Improving quality in kidney care 2011

Supported by NHS Kidney Care
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Although it is treatable, the number of people in England with kidney disease continues to rise each year. It is thought to affect between 3 and 5 million people, and treatment costs account for around 3% of the total NHS spend.

Significant investment and reform since the publication of the National Service Framework for Renal Services seven years ago have resulted in real improvements in how we manage kidney disease, but there is more we can do for our patients. For example, the government’s recent White Paper, Equity and Excellence: Liberating the NHS, makes a clear commitment to shared decision-making, with the patient pledge: ‘no decision about me without me’.1

NHS Kidney Care is a clinically led organisation focusing on high-quality, affordable care for all kidney patients in England. Working alongside the Department of Health’s renal policy team, we support frontline NHS staff across the country to drive up quality and efficiency while tackling health inequalities. We work with local kidney care networks, commissioners, patients and partners to improve care.

In recent months, there have been a number of important developments in the care of people with kidney disease, many of which are described in this supplement.

Ensuring all patients have full access to the treatment of their choice is a key priority for NHS Kidney Care, with the promotion of self-care a vital component. Studies show that home haemodialysis (HHD) patients have improved quality of life and, with extended hours or high frequency of dialysis, better clinical outcomes. Economic analyses have also suggested that home therapies are cost-effective compared with in-centre treatment.

Nationally, just 2% of dialysis patients currently undertake HHD, although the National Institute for Health and Clinical Excellence (NICE) suggests that 10–15% of patients might opt for it.2 NHS Kidney Care has been working to encourage more NHS organisations to offer patients the choice of HHD where appropriate. We have also produced a peritoneal dialysis (PD) specification and key performance indicators as a tool to help broaden the delivery of high quality PD.

Choice about end-of-life care is equally important. We have worked with others, including the National End of Life Care Programme, to implement the framework for end-of-life care in advanced kidney disease. This is the first such framework tailored for a specific condition, and groups in Bristol, Manchester and London are currently implementing the framework to inform the delivery of high-quality end-of-life care for advanced kidney disease across England.

The problems faced by young adults with kidney disease are well documented. Denial and adjustment issues can have devastating consequences, including the rejection of a transplant and a return to dialysis. We are supporting five kidney care networks to develop innovative approaches to help young adults with kidney disease. These will support the implementation of the national You’re Welcome quality criteria, designed to help healthcare services become more ‘young people-friendly’, and the outcomes from the project will be rolled out across England.

The NHS faces challenging times, with considerable financial pressures. However, the initiatives outlined here – along with the introduction of NICE quality standards for CKD and important developments in the tariff for kidney care – offer significant opportunities to meet the challenge of increased productivity while delivering care of the highest quality, making real improvements to the lives of people with kidney disease.

If you would like to stay updated with the latest news from NHS Kidney Care, sign up to our e-newsletter, Kidney Care Matters. You can do this through our website (at www.kidneycare.nhs.uk), where you will also find project updates as well as a wealth of useful resources.

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References
Public health surveillance of chronic kidney disease (CKD) is important to guide prevention and detection, as well as treatment planning and evaluation. The UK has the well-established UK Renal Registry, which can monitor trends in renal replacement therapy, but there are no national population-based data on the prevalence of, or associations and trends in, CKD.

The Health Survey for England (HSE) is a series of annual surveys designed to measure health and health-related behaviours in adults and children in England. It has a number of core elements that are included every year and special topics that are included in selected years.

For the surveys in 2009 and 2010, NHS Kidney Care funded the inclusion of additional modules that will help determine the prevalence of CKD in the English population, as the HSE is a nationally representative sample.

As well as relevant questions about CKD, the modules also include measurement of serum creatinine, cystatin C and urine albumin:creatinine ratio. The analysis is undertaken by the HSE team at University College London (led by Dr Jenny Mindell) and the NHS Information Centre. Information on CKD forms a chapter in the HSE 2009 report that was published in December 2010.

The project is also funding the measurement of serum creatinine in stored sera from 2003–05.

The study is being led by Professor Paul Roderick from the University of Southampton Medical School. The project’s objectives aim:

- To derive the prevalence of CKD stages 3–5 (estimated glomerular filtration rate [eGFR] <60 ml/min/1.73 m²) and 3b–5 (eGFR <45 ml/min/1.73 m²) overall and by age, sex, socioeconomic status, and ethnic group in 2003–05
- To investigate the associations of these CKD stages with factors that are a focus of primary care detection and management strategies, and the yield of detection from different testing strategies
- To develop synthetic estimates of CKD prevalence at primary care trust level and to compare these with Quality and Outcomes Framework data on CKD prevalence
- To compare changes in population prevalence of CKD from 2003–05 to 2009–10 and explore the underlying reasons for these
- By linking to routine outcome datasets, to assess the prognostic impact of different levels of CKD on all-cause and cardiovascular mortality, and hospitalisation.

There will be scope for adding kidney function measure to future HSEs to monitor changing patterns of CKD.

References


Improved identification of chronic kidney disease in primary care

In the UK, there are gaps between the expected and actual prevalence of chronic kidney disease (CKD). In South Birmingham, prevalence of CKD stages 3–5 is around 5%, while it is expected to be 8%. Although around 80% of CKD patients are on registers for other chronic diseases and should be regularly tested for CKD, that leaves 20% who are not regularly screened.

To address this, South Birmingham Primary Care Trust devised a locally enhanced service, which has been taken up by nearly 95% of GP practices. Everyone registered with a practice aged 40–74 who is not on a vascular disease register is invited to an enhanced NHS Health Check, which includes CKD screening. It is hoped that the active engagement of primary care clinicians will uncover at least part of the ‘hidden iceberg’ of CKD and that the gap between expected and actual prevalence in South Birmingham will be reduced.

Rajib Pal, GP, Hall Green Health, Clinical Director (Cardiac/Stroke/Renal Services), South Birmingham PCT

NHS Health Check programme update

From April 2009, primary care trusts began phased implementation of the NHS Health Check programme for eligible people in England aged 40–74, for which funding has been provided. The NHS Health Check programme is a systematic prevention programme that assesses an individual’s risk of heart disease, stroke, diabetes and kidney disease, and helps them stay well for longer. As such, it is included in the government’s public health White Paper Healthy Lives, Healthy People and the Operating Framework for the NHS in England 2011/12.

Basic information such as height, weight, age, family history, smoking status and blood pressure is recorded and a simple blood test for cholesterol and (in some cases) glucose levels is taken. Those whose initial blood pressure is high will go on to have a serum creatinine test under the programme in order to assess kidney function. The Department of Health has developed NHS Health Check: Vascular Risk Assessment and Management Best Practice Guidance which details the tests, measurements and risk-management interventions that make up the programme.

References

2. www.dh.gov.uk/en/Managingyourorganisation/FinanceandPlanning/Planningframework/index.htm (last accessed 14/02/2011)
Kidney Disease Profiles

The Kidney Disease Profiles are part of a joint work programme between NHS Kidney Care and the East Midlands Public Health Observatory, which leads on kidney disease on behalf of the Association of Public Health Observatories. This article is an introduction to the profiles, which are available on the NHS Kidney Care Website (www.nhskidney-care.nhs.uk). The profiles provide an overview of kidney disease within current primary care trust (PCT) areas using routinely available information. The target audiences are commissioning consortia, specialist kidney care commissioning teams and anyone working in kidney care in primary or secondary care. Individual profiles have been produced for each of the current English PCT areas, which may raise questions for further investigation among commissioners.

Background
There are multiple information sources on kidney disease at local level, but these are held by different organisations. Similar to the Diabetes Community Health Profiles,1 the Kidney Disease Profiles aim to bring these sources together in a short, easy to digest format, which covers a wide range of primary care, secondary care and public health data. For effective commissioning, there is an important need for comparative analysis and benchmarking localities against areas of similar demography. These profiles, where possible, compare indicators between similar areas and regional and national benchmarks. Where local areas vary from these benchmarks, this may be due to the differing sociodemographics, which are also outlined in the profiles.

Methods
Kidney disease PCT data sources were searched and evaluated in terms of their availability and reliability. A shortlist of routinely available data sources was produced, and the most recent data collated. These data include: a PCT map indicating areas with a drive time to the nearest renal centre of less than 30 minutes, a kidney disease risk factor profile, a summary of the primary care chronic kidney disease Quality and Outcomes Framework (QOF), and renal replacement therapy rates using UK Renal Registry data. An indicator of renal spend data against need for services is also included. A guidance document with details of the definitions and metadata used in the profiles has been produced as an aid to interpretation. The information was collated and an automated method of producing a PDF version for each area developed. The profiles are available electronically, which makes them easy to access – just download and print.

Results
The differences in 30-minute drive times relate largely to areas where low population density or geographical inaccessibility make access to centres difficult. There is a wide range of recorded CKD prevalence at local level; this varies from 1.3–7.7%, and this range is higher when looking at the variability at practice level within a PCT.

The renal replacement therapy acceptance, prevalence, and transplant prevalence also vary between areas. Some of these differences may be explained by the differing population characteristics, so it is important to take into account the kidney disease risk factor profiles when considering these findings. The QOF outcome measures were less variable; with the exception of one PCT area, blood pressure measurement varied by just over 2%, while the other indicators varied by about 10%. There were some significant differences across areas in the mortality from chronic renal failure. The spend on renal problems does not always correspond with the measure of need.

Conclusions
The kidney disease profiles will prove a useful tool for commissioning consortia and others involved in primary and secondary care and public health, to assess levels of kidney care need and current service levels in order to inform planning. These profiles will enable commissioners and providers to drive up the quality and productivity of services provided by primary care for those with chronic kidney disease.

The profiles and accompanying data guide are available from NHS Kidney Care (at www.bit.ly/pctprofiles)

Acknowledgement
The authors would like to thank Cherry Bartlett, John Langley, The UK Renal Registry, The NHS Information Centre, YHPO, Robert Davies and Penny Siebert.

Reference
Diabetic nephropathy (DN) is the leading cause of renal failure in the UK. It is characterised by evolving albuminuria, hypertension and falling glomerular filtration rate (GFR), all easily identified in primary care and now well established in diabetes guidelines and public health initiatives.

The National Diabetes Audit (NDA) was instigated in 2004, aiming to collect patient-level data from primary and secondary care diabetes systems in England and Wales. In its first year it collected data on around 250,000 patients, but within five years it had grown to include clinical and demographic data on 1.42 million patients with diabetes, representing two-thirds of diabetes patients.

It has gathered data from 152 primary care trusts (PCTs) incorporating 5,359 GP practices and is widely regarded as the largest annual clinical audit in the world.

**Assessing chronic kidney disease**

The major aim of this project is to assess the burden of chronic kidney disease (CKD) in diabetes patients within the NDA.

It involves using information already gathered in the NDA to produce prevalence and management data for a variety of markers of kidney disease in diabetes patients. Specifically, the project seeks to:

- Assess the prevalence of CKD by estimated GFR stage and DN stages based on albumin:creatinine ratio levels/read codes or albuminuria, stratified by age, gender, ethnicity and strategic health authority (SHA)/PCT.
- Compare blood pressure (BP) and glycaemic control within these groups with respect to compliance with national targets.
- Explore the association of renal complications at PCT and SHA level and how this relates to rates of end-stage diabetic renal failure reported to the UK Renal Registry.

**Quality requirements and standards**

This project meets two of the quality requirements (QRs) of the National Services Framework for Renal Services – Part Two:1 QR one – Prevention and early detection of chronic kidney disease and QR two – Minimising the progression and consequences of chronic kidney disease.

It also meets two of the standards from the National Service Framework for Diabetes:2 Standard 10 – All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes, and Standard 11 – The NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.

**Future projects with NDA data**

This is a ‘proof of concept’ project that will inform decisions on potential linkage of the NDA and the UK Renal Registry. There are benefits to the care of patients with diabetes at risk of renal disease and, in particular, for the provision of renal services in those with high rates of diabetic kidney disease (ethnic minorities and those in urban areas). Disparities in primary care processes may be relevant to progressive renal disease and the major outcomes assessed in the national registries.

DN remains one of the most readily identifiable kidney diseases. Screening and management of DN represents one of the most cost-effective ways to prevent a devastating long-term condition.3 Indeed, only five patients with type 2 diabetes require multifactorial intervention to prevent one major vascular event or the development of more significant DN, an impressive return for patients and health services alike.4

Details on the project can be obtained from d.fogarty@qub.ac.uk

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**References**

1. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4101902 (last accessed 16/02/10)
The Kidney Quality Information Partnership (KQIP) has been formed to co-ordinate the development of information work streams, which will enhance access to, and use of, information in kidney care services, enabling consistent implementation of the National Service Framework for Renal Services.

Aims and objectives
KQIP is chaired by Donal O’Donoghue, National Clinical Director for Kidney Care at the Department of Health. Members have been drawn from various general healthcare, and kidney care-specific, organisations and sectors (see Box 1). The key aims incorporate strategic, technical and communications objectives.

KQIP aims to provide leadership alongside the custodians of information relevant to kidney services and care, to ensure patient access to quality information, to facilitate information transfer, and to provide a single point of contact for those planning data-sharing work.

KQIP will enable integration of kidney care information products from disparate organisations, and aims to advise on new kidney care informatics products required to support providers, commissioners and reporting on services. KQIP aims to monitor the development of new kidney care informatics products and to ensure clinical input to support the development and maintenance of information standards relevant to kidney care.

KQIP will advise on how the kidney care community can be supported by partnership working to develop and gather high-quality information on kidney care, comprising complementary products from many organisations, and help to minimise unnecessary duplication of functionality relating to informatics products.

The work programme
Key work programmes for KQIP include:

Intra-operability of IT systems
- Transferring patient records
- Enhancing Renal Patient View (see page 22).

Measurement of kidney care resources
- Improved understanding of programme budgeting for kidney care

Box 1. Membership of KQIP
- National Clinical Director, Department of Health
- Renal Policy Team
- NHS Kidney Care
- Renal Advisory Group
- NHS Information Centre
- Renal Association (UKRR)
- NHS Blood and Transplant
- Renal Information Exchange Group (RIXG)
- Primary Care
- Pathology IT
- East Midlands Public Health Observatory
- Health Protection Agency
- Specialised Commissioning
- Research Capability Network
- Programme Budgeting
- National Vascular Society
- Connecting for Health

- Embedding the Model for Optimising Renal Replacement Investment and Services (see page 7) and the National Renal Dataset (see pages 25–26).

Development of datasets
- Upgrading the national vascular dataset to incorporate data items to identify acute kidney injury (AKI)
- Supporting the establishment of the UK Renal Rare Disease Registry (RaDaR).

Ensuring there is sufficient information on predialysis preparation
- Embedding Payment by Results for patients with advanced kidney disease.

Health-related measure of quality of life
- Collating patient-reported outcome measures

Communications on information
- Establishing an informatics datawall
- IT systems – examples of what works.

The establishment of KQIP is a huge step forward in boosting and improving the profile of informatics in kidney care. NHS Kidney Care is moving forward with a number of additional informatics priorities which will sit alongside KQIP, including the appointment of James Medcalf as clinical lead to lead on informatics, the funding of test sites to explore primary and secondary care IT connectivity for end-of-life care, and the prioritisation of IT for approved sites in supporting young adults with kidney disease.

Going forward, NHS Kidney Care will strive to ensure that relevant organisations and associations work in partnership to keep informatics
Quality standards for CKD

The National Institute for Health and Clinical Excellence (NICE) has published a set of quality standards for chronic kidney disease (CKD). These set out the standards of care that people with CKD should expect at various stages of the care pathway.

NICE was commissioned by the Department of Health to manage the process of developing independent quality standards in 2009. Quality standards in stroke, dementia, venous thromboembolism prevention and specialist neonatal care were published in 2010, and CKD is one of the next nine clinical areas prioritised by the National Quality Board and referred to NICE by ministers.

Box 1. Quality statements for chronic kidney disease

<table>
<thead>
<tr>
<th>No</th>
<th>Quality statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>People with risk factors for chronic kidney disease (CKD) are offered testing and people with CKD are correctly identified.</td>
</tr>
<tr>
<td>2</td>
<td>People with CKD who may benefit from specialist care are referred for specialist assessment in accordance with NICE guidance.</td>
</tr>
<tr>
<td>3</td>
<td>People with CKD have a current agreed care plan appropriate to their stage and rate of progression of CKD.</td>
</tr>
<tr>
<td>4</td>
<td>People with CKD are assessed for cardiovascular risk.</td>
</tr>
<tr>
<td>5</td>
<td>People with higher levels of proteinuria and people with diabetes and microalbuminuria are enabled to safely maintain their systolic blood pressure within a target range of 120–129 mmHg and their diastolic blood pressure below 80 mmHg.</td>
</tr>
<tr>
<td>6</td>
<td>People with CKD are assessed for disease progression.</td>
</tr>
<tr>
<td>7</td>
<td>People with CKD who become acutely unwell have their medication reviewed and receive an assessment of volume status and renal function.</td>
</tr>
<tr>
<td>8</td>
<td>People with anaemia of CKD have access to anaemia therapy and receive it in accordance with NICE guidance.</td>
</tr>
<tr>
<td>9</td>
<td>People with progressive CKD whose eGFR is less than 20 ml/min/1.73 m² and/or who are likely to progress to established kidney failure within 12 months receive unbiased personalised information on established kidney failure and renal replacement therapy options.</td>
</tr>
<tr>
<td>10</td>
<td>People with established renal failure have access to psychosocial support appropriate to their circumstances, relating to personal, family, financial, employment and social aspects of their lifestyle.</td>
</tr>
<tr>
<td>11</td>
<td>People with CKD are supported to receive a pre-emptive kidney transplant before the need for dialysis, if they are medically suitable.</td>
</tr>
<tr>
<td>12</td>
<td>People with CKD on dialysis are supported to receive a kidney transplant, if they are medically suitable.</td>
</tr>
<tr>
<td>13</td>
<td>People with established kidney failure start dialysis with a functioning arteriovenous fistula or peritoneal dialysis catheter in situ.</td>
</tr>
<tr>
<td>14</td>
<td>People on long-term dialysis receive the best possible therapy, ideally regular and frequent application of home or self-care dialysis.</td>
</tr>
<tr>
<td>15</td>
<td>People with CKD receiving haemodialysis or training for home therapies who are eligible for transport have access to an effective and efficient transport service.</td>
</tr>
</tbody>
</table>

With the development of the Health and Social Care Bill 2011, NICE, and in particular the Quality Standards programme, will play an increasing role in improving and reducing the variation in the quality of care that patients receive. The Quality Standards programme will be extended to create a broad library of standards for all the main pathways of care and will be key to supporting the work of the NHS Commissioning Board through developing quality standards along each part of the patient pathway, and outcome indicators for each step. Commissioning guidelines will be set on the basis of these clinical quality standards, which will be maintained through robust inspection by the Care Quality Commission.

What are quality standards?

A quality standard is a set of specific, concise statements that act as markers of high-quality, cost-effective patient care across a pathway or clinical area, covering treatment or prevention. They are derived from the best available evidence and are produced collaboratively with the NHS and social care, along with their partners and service users. There are two components of the CKD quality standard (see Box 1). The first is qualitative statements that describe the key infrastructural and clinical requirements for high-quality care, as well as the desirable or expected outcomes. The second is quantitative measures that set the expected degree of achievement for each standard. These will be ‘quality indicators’.

When sourcing indicators for the quantitative component of quality standards, measures from the menu of Indicators for Quality Improvement developed by the NHS Information Centre will be highlighted where they exist and are appropriate. Quality standards are not a new set of targets or mandatory indicators for performance management, but they will have a key role to play within Quality Accounts as part of the continuous process of quality improvement. Commissioners will be interested in quality standards as markers of high-quality care, and patients and the public will see clear statements of what they can expect from services. The Care Quality Commission and Monitor may find quality standards useful as a marker of the quality of care offered to patients during their registration and assessment processes.

At a more local level, quality standards can be used to inform clinical audit and quality
The demand for renal replacement therapy (RRT) has risen steadily over the past decade. Predicting future demand and its impact on service delivery requires consideration of a range of factors, including demographic changes, acceptance rates, transplant supply and patient survival. Previous studies have predicted that even with an optimistic growth in transplant supply there will still be a substantial rise in demand for haemodialysis (HD) over the next decade. Planning is essential due to the high cost and resource-intensive nature of HD, and the lead times involved in bringing new capacity into operation.

**Development of MORRIS**

The Model for Optimising Renal Replacement Investment and Services (MORRIS) has been constructed by the Department of Health to support policy-making and commissioning for RRT services for adults in England. It works at national, regional (strategic health authority) and renal centre level and provides forecasts of RRT patient volumes, given a set of parameters that can be adjusted by the user. The model provides projections of the number of adults (aged 18 and over) likely to require dialysis and transplant treatment over the next ten-year period.

Dialysis patients are further divided into modality (HD in a centre, home HD and peritoneal dialysis [PD]). The model also provides estimates of the cost of providing this volume of treatment. It has been set up as a ‘what if’ tool to allow users to change the model assumptions and see the impact this is likely to have on patient numbers and costs.

**Data and parameters**

The model is populated with current levels of RRT patients in each region in four age bands and contains population projections by region, age band and ethnic group. Default values for parameters determining take-on, transplants, mortality rates and so forth, which have been derived from recent national data, are provided, but can be adjusted by the user to more accurately represent local conditions or to test an alternative scenario.

**Model structure**

MORRIS uses a combination of a Microsoft Excel spreadsheet and a dynamic simulation software model built in the software package ithink (developed by isee systems). A freely downloadable runtime version of the software, isee Player, is required to run the model.

The Excel file contains the input data and parameters for the model, most of which can be manipulated by the user. The Excel file is linked to the ithink file, where the calculations are defined and the model is run. Results are exported back into the Excel model file.

**Conclusion**

MORRIS is a robust model that provides specialist commissioners and policy-makers with the means to predict the future demand for RRT and investigate the impact of initiatives such as raising the supply of organs for transplant or increasing the prevalence of home therapies, thereby allowing better planning for service delivery.

The latest version of the model is available from www.bit.ly/morrismodel. There will be practical demonstrations of how the tool can be used on the NHS Kidney Care stand at the British Renal Society/Renal Association conference, taking place in Birmingham, 6–9 June 2011.

**References**

2. www.iseesystems.com (last accessed 21/01/11)
End-of-life care for advanced kidney disease

The National Service Framework (NSF) for Renal Services was the first to tackle the issues of death and dying. Part Two of the NSF sets a specific aim to support people with established kidney disease to live as full a life as possible and to die with dignity in a setting of their own choice.

Following publication of the NSF, several strategic documents were released; these provided further impetus to the importance of developing models of care for all patients approaching the end of life. A workshop organised by the Department of Health brought together stakeholders to initiate development of implementation strategies in kidney services, and key themes were identified. A steering group integrated these themes and the principles of the end-of-life care pathway within the End of Life Care Strategy with kidney-specific elements to produce the Framework for Implementation.

Putting the framework into practice

Kidney centres need to transform the framework guidance into practice that fits with the local situation, facilities, patient population and methods of working. The diagram on page 12 describes the Cause for Concern register, which is the first step in the pathway, and the organisational factors to be considered. A paper in the British Journal of Renal Medicine describes the experience of one kidney centre when establishing a register. NHS Kidney Care has established a Board to co-ordinate the development and progress of end-of-life work in kidney care, enabling consistent implementation of the NSF.

One of the work streams facilitated and overseen by the board and led by NHS Kidney Care supports the introduction of the Framework within kidney centres, working in partnership with primary care and palliative care organisations. Three project groups have been selected to work through implementation over eighteen months so that experience of ‘what works’ and lessons learned in the process are made available as a resource across the kidney community. The work of all the project groups concentrates on the six steps of the end-of-life care pathway for kidney services described in the Framework.

Step 1. To ensure that all those who need it receive appropriate care, they must first be identified. A Cause for Concern register is recommended for all renal centres; this may ultimately be linked with GP palliative care registers to ensure seamless care across healthcare sectors.

Step 2. People vary in the level of involvement that they wish to take in the planning of their care at the end of life; consequently, planning needs to be sensitive to individual requirements. This plan should be available to all staff who may be involved with caring for the patient during the end-of-life phase.

Step 3. Delivery of care should be co-ordinated across the healthcare services involved. Identification of key staff in the organisations involved and appropriate use of IT can help to ensure that responsibilities are carried through and information is available at the point of care.

Step 4. Kidney centres need to provide high-quality services to those approaching the end of life, whether through choosing conservative care or with advanced kidney disease being treated within the kidney centre. Appointment of clinical leads (medical and nursing) will provide a focus for the kidney unit and for establishing working relationships with other care providers.

Step 5. The emphasis of care in the last days of life should reflect the preferences indicated by patients through the care planning process, and should be facilitated through a local action plan.

Step 6. Support for families and carers underpins the pathway; it need not cease at death.

In addition, training needs for the staff groups concerned with implementing the recommendations across the healthcare sectors involved should be identified, and professional development needs to be delivered.

The project groups that will be creating models of care are North Bristol Health Economy, Greater Manchester Managed Kidney Care Network and King’s Health Partners.

The project in Bristol commenced in May 2009, with the other two groups starting their projects in early 2010. An extension to the project period has been agreed with Bristol, and all the groups will be completing at the end of 2011.

Project groups

North Bristol Health Economy

The project operates across the North Bristol NHS Trust renal service, working with primary care and local palliative services. A Cause for Concern register, called the Kidney Patients’
Gold Standards Pathway (KPGSP), linked to the primary care Gold Standards Framework (GSF) or an equivalent system, has been developed. A rolling programme has enabled the KPGSP to be set up across sites within the group. An assessment and review tool used by nursing staff with all dialysis patients includes a section to screen for patients to be registered. Haemodialysis patients were the first to be covered and work is ongoing to roll out the system. Assessments are carried out every three months. Carer assessment is also being developed; this will become a standard part of a regular dialysis care plan.

A positive score in the screening section of the assessment tool triggers a referral to the consultant to discuss the situation and, if agreed, registration follows. Confirmation by the consultant initiates the patient on the pathway, with letters going to the GP and district nurses. The local IT system can gather information from regular assessments and the details of key workers, and monitor the progress of the patient on the pathway. Alongside developing the register, training sessions have been running for the nursing and medical staff. Advance care planning is to be offered to all patients and is being rolled out across the centre. Regular audit has been built into the project. Overall, the project aims to embed the use of the tools that have been developed with representatives of the renal multidisciplinary team, patients, the primary care trust and primary care, and make these tools available as a resource for the kidney community.

Greater Manchester Managed Care Network
The Central Manchester University Hospitals Foundation Trust and the Salford Royal NHS Foundation Trust, which form the Greater Manchester Managed Care Network, are building on established relationships with primary and palliative care for their end-of-life care project. As part of their objectives, a screening tool is being developed for the identification of patients suitable to be placed on the Cause for Concern register. IT systems have been adapted toembed the use of the tools that have been developed with representatives of the renal multidisciplinary team, patients, the primary care trust and primary care, and make these tools available as a resource for the kidney community.

King’s Health Partners
The Advanced Renal Disease Care (ARC) project is being undertaken within Guy’s and St Thomas’ NHS Foundation Trust and King’s College Hospital (KCH) NHS Foundation Trust. They are already working in collaboration in renal palliative care supported by the palliative care department at KCH, and serving some of the most deprived areas of south-east London.

Multidisciplinary team meetings are the first step in identifying potential patients for the Cause for Concern register; meetings are being rolled out across the group. More detailed criteria are then applied to focus on those to be placed on the register. IT systems have been adapted to collect the data associated with the project. Training programmes for renal staff will be delivered across the centres involved. Evaluation of outcomes in the denominator population and end-of-life population will be conducted. The objective of the ARC project is to deliver improved care, and better continuity and experience for patients with advanced kidney disease, extending across the last years of life, and to integrate acute and community care provision.

Summary
These projects will provide a valuable resource of experience in implementing the framework; regular Learning Network meetings are held to share experience. Many kidney centres are already developing their services to provide end-of-life care and NHS Kidney Care is compiling a repository that will be available on its website (www.kidneycare.nhs.uk) to enable the spread of experience, ‘what works’ and lessons learned. Models of care will be created to provide patients with kidney disease, near the end of life, choice and dignity in death.

References
1. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_401902 (last accessed 04/02/10)
2. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453 (last accessed 04/02/10)
3. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PolicyAndGuidance/DH_085825 (last accessed 04/02/10)
4. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PolicyAndGuidance/DH_086277 (last accessed 04/02/10)
7. www.goldstandardsframework.nhs.uk/ (last accessed 04/02/10)
Cause for Concern Register

THE REGISTER

A Cause for Concern register identifies patients ‘deteriorating despite dialysis’ and patients deteriorating during conservative management, as potentially approaching the end of life phase. It promotes a consistent and pro-active approach in supporting patients and staff to facilitate communication and care planning.

The register enables regular review by the multidisciplinary team of those on the register and of new referrals.

The register links to a care pathway which incorporates the Gold Standards Framework, Preferred Priorities for Care, Advance Care Plans and the Liverpool Care Pathway.

ORGANISATIONAL CONSIDERATIONS

- How will patients be identified for consideration to be included on the Register?
- Who will initiate registration discussion with the patient?
- Where will the Register be held eg IT system?
- How will registration be confirmed?
- What communication channels will be established with Primary/Palliative Care Services?
- What data collection and documentation will be required?
- How will training requirements be identified and delivered?
- How and how often will review take place?
- How will families and carers be supported?
- What audit and/or evaluation will be conducted and how will it feed back into the service?

End-of-Life Care in Advanced Kidney Disease:
A Framework for Implementation
Green nephrology: reducing kidney care’s carbon footprint

A recent joint *Lancet* and University College London Institute for Global Health Commission considered climate change to be ‘the biggest global health threat of the 21st Century’.1 However, the very provision of healthcare itself has a significant environmental impact and the NHS must act to reduce its carbon footprint. Furthermore, a growing appreciation of the potential health co-benefits and financial savings associated with many carbon reduction strategies has led to an increasing interest in linking climate and health policies.2

Through the Green Nephrology Programme, renal medicine has been among the first specialties to pursue the changes that will be required once carbon rationing influences how NHS services are provided. Delivered by the Campaign for Greener Healthcare, the programme seeks to explore and improve the sustainability of kidney care, and has the support of the Renal Association, the British Renal Society, the NHS Sustainable Development Unit, the National Kidney Federation, and the Association of Renal Industries. NHS Kidney Care sponsored the first Green Nephrology Fellowship, in which a nephrology trainee was seconded to work within the programme, and remains a key stakeholder.

**The Green Stars Initiative**

The Green Stars Initiative is an integral part of the programme’s vision for sustainable kidney services. Renal units can collect stars by having a Green Nephrology Local Representative (more than 70 units now do), nominating a patient representative, submitting a Green Action Plan, and contributing case studies to the library.

**Research**

In order to inform its future work, the Green Nephrology Programme also seeks to improve our understanding of the nature and extent of the environmental impact of kidney care. A wide-ranging survey of sustainable practices within renal services, to which 58 units contributed, was an early step towards this.3 A recent study of the greenhouse gas emissions of a typical UK renal service identified the emissions arising within the supply chains to be an important focus for carbon reduction strategies.4 A report of the carbon footprint of home and in-centre haemodialysis is also due to be published.5

**Case studies**

The programme is developing a library of Green Nephrology case studies (or ‘how to’ guides). These describe initiatives in terms of their environmental, financial and patient-care benefits and provide guidance for individual renal units wishing to adopt such strategies. Examples of recent case studies include the conservation of water during haemodialysis, the use of telephone clinics to provide follow-up to transplant patients, and the reduction of waste during dialysis (www.greenerhealthcare.org/nephrology-resources). The 10:10 Renal Checklist (http://greenerhealthcare.org/1010-renal-checklist) provides further ideas.

**Further work**

In the light of the findings of the studies, the programme is now working with the Association of Renal Industries and individual procurement departments to reduce supply chain emissions. Patients have an important role to play and the team is exploring possibilities with the National Kidney Federation. The Green Nephrology Programme also works to encourage the adoption of lower carbon lifestyles, which offer health co-benefits to both patients and staff.6

The Green Nephrology Programme aims to align the provision of more sustainable healthcare with higher quality care at lower financial costs. For more information, see www.greenerhealthcare.org/green-nephrology-programme or watch the video (http://greenerhealthcare.org/podcasts/2010/09/green-nephrology-video).

**References**

Until the 1980s, haemodialysis (HD) in the home was the predominant form of renal replacement therapy. Since then, the emergence of continuous ambulatory peritoneal dialysis and a sharp rise in the number of patients with established renal failure (from 7,000 to 45,000 between 1982 and the present), and an associated significant increase in the median age of the dialysis population, led to a move away from home HD, with treatment in hospital satellite units being the fastest-growing dialysis modality.

The National Institute for Health and Clinical Excellence (NICE) guidance produced in 2002 suggests that 10–15% of dialysis patients might opt for HD treatment at home with appropriate education. Furthermore, there is fairly substantive evidence that patients able to dialyse more frequently and for longer (which, given hospital and satellite unit capacity, is realistically only possible at home) benefit from improved clinical outcomes. Despite this, there has been no overall increase in the proportion of people undertaking home HD.

Currently, only 2% of the total number of dialysis patients receive home HD, and the percentage of patients receiving home HD among renal units offering the treatment ranges from 0.3% to 11%. To address this fact, the Renal Association has produced a report with recommendations towards improving home HD uptake, crucial components of which are patient education and empowerment.

Therefore, after briefly summarising the evidence as to the clinical effectiveness of home HD, this article examines what can be done to promote more home HD from the perspective of the patient experience. This learning is incorporated within a five-step home HD toolkit for clinicians, the implementation of which could help efforts by hospital and satellite dialysis units to encourage increased uptake of home HD.

Evidence of clinical effectiveness

The opportunities for longer and more frequent HD sessions in the home than it is generally possible to undertake in hospital is the main clinical argument for home HD being preferable to unit-based dialysis. There is fairly substantive evidence to support the superior clinical effectiveness of more frequent and longer HD, in particular nocturnal daily HD, as compared with the conventional three-times-weekly HD available in most hospital and satellite dialysis units.

Patients able to dialyse more frequently and for longer clearly benefit from improved clinical outcomes. In this respect, there is robust evidence to demonstrate better blood pressure control, with fewer or no anti-hypertensive medications. Although often limited by small patient numbers and by study design, the weight of evidence also suggests there are better measures of anaemia, higher levels of dialysis control, fewer hospitalisations, better nutritional status, and fewer adverse effects overall during HD. There is also strong evidence that more frequent daily HD, especially daily nocturnal HD, offers morbidity and mortality benefits versus three-times-weekly HD.

The patient experience and What Works

NHS Kidney Care visited a selection of hospital renal units across the country, to learn what those who currently manage home HD patients think works well, in terms of assisting the uptake of home HD. Qualitative interviews with home dialysis patients were also undertaken to understand their feelings and experiences about moving to home HD, and learn from their perspective what works well in terms of the advice, information, training and support they receive.

Informating and educating patients

Patients ideally want to have each of the different dialysis treatment options clearly explained to them before making a decision. They also appreciate being fully informed about which option or options would best suit their individual circumstances and the reasons why. They do not appear to have any strong preferences as to whether this information should be provided by a dialysis nurse or a consultant in the first instance. However, patients like having an adequate amount of time to discuss the options at some length and to get considered responses to their questions.

Patients are also very keen to hear the opinions of their consultant; this can have a strong
influence on choice. Patients do not appear adverse to clinicians actively promoting home HD as the best choice to suit their circumstances.

**Value of learning from other patients**

While generally very appreciative of the information provided by nurses and consultants, patients find listening and talking to people already on home HD most helpful and informative; it also gives them more confidence and reassurance. Information leaflets and DVDs containing patient views and experiences are found useful, but the strongest plaudits are for opportunities to spend time directly listening to, and asking questions of, people who are on home HD. Some patients prefer to do this face-to-face, others by phone or internet, but irrespective of the forum, the substantive value is being able to hear, from those with actual experience, about what it is really like. Patients feel they get a ‘truer’, more rounded and insightful picture of what home HD involves and how it feels. They can discuss their worries and concerns, the best ways to overcome problems and difficulties, and how the benefits really affect people’s lives.

‘Having someone who was actually doing it, they told it as it was, as they saw it. I trust the nurses and doctors, but, if you like, they are going to stand there and say, “This is what happens,” but that’s no substitute for someone saying, “I do it and this is what happens to me. This is how I feel when I finish, this is what I experience”.’

**Why patients want to home dialyse**

Some patients have one clear motivation that drives them towards home HD, but most tend to carefully weigh up a number of perceived advantages against potential disadvantages of the treatment before making a choice. A key reason why many patients choose home HD is the belief it will give them more control over their dialysis regime. They are attracted by the opportunity for greater choice and flexibility over when and how often they dialyse. They want freedom from the time-consuming frustration of having to travel to and from a dialysis unit three times a week. In turn they feel this will give them more time to get on with, and enjoy, their lives.

For some patients considering the move from unit to home HD, an important impetus is that, by being able to dialyse more frequently, they might avoid the negative ‘weekend experience’ of feeling sick, weak and depressed. They no longer need to endure the three-day gap in dialysis from Friday to Monday, which can cause such detrimental emotional and physical effects.

‘A major aspect was going from Friday to Monday. Sunday I was very ill and Monday I was very ill. So two days a week I wrote off completely. Most Sunday nights, I couldn’t breathe very well or see very well. I had to sleep sitting up. It was very distressing. Monday’s dialysis, there’d be cramp, nausea, completely flattened.’

**Continued on page 18**
**FIVE-STEP TOOLKIT FOR HOME HEMODIALYSIS (HHD)**

<table>
<thead>
<tr>
<th><strong>STEP 1 Self-care for all</strong></th>
<th><strong>STEP 2 Training and preparation</strong></th>
<th><strong>STEP 3 The environment</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Understand the potential for self-care</strong></td>
<td><strong>Demonstrate self-care to all</strong></td>
<td><strong>Undertake initial assessment of the patient's home</strong></td>
</tr>
<tr>
<td>• Kidney care networks to work with commissioners, patients and providers of kidney services to develop a self-care framework, defining various levels of competence, aiming towards making self-care available for all</td>
<td>• Improved determination and confidence may come from enabling patients to share experiences and compare levels of competence</td>
<td>• This should be undertaken by renal technicians or local contractors to review with the patient the preferred place for the equipment, taking into consideration:</td>
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<tr>
<td></td>
<td>• It may result in patients who had previously been uncertain about their own ability or suitability to perform HHD deciding to try it</td>
<td>– Space required for dialysis machine, chair and reverse osmosis unit</td>
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<td></td>
<td>• Seeing another patient performing self-care tasks can be a powerful tool</td>
<td>– Type of waterproofing measures</td>
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<td></td>
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<td>– Storage space for needles, fluids, and day packs</td>
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<td></td>
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<td>– Choice of machine</td>
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<tr>
<td><strong>Access to reliable patient education and information resources</strong></td>
<td><strong>Identification of appropriate locations for training</strong></td>
<td><strong>Ensure development of required contractor relationships</strong></td>
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<tr>
<td>• Signpost useful sources of information; eg NHS Choices and the National Kidney Federation</td>
<td>• Develop training stations near to, but separate from, the main dialysis unit to support independence while providing easy access to support for patients and training staff</td>
<td>• Successful relationships are required to support the provision of dialysis in a patient’s home</td>
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<td></td>
<td>• Provide designated stations in hospital and satellite units for self-care dialysis with independence for patients who use them; eg flexible dialysis times</td>
<td>• These may be developed independently; however, many units find it easier to use a single point of contact</td>
</tr>
<tr>
<td><strong>Facilitate shared decision-making, offering a genuine choice of all treatment options</strong></td>
<td><strong>Set out agreed training programme as part of the patient care plan</strong></td>
<td><strong>Water supply</strong></td>
</tr>
<tr>
<td>• Ensure consideration is given for all patients to choose their preferred place of treatment as part of initial and ongoing discussions</td>
<td>• Develop an individually tailored training programme with an expectation of the patient being able to dialyse at home within 12 weeks</td>
<td>• Initial assessment by contracted plumber to check aspects of the water supply, such as water pressure, availability of supply in the proposed dialysis space, and whether the supply is metered</td>
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<tr>
<td>• Open patient choice should be a key step as part of shared decision-making</td>
<td>• The training programmes will include flexible schedules that could be undertaken to suit individual patient needs; eg during evening and weekends, or increased frequency of sessions during the week</td>
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<tr>
<td>• If patient chooses home therapies, focus on how to make it work, rather than on obstacles</td>
<td>• While remaining clinically safe, be less risk-averse; invite fully informed patients to accept the risks associated with HHD</td>
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<tr>
<td>• Provide a ‘choice room’ where the patient and family can discuss choices in confidence with a healthcare professional, allowing patient time to consider options and ask questions</td>
<td>• Engage in ongoing dialogue with patients about their choices and establish fixed review times</td>
<td></td>
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<tr>
<td>• Allow patients time for reflection, access to additional resources, health professionals, decision aids, information materials and other patients before making a decision</td>
<td><strong>Peer support network</strong></td>
<td><strong>Electricity</strong></td>
</tr>
<tr>
<td>• While remaining clinically safe, be less risk-averse; invite fully informed patients to accept the risks associated with HHD</td>
<td>• Provision of a peer support network can be very helpful in assisting patient choice</td>
<td>• Initial assessment by contracted electrician to make assessment and provide advice on changes that may be necessary</td>
</tr>
<tr>
<td></td>
<td>• Engage in ongoing dialogue with patients about their choices and establish fixed review times</td>
<td><strong>Telephone</strong></td>
</tr>
<tr>
<td><strong>Involve carers and partners as appropriate</strong></td>
<td><strong>Establishing reliable vascular access</strong></td>
<td>• Initial assessment by contracted provider, as 24-hour telephone support is required</td>
</tr>
<tr>
<td>• Carers and partners should have a clear understanding of the potential impact of the patient’s chosen treatment and be involved in the agreed training plan</td>
<td><strong>Vascular access should be established as per Renal Association guidelines</strong></td>
<td></td>
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<tr>
<td>• Whether the presence of carers or partner is required for patient to perform HHD, or whether lone HHD is appropriate, requires discussion between the individual patient and their renal unit</td>
<td>• Tunnelled dialysis catheters are suitable for HHD for some patients in whom fistula formation has failed</td>
<td></td>
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<tr>
<td><strong>Maximising safe methods for managing fistulae</strong></td>
<td><strong>Maximising safe methods for managing fistulae</strong></td>
<td><strong>Installation</strong></td>
</tr>
<tr>
<td>• Positive approaches to support the patient managing their own fistula should be in place, including self-needling, using the most appropriate method for the individual patient</td>
<td>• Buttonhole needling is considered the preferred method as this technique, when established, allows use of blunt ended needles to gain repeated reliable access to the fistula</td>
<td>• The training programme should identify the key point in time that signifies satisfactory progress for initiating equipment installation (provided the assessments outlined above are satisfactory).</td>
</tr>
<tr>
<td>• Once a location has been determined, responsibility for installation can vary between in-house responsibility and private company tender</td>
<td><strong>Empowerment</strong></td>
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**STEP 4 Providing support**

<table>
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<tr>
<th>Clarification of access to clinical and technical support</th>
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<tr>
<td>• All patients who dialyse at home will need access to 24-hour clinical and technical support, in case of an untoward incident or emergency:</td>
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<tr>
<td>• This may be a single point of dedicated support or shared with an agreed out of hours plan</td>
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<tr>
<td>• The patient should be registered as an HHD patient with their water, electricity and telephone suppliers in case of supply failure</td>
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<td>• The patient’s individual care plan should include clear contact arrangements</td>
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<tr>
<th>Agree with patient how monitoring will be undertaken</th>
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<tr>
<td>• Ensure the care plan has clear arrangements for monitoring to be undertaken. These may include:</td>
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<tr>
<td>– Monitoring vascular access</td>
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<td>– Blood samples being posted securely on monthly basis by the patient</td>
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<td>– Planned formal follow-up</td>
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<tr>
<td>– Regular review of patient satisfaction with chosen treatment option</td>
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<tr>
<td>– Access to respite care</td>
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<td>– Using Renal Patient View</td>
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<tr>
<th>Home Therapies Team</th>
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<tr>
<td>• The most successful units have dedicated staff for home therapies, skilled in training, monitoring and support</td>
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<tr>
<th>Materials</th>
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<tbody>
<tr>
<td>• Support materials can be delivered by community team</td>
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<tr>
<td>• Removal and disposal of used supplies will need to be organised</td>
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<tr>
<th>Equipment maintenance</th>
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<tbody>
<tr>
<td>• Technicians or locally contracted providers maintain and upgrade equipment, and deliver products as required</td>
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<th>Support networks</th>
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<tr>
<td>• Access to an appropriate peer support network can be helpful in preventing HHD patients feeling isolated:</td>
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<tr>
<td>• This applies equally to carers, who often combine a larger share of household duties with HHD assistance</td>
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**STEP 5 Sources of funding**

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<tr>
<th>Gaining trust management sign-up and engagement with commissioners</th>
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<tr>
<td>• Provide business case to demonstrate impact locally for increased patient numbers on HHD. Key elements may include:</td>
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<tr>
<td>– Cost of providing future in-centre capacity</td>
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<tr>
<td>– Set-up costs</td>
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<tr>
<td>– Cost benefits of reductions in travel, medications, staffing and overhead requirements, ability of some patients to return to work</td>
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<tr>
<td>– Ongoing costs for monitoring and quality assurance</td>
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<table>
<thead>
<tr>
<th>Clarification regarding local arrangements to secure set-up costs for training and installation</th>
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<tr>
<td>• Units use different funding models and there is no standard model</td>
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<tr>
<td>• Proposed non-mandatory dialysis tariff will be on a full absorption basis</td>
</tr>
<tr>
<td>• Typical installation costs are £3,500-£5,000 but can vary depending on local factors</td>
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<tr>
<td>• There is no definitive period as to when set-up costs are recouped, but available evidence suggests 14 months</td>
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<tr>
<th>Clarification regarding covering ongoing costs to the patient</th>
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<tr>
<td>• Costs incurred by the patient as a result of HHD will need to be monitored and reimbursed by the host trust</td>
</tr>
<tr>
<td>• These include electricity, water (if metered) and telephone</td>
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<tr>
<th>Understanding the funding sources</th>
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<tr>
<td>• The proposed non-mandatory tariff is based on statutory reference costs returns made by trusts, providing an indication of the price for dialysis regardless of setting</td>
</tr>
<tr>
<td>• The reference costs are set up to be full absorption, inclusive of capital expenditure</td>
</tr>
<tr>
<td>• Payment by Results guidance recommends applying the prices per haemodialysis session to each session of HHD, while acknowledging patients dialysing at home may wish to have 4 or 5 sessions a week</td>
</tr>
<tr>
<td>• There should be no cap of the number of patients having access to HHD or the total number of HHD sessions that can be prescribed</td>
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</tbody>
</table>
A few patients are motivated by the potential long-term medical benefits of dialysing more frequently and for longer. They are persuaded that dialysing this way will be better for their blood pressure and remove more adverse toxins from their body. However, some patients claim not to have been aware of these advantages until after they had made their choice of treatment and started home HD training.

What patients worry about
Concern about not being able to needle is an almost universal worry among patients considering home HD. Some patients may have a phobia about needles, others just think they will never be able to put a needle in their own arm. Many worry about whether they will be able to manage the training to a level where they will be allowed home. There is also fairly widespread concern about handling the dialysis machine at home and how they will be able to deal with the situation if something goes wrong with the machine.

Another important concern for patients whose partner will be helping them dialyse at home is how this might have an impact on, and effect change in, their relationship. They worry about how their partner will cope with the responsibilities involved and the stress this may generate. Patients, particularly those with young children, have additional concerns about the changes to family life that might be required, and the extent they will appear ‘ill’ to their children.

Easing and enhancing the training process
The more involved patients moving from unit HD to home HD have been in self-caring, the less worried they tend to be about the training. They also find the training easier to handle, and this can help them complete it faster. Patients like training that is structured to their personal needs and sensitive to their individual pace and progress of learning, yet they also express appreciation of consistently being pushed to achieve more and not having their ‘wimpy’ concerns too easily tolerated.

‘I just couldn’t see myself needling, putting a needle in my own arm ... In fact, what made me finally do it was there was a young girl of 21 on the unit and I thought if she could fearlessly put a needle in her own arm, I can. I could see her doing it and I just thought, “Come on, be a bit tougher. It’s all that’s really needed”.’

Ongoing support for patients (and their carers) is also extremely necessary

Patients are consistent in giving strong praise for the technical support available to them at home. They particularly appreciate technicians being accessible by phone evenings and weekends, as well as weekdays. Many technical problems that arise can be resolved through advice given over the phone; others require home visits, for which patients are very grateful. This degree of support can both reassure and help build confidence. Watching others train can also help the learning process and encourage more progress, especially in relation to needling.

‘I just couldn’t see myself needling, putting a needle in my own arm ... In fact, what made me finally do it was there was a young girl of 21 on the unit and I thought if she could fearlessly put a needle in her own arm, I can. I could see her doing it and I just thought, “Come on, be a bit tougher. It’s all that’s really needed”.’

Ongoing support
Patients are consistent in giving strong praise for the technical support available to them at home. They particularly appreciate technicians being accessible by phone evenings and weekends, as well as weekdays. Many technical problems that arise can be resolved through advice given over the phone; others require home visits, for which patients are very grateful. This degree of support is important in maintaining patients’ confidence and reassurance. Where technical support is not directly available to patients 24/7, they can feel some additional stress.

Ongoing support for patients (and their carers) is also extremely necessary. Some patients feel very well supported by nursing and medical staff. They are able to talk at any time to a home HD nurse, and the help and advice given is highly valued. They are strongly appreciative that nurses have been able to talk them through dealing with medical problems that have arisen while dialysing clearly and calmly. At times, home HD nurses also provide a vital emotional crutch for

What Works – self-care training
Brighton and Sussex Hospitals promote as much self-care as possible, even if the patient never gets home.

- From day one, all patients if possible start self-care training, irrespective of chosen haemodialysis location
- Avoid exposure to the main dialysis unit
- Focus is on people going home
- More motivating environment for self-care with absence of sicker patients dialysing
- Training carried out at a pace to suit patient and carer
- No time limit to training, but usually 8–16 weeks
- In the last 3 weeks of training, patient is moved to a separate room to help ‘cut apron strings’

What Works – technical support
The technical support provided on an ongoing basis to home haemodialysis patients by Leicester General Hospital includes:

- 24/7 on-call phone service direct to a technician
- Patients encouraged to call at any time if they have a technical problem
- Try to resolve issues by phone advice, but always prepared to make a home visit if necessary
- Pre-arranged home visit every 3 months to check the water purifier; and a co-ordinated visit every 6 months to check the dialysis machine
some patients who just want to talk through an emotional issue that they find is troubling them.

‘It gives you loads of confidence when you can talk, that there are people always there.’

Other patients, especially those without this nursing support, can feel isolated. Even those well-supported by professionals can at times feel emotionally deflated. On an HD unit, it is fairly easy to strike up a conversation with another patient that can help relieve these negative feelings. Some patients say they want more ongoing contact to share thoughts and experiences with other people on home HD. Greater emotional support of home HD patients would clearly help their overall experience of the treatment choice.

‘The worst thing is you’re isolated. So if I’m having a problem, I’ve got to do it via a nurse. I can’t just say, “I’m having a bad day, how’s your day?” which you can on a unit. I think that definitely needs addressing. We need some sort of home dialysis chatline.’

Benefits from the patient perspective

Home HD appears to fully meet patients’ expectations in delivering flexibility and choice. They are able to increase or decrease the frequency and duration of treatment, and change the days and times they dialyse to meet the needs of their lifestyles. For many patients this reduces feelings of frustration and dependency they had when using an HD unit. They are more in control of their own treatment and this generates a positive sense of freedom. Very importantly, it allows many patients to lead what they consider a more normal and everyday life. Some are able to work full- or part-time or do voluntary work, which had generally not been possible when they were on unit HD. Others talk enthusiastically about spending more time with family, socialising or enjoying their personal hobbies and interests.

Many patients notice they feel significantly better physically soon after starting to dialyse more frequently and/or for longer. They vari- ously mention phosphate and potassium readings coming down quickly, blood pressure results becoming more normal, having more energy, less incidence of restless legs, and having a clearer head. They no longer feel very poorly over the weekend. Being able to enjoy a less rigid dietary and drink regimen is also very important for some patients. They can choose to eat more of the food they really like and drink more fluids which enhances their quality of life and emotional well-being. Significantly, patients are unanimous in their strong desire not to return to unit HD unless absolutely necessary.

‘I doubt very much there’s anyone who’s done home HD that would dream of going back to a unit now unless they had to.’

The Home Haemodialysis Toolkit

NHS Kidney Care has developed a Home Haemodialysis Toolkit, an abridged version of which is provided on pages 16 and 17. The Toolkit presents a five-step approach for renal units (and patients) who wish to explore or expand the option of using home HD, and incorporates key learning of ‘what works’ from the patient perspective. The Toolkit is available online (at www.kidneycare.nhs.uk).

The future development of home haemodialysis

There is fairly substantive evidence that patients who undergo home HD, being able to dialyse more frequently and for longer, benefit from improved clinical outcomes, as compared with patients undertaking the conventional three-times-weekly HD that is available in most hospital and satellite dialysis units.

However, this has not resulted in significant numbers of dialysis patients undertaking home HD. Other drivers are needed, and giving more consideration to ‘what works’ in relation to the patient experience offers an important perspective from which to help promote more access to home HD.

References

2. www.nice.org.uk/guidance/ta48 (last accessed 04/01/2011)
The intricacies of the NHS funding system feel a million miles from the realities of caring for patients on the ward and in the clinic. Indeed, it can be tempting to assume that clinicians simply provide the best quality care they can within the resources available to them. However, quality of care is increasingly being aligned with the funding system, offering clinicians and managers powerful levers to improve services and outcomes for their patients.

**Changes to Payment by Results**

From April 2011, a series of changes have been made to the Payment by Results (PbR) system, some of which will have a significant impact on the quality and safety of care provided to kidney patients. Traditionally, PbR rewarded trusts for increased activity, and this was successful as a way of reducing waiting times. Now, however, the use of best practice tariffs encourages services to improve the quality and safety by applying best clinical practice, National Service Framework requirements and National Institute for Health and Clinical Excellence (NICE) guidelines.

The new tariff for haemodialysis rewards services that apply best clinical practice by paying significantly more for dialysis sessions that are delivered through definitive access (arteriovenous fistula or graft) than for those that are not. This is known to be better for patients because the faster flow rates result in more effective and efficient dialysis and it is much safer due to the reduced risk of infection. The level of the tariff has been set so that providers with 75% of their patients on definitive access will receive the same level of funding as under the previous system. In addition to rewarding services that do better than this, the tariff also provides a strong lever for those that are below this level to bring their services in line with best clinical guidance.

These changes are not about improving the financial system as an end in itself; they are about getting the right financial system in place to support the very best patient care and to offer greater patient choice and control.

The new tariff for multiprofessional outpatient clinics is another good example. By paying more for patients with complex needs to see a multiprofessional team (for example, a doctor and a psychologist or social worker), patients are given more choice and control and are able to move to their chosen treatment pathway more quickly.

**Looking to the future**

It is important to recognise that these changes are a work in progress and more needs to be done. For example, we need to find ways to better reward services that provide multidisciplinary clinics outside the hospital setting, and we need to make sure that providers don’t ‘cheat’ the system by providing multidisciplinary clinics where they are unnecessary.

We are also looking at the costs of home haemodialysis with a view to incorporating it into PbR in the future, to support fully informed choice of all appropriate treatment options. In addition, we are exploring the scope for improving patient care and outcomes by encouraging more pre-emptive transplants through PbR.

While work continues on aligning the financial system with quality improvements, these changes are a great stride in the right direction and will lead to real improvements in patient care. They provide powerful levers for clinicians and managers to deliver the very highest clinical standards, improved safety and outcomes, and greater control and convenience for patients.
Frequently asked questions on Payment by Results

Why is a best practice tariff for dialysis being introduced?
The aim of Payment by Results (PbR) is to provide a transparent, rules-based system for paying trusts that rewards efficiency, supports patient choice and diversity, and encourages best practice. Payment is linked to activity and adjusted for case mix, and ensures a fair and consistent basis for funding.

Best practice tariffs have evolved out of a commitment to make quality the organising principle of the NHS, while also responding to the need to improve efficiency and value. The best practice tariff for dialysis provides a clear financial incentive to improve the rate of definitive vascular access, which is a key determinant of the quality of patient care and overall outcomes. Over a three-year period, the best practice tariff will bring rates of definitive vascular access up to the level recommended in professional guidance.

What will be the impact on funding for renal services?
The best practice tariff prices have been calculated on the basis that in 2011/12, renal dialysis units having 75% of haemodialysis patients on definitive access (arteriovenous fistula or graft) should receive the same level of income as if prices were calculated at the national average cost. This percentage will be set at 80% for 2012/13 and 85% for 2013/14. 2011/12 is a transitional year in moving into tariff, with a mandatory shift from current contract prices 50% towards the national tariff prices. This provides a period of time for the transition to be managed, while clearly signalling the direction of travel. Tariff prices are calculated from reference cost returns and are adjusted locally by the Market Forces Factor (MFF), so that they are net of the unavoidable differences in costs that the MFF captures.

What is, and what is not, included in the tariff price?
The tariff excludes all modalities of paediatric dialysis and dialysis for patients with acute kidney injury/acute renal failure. Funding for dialysis in these patients is for local arrangement. The tariff also excludes home haemodialysis, for which we are publishing non-mandatory prices pending further collection and refinement of cost data during 2011/12.

Patient transport will continue to be commissioned separately; otherwise, costs are included on a full absorption basis.

Are ESAs and mineral bone disorder drugs included in the tariff price?
The tariffs for dialysis and nephrology outpatient attendances are not intended to fund the costs of certain drugs, including the erythropoiesis-stimulating agents darbopoetin alfa and epoetin alfa, beta, theta and zeta; and drugs for mineral bone disorders cinacalcet, sevelamer and lanthanum.

Due to the variation in funding and prescription practices across the country, the drug costs should not be reimbursed through a national tariff in 2011/12 and organisations should continue with current funding arrangements for these drugs in respect of renal dialysis or for outpatient attendances against the nephrology treatment function code. These drugs are only excluded from the adult dialysis and nephrology tariffs. Where they are used for patients not on dialysis or being treated in nephrology outpatient clinics, their costs are included in the tariff and, therefore, should not be funded separately. The intention is that in due course the cost of these drugs should be reimbursed through the tariff, and we will work with the renal community to achieve this aim in the shortest feasible timeframe.

Is the best practice threshold appropriate, given case mix and patient choice?
The 75% threshold for definitive dialysis access for 2011/2012 has been set with reference to the Renal Association Vascular Access Guidelines; the Joint Working Party Report on Vascular Access from the Renal Association; the Vascular Society of Great Britain and Ireland; and the British Society of Interventional Radiology. The threshold has deliberately been set initially below their
recommendations to allow time for units more reliant on tunnelled lines to move towards the suggested 85% of prevalent dialysis patients dialysing through an arteriovenous fistula. Indeed, even at 85% the best practice tariff remains more conservative than the guidelines by its inclusion of grafts in the higher tariff rate, in recognition of the fact that a proportion of patients cannot have an arteriovenous fistula for technical reasons. There should be scope for allowing for patient choice within the 25% to 15% allowed for dialysis by tunnelled line in 2011/12 to 2013/14.

Why is a national mandatory tariff price for home haemodialysis not included?

We have made it clear that home therapies – including home haemodialysis and peritoneal dialysis – should be offered to all suitable patients as part of their choice of treatment modality. There is, at present, a paucity of cost data on home haemodialysis on which to base a mandatory tariff, with set-up costs in particular likely to be subject to significant variation. Further work is being planned for 2011/12 to collect data on home haemodialysis costs, with a view to their being incorporated within the scope of PbR in due course.

What flexibilities will exist around prices in 2011/12?

In 2011/12, there is a mandatory move from renal units’ current contract prices halfway towards the national tariff prices. The guidance also draws attention to the desire to encourage assisted peritoneal dialysis where appropriate, and states that, as the tariff paid for LD12A is unlikely to reimburse sufficiently a higher rate of assisted peritoneal dialysis, organisations may need to agree an appropriate increase to the listed price of LD12A, in line with the service redesign flexibility.

Has the dataflow been tested? Why does it differ from other PbR?

Yes: the NHS Information Centre contacted a number of different trusts that use the various renal systems to test the new HRG design, and also to check that the data were easily available from the units. The new HRGs have been built into the Local Payment Grouper for 2011/12, which will allow organisations to generate HRGs from patient data extracted from their own systems. The PbR team will work with the NHS Information Centre to provide a national reporting solution in 2012/13, with an expectation that this will be Secondary Uses Service (SUS) PbR.

How does the reporting process differ from other tariff-based services?

In order to support the best practice tariff policy, as well as be more clinically meaningful, the new HRGs in sub-chapter LD require seven data items defined in the mandatory National Renal Dataset. These data items are not contained in the Commissioning Data Set and do not flow into SUS PbR. We therefore expect organisations to implement local reporting in 2011/12 while we continue to work towards a national solution in 2012/13. The Local Payment Grouper, by including the new design of LD HRGs for renal dialysis, will allow organisations to generate HRGs from patient data extracted from their own systems.

Why do the tariff prices not differentiate between in-centre and satellite dialysis?

The intention is that the tariff price should be independent of setting and this applies across PbR. In some health economies, the place where patients dialyse may be influenced by the complexity of their clinical needs. For example, less complex patients may dialyse at satellite units, whereas the more complex patients receive dialysis in the hospital setting. For reimbursement policy, the consensus of clinical advice received is that the presence of blood-borne viruses is the only dimension of complexity needed to differentiate for resource use.

What is the anticipated impact on dialysis away from base?

The National Service Framework for Renal Services and subsequent Department of Health guidance makes clear that people on dialysis should have the opportunity for dialysis away from their home unit, for example when on holiday or away for the purposes of work. It is expected that the introduction of a national tariff for dialysis should make it easier to arrange dialysis away from base in the future by providing a consistent basis for financial flows.

Outpatient tariff – what impact do we anticipate?

For 2011/12 we are introducing a national tariff for multiprofessional nephrology outpatient clinics. Such outpatient attendances should include (although not exclusively consist of) three areas where preparation and choice are essential to good patient experience and achieving optimal outcomes: preparation for dialysis and/or transplantation; delivery of conservative/end of life kidney care, and management of people on immunosuppressive drugs.
Supporting young adults with kidney disease

NHS Kidney Care has developed a project to explore options for supporting young adults with kidney disease, and is working with five kidney care networks to develop approaches to improve services for young people.

The five networks are East Midlands, London, North East, South Central and South West. The project includes patients transferred from paediatric services and those presenting with kidney disease in young adulthood. Approaches focus on the role of a key worker, who is based in an adult service, but works across adult and paediatric kidney services, as well as primary care, social care and other settings. Success will be measured by criteria including: clinic attendance, emergency admissions, infection rates, quality of life, vocational readiness markers, self-management skills, patient, family and staff satisfaction, transition health plans, written transition policies, number of You’re Welcome quality criteria achieved, and staff training and development. This project will:

1. Identify suitable approaches and resources for supporting young adults with kidney disease, which will adapt to different localities
2. Raise awareness of existing best practice and disseminate effective models of care via presentations and/or published papers, abstracts and reviews at professional meetings
3. Consider health inequalities experienced by young adults with kidney disease including ethnicity and co-morbidities
4. Involve young people from the outset in project development and staff recruitment
5. Be evaluated by an independent research and evaluation organisation.

Evaluating different approaches

NHS Kidney Care has commissioned a two-year evaluation to explore approaches and resources for supporting young adults with kidney disease. Test sites are being encouraged to provide detailed thinking that will help to shape various strands of the project, including the evaluation. The evaluation has ten objectives.

1. To explore how different approaches have affected the experiences of patients, carers and staff, commissioners of services, and wider organisational issues across adult and paediatric services, primary and social care, and third sector providers.
2. To explore the impact of different approaches on success criteria, as agreed with the test sites.
3. To explore how to involve young adults in services development and evaluation.
4. To reflect on the feasibility of delivering different models and approaches.
5. To assess the impact of different approaches on the service in terms of patient pathways, networking and seamlessness.
6. To identify the drivers to a smooth transition process for young people and their families.
7. To reflect on financial and commissioning issues related to sustainability of the models and approaches at the end of the funding period.
8. To reflect on any unintended consequences.
9. To identify transferable finding in terms of policy implications, practical suggestions and theoretical underpinnings.
10. To assess the impact on health inequalities in young adults with kidney disease.

NHS Kidney Care went through a rigorous process of commissioning this external evaluation, with the team in place in April 2010. It focuses both on process and outcome, using qualitative and quantitative data to examine well-being and health outcomes (see Box 1). The researchers will act as ‘critical friends’. Outcomes of the evaluation will include transferable learning to other long-term conditions; a feasibility assessment; an account of the processes; examples of good practice; and a final report and articles in peer-reviewed journals. There is ongoing contract management, with key performance indicators agreed for the evaluation contract.

Box 1. Areas that the NHS Kidney Care evaluation focuses on

- Examples of best practice and key learning
- The impact of different approaches on patients, parents, carers, and staff and their experiences, and on commissioners of services
- The pathway, where the focus will be on the individual patient perspective, but also needs to include wider organisational perspectives, reflecting networks
- Different stakeholders (individuals and organisations) involved in the transition models
- Holistic aspects of care, such as education, relationships and employment

Reference
1. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/
Funding improvements to Renal Patient View

Improving self-care, patient empowerment, and engaging patients in care planning are widely acknowledged as being key to improving health outcomes and the patient experience for people with long-term conditions.

NHS Kidney Care is supporting the development of an innovative internet-based tool for kidney patients, which provides users with up-to-date information about their condition.

What is Renal Patient View?
Renal Patient View (RPV) is an internet-based system, through which kidney patients can view their live health test results online and obtain information. It is secure, easy to use and provides advice, helping patients manage their conditions. GPs and other healthcare workers, with the patient’s permission, are also able to see this information; this includes non-renal staff, who increasingly encounter kidney patients with existing co-morbidities. It can facilitate information-sharing and thereby aid the care of patients who attend more than one unit or go to another centre for a renal transplant. RPV users complete a consent form upon enrolment, explaining how data are stored securely and shared with the healthcare professionals involved in their care.1

Once logged in, the user’s diagnosis is shown on-screen, with links to information about the condition and its treatment for patients and clinicians, including explanations of the diagnosis for patients and treatment guidelines and decision support for healthcare staff. Recent test results particularly important to kidney patients are also shown. New results were added in 2009, including liver function tests and iron values.

RPV is managed as an ‘arm’s length’ body of NHS Kidney Care, a separate entity from patient groups and bodies across the whole renal community. It has a similar governance structure and a formal management committee, with representation from patient groups and bodies across the whole renal community.

Use of Renal Patient View
The data2 suggest those on dialysis are the most active RPV users. There is an equal ratio of male to female users, which is encouraging, as in other disease areas, it has been challenging to engage male patients in self-care. Feedback from clinicians3 has highlighted the potential for RPV to improve the quality of the patient-clinician consultation, and there is some evidence of kidney patients becoming more active in planning for the longer-term outcomes of their disease.

RPV is now available in 43 of the UK’s renal units, with over 15,000 registered users; installation is scheduled or anticipated in the other units. Within England, the South West Strategic Health Authority (SHA) region has the highest number of RPV registered patients, followed by the SHAs of East Midlands, Yorkshire and the Humber, and London. The RPV committee is encouraging regions with lower levels of RPV registration to increase participation.

NHS Kidney Care’s involvement
NHS Kidney Care provided funding over 12 months to the Renal Patient View Committee to support the introduction of additional features to RPV. A summary of the additional features can be seen in Table 1. Some of these new features went live in August 2010, including the online discussion forum and the option for patients to enter their own blood pressure, weight and glucose readings. The development of patient-entered comments, which will be added to a personal health blog, is in progress.

The uptake of the new features has been encouraging – currently, there are over 11,000 active users of RPV.3

NHS Kidney Care will conduct an evaluation of the uptake and impact of these new features in 2011. For more information about RPV, visit the website (www.renalpatientview.org/)

Table 1. New features added to Renal Patient View

<table>
<thead>
<tr>
<th>Added feature</th>
<th>Rationale for introduction</th>
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<tbody>
<tr>
<td>Patient able to enter their own blood pressure,</td>
<td>To encourage patients to become more actively involved in</td>
</tr>
<tr>
<td>glucose and weight reading, and to enter a</td>
<td>managing their condition, planning their care and understanding</td>
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<tr>
<td>dated comment about their condition in a new blog</td>
<td>their diagnosis and treatment</td>
</tr>
<tr>
<td>feature</td>
<td></td>
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<tr>
<td>Discussion forum</td>
<td>Provides kidney patients with the opportunity to make contact</td>
</tr>
<tr>
<td></td>
<td>with fellow patients and provide support, information and advice</td>
</tr>
</tbody>
</table>

References
1. www.renal.org/pages/media/download_gallery/RIXGenrole.doc (last accessed 05/02/10)
Patients with established renal failure receiving renal replacement therapy are at increased risk of bacteraemia. This, in turn, is associated with increased mortality and morbidity within this patient group. The principal risk factor for this is the use of venous catheters for access to the circulation. Since the publication of the first UK Renal Registry report on vascular access, there has been recognition both that methicillin-resistant *Staphylococcus aureus* (MRSA) bacteraemia is common within the dialysis population as a whole, and that the risk for an individual dialysis patient is elevated.

**Data collection**

With the mandatory reporting of MRSA bacteraemia within England via the healthcare-associated infection data capture system (formerly known as the Mandatory Enhanced Surveillance System, or MESS), an enhancement of data collection for those patients receiving dialysis was instituted in April 2007. The second year of data collection covered the period from 1 April 2008 until 31 March 2009. The methodology has been described previously, but three stages of data collection are required.

First, an MRSA bacteraemia is identified by the microbiology laboratory. Second, the record is shared with the renal centre, triggering an email alert for further data collection. The renal centre then completes additional renal data on the type of access and modality. This year, with the assistance of NHS Kidney Care, an additional step of validation and data capture was introduced to complete records.

**Results**

In the reporting period April 2008 to March 2009, 171 discrete episodes of MRSA bacteraemia were identified in patients on dialysis or in established renal failure; 18 of those records were rejected as not being associated with patients on long-term dialysis, or being duplicates of other records. In 139 episodes, the type of vascular access in use was documented – 70% were dialysing on a non-tunneled or tunneled venous catheter. Eleven patients had recurrent episodes during the reporting year; these accounted for 22% of all episodes of MRSA bacteraemia within the dialysis population.

**Summary**

There was a 23% reduction in episodes from the previous year. The median centre-specific rate of MRSA bacteraemia was 0.64 (range 0–3.49) episodes per 100 haemodialysis patients per year. Figure 1 shows the MRSA rate by centre. Venous catheters remain the principal risk factor for MRSA bacteraemia, with a relative risk around seven times higher than that of patients receiving haemodialysis via an arteriovenous fistula.
The second year of reporting has demonstrated improvement in the rates of MRSA bacteraemia within the dialysis population. However, there is still marked variation between centres, which requires further analysis. Vascular access quality remains the predominant modifiable risk factor in this population. The mechanism for reporting MRSA bacteraemia has been enhanced by having the final validation step, although this has increased the workload required in collecting the data. This aspect of data collection may require further refinement to improve the quality of data while improving reliability of collection.

References

Reducing MRSA bloodstream infections

In March 2006, the Healthcare Associated Infection and Cleanliness Division of the Department of Health (DH) launched a national work stream to support healthcare professionals working in renal services to reduce the incidence of MRSA bloodstream infections in their patient group. Patients receiving renal replacement therapy accounted for 8% of all MRSA bacteraemias reported to the Health Protection Agency (HPA) via MESS between October 2005 and March 2006.

The renal work stream had three main ‘deliverables’. First, to produce tools that would enable healthcare staff to review the systems and processes in place for delivery of service improvement in both clinical practice and HCAI management, namely the Safer Practice in Renal Medicine and the Renal Dialysis Catheter Care Bundle. Second, to work with any renal units significantly challenged to reduce the incidence of MRSA bloodstream infections and provide recommendations for improvement, followed by an offer of bespoke support. The final aim was to launch a DH-sponsored forum for healthcare professionals to share experiences and good clinical practice shown to reduce HCAI – the renal performance improvement network (PIN) event.

Since August 2007, 40 renal units have received bespoke support to review their systems. Six renal PIN events have been delivered, covering a broad range of national and local issues relating to reducing HCAI. These have been well attended and evaluated. This triangulated approach to clinical improvement has achieved a 68% reduction in MRSA bloodstream infections in nephrology patients reported via MESS over three years.

While great reductions have been made and sustained nationally, there are still a small number of renal units that are challenged to make reductions in MRSA bloodstream infections if continuous improvement is to be delivered. Areas that have been highlighted by healthcare professionals through the renal PIN events are standardisation of catheter management, effective clinical leadership of the HCAI agenda, assurance of workforce competence, and performance management through regional renal networks as part of the quality agenda. Kidney services should continue to be vigilant and have zero tolerance of catheter infection; for example, by participating in ‘Matching Michigan’, a quality improvement project developed in the USA which, over 18 months, saved around 1,500 patient lives. It sets out a series of data definitions, technical interventions (changes in clinical practice) and non-technical interventions (linked to leadership, teamwork and culture change), which have been shown to reduce catheter infections.
In 2009, kidney care became the first specialty to have a mandated national dataset that covers all aspects of a clinical pathway. This will equip all members of the renal team with the information needed to make measurable improvements in the standards of care that they provide. The NHS Information Centre has compiled a list of frequently asked questions on the National Renal Dataset (NRD).

**What is the National Renal Dataset?**
The dataset specifies the information to be collected by renal services in England, in order to assess progress against the *National Service Framework for Renal Services*. It provides standard definitions for all renal services to adhere to, so information can be directly compared.

**What is unique about this dataset?**
The NRD is the first dataset to cover the whole of a clinical pathway. Other specialties have datasets for part of their care pathway, (for example, retinopathy screening in diabetes), whereas this dataset covers all aspects of the patient pathway for preparation and delivery of renal replacement therapy.

**What information will it provide?**
It will provide information to support the development of renal services, ultimately to the benefit of renal patients. The NRD builds upon the existing collections of the UK Renal Registry (UKRR) and NHS Blood and Transplant (NHSBT, formerly UK Transplant), and formalises the collection as an information standard in England.

The dataset has been designed to meet all the information requirements of the NSF. This means that there are some additional items within the NRD that were not previously collected by UKRR or NHSBT. For example, items about vascular access are a new area of information to be recorded by trusts.

**How is the information specified?**
Each data item has a name, a definition, a description and details of the values that can be recorded, along with a marker to state whether it is part of an existing collection (for example, UKRR) or whether it is new. Each data item has a ‘primary information requirement’ specified as part of the definition. This shows how the data item relates to the NSF. A data item may support more than one information requirement. Clinical terminology to support implementation in clinical systems will be published by NHS Connecting for Health.

**How do trusts know that they have to collect the data?**
The official notification to the NHS and system suppliers is the Data Set Change Notice (DSCN). The reference number for the DSCN is 27/2008. This is issued by NHS Connecting for Health. The Review of Central Returns licence number for this collection is ROCR/OR/0192/FT6/001; this is a mandatory collection from all renal medicine departments in acute Trusts, both foundation and non-foundation.

**How do I know that the data can be collected?**
The process of development has included wide-ranging consultation with clinicians across England and the dataset has been tested operationally through collection at six renal units.

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**Best practice: Yorkshire and the Humber – Kidney Care Network Managers**

NHS Kidney Care funds the appointment of a network manager in some kidney care networks – in Yorkshire and the Humber, the role belongs to Rebecca Campbell. As Kidney Care Network Manager, Rebecca works to support the strategy group and local implementation groups, share best practice and encourage excellence, encourage kidney centres to operate consistently across the region, support implementation of the National Service Framework for Renal Services, and to increase patient and public involvement. Rebecca is in the final stages of developing a five-year strategy and work plan for the network, which will be supported by the development of clear standards, performance-monitoring mechanisms and commissioning frameworks.

Recent highlights of work carried out in the Yorkshire and the Humber Renal Network include the development of an integrated model for providing specialist palliative care to kidney patients at Leeds Teaching Hospital Trust, Bradford Hospital Trust’s adoption of e-consultations, and the creation of a Yorkshire and Humber virtual GP renal reference group, an informal supportive group providing the opportunity for interested GPs to communicate and discuss issues.
for a two-month period. Evidence of this work had to be provided to the NHS Information Standards Board (ISB) for the dataset to be approved as a national standard.

**What is meant by ‘mandated’?**

Providers of renal services in the NHS are obliged to return the information. This requires that trusts housing renal services use IT systems that allow capture of all of the mandatory data items and the preparation of data extracts for the UKRR for those items collected electronically by the UKRR. Capture of data items that are collected by NHSBT may be done electronically or in paper format. Trusts have an obligation to ensure that systems are in place that support the reliable capture of each of the mandatory data items.

**Why are there different dates for the data collection to commence?**

The NRD is a large dataset, which originally contained 953 data items, although in a significant review of the dataset in 2010, 88 items were removed as duplicates or as no longer useful for national audit. For renal services to implement the dataset, a phased approach to implementation has been agreed – 693 data items were mandated for collection from May 2009. A further 188 data items were mandated for collection from April 2011. Some data items in the dataset are optional. These can be used for local collections, if required. Subject to further operational testing and approval by ISB, these data items may be mandated for collection in the future.

**How will the data be collected?**

Many of the mandatory data items are recorded in the clinical IT systems within renal units. This information is extracted and sent to UKRR, where it is validated and analysed. Data relating to transplants are collected by NHSBT via electronic or paper forms. Some data items are reported via coding to the Hospital Episode Statistics (HES) database. Guidance on which items should be reported to the UKRR or to NHSBT is available from the respective organisations. The UKRR will provide detailed guidance to IT suppliers on the format in which the data should be coded and transmitted. This format may differ from the outputs specified in the NRD and will often be more detailed. NHSBT can also provide guidance on formats.

**Will reports be available?**

Reports are already available on many of the data items from the UKRR and NHSBT. The UKRR provides an annual report and an executive summary for commissioners, and also provides geographical mapping software, enabling the preparation of customised analyses. The UKRR is also developing centre-specific analyses that will be provided quarterly to each renal centre.

NHSBT provides annual reports and centre-specific analyses on its website, and also provides a comprehensive enquiry service. The NHS Information Centre is developing functionality in the Secondary Uses Service that will enable data from UKRR, NHSBT and HES to be joined together and linked to data for other clinical specialties. This will enable authorised users of the Secondary Uses Service to access the data and run pre-defined reports, or create bespoke queries on the data.

**Does mandatory collection of the dataset apply to paediatric services?**

All paediatric data items are specifically covered by the DSCN and were mandated for collection from 31 May 2009.

**Where can I get more information?**

The National Datasets Service website provides details on the NRD. From this page you can download both the dataset specification and supporting documents, such as guidance for renal services implementing the dataset.

**How will the NRD be kept up to date?**

The dataset will be maintained by the National Datasets Service, working with renal clinicians to ensure that the definitions remain up to date and fit for purpose.

During 2010, the NRD underwent a revision, with a significant reduction in the number of data items (a removal of 88), and the clarification and improvement in the descriptions of a further 79. As a result, the NRD has addressed many of its criticisms, with the removal of duplicate items and those no longer needed for national audit and quality improvement. Where necessary, the descriptions have been improved, and the whole NRD has now been scrutinised for consistency and adopted by the NHS data dictionary.

The new version of the dataset (2.2) is available from the NHS Information Centre website (www.ic.nhs.uk/services/datasets/document-downloads/renal). If you have any questions about the data definitions, please contact the National Datasets Service via email (datasets@ic.nhs.uk). Please state ‘national renal dataset’ in the subject line.

**Reference**

1. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4070359 (last accessed 08/03/10)
Atypical haemolytic uraemic syndrome

Haemolytic uraemic syndrome (HUS) is a disorder marked by kidney failure, haemolysis (destruction of red blood cells) and thrombocytopenia (platelet deficiency). The syndrome is most common in children, and typically occurs after a gastrointestinal infection with enterohaemorrhagic Escherichia coli.

Less common forms – atypical HUS (aHUS) – are associated with other conditions, such as some non-enteric infections, drugs, malignancies, metabolic disorders, diseases of the immune system and, in particular, some instances of inherited or acquired abnormalities of the complement system; aHUS is life-threatening and chronically debilitating due, in particular, to kidney disease and a high likelihood of recurrence of the disease in a kidney transplant.

The specification

NHS Kidney Care has produced a specification that sets out what is required of a clinically safe and effective service providing care for people with aHUS, the majority of whom will be children and young adults. This describes the interventions and actions required along the patient pathway. It comprises the following sections.

Service elements

Different referral pathways, including planned and unplanned referrals from adult and paediatric clinics, are considered. Preparation is key, and should include ensuring that relevant infrastructure is in place and raising awareness of aHUS in the medical profession. Training must be given to the multidisciplinary team, to enable them to educate the patient and family. Robust IT support should be in place, including access to the UK Registry for Rare Kidney Diseases (RaDaR) database. Robust processes will ensure that education and preparation can be appropriately timed and delivered according to best practice.

Service delivery

Populations and geographical barriers must be considered, and efficient transport arrangements must be established.

Quality and governance

Service providers will be required to deliver significant efficiency savings while retaining high-quality care for all. Practitioners must optimise the care they provide for patients diagnosed with aHUS by enhancing the knowledge that underpins their practice and by gaining confidence through perfecting their practice.

Quality indicators and measurable outcomes

Appropriate investigations to identify the cause of aHUS are essential to manage the condition effectively. The specification describes elements that must be included in specialist blood testing, and provides details of laboratories in the UK for sample analysis. UK treatment centres are listed and treatment options – including plasma exchange, kidney transplant, and liver or combined liver/kidney transplant – are considered.

Sustainability

To ensure that the most up-to-date advice is available to all renal units, the specification proposes the establishment of an independent advisory group. This would be a function of an aHUS-specific working group integrating translational research, patient information and empowerment, and audit. The working group would operate with the RaDaR database and its members would include, among others, a transplant lead, and an adult and a paediatric nephrologist.

Once a clinician has entered the details of the patient onto the system, the working group would be alerted. The system would enable a series of guidelines to be accessed to ensure that the appropriate investigations are performed. The RaDaR database would be accessible by patients/parents and clinicians alike, thereby empowering patients and their families with current concepts of investigation and clinical management. The responsibility for clinical decision-making would lie with the local nephrologist, but they would be able to request advice from a panel of named advisers within the membership of the working group.

Conclusion

The aHUS specification provides a useful guide for commissioners and service providers in planning effective treatment for children and adults with aHUS. It can be downloaded from the NHS Kidney Care website (www.kidneycare.nhs.uk/ResourcesToDownload-Specifications.cms). 

Acknowledgement

Thanks to Mark Taylor, Paediatric Nephrologist at Birmingham Children’s Hospital Foundation Trust.
Acute kidney injury (AKI), formerly known as acute renal failure, is both common and serious. Epidemiological studies suggest that as many as one in five people admitted as an emergency to hospital suffer from AKI, and it has a significant impact on patient outcomes and NHS resources.

**The dangers of AKI**

The spectrum of severity is wide – those with the most severe AKI may need treatment in an intensive care unit and only half of these patients will survive to discharge. However, even minor degrees of AKI are associated with increased long-term mortality and increased lengths of stay. AKI usually occurs in the setting of acute illness and is often multifactorial – the triad of infection, dehydration and nephrotoxic medications is especially common. Moreover, some people are at significantly greater risk of AKI, for example those with diabetes, heart failure or pre-existing chronic kidney disease.

Identifying those at highest risk and early recognition of AKI are important, as simple interventions at this stage can prevent deterioration, for example by ensuring that patients are adequately hydrated and have infection promptly identified and treated (see Figure 1). Indeed, studies suggest that up to 30% of AKI cases are entirely avoidable or preventable. Delayed recognition of AKI may miss this early ‘therapeutic window’ where AKI is rapidly reversible – the treatment of more severe AKI focuses more on supportive therapy (such as dialysis) and the management of the complications of AKI. Two recent reports from the National Confidential Enquiry into Patient Outcomes and Death (NCEPOD) have highlighted issues relating to the care of people with AKI. *Adding Insult to Injury* (June 2009) reported on the care received by people who died from AKI. It found that only 50% of these patients received good care and identified significant delays in the recognition of AKI. *An Age Old Problem* (November 2010) investigated deaths in elderly patients following surgery, and found that there were frequent deficiencies in the assessment of risk factors for AKI.

These measures are not intended to replace the need for local action, which will be essential

An example AKI Commissioning and Quality Innovation (CQUIN) payment scheme has been devised for 2011–12. It includes a number of measures aimed at preventing AKI in those with acute illness, and incorporates recommendations from NICE Clinical Guideline 50 on Acutely Ill Patients in Hospital.

The AKI Care Initiative (AKICI) Conference, facilitated by NHS Kidney Care, was held in March 2009 and saw representatives from many specialist communities agree to work collaboratively on a range of key issues relating to AKI. These are being followed up by the AKI Delivery Group, a multiprofessional and multidisciplinary group charged with driving

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**Box 1. The National Vascular Database**

NHS Kidney Care has commissioned the Vascular Society of Great Britain and Ireland to identify and record the key markers of acute kidney injury (AKI) and then to analyse/review AKI in surgical patients undergoing aortic aneurysm repair. The study will lead to a greater understanding of the potential impact of AKI on patient outcomes, and will examine the resource implications of AKI on acute services.

The study involves routinely collecting, through the National Vascular Database, data on aortic aneurysm patients coming to surgery. Vascular units are gathering a detailed post-operative dataset to include clinical observations and haematological and biochemical data, plus data on admission to intensive care and nephrology referral. Data on interventions such as dialysis, filtration, ventilatory and blood pressure support will also be collected, as well as data on survival at one year post-procedure.

Data will then be analysed to look for rates of AKI, with patients stratified by stage of AKI to examine the effect of AKI on survival at 30 days and one year. Regression analysis will be used to look at the effect of defined complications on the development and impact of AKI, and patient survival. Results of this study are expected in mid-2012.

Bringing about change

The National Clinical Director for Kidney Services, Donal O’Donoghue, is putting in place a series of actions that the Department of Health (DH), working with a range of organisations, including NHS Kidney Care, will oversee at the national level to improve the prevention, recognition and management of AKI.
service improvements in the care of people with AKI. Primary ‘deliverables’ that the Group seeks to implement at the national level are listed below.

- Developing AKI-related competences for inclusion in the curricula for multiprofessional training
- Working with hospital and community pharmacists to develop the role of medicines management in the prevention and management of AKI
- Surveying the capacity of the NHS to care for people with AKI
- Bringing together critical care and kidney care networks to improve the care of people with more severe AKI
- Developing and piloting AKI risk assessment tools
- Improving the recognition of AKI by the use of flags and alerts
- Piloting data collection and audit through extension of the Vascular Society of Great Britain and Ireland’s National Vascular Database, funded through NHS Kidney Care (see Box 1).

Many local initiatives are underway to improve the care of people with AKI. This national plan of action has been devised to support these, foster local innovation and build on their success.

Conclusion

The ongoing work of the AKI Delivery Group, the DH and NHS Kidney Care is intended to contribute to a rapid and marked improvement in the care of patients at risk of AKI at a national level, leading to a significant difference in patient safety and outcomes.

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