not captured through trust electronic purchase order systems with comparative product codes to allow tracking and benchmarking of consumable or equipment costs in a meaningful way. The same applies to service contracts, which are rarely captured in electronic purchasing systems with comparative codes and descriptions.

Some NHS renal providers were reluctant to share procurement costs with GIRFT, particularly for independent sector HD provision which they considered commercially sensitive. Procurement of PD, where a national pricing framework exists, is a notable exception, although this framework has been subject to criticism.

The majority of the data shown below is derived from GIRFT questionnaires. Prices are self-reported and the completeness of the returns was variable. To obtain a more detailed picture of contracted-out HD provision, a second questionnaire was returned by a representative sample of trusts after the deep dives, with follow-up phone calls to ensure completeness.

Consumables for haemodialysis (HD)

HD consumables include dialysers, lines for HD machines, dialysate and needles for vascular access. We did not find huge variation in the price paid for typical HD consumables. As a simple example, the costs for a 'standard' dialyser used by centres in England (determined by centre choice, irrespective of manufacturer or specification) ranged from £4.30 to £8.40 with an average of £5.70. Of the responding trusts, 71% were within a 20% margin of the average price, a degree of variation that is likely to be explained by differences in volumes purchased or specification.

[209] *As at June 2020.*

[210] *https://www.akesoco.com/*

[211] *https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2017/06/GIRFT-National-Report-Mar15-Web.pdf*

[212] *https://www.digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/spend-comparison-service*

Machines for haemodialysis (HD)

The average price paid for the purchase of an HD machine was £12,685 (range £6,497 to £15,600). Only five centres had a unit cost that was outside a 20% margin of the average. Again, this degree of variation is likely to be largely explicable by differences in volumes purchased or specification; some HD machines have greater therapeutic range, monitoring capability and IT connectivity than others. Fourteen trusts lease rather than purchase HD machines, a strategy that offers a number of potential advantages, including:

- maintenance is included in the contract, reducing the burden on in house renal technologist and medical engineering capacity;
- consumables may be co-purchased as part of a managed equipment service with reduced cost relating to VAT; and
- reduced pressure on trust capital budgets.

We are not in a position to make a judgment on whether leasing or purchase is more cost effective in the long term.

Haemodialysis (HD) delivered for the NHS in partnership with the independent sector

GIRFT has found that 36% of satellite HD is delivered in partnership with the independent sector and for some trusts all chronic HD activity is provided in this way. In a few trusts, support for acute HD is delivered by the independent sector. In financial terms, this represents one of the largest areas of NHS England spend in the independent healthcare sector: spend on independent sector satellite HD alone is estimated at £103m per annum. The growth in independent sector HD has been driven by the lack of available capital in provider trusts, and the high cost and turnover of HD facilities, which require significant investment. One positive outcome of this development has been that the independent sector takes on the financial risk of the capital spend.

The relationship with the independent sector has been a successful one and the companies involved have a good track record of delivering high quality facilities with state-of-the-art equipment. Patient-centred facilities such as freely available WiFi and parking are often superior to those offered by the NHS. At deep dives most NHS centres reported good or acceptable working relationships with their independent sector partners.

A lack of transparency about price and contractual arrangements with the independent sector makes it difficult for NHS providers to benchmark the cost-effectiveness of these facilities. UKRR does not publish metrics at facility level because patients in satellite units are typically less frail and comorbid, so comparison is unlikely to be meaningful. There is no national framework contract and there is a lack of shared learning between NHS providers, such that deficiencies in existing contractual arrangements may be recreated in new ones. NHS trusts are not all well equipped to develop robust contracts that ensure the highest governance standards. A single national contract is unrealistic but a baseline that could be flexed to local requirements would be an advantage. A mandatory NHS Digital register for service contracts should be explored to enable benchmarking of specification, cost and value.

A number of independent sector HD facilities were subject to urgent peer review by the NHS England Quality Surveillance Team in 2016, triggered by concern over the handling of serious incidents (SIs). Responsibility for ensuring good clinical governance of such facilities is shared by the NHS and independent sector providers. Any failings in this area may reflect deficiencies on either side.

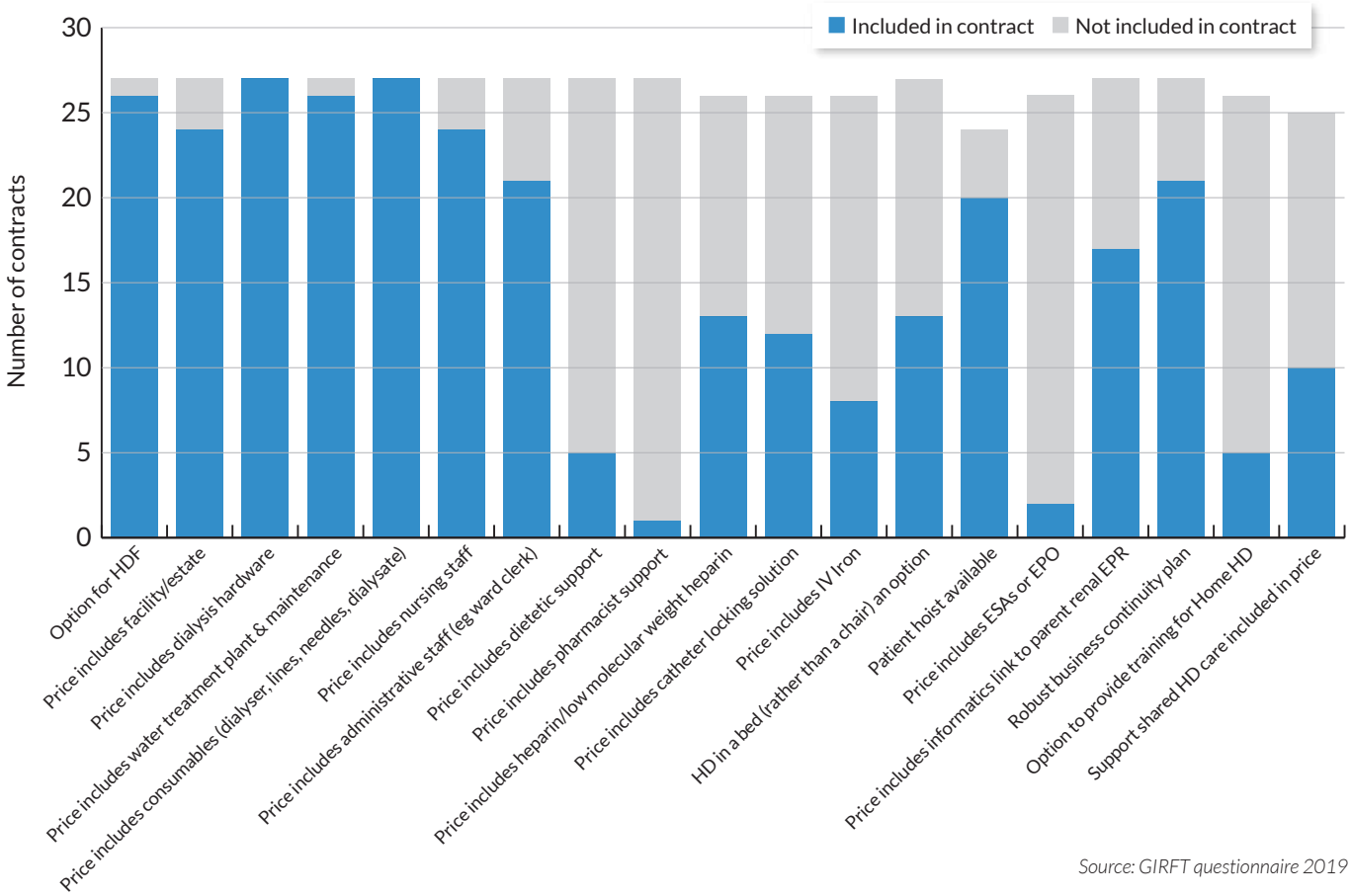
To date, NHS Supply Chain has not had any involvement in the procurement of independent sector HD and there is little in the way of central guidance on contract specification or review arrangements. A large 16-facility procurement in the north of England was contracted by the Department of Health in 2007 but this is the exception, and the per treatment dialysis cost after this procurement was above the national average.

HD in the independent sector is paid for on the basis of cost per HD session. The specification of contracts with the independent sector is highly variable but there are two main models:

- provision of a full HD service including independent sector nursing staff;
- provision of an HD facility, equipment and consumables, with care delivered by NHS employed nursing staff (sometimes also called a managed equipment service).

Unlike independent sector HD in other developed healthcare systems, medical staff and overall clinical responsibility in the UK for patients remains with the host (NHS) provider. This is vital because the whole renal pathway, including vascular access and transplantation, is so inter-connected. Allied healthcare professionals are also provided by the NHS. There is huge variation in other aspects of the partnerships, as illustrated in **Figure 51**. One particular area of concern is the lack or infrequent nature of regular clinical governance and contract review meetings between the two parties.

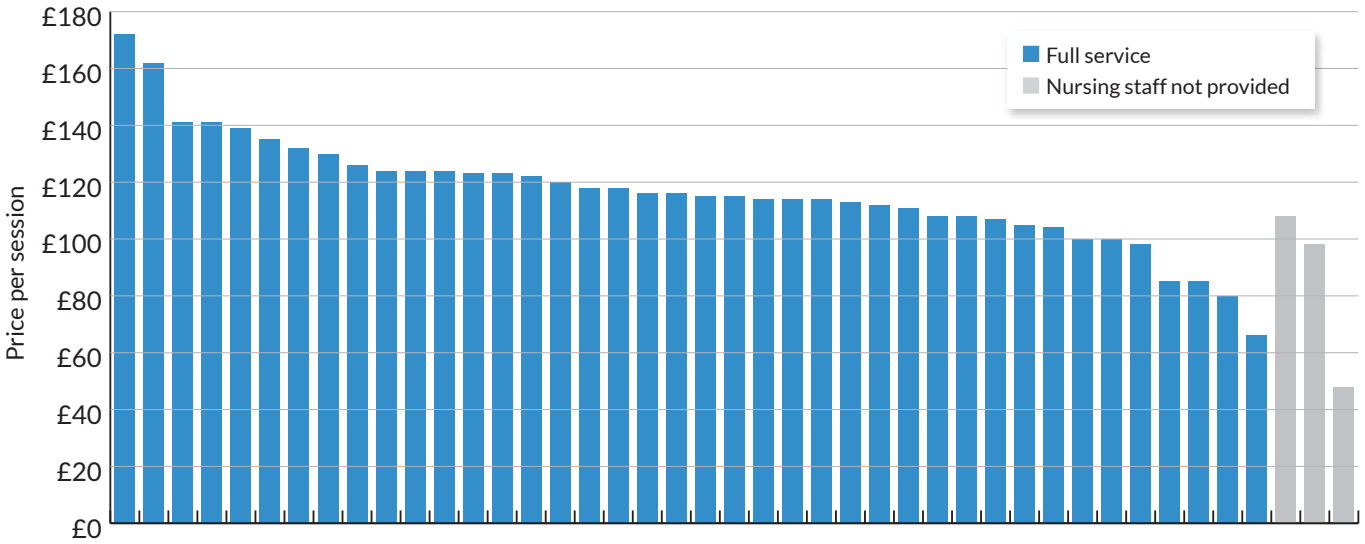
Figure 51: Variation in independent sector haemodialysis contracts



Source: GIRFT questionnaire 2019

The highly varied specification of contracts makes it difficult to compare costs per HD session. The single biggest difference is whether nursing staff are included. **Figure 52** illustrates the range in cost per HD session in a representative sample of facilities, where the analysis of a full HD service and a managed equipment service are considered separately.

Figure 52: Variation in price per dialysis session in independent sector contracts*



* No adjustment has been made for market forces factor (MFF)[213]. The high cost centres are not skewed to trusts in regions with a high MFF, suggesting this is not primarily about geography.

Source: GIRFT questionnaire, 2019

The range in cost per HD session is significant. When translated into an annual HD cost for the typical patient, the range is from £10,250 to £26,800 per annum for a full service and £7,475 to £16,880 for a managed equipment service. It is unlikely that this differential is justified by subtle variations in completeness of service or geographical cost pressures. In some cases, the cost is higher than tariff for HD, even though the costs of medical staff and other supporting resources are not included in the price. In mitigation, some centres with above average costs reported that their contracts had 'added value' as a consequence of a long-term relationship with a supplier, including support with IT connectivity and the introduction of more advanced HD technologies.

Home therapies delivered for the NHS in partnership with the independent sector

PD procurement has been largely under the terms of a national framework since 2011. The cost of PD includes home delivered consumables but also delivery of associated equipment such as cycling machines for automated PD. Cycling machines are owned and maintained by the commercial provider and their cost to the NHS is built into that of the consumables.

While there are advantages to a national procurement arrangement, the national framework price resulted in a significant cost pressure to many centres. The framework was designed to include incentives for growth in PD therapy, but this growth was not realised. Attempts by large centres to procure outside this framework did not progress. As is the case for HD, commercial PD partners often add value to contracts with training and quality improvement opportunities for NHS staff.

On deep dives it was apparent that clinicians did not feel that they had been sufficiently engaged when this framework was developed and that key performance indicators (KPIs) were sometimes driven by commercial considerations, resulting in cost pressure and an enhanced monopolistic position. Better clinical engagement in future contracting activity would mitigate against this, although it should be noted that a nephrology advisory team was involved in the 2011 procurement.

Home HD care is procured in a variety of ways by the NHS. The traditional model is NHS staff for training and support, NHS procured or leased machines and delivery of consumables by a contracted independent sector provider. An alternative model is one where all equipment and consumable needs are met by an independent sector partner, sometimes with training, and the contracted payment is per HD session. Home HD has been an area of technological advance with a number of new commercial partners offering technologies that are simpler for patients to use and portable at least to some extent (see *Home therapies*, page 62). Home HD often has a significant set-up cost for home conversion, reported as ranging from £0 to £3,500 by English centres. Set-up costs for new technologies are significantly lower and this is the likely explanation for much of this variation.

[213] *https://www.improvement.nhs.uk/documents/475/Guide_to_the_market_forces_factor.pdf*

NHS Supply Chain operating model and renal procurement

The NHS Supply Chain operating model (formerly known as the Future Operating Model) is a nationally co-ordinated strategy that aims to optimise procurement within the NHS[214]. Most aspects of renal procurement fall within the remit of this programme. A national procurement framework for HD consumables and equipment, PD services and home HD are all currently out to tender.

The programme is being run by AKESO in partnership with NHS Supply Chain. The stated aim is to deliver 80% of renal procurement within this framework, although it is too early to judge whether this will be successful. For HD consumables it is likely that some centres or networks will choose to procure independently but, as discussed above, this may not be readily achieved for PD. Although the framework includes a baseline for the procurement of an HD managed equipment service, local negotiation of specification will still be required and procuring a full HD service through the framework is not an option.

There are inherent tensions in the design of such a national framework. Large providers with high volume procurement require sufficiently generous volume-based price discounts to encourage them to use the framework. Conversely, an important aim of a national framework is to ensure that smaller providers are not disadvantaged and that they reap the benefits of a national programme. Commercial partners offering home therapies where staff or support in the home is required, such as assisted APD, may not offer comprehensive geographical coverage, disadvantaging those NHS providers that serve a more rural population.

Clinicians have expressed concern about the level of clinical engagement in this process. Representatives from the NHS England Renal and Transplant CRG as well as GIRFT have had the opportunity to feed into the specification. One success has been the involvement of Patient and Public Voice members of the CRG in the consultation. It is essential that the new framework will be more focused on clinical quality and patient-centred KPIs, such as the reliability of home delivery schedules, rather than on the commercial priorities of independent sector partners. KPI-based reimbursement and iterative annual awards would be worth exploring in the future to incentivise performance and stimulate competition.

Recommendation

Recommendation	Actions	Owners	Timescale
17. Ensure that procurement of HD facilities and home therapies delivered in partnership with the independent sector offers consistent quality and cost-effectiveness across the NHS in England.	**a** Minimum specification contracts to be developed for independent sector HD and managed equipment service facilities, with scope for local flexibility. Contracts to include framework for price and clinical governance arrangements.	NHS England Specialised Commissioning, NHS Supply Chain	Within 12 months of report publication
	b A central register of procurement activity of dialysis facilities and services to be developed; price per therapy should be transparent in the NHS Spend Comparison Service (SCS) or an alternative NHS Digital mandatory contracts register.	NHS Digital, NHS Supply Chain	Within 12 months of report publication
	c NHS England and NHS Improvement to develop a catalogue of standard consumable, equipment and service codes that can be used in purchase orders, enabling benchmarking of costs and ensuring consistency across the system.	NHS England and NHS Improvement	Within 12 months of report publication
	d National contracts to be developed with the independent sector for home therapies which are patient-centred and include guarantees of geographical completeness.	NHS Supply Chain	Within 12 months of report publication

[214] *https://www.supplychain.nhs.uk/*

Reducing the impact of litigation

Each GIRFT workstream team has been asked to examine the impact and causes of litigation in their field – with a view to reducing the frequency of litigation and more importantly reducing the incidents that lead to it. Ensuring clinical staff have the opportunity to learn from claims in conjunction with learning from complaints, SIs/Patient Safety Incidents (PSIs) and inquests will lead to improved patient care and reduced costs both in terms of litigation itself and the management of the resulting complications of potential incidents.

The renal community comprising the BRS and the RA have a standing committee proactively assessing patient safety issues relevant to kidney care[215]. This includes review and analysis of incident reports to the National Reporting and Learning System (NRLS)[216] which identifies opportunities for learning. Examples include Section 28 coroners' reports on fatal haemmorhage following CVC removal and opiate dosing in ESKD.

Litigation in renal medicine

The NHS Resolution database identifies 299 clinical negligence claims attributed to renal medicine over five years between 2013/14 and 2017/18. The total value of these claims was £49m and there is a modest trend of year on year increase in value and to a lesser extent number of claims (see **Table 3**).

Table 3: Volume and cost of medical negligence claims attributed to renal medicine notified to NHS Resolution 2013/14–2017/18

Notification year	Total no. of claims	% change in claims	Total claim cost (£)	% change in cost
2013/14	50	-	7.09m	-
2014/15	51	2%	7.88m	11%
2015/16	60	18%	9.93m	26%
2016/17	71	18%	10.89m	10%
2017/18	67	-6%	13.32m	22%
Grand Total	**299**	**-**	**49.1m**	-

Source: NHS Resolution 2013/14 to 2017/18

The methodology by which claims are attributed to renal medicine is imperfect and is wholly dependent on clinical coding practice, as evidenced by the fact that about 20% of the claims by value are reported in trusts without a renal hub (£40.08m in trusts with a renal hub). There were 52 trusts with a renal hub at the time of this analysis, so even if all these cases do relate to renal medicine, this represents just over one claim per renal centre in each year. Conventional GIRFT analysis reports the financial impact of litigation as cost per admission. However, dialysis is the largest component of practice and spend in renal medicine, is largely outpatient delivered and it is not captured in HES. Litigation in renal medicine is more appropriately reported as cost per £1,000 of total renal expenditure, derived from NHS reference costs. When expressed in this way, litigation in the 52 trusts with a renal service represented less than 1% of total expenditure at £7.69 per £1,000 spend. Over this five-year period there were over 250,000 patient-years of RRT follow-up and almost 20 million HD sessions, so while we cannot produce a litigation cost per unit activity which is directly comparable with other specialties, we can see that it is low. The only GIRFT medical specialties with a lower total litigation spend during this period are rheumatology, dermatology and endocrinology. Pure surgical specialties typically report much higher values.

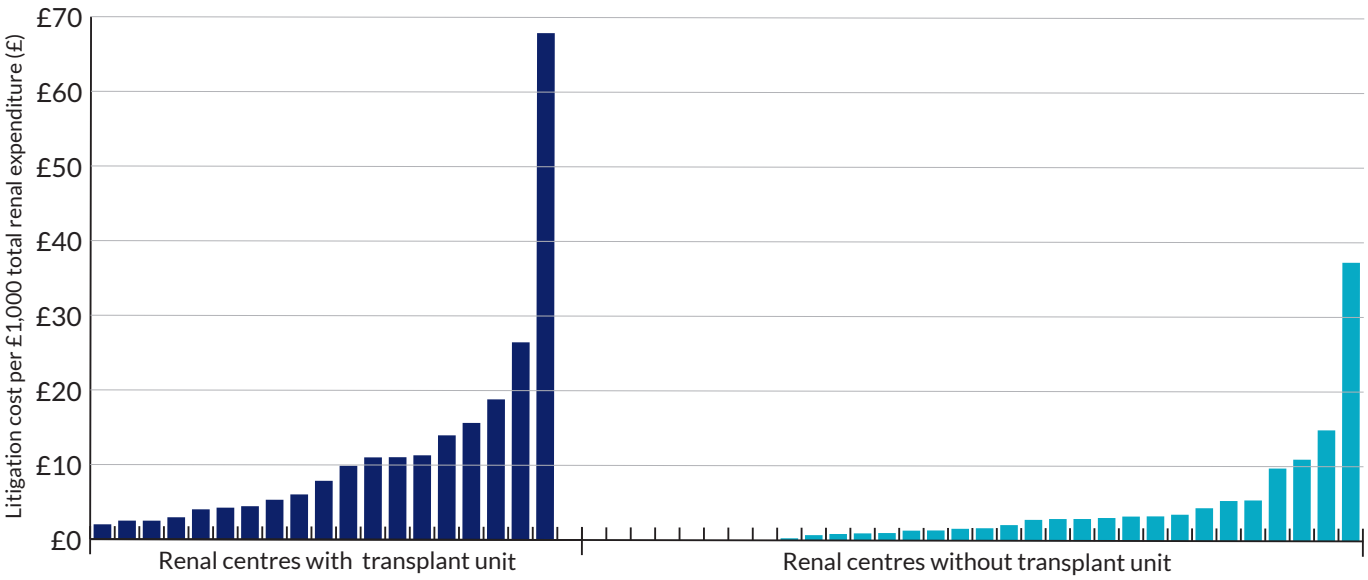
[215] *https://www.renal.org/patient-safety-committee*

[216] *https://www.improvement.nhs.uk/documents/843/OPSIR_guidance_notes_March_2017.pdf*

Variation in average litigation costs

The 19 transplant centres are not directly comparable with the 33 non-transplanting centres and we have chosen to analyse these separately. The transplant centres had a mean litigation cost of £10.25 per £1,000 total renal expenditure, just over twice that of the non-transplanting centres where the mean was £4.47. Within each group, there are wide differences between providers with estimated litigation costs of £1.99 to £67.90 per £1,000 total renal expenditure in transplant centres and £0 to £37.61 in non-transplanting renal centres (see **Figure 53**).

Figure 53: Variation in England between trusts in estimated litigation costs for renal medicine per £1,000 total renal expenditure



Source data: NHS Resolution 2013/14 to 2017/18, denominator derived from 5 x total renal expenditure from 2016/17 NHS England reference costs

We are cautious about the interpretation of this analysis for a number of reasons:

- 17% of the claims relate to surgical procedures and there is significant variation between trusts as to how they report renal access surgery activity, both in HES and reference costs. For example, only 34% of AVF surgery is reported as renal medicine, 32% of vascular surgery, 18% of general surgery and 14% of transplant surgery[217].
- The overall claim rate is very low, even when averaged over a five-year period, and for any one centre a single large claim may be in the time window of analysis or just outside it.
- The attribution of the cases to renal medicine is not wholly reliable as this process is carried out inconsistently at trust level and sometimes without clinical input.

It was clear during GIRFT visits that many providers had queries about the attribution of claims to renal services. It is also clear that further work is needed at both a local and national level to analyse claims to maximise this opportunity to improve patient care. We hope the GIRFT litigation pack will facilitate this learning at the local level.

Every effort must be made to learn from clinical negligence claims, to improve the safety and quality of patient care, and to reduce the costs of litigation. Effective learning from claims allows good practice to be shared and has the potential to reduce claims and to ensure that resources are not unnecessarily diverted from front line care. Most importantly, this learning means more patients receive the right care first time with fewer failed or ineffective treatments, decreased length of stay, fewer follow up appointments, and less care packages needed by patients suffering complications.

The recommendation and actions (the five-point plan 18a-e) below are included in all GIRFT specialty reports. Two specific actions regarding case allocation (18f-g) have been added which are specific to renal medicine.

[217] *HES 2017–18.*

Recommendation

Recommendation	Actions	Owners	Timescale
18. Reduce litigation costs through application of the GIRFT programme's five-point plan (actions a-e) in addition to actions f and g which are specific to renal medicine.	**a** Clinicians and trust management to assess their benchmarked position compared with the national average when reviewing the estimated litigation cost per activity. Trusts would have received this information in the GIRFT litigation data pack.	Clinicians, trust management	Upon report publication
	b Clinicians and trust management to discuss with the legal department or claims handler claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Trusts to inform NHS Resolution of any claims that are not coded correctly to the appropriate specialty via ***CNST.Helpline@resolution.nhs.uk***	Clinicians, trust management	Upon completion of 18a
	c Once claims have been verified clinicians and trust management to further review claims in detail including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims handler needs additional assistance with this, each trust's panel firm should be able to provide support.	Clinicians, trust management	Upon completion of 18b
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (Sis); where a claim has not already been reviewed as an SI, this should be carried out to ensure no opportunity for learning is missed.	All trusts	Upon completion of 18c
	e Where trusts are outside the top quartile of trusts for litigation costs per activity, GIRFT will be asking national clinical leads and regional hubs to follow up and support trusts in the steps taken to learn from claims. They will also be able to share with trust examples of good practice where it would be of benefit.	GIRFT	For continual action throughout the GIRFT programme
	f NHS Resolution, in collaboration with GIRFT, the renal providers and professionals, to define and publish the criteria by which they identify cases attributed to renal medicine, including all relevant surgical cases.	NHS Resolution and GIRFT	Upon report publication
	g Trusts to adopt these criteria when cases are referred to NHS Resolution and use them when reviewing claims as part of the GIRFT Programme's five-point plan.	All trusts	Within 12 months of report publication

Notional financial opportunities

This report sets out a series of ways to improve the delivery of renal services using the existing resources available to the specialty. While the impact in some areas is difficult to measure, in others there is a clear tangible benefit.

The most important clinical improvements covered in the recommendations are to patient care and choice and it is essential not to lose sight of these. However, among the many areas covered, the report includes recommendations regarding improved kidney transplantation rates, length of stay linked to transplantations, increasing day case rates in vascular access and reducing hospitalisation in HD and PD patients. In each case, a number of opportunities are identified for delivering tangible financial benefits. These are summarised in **Table 4**. It should be noted that this is not a comprehensive health economic evaluation. The figures are based on a selection of metrics and provide an indication of what may be possible. The metrics do not represent a comprehensive set of all opportunities discussed in the report.

We calculate the notional financial opportunity from specific changes to renal practice as being between £28.8m and £52.3m a year. These figures provide a financial value for a wide range of efficiency opportunities, which may not all be cash-releasing. The two areas highlighted as offering opportunities for the highest savings are the reduction of hospitalisation of HD patients (estimated at between £7.1m and £14.9m) and the reduction in new nephrology outpatient appointments (estimated at between £4.8m and £9.0m). In reality, any reduction in new nephrology outpatient attendances would be balanced by growth in virtual nephrology consultations, so this opportunity is an example of one that is not cash-releasing. It should be noted that reference costs for HHD are unreliable and therefore the notional impact for growth in home dialysis is based on national tariff.

Modelling the health economic impact of transplantation is complex and we have used an existing economic model developed in the UK, albeit in 2010[218]. Growth in transplantation may be underestimated in **Table 4**. It is based on achieving up to 259 more transplants by two years after the start of RRT and assumes that all centres realise the rates achieved by those currently in the top quartile. This is a conservative estimate of growth, because NHSBT predicts 500-600 more transplants per annum in the UK as a result of the 'opt out' legislation and other initiatives.

We have not attempted to estimate financial opportunities arising from renal procurement. While we are confident that such opportunities exist, especially for independent sector satellite HD provision, we did not have a sufficiently comprehensive dataset to estimate their financial value.

AKI complicates a very large number of hospital episodes. There were 306,868 admissions to 103 trusts in England in 2017. As a consequence, even a small reduction in the LoS for AKI admissions has a very large notional impact: an estimated £150m in savings, and 395,000 bed days[219]. A recent UK randomised controlled trial demonstrated reduction in LoS for AKI admissions by structured introduction of AKI e-alerts, an AKI care bundle and an education programme. AKI admissions are managed by a broad range of acute medical and surgical specialties, often supported by critical care in the most severe cases. One UK centre found that 7.5% of AKI admissions were managed directly by renal medicine and the patients under renal teams mainly have AKI3[220]. Nevertheless, renal teams often play a supporting role in many of these admissions and have been drivers of quality improvement in AKI care. The notional financial opportunity from improved AKI care is large and realisable but it would be shared across all acute medical specialties and so has not been included in **Table 4**.

[218] *Organs for Transplants, West Midlands Specialised Commissioning Team, October 2010.*

[219] *https://www.renal.org/resource/aki-report*

[220] *Selby NM, Crowley L, Fluck RJ, et al. Use of electronic results reporting to diagnose and monitor AKI in hospitalized patients. Clin J Am Soc Nephrol. 2012;7(4):533-540. https://www.pubmed.ncbi.nlm.nih.gov/22362062/*

Table 4: Summary of improvements and financial opportunities*

* The gross notional financial opportunities put an estimated value on the resource associated with variation based on all providers achieving at least the average or best quartile performance.

Improvement (opportunities are per annum)	National average or better			Top quartile or better		
	Target	Activity opportunity	Gross notional financial opportunity	Target	Activity opportunity	Gross notional financial opportunity
Improvement in kidney transplantation rates* *Source: UKRR 2017*	21% of incident patients transplanted within 2 years	144 more patients transplanted	£2.1m	24% of incident patients transplanted within 2 years	259 more patients transplanted	£3.7m
Reduction in length of stay for transplant patients *Source: HES 2018*	Deceased donor - 10.6 days Living donor - 9.5 days	3,100 bed days	£1.2m	Deceased donor - 8.2 days Living donor - 7.5 days	7,000 bed days	£2.6m
Increase vascular access surgery day case rate *Source: HES 2018*	Day case rate - 69%	1,060 admissions	£0.4m	Day case rate - 81%	2,170 admissions	£0.8m
Increase proportion of dialysis on home treatments** *Source: UKRR 2018*	Home treatment rate - 20%	937 patients	£5.0m	Home treatment rate - 20%	937 patients	£5.0m
Reduction in follow up outpatient appointments in the first 6 months following transplant *Source: HES Jun 17–May 18*	25 outpatient follow ups in 6 months following transplant	6,774 follow up outpatient attendances	£1.1m	24 outpatient follow ups in 6 months following transplant	8,421 follow up outpatient attendances	£1.4m
Reduction in new nephrology outpatient appointments *Source: RightCare 2017–18*	236 new outpatients per 100,000 weighted population	20,625 new outpatient attendances	£4.8m	158 new outpatients per 100,000 weighted population	38,900 new outpatient attendances	£9.0m
Reduction in emergency hospitalisation of HD patients *Source: UKRR 2018*	12 emergency inpatient hospital days per HD patient	19,000 bed days	£7.1m	10 emergency inpatient hospital days per HD patient	40,000 bed days	£14.9m
Reduction in emergency hospitalisation of PD patients *Source: UKRR 2018*	11.6 emergency inpatient hospital days per PD patient	4,700 bed days	£1.7m	9.1 emergency inpatient hospital days per PD patient	8,900 bed days	£3.3m

Improvement (opportunities are per annum)	National average or better			Top quartile or better		
	Target	Activity opportunity	Gross notional financial opportunity	Target	Activity opportunity	Gross notional financial opportunity
Reduction in emergency hospitalisation of transplant patients *Source: UKRR 2018*	4.2 emergency inpatient hospital days per transplant patient year	10,755 bed days	£4.0m	3.3 emergency inpatient hospital days per transplant patient year	27,280 bed days	£10.2m
Prescribe cinacalcet using generic drug *Source: Define July 2019–June 2020*	100% generic rate		£1.4m	100% generic rate		£1.4m
Total			**£28.8m**			**£52.3m**

* Annual saving for transplanted patients relative to dialysis taken from Organs for Transplants, West Midlands Specialised Commissioning Team, October 2010.

** Difference in cost between hospital HD and home treatments calculated using National Tariff 2019¬20 due to data quality issues in reference costs for home dialysis. All bed day costings based on 2017–18 reference costs. All admission and outpatient costings based on 2018–19 reference costs uplifted for inflation.

About the GIRFT programme

Getting It Right First Time (GIRFT) is a national programme designed to improve medical care within the NHS.

Funded by the Department of Health and Social Care and jointly overseen by NHS England, NHS Improvement and the Royal National Orthopaedic Hospital NHS Trust, it combines wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

Working to the principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. While the gains for each patient or procedure may appear marginal they can, when multiplied across an entire trust – and even more so across the NHS as a whole – deliver substantial cumulative benefits.

The programme was first conceived and developed by Professor Tim Briggs to review elective orthopaedic surgery to address a range of observed and undesirable variations in orthopaedics. In the 12 months after that pilot programme, it delivered an estimated £30m–£50m savings in orthopaedic care – predominantly through changes that reduced average length of stay and improved procurement.

The same model is now being applied to over 40 different areas of clinical practice. It consists of four key strands:

1. A broad data gathering and analysis exercise, performed by health data analysts, which generates a detailed picture of current national practice, outcomes and other related factors.
2. A series of discussions between clinical specialists and individual hospital trusts, which are based on the data – providing an unprecedented opportunity to examine individual trust behaviour and performance in the relevant area of practice, in the context of the national picture. This then enables the trust to understand where it is performing well and what it could do better – drawing on the input of senior clinicians.
3. A national report, that draws on both the data analysis and the discussions with the hospital trusts to identify opportunities for NHS-wide improvement.
4. An implementation phase where the GIRFT team supports providers to deliver the improvements recommended.

Implementation

GIRFT works in partnership with NHSE/I regional teams to help trusts and their local partners to implement improvements and address the issues raised in both the trust data packs and the national specialty reports. The GIRFT team provides support at a local level, advising on how to reflect the national recommendations into local practice and supporting efforts to deliver any trust specific recommendations emerging from the GIRFT visits. GIRFT also helps to disseminate best practice across the country, matching up trusts who might benefit from collaborating in selected areas of clinical practice. Through all its efforts, local or national, the GIRFT programme strives to embody the 'shoulder to shoulder' ethos that has become GIRFT's hallmark, supporting clinicians nationwide to deliver continuous quality improvement for the benefit of their patients.

Glossary

Clinical terms

Acute kidney injury (AKI)
Acute kidney injury is where the kidneys suddenly stop working properly. It can range from minor loss of kidney function to complete kidney failure.

Advanced clinical practitioners (ACPs)
Advanced clinical practitioners are healthcare professionals educated to master's level, from a range of professional backgrounds including nursing, pharmacy, paramedics and occupational therapy.

Advanced kidney care clinic (AKCC)
The role of the advanced kidney care clinic includes monitoring renal function and providing advice on treatment options for patients with chronic kidney disease.

Arteriovenous fistula (AVF)
An arteriovenous fistula is a blood vessel created in the arm by connecting an artery to a vein. This makes the vessel wider and stronger than it would otherwise be. Blood passes through the AVF to the dialysis machine and back again during haemodialysis.

Arteriovenous graft (AVG)
An arteriovenous graft is a synthetic tube which is placed under the skin to form a bridge between an artery and a vein. Grafts are used as the long-term choice of dialysis access when veins are unsuitable for an arteriovenous fistula.

Autosomal dominant polycystic kidney disease (ADPKD)
An inherited condition that causes small fluid-filled sacs called cysts to develop in the kidneys.

Central venous catheter (CVC)
A catheter (tube) that is passed through a vein to end up in the thoracic portion of the vena cava (the large vein returning blood to the heart) or in the right atrium of the heart.

Chronic kidney disease (CKD)
Chronic kidney disease is a long-term condition where the kidneys no longer function as well as they should. CKD is a common condition, associated with ageing.

Commissioning
The process of identifying local health needs, and purchasing and reviewing services to meet those needs.

Commissioning for Quality and Innovation (CQUIN)
The NHS England Commissioning for Quality and Innovation (CQUIN) framework supports improvements in the quality of services and the creation of new, improved patterns of care.
https://www.england.nhs.uk/nhs-standard-contract/cquin/

Comorbidities
The simultaneous presence of two or more chronic diseases or conditions in a patient.

End stage kidney disease (ESKD)
End stage kidney disease, also known as end stage renal failure (ESRF) or established renal failure (ERF), is an irreversible, long-term condition as a result of chronic kidney disease (or less commonly acute kidney injury) for which renal replacement therapy in the form of regular dialysis treatment or transplantation is required if the patient is to survive.

Glomerular filtration rate (GFR)
Glomerular filtration rate is a measurement of how many millilitres of waste fluid the kidneys can filter from the blood in a minute.

Haemodialysis (HD)
Haemodialysis involves diverting blood into an external machine, where it is filtered before being returned to the body.

Hospital Episode Statistics (HES)
Data collected during a patient's time at hospital and submitted to allow hospitals to be paid for the care they deliver. The aim is to collect a detailed record for each "episode" of admitted patient care delivered in England, either by NHS hospitals or delivered in the independent sector but commissioned by the NHS.

Integrated care systems (ICSs)
NHS organisations, in partnership with local councils and others, taking collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve.

https://www.england.nhs.uk/integratedcare/integrated-care-systems

Interventional radiology (IR)
A range of techniques that use radiological images to diagnose and treat diseases in a minimally invasive way.

Length of stay (LoS)
The number of days that a patient is in hospital as an inpatient. Can be pre-operative, post-operative, or the sum of both.

Managing Access by Generating Improvements in Cannulation (MAGIC)
A national QI initiative, aimed at promoting AVF use and longevity through good cannulation practice.

Multidisciplinary team (MDT)
A team of healthcare professionals from different disciplines who work together in caring for the patient.

Non-emergency patient transport (NEPT)
Patient transport is a service provided for patients who are unable to attend hospital appointments (including for dialysis) by public transport or any other means (including private minicab) due to their medical condition.

Peritoneal dialysis (PD)
Peritoneal dialysis involves pumping dialysis fluid into the space inside the abdomen to draw out waste products from the blood passing through vessels lining the inside of the abdomen.

Proteinuria
The presence of protein in the urine. This can be an indication of poor kidney function.

Renal replacement therapy
Renal replacement therapy (RRT) describes the range of therapies used to treat patients whose kidneys are no longer functioning. It includes haemodialysis, peritoneal dialysis and transplantation.

Tunnelled catheter
A tunnelled dialysis catheter (or tunnelled line, or tunnelled central venous catheter (CVC)) is a small soft plastic tube inserted through the skin into a large vein in the neck. It is used to connect the patient to the dialysis machine for haemodialysis. It is often used as a temporary measure until more permanent access (e.g. arteriovenous fistula) can be created. A non-tunnelled line is a similar tube, inserted into a blood vessel and held in place by stitches.

Vascular access
Vascular access describes any means of enabling blood to leave and return to the body,whether via arteriovenous fistula, graft or tunnelled (or non-tunnelled) line.

Organisations

Association of Nephrology Nurses UK (ANN UK)

The Association aims to provide professional and clinical support, education, training and develop clinical standards of care for all levels of registered and non-registered nurses working in kidney care.

https://www.britishrenal.org/ann-uk/

British Association of Day Surgery (BADS)

The British Association of Day Surgery provides information about day and short stay surgery for patients, relatives, carers, healthcare professionals and members.

https://www.daysurgeryuk.net/en/home/

British Renal Society (BRS)

The British Renal Society is a charity that exists to advance education in the area of renal disease and renal replacement therapy, and to fund and support multi-professional research into kidney disease and its management.

https://www.britishrenal.org

British Society of Interventional Radiology (BSIR)

The British Society of Interventional Radiology is a charitable foundation founded to promote and develop the practice of Interventional Radiology.

https://www.bsir.org

British Transplant Society (BTS)

The British Transplantation Society is a non-profit professional body representing the community of physicians, surgeons, nurses, allied health professionals and scientists involved in organ transplantation in the UK.

https://www.bts.org.uk

Health Education England (HEE)

Health Education England is the national leadership organisation for education, training and workforce development in the health sector. HEE is an executive non-departmental public body, sponsored by the Department of Health and Social Care.

https://www.hee.nhs.uk

Intensive Care National Audit and Research Centre (ICNARC)

The Intensive Care National Audit and Research Centre provides information about quality of care to those who commission, manage, deliver and experience critical care (both within and outside the NHS) through national clinical audits and research studies.

https://www.icnarc.org

Joint British Diabetes Society for Inpatient Care (JBDS-IP)

The Society aims to improve inpatient diabetes care across the UK through the development and use of high-quality, evidence-based guidelines and inpatient care pathways.

https://www.diabetes.org.uk/professionals/resources/shared-practice/inpatient-and-hospital-care/joint-british-diabetes-society-for-inpatient-care

Joint Royal Colleges of Physicians Training Board (JRCPTB)

The Board improves patient care by setting and maintaining standards for the highest quality of physician training in the UK on behalf of the Royal College of Physicians of London, Royal College of Physicians of Edinburgh and the Royal College of Physicians and Surgeons of Glasgow.

https://www.jrcptb.org.uk

KDIGO

KDIGO is the global organisation developing and implementing evidence based clinical practice guidelines in kidney disease. The KDIGO classification provides a framework for assessing the severity of acute kidney injury.

https://kdigo.org

Kidney Care UK

Kidney Care UK is a kidney patient support charity, providing practical, financial and emotional support for kidney patients and their families and campaigning to improve care services across the country.

https://www.kidneycareuk.org

Kidney Quality Improvement Partnership (KQuIP)

The Kidney Quality Improvement Partnership is a network of kidney health professionals, patients and carers who are committed to developing, supporting and sharing quality improvement in kidney services in order to enhance outcomes and quality of life for patients with kidney disease.

https://www.thinkkidneys.nhs.uk/kquip/

Kidney Research UK

Kidney Research UK is a charity that funds research that focuses on the prevention, treatment and management of kidney disease.

https://www.kidneyresearchuk.org

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

The purpose of the Enquiry is to assist in maintaining and improving standards of care for adults and children for the benefit of the public by reviewing the management of patients, by undertaking confidential surveys and research, by maintaining and improving the quality of patient care and by publishing and generally making available the results of such activities.

https://www.ncepod.org.uk

NHS Blood and Transplant (NHSBT)

NHS Blood and Transplant is an executive non-departmental public body of the Department of Health and Social Care. It is responsible for managing NHS blood donation services in England and transplant services across the UK.

https://www.nhsbt.nhs.uk

Renal Association (RA)

The Renal Association is the professional association for UK nephrologists (renal physicians, or kidney doctors) and renal scientists.

https://www.renal.org

Renal Services Transformation Programme (RSTP)

Commissioned by NHS England and NHS Improvement, this is a large scale transformation programme spanning the full range of renal services.

Royal College of Physicians (RCP)

The Royal College of Physicians is an independent patient-centred and clinically-led organisation, that drives improvement in the diagnosis of disease, the care of individual patients and the health of the whole population both in the UK and across the globe.

https://www.rcplondon.ac.uk

Royal College of Radiologists (RCR)

The Royal College of Radiologists works with its members to improve the standard of practice across the fields of radiology and oncology.

https://www.rcr.ac.uk

Royal College of Surgeons (RCS)

The Royal College of Surgeons of England is a professional membership organisation and registered charity, which exists to advance patient care.

https://www.rcseng.ac.uk

UK Renal Registry (UKRR)

The UK Renal Registry is part of the Renal Association. It collects analyses and reports on data from 71 adult and 13 paediatric renal centres. Currently, data is collected quarterly and published annually.

https://www.renalreg.org

Vascular Access Society of Britain & Ireland (VASBI)

The Vascular Access Society of Britain & Ireland is a multi-disciplinary society focused on the creation and use of safe and reliable vascular access for patients who require haemodialysis. Its membership includes nephrologists, radiologists, surgeons, nurses, radiographers, sonographers and technicians.

https://www.vasbi.org.uk

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