Achieving Excellence in Kidney Care
Delivering the National Service Framework for Renal Services
**Title**

Achieving Excellence in Kidney Care: Delivering the National Service Framework for Renal Services

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**Target audience**

PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, PCT Chairs, NHS Trust Board Chairs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads

**Description**

The National Service Framework for Renal Services set out the first ever set of national standards for the treatment of renal disease. This report highlights progress over the five years since the publication of the National Service Framework

**Cross reference**

The National Service Framework for Renal Services, Part One and Two.

**Superseded documents**

N/A

**Action required**

N/A

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N/A

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Foreword by the Secretary of State for Health

The National Service Framework (NSF) for Renal Services provided for the first time a compelling vision for kidney services centred on the needs of each patient.

Real progress to implement the vision set out in the NSF has been made through the efforts of patients, carers and practitioners. The NHS now leads on the international stage in early detection and prevention of kidney disease, with increasing numbers of patients being effectively managed in primary care. Dialysis capacity has expanded as more facilities and satellite units have come on stream, and the number of registered organ donors in England now exceeds 13 million. Rates of hospital-acquired infection among kidney patients have been driven down through increasing adoption of best practice in vascular access.

Against this backdrop, the number of people with kidney disease continues to rise year on year. This is because kidney disease shares many of the same risk factors as other vascular diseases such as diabetes. This makes the continued implementation of the NSF in conjunction with other preventative initiatives, such as the NHS Health Check programme, of the utmost importance.

This report records and celebrates progress over the five years since publication of the NSF. The NHS has changed enormously over this time. It is now led by frontline staff, which enables local services to listen to their local population and provide services that are tailored to their communities.

In the next five years and beyond, our mission must be to take NHS services from good to great, making them more preventative and people-centred, keeping people well and out of hospital, and empowering them to choose what they know is best for them and where they want to be treated.

Variation in detection rates for chronic kidney disease needs to be addressed, and more attention given to the recognition and management of acute kidney injury. The service needs to move towards being more patient-centred, giving people choice and control over how they manage their condition; in particular, choice for patients wishing to self care at home must be improved, including provision of home haemodialysis as recommended by the National Institute for Health and Clinical Excellence (NICE). The big challenge now is to make innovative changes through service reform – with timely intervention and by doing things right first time – to ensure that resources are used to best effect, and that patients get the best outcomes.
Renal services, together with the improvement organisation NHS Kidney Care, are well placed to reap the benefits of this approach. I look forward to a celebration of the next five years’ achievements in improving kidney care.

Andy Burnham MP
Secretary of State for Health
Publication of the NSF was a seminal moment, and has led to a social movement within the kidney community, with the vision of transforming the experience and, when possible, the outcomes for every person with kidney disease.

There has been real progress over the last five years, and many exciting developments at every level, from national commissioning right through to putting individual patients at the centre of shared decision-making. Better preparation and choice for those with advanced kidney disease, developments in transplantation and improvements in vascular access for dialysis have contributed to kidney units being safer places that deliver improved outcomes and quality of life. NHS Kidney Care has played a vital role in facilitating the development of local kidney care networks and has supported the implementation of effective care planning by developing a personalised care plan for all kidney patients.

Yet, we know that there is still considerable variation in access to care, there are missed opportunities for prevention, unnecessary delays in treatment and often a failure to provide the conditions for shared decision-making.

We need to accelerate implementation of what we know works, such as earlier and better blood pressure control, implementation of the NICE guidance on chronic kidney disease and anaemia management, and timely preparation for replacement therapy or conservative care. We need to be bold, to innovate and challenge the norm so that we can achieve improvements. This requires co-ordination, partnership and leadership by commissioners and providers, and by clinical, social care professionals and managers, in and between primary and specialist care.

Change happens locally. Fundamental service improvements are led by local teams working in an empowering environment. They need to be given the responsibility to achieve, and permission to take risks, as part of a learning organisation. National policies and guidelines set the framework, but it is through the grass-roots understanding of quality and productivity that development of innovative approaches, which lead to lasting improvements, happens. At the centre of this are patients and the high-quality relationships built between them and empathetic, motivated and skilled practitioners.
Kidney disease is common, harmful and treatable. An improved understanding of the implications of kidney disease will support the behavioural and lifestyle changes that can deliver the preventative dividend. A change in emphasis from disease management to promoting health is needed, supporting our staff, motivating people with kidney disease and encouraging a 'can do' mentality in our system, informed by more research and better evidence. We should strive to intervene early; endeavour to motivate patients to keep themselves well; and provide evidence-based, accessible information to support our patients. When we engage service users fully in setting goals and planning their own care, great steps forward can be made.

Improving coding, measurement, analysis and reporting of patient experiences, clinical effectiveness, costs, safety and outcomes will help to inform service transformation.

This will not be easy. It will require local and national leadership, new partnerships, difficult choices and a systematic approach in supporting individuals to achieve optimal health at every stage of the kidney care pathway. The prize – moving our services from being good in parts to being great everywhere – is worth that effort. I would like to thank the kidney community for their enthusiasm, passion and dedication to improving care across the entire kidney care pathway. I look forward to working alongside them to deliver the NSF vision.

Dr Donal O'Donoghue
National Clinical Director for Kidney Care
Summary of National Service Framework standards, quality requirements and markers of good practice

These standards and quality requirements apply to all people with, or at risk of, kidney failure. In some cases, for example children and young people and some older people, they will also apply in varying degrees to families, guardians or carers.

Part one of the NSF:

STANDARD ONE: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.

Markers of good practice

- Provision of high quality, culturally appropriate and comprehensive information and education programmes.
- Education programmes tailored to the needs of the individual.
- Individual care plans, regularly audited, evaluated and reviewed.
- Access to a multi-skilled renal team whose members have the appropriate training, experience and skills.
- For children and young people, meeting the standards of Getting the right start: National Service Framework for Children, Young People and Maternity Services.

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Markers of good practice

- Referral to a multi-skilled renal team, where possible at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation. This principle should also be followed for people with a failing transplant.
- Accelerated process with intensive input from the renal team for those who present late to renal units or as acute uremic emergencies.
- People with ESRF given information about all forms of treatment so that an informed choice can be made.
- Patients put on the national transplant list within six months of their anticipated dialysis start date if clinically appropriate.
- Anaemia treated to maintain an adequate haemoglobin level.
- Management of cardiovascular risk factors and diabetes according to the National Service Frameworks for Coronary Heart Disease and for Diabetes.

STANDARD THREE: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.

Markers of good practice

- Early referral for assessment and investigation for the best means of access, and timely surgery (current best practice being six months before haemodialysis, four weeks before peritoneal dialysis) which enables patients to begin dialysis with their vascular or peritoneal dialysis access established and functioning.
- Monitoring and early intervention to minimise complications of the access.
- Recording and regular auditing of the type of access in use at the start of dialysis, time from referral to surgery, and complication rates for each procedure. Temporary access replaced by permanent access as early as possible.
- Proper training for patients, carers and members of the renal team in the care of the access.
- For children and young people: Dialysis access surgery to follow the principles set out in Getting the right start: the National Service Framework for Children, Young People and Maternity Services – Standard for Hospital Services.

STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.

Markers of good practice

- All dialysis methods available interchangeably for patients, including home haemodialysis and automated peritoneal dialysis.
- Patients receive an adequate and effective dialysis dose.
- Peritonitis rates to be less than one per 18 patient months for adults undergoing peritoneal dialysis, one per 14 patient months for children.
- Patients have their nutritional status monitored and appropriate nutritional support in place.
- Efficient patient transport services available.
- Specialist renal staff, equipment and care available throughout admission, whatever the setting, for patients with established renal failure admitted to hospital.

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Markers of good practice

- Early provision of culturally appropriate information; discussion with and counselling of patients, relatives and carers about the risks and benefits of transplantation.
- Application of a national matching scheme using criteria agreed through UK Transplant to optimise blood group and tissue matching for kidneys from deceased donors.
- Effective preventive therapy to control infections.
- Timely operating theatre availability to ensure optimal cold ischemia times.
- Appropriate immunosuppression and anti-rejection treatment in accordance with forthcoming NICE guidance and effective monitoring and treatment to minimise the risks of adverse effects of immunosuppressive treatment.
- Clear explanation for patients of tests, procedures and results, and especially information and education about anti-rejection therapy.
- Specialist advice from the transplant team available for patients with a renal transplant admitted to hospital, whatever the setting.
Part two of the NSF:

QUALITY REQUIREMENT ONE: People at increased risk of developing or having undiagnosed chronic kidney disease, especially people with diabetes or hypertension, are identified, assessed and their condition managed to preserve their kidney function.

Markers of good practice

- All people at increased risk of CKD are identified, and given appropriate advice, treatment and support (which is sensitive to the differing needs of culturally diverse groups) to preserve their kidney function.
- People identified as having an increased risk of CKD have their kidney function assessed and appropriately monitored, using estimated GFR.
- Implementation of the NICE clinical guideline on the management of Type 1 diabetes.
- Implementation of the NICE clinical guidelines on the management of Type 2 diabetes: renal disease; blood glucose; blood pressure and blood lipids.
- Implementation of the NICE clinical guideline on the management of hypertension in adults in primary care.
- For children and young people with potential urinary tract infection, accurate diagnosis and prompt antibiotic treatment, and investigation sufficient to identify structural renal defects and to prevent renal scarring.
- For children and young people with bladder dysfunction, planned investigation and follow-up, with access to urology services with paediatric expertise.

QUALITY REQUIREMENT TWO: People with a diagnosis of chronic kidney disease receive timely, appropriate and effective investigation, treatment and follow-up to reduce the risk of progression and complications.

Markers of good practice

- All people diagnosed with CKD have access to care which is sensitive to the differing needs of culturally diverse groups, to maximise the benefits of treatment and minimise the effects of the disease; and have a care plan.
- Use of the best available evidence to inform the management of blood pressure, cardiovascular disease and cardiovascular risk, and urinary tract obstructions and infections in people with CKD.
- In people with diabetes and CKD, interventions to reduce microvascular complications, in accordance with the National Service Framework for Diabetes.
- Implementation of the forthcoming NICE guideline on the treatment of anaemia in CKD.
- Referral from primary care to the specialist renal service at an appropriate stage to optimise outcomes.

QUALITY REQUIREMENT THREE: People at risk of, or suffering from, acute renal failure are identified promptly, with hospital services delivering high quality, clinically-appropriate care in partnership with specialised renal teams.

Markers of good practice

- Timely identification and referral to renal and critical care services for specialist, culturally appropriate advice and assessment.
- Appropriate pre-operative testing and interventions, in accordance with the NICE guideline on pre-operative testing.
- Involvement of local critical care networks in planning, commissioning and monitoring the delivery of critical care services to acutely ill renal patients.
- Liaison with specialist renal services to facilitate optimal management of people with ARF in the most clinically appropriate setting.
- For children and young people: Treatment and care in accordance with Getting the right start: National Service Framework for Children, Young People and Maternity Services.

QUALITY REQUIREMENT FOUR: People with established renal failure receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences.

Markers of good practice

- The renal multi-skilled team has access to expertise in the discussion of end of life issues including those of culturally diverse groups and varied age groups, the principles of shared decision making, and training in symptom relief relevant to advanced non-dialysed ERF.
- Prognostic assessment based on available data offered to all patients with stage 4 CKD as part of the preparation for RRT described in standard two of part one of this NSF.
- People receive timely information about the choices available to them, such as ending RRT and commencing non-dialytic therapy, and have a jointly agreed care plan built around individual needs and preferences in line with palliative care principles.
- People who are treated without dialysis receive continuing medical care including all appropriate non-dialytic aspects of CKD, and wherever possible are involved in decisions about medication options.
- Individuals are supported to die with dignity, and their wishes met wherever practicable regarding where they die, their religious and cultural beliefs, and the presence of the people closest to them.
- The care plan includes culturally appropriate bereavement support for family, partners, carers and staff.
1 A patient-centred service

National Service Framework standard/quality requirement:

All children, young people and adults with chronic kidney disease (CKD) are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.

Key progress to date includes:

- the launch of My Kidney Care Plan\(^1\) resources to support care planning, and the Renal Haemodialysis Patient Checklist\(^2\)
- a new NHS Choices website including an online kidney disease self-assessment tool
- provision of advocacy officers by the National Kidney Federation\(^3\) to support patients with kidney failure.

Since the introduction of the NSF for Renal Services, the publication of the NHS Next Stage Review\(^4\) rightly placed further emphasis on the empowerment of patients and made quality the organising principle of the NHS. Patients must be given more information and choice, increased control over treatment of their condition and inclusion in the planning of services if they are to offer quality, value for money and improved outcomes. This concept also underpins implementation of the NSF.

We are working to ensure that kidney services continue to be responsive to every individual, focused on prevention of ill-health, and capable of engaging patients and clinicians in shared decision-making at every stage of the care pathway.

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1. [www.kidneycare.nhs.uk](http://www.kidneycare.nhs.uk)
3. [www.kidney.org.uk](http://www.kidney.org.uk)
Information for patients

Information is vital in involving patients at all stages of kidney disease and much work has been done to improve educational information. NHS Choices, which provides a single ‘front door’ for the public to all NHS online services and information through the country’s biggest health website, has created a means of unlocking the information resources of the NHS. At a national level, NHS Kidney Care is continuing to develop and refine the content on the prevention, diagnosis and treatment of kidney disease.

Charities, industry, patient groups and health professionals continue to work together to produce many valuable information materials. One example is the Living with Kidney Disease DVD project. This is a unique health awareness resource produced with the involvement of the British Renal Society Kidney Research UK, the Renal Association, the British Transplantation Society and the National Kidney Federation. The DVD covers understanding of kidney disease for newly diagnosed patients and practical advice for those beginning dialysis.

5  www.nhs.uk/Pages/HomePage.aspx
The ABLE Programme

The ABLE (A Better Life through Education and Empowerment) programme is committed to ensuring that health inequality issues are prioritised along the whole spectrum of, and even before, CKD is diagnosed in black and minority ethnic, and other at-risk groups. This has taken place through a portfolio of research and awareness projects, the development of literature and DVDs and the development of a peer educator model with funding support from the Department of Health.

The use of peer education is an established methodology for promoting health awareness in groups that are difficult to access. Peer educators are lay members of a community who are trained and supported to impart key messages. They have linguistic and cultural empathy as well as an understanding of shared health experiences. Kidney Research UK has been utilising this model in several of its ABLE projects.

One patient said: “Had a project like ABLE been in place long before, I feel that my renal failure may have been prevented or at least delayed and my family and I would have been prepared. I am sure many patients’ thoughts mirror mine.”

Through ABLE, Kidney Research UK aims to determine effective methods of attracting individuals from different ethnic communities to participate in health awareness programmes. This will help to determine the most effective methodology and inform best practice.

A recently completed ABLE study into attitudes towards organ donation highlighted the need for more resources about organ donation to be available for black and minority ethnic groups. These resources are needed in order to facilitate discussion and decision-making. Kidney Research UK believes peer educators play a key role in facilitating these discussions.

Care planning

In England, 15.4 million people have a long-term condition. As a result of an ageing population, it is estimated that by 2025, there will be 42% more people in England aged 65 or over. This will mean that the number of people with at least one long-term condition will rise by nearly 3 million to 18 million.

The vast majority of patients with long-term conditions, including kidney disease, want to be involved in decisions about their care. They want to choose which treatment process best suits their needs, and to share responsibility for managing their condition. We know that health improves when patients are given more information and control over their treatment options.
Both the NSF and the Next Stage Review have set out a vision for patients of all ages to optimise the role they take in management of their own care. Individual care plans, education and access to a multi-skilled team all play a role in this. Guidance issued by the Department of Health, *Supporting people with long-term conditions to self care,* highlighted the need to create a fully integrated system, with appropriately trained frontline staff, to enable people with long-term conditions to take greater responsibility for their own care. To help with implementation, *Your Health, your way – a guide to long-term conditions and self care* was launched on NHS Choices in November 2008. This provides information about the choices that should be available locally to support self-care in partnership with health and social care professionals.

### My Kidney Care Plan

Individual care plans are a critical part of care and are now used effectively in many kidney units. Agreed care plans provide individuals with personal information and peace of mind, but they also help to build improved partnerships between patients, the clinicians and the whole multidisciplinary team. Care plans for children and young people continue to involve parents as well as the kidney care team.

NHS Kidney Care launched *My Kidney Care Plan* on World Kidney Day in March 2009. Every adult patient with CKD will now be given a personal folder. They will be able to use them to discuss in detail their needs and concerns with a specialist nurse, or other trained member of their kidney team, and keep notes in their folder. Care planning is not, however, simply about filling in forms. It is a discussion that puts the person, their needs and choices at the centre with a focus on achieving outcomes. *My Kidney Care Plan* allows time for patients to ask questions that really concern them about aspects of their disease and how it affects their daily life.

For haemodialysis patients, the Department of Health, in partnership with the National Kidney Federation and the British Renal Society, have produced the *Renal Haemodialysis Patient Checklist*. This is a checklist of questions that patients highlighted as particularly important to ask from time to time and to discuss with a nurse or doctor. The checklist was distributed by the National Kidney Federation.

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In addition, the NHS Institute for Innovation and Improvement published *Focus on: Preparing for End Stage Renal Disease*\(^{10}\) in early 2008, providing answers to questions on all aspects of an effective clinical pathway from diagnosis of end stage renal failure, through to assessment and addition to the transplant list. The aim of the ‘Focus on’ series is to help local health communities and organisations improve the quality and value of the care they deliver.

Patient involvement in the planning of services is also improving at a personal, local and national level. In the last two years, major stakeholder conferences involving patients have been held at national and local level. Patient engagement has been achieved within kidney units, and is being facilitated by the creation of local kidney networks.

The Department of Health produced the Vascular Programme Briefing Packs\(^{11}\) to provide the 10 strategic health authorities (SHAs) with an assessment of progress, opportunities and future challenges in key areas of vascular disease, including renal disease. They provide data about renal disease from the various sources available, including the Quality and Outcomes Framework (QOF)\(^{12}\) and Hospital Episode Statistics (HES)\(^{13}\). This data can be used to facilitate implementation of the NSF.

**Summary**

Progress continues to be made in providing patients with better information and resources to support choice and a real partnership with professionals in the planning and delivery of their care. This must remain a key focus and become fully embedded across the care pathway if the best quality outcomes for people with kidney disease are to be achieved.

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12 www.dh.gov.uk/en/Healthcare/Primarycare/Primarycarecontracting/QOF/index.htm

13 www.hesonline.nhs.uk
2 Prevention, early detection and management of chronic kidney disease

National Service Framework standard/quality requirements:

**People at increased risk of developing or having undiagnosed chronic kidney disease, especially people with diabetes or hypertension, are identified, assessed and their condition managed to preserve their kidney function.**

**People with a diagnosis of chronic kidney disease receive timely, appropriate and effective investigation, treatment and follow-up to reduce the risk of progression and complications.**

Key progress to date includes:

- increased diagnosis and management of chronic kidney disease in primary care
- introduction of NICE guidance on the early identification of chronic kidney disease
- inclusion of kidney and other vascular indicators in the QOF in primary care
- production of a patient leaflet on identifying unhealthy kidneys.

CKD is thought to affect up to 1 in 8 people in England. It is a common, harmful and treatable condition, and without early diagnosis patients are subject to progressive illness and possible irreversible established renal failure, resulting in the need for transplantation, dialysis or conservative management.

**Prevention of chronic kidney disease**

Kidney disease is on the increase – it is closely linked with other conditions, including diabetes and hypertension, which have increasing prevalence. These conditions all share similar risk factors, including obesity. Incidence of CKD increases with age, which is highly significant in view of the increasing proportion of older people in our population. Also, CKD tends to be more prevalent among black and minority ethnic communities. CKD is also a risk factor for acute kidney injury.
One of the greatest challenges facing kidney services now, and over the coming years, is raising awareness about kidney disease and its prevention. It is only by understanding the effect that wider influences and risk factors, such as other diseases or modifiable lifestyle factors including obesity, have on kidney disease, that prevention and treatment will be improved.

**Change4Life**

*Change4Life* was launched in January 2009. It is a society-wide movement that encourages everyone to make changes to their diet and activity levels in order to reverse the growing trend of obesity and obesity-related illnesses. This, along with *Healthy Weight, Healthy Lives* and the NICE guidance *Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children*, demonstrate the commitment to tackling risk factors associated with kidney disease at a community level.

**Early detection and management**

Early diagnosis and good management of CKD within primary care are vital. Given the strong links between kidney disease and other diseases, NICE guidelines on CKD, diabetes, hypertension and anaemia are proving critical in prevention and management of kidney disease. In addition, the NHS Health Check programme (see box opposite) is a major initiative aimed at preventing and reducing the risk of heart disease, stroke, diabetes and kidney disease.

14  www.nhs.uk/Change4life
NHS Health Check

Phased implementation of the NHS Health Check\textsuperscript{17} programme began in early 2009. Everyone between the ages of 40 and 74, who has not already been diagnosed with one of these conditions, will be invited, once every five years, to have a check to assess their risk of heart disease, stroke, kidney disease and diabetes. They will be given support and advice to help them reduce or manage that risk.

At full roll-out this programme could detect at least 20,000 cases of diabetes or kidney disease earlier, allowing individuals to be better managed and improve their quality of life.

NHS Choices also hosts an online kidney disease self-assessment tool.\textsuperscript{18} This tool complies with NICE guidance and helps to assess an individual’s risk of kidney disease based on simple questions, including medical and drug history.

NICE guidelines, \textit{Early identification and management of chronic kidney disease in adults in primary and secondary care},\textsuperscript{19} published in 2008 are proving a vital tool for healthcare professionals through provision of definitive, evidence-based advice on optimum treatment and care of patients. The guidelines set out how best to identify those at risk of progression and serious complications, and outline how to manage their care.

We have seen real progress in the diagnosis and early management of kidney disease over the last five years, and it is an area to be proud of and to continue to build on. The NHS is a world leader in the area of kidney disease prevention and early detection. This has come about following the standardisation of tests for kidney disease using estimated Glomerular Filtration Rate (eGFR) and the introduction of the NICE guidelines in 2008, which include; guidance on proteinuria testing.

Before 2006, CKD was rarely identified in primary care. The introduction of the QOF, with GPs rewarded partly based on how well they manage patients with kidney disease, has helped to ensure better diagnosis in primary care. The introduction of the QOF has seen a dramatic increase in the number of patients being diagnosed with CKD, who previously may not have been identified.

\textsuperscript{17} www.nhs.uk/planners/nhshealthcheck/Pages/NHSHealthCheck.aspx  
\textsuperscript{18} www.nhs.uk/Tools/Pages/Kidneydisease.aspx?Tag=Lifestyle+checks  
In the year 2007/08, the number of adults identified as having CKD increased by 24%, with a further increase of 10% in 2008/09. However, as the figure below shows, further increases in detection are required when comparison is made to the estimated prevalence of CKD.

**England: CKD stages 3–5 QOF prevalence aged 18 yrs plus, 2006/7 to 2008/9, and CKD estimated prevalence 2006**

With the addition of CKD into the QOF, there has been much demand for education for GPs and practice nurses. The Department of Health and the CKD Forum of the British Renal Society initiated an online learning resource for CKD in primary care\(^\text{20}\) to develop understanding of the principles behind the NICE guidelines and the QOF. This resource provides authoritative and up-to-date education tailored to the needs of the primary care multidisciplinary team.

A three-year quality improvement programme is being co-ordinated by Kidney Research UK, St George’s, University of London and the University Hospitals of Leicester NHS Trust. The overall aim is to develop, implement and evaluate a range of quality improvement interventions in CKD in primary care and deliver the evidence base to enhance the quality of care and treatment of CKD. Audit work in over 130 practices is taking place; and alongside is the development and evaluation of a patient empowerment programme and a ‘care bundle’\(^\text{21}\) approach to enhance CKD management.

\(^{20}\) [www.ckdonline.org/](http://www.ckdonline.org/)

\(^{21}\) Collection of evidence-based interventions
The Department of Health, in association with the National Kidney Federation, and the British Renal Society, has produced an information leaflet for patients who have been offered a test for proteinuria. *Identifying unhealthy kidneys: what do I need to know about proteinuria?* This leaflet includes information about the causes of proteinuria, the tests and the implications of managing unhealthy kidneys together with diabetes and high blood pressure.

Building a greater understanding of CKD at primary care level and ensuring that care is integrated between primary and secondary organisations is one of the key improvements brought about by the NSF with more effective sharing of information between organisations across the care pathway. In Middlesbrough, for example, nephrologists are offering an email helpline for GPs with all queries answered within 24 hours. Another example of innovation in this area is the development of e-consultations in Bradford and Airedale (see box).

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Electronic consultation (e-consultation) in Bradford and Airedale

Primary care teams in England have recently assumed greater responsibility for the management of CKD. Improvements in the detection of CKD have led to a greater demand for specialist renal services. The availability to nephrologists of the clinical information contained in primary care electronic health records is likely to enhance communication, hence supporting the management of patients with relatively mild and non-progressive CKD in the community, allowing specialist resources to be directed towards supporting patients with more complex needs.

Dr John Connolly (General Practitioner, Bradford and Airedale Primary Care Trust and Primary Care Lead for Technology, NHS Yorkshire and the Humber) and Dr John Stoves (Consultant in Nephrology, Bradford Teaching Hospitals NHS Foundation Trust) have explored the use of e-consultation to support the ongoing management of patients with mild to moderate CKD in primary care, thus avoiding the need for initial assessment in a hospital clinic.

The Chronic Kidney Disease Electronic Advisory Service (CKDEAS) was developed using a centralised primary care IT system. The service allows GPs to send electronic referrals and share patients’ electronic health records with a renal specialist. GPs use local e-guidance to request an e-consultation. The renal specialist is able to view important clinical details in the electronic health record, such as patient co-morbidities, medication history, lifestyle factors and previous communications from other specialists. A decision is then made as to whether a patient should be referred to clinic, undergo tests or interventions in the primary care setting, or continue to be monitored and treated by the primary care team.

An evaluation of the service has confirmed that, in selected patients, e-consultation is a feasible alternative to hospital referral. Dr Stoves commented: “Many patients don’t need to attend a hospital clinic. e-consultation is an excellent way of supporting their care in the community. I can access a wealth of clinical information and this allows me to make a detailed clinical assessment and give timely specialist advice. GPs value the educational element of the service, and they feel better able to manage uncomplicated CKD.” Dr Connolly added: “GPs appreciate getting specialist advice about the management of borderline cases. This pathway makes efficient use of NHS resources and improves patient experience simultaneously.”

The potential environmental benefits of e-consultation have been recognised by the Greener Healthcare Campaign. Regional initiatives supported by Yorkshire and the Humber SHA may lead to formal commissioning of such services in the future.
Summary

There has been a step-change improvement in the recognition of CKD in primary care but there is still work to be done. Although many more patients are now identified as having CKD, not all are receiving best-practice care – for example having their blood pressure controlled. We know from the improved collection of prevalence data that there is still considerable variance in detection rates between practices within each primary care trust area.

Appropriate support must continue to be given to ensure that those most at risk are diagnosed and offered the necessary care and management across the whole of the NHS, to reap the full benefits of the dramatic improvements in detection.
3 Preparation, choice and dialysis access surgery

National Service Framework standard/quality requirements:

All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.

Key progress to date includes:

- a decrease in the number of people presenting late with established renal failure
- a decrease in rates of methicillin-resistant *Staphylococcus aureus* (MRSA) infections in kidney patients
- development of an 18-week commissioning pathway for CKD
- audit of vascular access.

Patient choices should be available from diagnosis to end-of-life care, and this is particularly important during the time before dialysis. Patients with established renal failure should feel empowered to choose the type of renal replacement therapy that is best for their own personal circumstances, and their care plan should reflect this. Whether dialysis, transplantation or conservative management is chosen, quality of care is achieved when patients and their families understand the options, and how each choice will affect their quality of life, and ultimately length of life.

Data collected by the UK Renal Registry\(^\text{23}\) shows that there has been a sustained reduction in late referrals over the period 2002–07, more marked over the last two years, and also an increase in the percentage of patients referred over 12 months before dialysis initiation.
Timely preparation and informed choices

In order for patients to make informed choices, it remains critical that they have access to easy-to-understand, treatment-specific, comparable information on safety, experiences and patient satisfaction. The challenge is to ensure that suitable information is available for all audiences. Information is available online via NHS Choices on the different treatment modalities available and the 18-week commissioning pathway\(^\text{24}\) clearly sets out the need for timely information, education and review.

Renal PatientView\(^\text{25}\)

Liaison with different members of the kidney multidisciplinary team is becoming standard, and IT is now being used more widely to support patients. More than 11,000 patients are now registered with Renal PatientView and this number continues to grow each month. Renal PatientView is an award-winning initiative that uses technology to give patients rapid access to their blood results, clinic letters and information about their diagnosis and treatment, all via a secure internet login. This technology offers an opportunity for greater patient involvement throughout the care pathway. Renal PatientView was developed by the renal community in conjunction with the Renal Association and the Renal Information Exchange Group.

The year before renal replacement therapy

In 2006/07, Phase II of the Renal Action Learning Set programme, sponsored by the Department of Health, included two action learning sets from Cambridge (Addenbrooke’s Hospital) and North Yorkshire (York Hospital). Their learning sets focused on why patients may be referred with insufficient time for adequate preparation and how this could be improved. The learning and good practice examples are captured in *Driving Service Improvement through Patient Focus: Report of the Phase II Renal Action Learning Sets 2006–2007.*\(^\text{26}\)

Kidney Research UK is undertaking research specifically focused on the dialysis population to explore the impact of patient choice in relation to the types of dialysis treatment and its impact on the patient’s ability to cope with their treatment. In its third year, the Broadening Options for Long-term Dialysis in the Elderly (BOLDE)\(^\text{27}\) research study is already showing promising primary outcomes; for example, there is a difference in perceived mental well-being


\(^{25}\) [www.renalpatientview.org](http://www.renalpatientview.org)


\(^{27}\) [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)
between peritoneal dialysis patients and haemodialysis patients. A publication is due out shortly on the initial results.

**Transfer from paediatric to adult services**

Transfer from paediatric to adult services is an area that needs improving. Getting transitional care right for young people with CKD is crucial. It requires recognition of the complexity of transition, and the change in culture between paediatric centres and adult renal services. If not properly addressed, it can lead to non-concordance with medication or treatment regimes, with significant clinical and psychological consequences.

The Renal Action Learning Set programme included two action learning sets on transitions from London and Birmingham. They identified that transition was a process that requires thought, time and resources. Planning should be over a period of time, involving both paediatric and adult teams, rather than simply arranging a transfer date. Their learning and good practice examples are captured in *Driving Service Improvement through Patient Focus: Report of the Phase II Renal Action Learning Sets 2006–2007*.

In July the British Association for Paediatric Nephrology and the Renal Association published a transition strategy, which considers the organisation of services, components of transition and workforce requirements. NHS Kidney Care is looking at ways to support young adults with kidney disease and how to sustain and spread good practice. It is in the process of asking for expressions of interest from renal networks to fund a key worker for 18 months. The key worker’s role will be not only to create links with the different services, but also to look at the geographic placing of services and inequalities, especially for minorities and disabled patients.

**Dialysis access surgery**

One of the principal aspects of pre-dialysis care for patients is the timely formation of vascular access for patients planning to receive haemodialysis, or the appropriate placement of a catheter for peritoneal dialysis.

For haemodialysis patients, surgery to create an arteriovenous fistula provides the best long-term vascular access with the fewest complications. Arteriovenous fistulas take between one and two months to develop and time must be built into care plans for possible revision work. Achieving best practice in every case is challenging given surgical priorities and the need to establish permanent access six months prior to starting dialysis.

For peritoneal dialysis, patients must always be involved in decisions about the positioning of the catheter and it should be inserted in good time before the start of dialysis.

28  www.bapn.org/
29  www.renal.org/
Audit of vascular access

The NHS Information Centre for health and social care has been commissioned to conduct an audit of vascular access over three years (2009–11). The key aim is to find out whether the proportion of patients starting haemodialysis with functioning permanent access meets the Renal Association and Vascular Society guidelines for permanent vascular access, which recommend that 80% of patients commence dialysis with appropriate access and what the healthcare-associated infection rates associated with vascular access are in the maintenance haemodialysis population and how this compares with the national average and best performance.

It is through learning from the findings of such audits that we will be able to improve services for patients and ensure that access surgery is appropriate and providing effective and safe care.

Minimising infections

As well as providing timely and appropriate access for dialysis, the additional key issues surrounding dialysis access surgery include infection, thrombosis and stenosis (narrowing of the arteries). Patients receiving haemodialysis for kidney failure are at increased risk of infection, particularly if they do not have appropriate vascular access. The evidence suggests that the risk of MRSA bacteraemia is eight times higher for patients with a catheter compared with a patient receiving dialysis via an intravenous fistula. MRSA bacteraemia may be a major contributor to the higher mortality of those patients who present late with end-stage renal failure.

Between April 2007 and March 2008, 188 MRSA bacteraemia cases were reported in patients receiving dialysis, representing 4.2% of all MRSA bacteraemia cases reported during this period. Where data on access was available, the majority of patients suffering from MRSA bacteraemia had a venous catheter, or had used one in the previous 28 days.

The Health Protection Agency’s national surveillance system for the collection of data on MRSA bacteraemia – the Mandatory Enhanced Surveillance System (MESS) – has been adapted following a pilot project in eight renal units and associated satellites in 2006. This supports collection of data on those patients who develop MRSA bacteraemia and who are on renal replacement therapy and will help audit and improve services. Data from the 2008 UK Renal Registry annual report on reported MRSA episodes shows a 62% reduction in MRSA bacteraemia rates among dialysis patients in England since 2004.

30  www.ic.nhs.uk/services/national-clinical-audit-support-programme-ncasp/kidney-care/vascular-access
31  www.vascularsociety.org.uk/home.html
32  www.hpa.org.uk/web/HPAweb&Page&HPAwebAutoListName/Page/1191942169773
Summary

Progress continues to be shown in preparing patients, both through the provision of information resources and vascular access for dialysis patients, geared to optimise outcomes for people in need of renal replacement therapy. Good results have been shown in driving down the number of hospital-acquired infections affecting kidney patients. A continued effort is required to implement timely best practice in preparing all patients for renal replacement therapy (RRT), both to minimise complications of their condition and to maximise choice.
4 Dialysis

National Service Framework standard/quality requirement:

Renal services are to ensure the delivery of high-quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.

Key progress to date includes:

- expansion of haemodialysis capacity
- development of the MORRIS capacity planning tool for renal replacement therapy
- development of a peritoneal dialysis commissioning specification
- development and mandating of the National Renal Dataset
- completion of the first national transport audit.

Demand for RRT, and especially dialysis, is on an upward trend. This is due in part to the ageing population, together with the increasing incidence of diabetes and better survival rates for patients on RRT. Overall demand for renal replacement therapy rose by 4% per annum between 2002 and 2007.

Capacity and choice

Many factors influence dialysis treatment choice and options, including geography, local population density, age distribution, ethnic composition and the social deprivation index of the local population. In addition, local resources and professional understanding and experience of dialysis options affect availabilities of modalities.

Given its significance within the NHS, dialysis capacity was brought to the attention of the NHS leadership and highlighted in the 2008/09 operating framework\(^{34}\) as an area that primary care trusts and specialised commissioning groups will wish to consider. NHS Kidney Care is working closely with specialised

commissioning groups to review dialysis capacity. This will include ensuring that expansion plans are based on sound assessment of local need and are comprised of a balanced portfolio of treatment options.

A Payment by Results\(^{35}\) (PbR) project group has been set up to review the key issues in relation to the quality of costing, and the recommendations for national tariffs, in kidney services to encourage best practice. Sixteen renal units have taken part in supplying detailed reference cost data, which has been used to inform the production of a checklist to ensure comprehensive and consistent returns from all 52 trusts across England that have a kidney service. The aim is to produce a best practice tariff and to bring dialysis within the scope of PbR.

**Model for optimising renal replacement investment and services (MORRIS)**

In order to plan effectively for the growing demand for renal replacement therapy, we must gain an understanding of the complex relationships that exist in end stage renal disease, including the availability of organs for transplantation.

MORRIS is a model commissioned and built by the Department of Health to predict the cost and volume of renal replacement therapy, at both a national and local level, over a 10-year time horizon.

MORRIS represents the alternative treatment modalities of RRT and tracks over time the number of adults commencing RRT, moving between modalities (including receiving kidney transplants) and dying.

Testing of the basic model using national assumptions, including transplant rates and mortality rates, took place in the autumn of 2009. It will be used to generate an annually updated national forecast of demand. The current prevalence rate shows a 4\% growth on last year, in line with previous year on year 4\% annual growth over the past decade. Running the projection based on current assumptions produces the results shown in the graph opposite, which suggest the high levels of growth seen over the past decade will begin to slow over the next ten years.

The intention is that MORRIS will be available to commissioners to support local planning, using their local assumptions.

Actual and estimated number of total renal replacement patients
2001–2017 – England

Haemodialysis

The latest unpublished figures from the UK Renal Registry show that in 2008 there were 17,349 patients on haemodialysis and 3,564 patients on peritoneal dialysis in England. Fifty-two acute trusts now offer haemodialysis, and, together with satellite units, the service is now provided on 213 sites across England.

The Department of Health has facilitated the Independent Sector Treatment Centre electives programme to provide expanded haemodialysis capacity in new facilities, such as those facilities in Southport, Bassetlaw and Bridlington. It is expected that this scheme will deliver capacity for approximately 178 additional haemodialysis stations over a seven-year period.

The increasing number of satellite units means that many patients are now beginning to benefit from dialysis closer to home. However, with the dialysis population increasing, full consideration of all options, including in particular dialysis at home, is needed to match availability with patient choice.

The Ashfurlong Dialysis Centre was the first unit in England to be based in a primary care setting, and was ‘Highly Recommended’ in the Health Service Journal awards in 2006.
Haemodialysis in primary care premises – a potential solution: the Ashfurlong Dialysis Centre

This is a joint venture between primary and secondary care providers.

The Ashfurlong Dialysis Centre houses five stations and is open six days a week. Up to 25 patients can be treated three times a week. The unit is nurse led, and supported by specially trained GPs from within the practice who hold review clinics fortnightly, and multidisciplinary meetings monthly. Further support is available from the consultants based at Heart of England Foundation Trust, if required.

Approval for the increased revenue costs were obtained from the pan-Birmingham, Staffordshire and Shropshire specialised commissioning groups. Approval was granted because this project was likely to deliver additional capacity at low capital cost, with a significant improvement in patient experience.

Outcomes are monitored monthly by audit against the Renal Association standards for dialysis provision. Overall, the performance against these standards has improved significantly for the patients who have transferred to Ashfurlong from larger units.

Experience at Ashfurlong Dialysis Centre has shown that haemodialysis can be provided in primary care, under the supervision of GPs, safely and effectively. Patients like the location and environment, and outcomes are good. At the Ashfurlong Dialysis Centre they have found this to be a capital-efficient method of providing haemodialysis capacity very quickly, with only a modest increase in revenue costs.

The majority of haemodialysis patients dialyse in hospital, with home haemodialysis accounting for just 2% of dialysis patients. The percentage of dialysis patients receiving home haemodialysis varied greatly, from zero in 20 centres to greater than 5% of all dialysis activity in six centres during 2008, and some have since improved on this position.

Action is still needed to close the gap between the numbers of patients who currently choose self-care, and the suggestion by NICE that up to 15% of chronic haemodialysis patients, where clinically appropriate, may be expected to choose home haemodialysis. While self-care may not be suitable for everyone, it can offer real benefits, including less hospitalisation, reduced medication and greater independence.

Dialysis away from base

The NSF emphasised that, for reasons such as work, education, holidays and family visits, it is important that patients are able to dialyse away from home.
The issue of dialysis away from home (now referred to as dialysis away from base (DAFB)) is a continuing problem.

The Department of Health issued guidance in June 2007, *Temporary haemodialysis away from home: funding arrangements for NHS patients resident in England*,[36] highlighting the need for trusts to make provision for DAFB and to develop local policies to manage this. However, progress in implementing this has been slow.

The Department of Health set up a working group in 2008, led by Bob Dunn, Regional Advocate for the National Kidney Federation, to look specifically at ways to improve a patient's experience of DAFB. Following the report from the working group, the Department of Health and NHS Kidney Care are currently working with specialised renal commissioners to identify ways in which we can improve the availability of dialysis for patients away from base.

The introduction of a standard tariff for dialysis, initially on a non-mandatory basis, will help to reduce the variations in the charges in England.

**Peritoneal dialysis**

Assisted peritoneal dialysis (PD) can offer an alternative for kidney patients, particularly those who are elderly or frail, whose only other options may be hospital haemodialysis or conservative management.

There is wide variation around the country, both in the number of patients on PD and in the types of PD available. It has been shown that 50% of patients given free choice will choose PD. A commissioning specification for PD[37] has been developed by NHS Kidney Care that has been written for patients, commissioners and providers of renal services. All recommendations are derived from published evidence, current best practice and consultation with stakeholders.

This specification provides a comprehensive guide to best practice PD, with outcome measures applicable at each stage. This will be a vital tool in broadening the delivery of high-quality care, driving forward service improvement by offering greater choice and flexibility for patients across England.

**National Renal Dataset**

The National Renal Dataset[38] (ROCR/OR/0192/001) has been approved by the Information Standards Board for Health and Social Care as a Full Operational Information Standard to monitor implementation of the NSF. The dataset

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is mandated for collection by the UK Renal Registry\(^\text{39}\) and NHS Blood and Transplant\(^\text{40}\). Implementation of the dataset is mandated in two phases:

- collection of 693 data items from May 2009 and
- collection of an additional 188 data items from April 2011.

**Transport**

Transport remains a major issue for the majority of patients receiving haemodialysis, with those on hospital-based dialysis making on average 312 journeys to and from their dialysis units every year.

In 2006, the Department of Health issued revised and updated guidance, *Income generation car parking charges best practice for implementation*,\(^\text{41}\) with a strong recommendation that trusts consider the provision of subsidised or free car parking for those patients attending regularly for ongoing treatment.

An example of an innovative transport solution can be found at Birmingham Children’s Hospital.

### Transport innovation in Birmingham

A good example of innovative solutions for renal transport is Birmingham Children’s Hospital’s option for parents to drive themselves, with a guaranteed free parking space and reimbursement for fuel. In the three years that the scheme has been running, the trust calculates that it has saved more than £110,000 on hospital transport costs.

In order to gather evidence of areas of particular transport challenges and to ensure appropriate good practice is commissioned, the Healthcare Quality Improvement Partnership has produced, via the NHS Information Centre, high-level results from a transport survey undertaken in October this year. Its first annual report, *National Kidney Care Audit, Patient Transport Survey Report*,\(^\text{42}\) made eight clear recommendations including a recommendation that no patient should have to pay for transport to and from dialysis units.

A second annual report will take the form of extended advice and good practice given to kidney units and commissioners, and a third report will assess returns provided by all of the kidney units during October and November 2010.

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39 www.renalreg.com/
40 www.nhsbt.nhs.uk/
Summary

If patients are to have real choice in their preferred mode of dialysis, and if supply is to keep pace with demand, there must be a continued focus on more strategic planning of haemodialysis, and increased options for DAFB. The provision of appropriate dialysis, and dialysis that meets the personal choice of every patient, including to dialyse at home and away from base, remains one of the major challenges facing the renal community today, over the next five years and beyond.
NHS Kidney Care was set up in 2008 and works closely with the Department of Health to improve renal services. This chapter details the organisation’s role and achievements to date.

The role of NHS Kidney Care

NHS Kidney Care works to enable the kidney community to build a kidney service that is fit for the 21st century, which offers a consistent, high standard of care across the country.

Programme Director, Beverley Matthews, heads up a team of 12 based across England, and works alongside the National Clinical Director for Kidney Care and the renal policy team at the Department of Health.

NHS Kidney Care has now been fully operational for a year, and is making real progress in facilitating the successful implementation of the NSF for renal services.

NHS kidney organisation chart
NHS Kidney Care – ‘Better Kidney Care for All’

Kidney Care

National Programme Director

PA to Programme Director

National Programme Lead

National Programme Lead

National Programme Lead

National Programme Lead
### What we do

NHS Kidney Care has clear objectives that enable us to deliver the standards and quality requirements outlined within the NSF for Renal Services. These objectives fall within the steps of the kidney care pathway:

- Primary prevention
- Kidney disease in primary care
- Advanced kidney disease
- Kidney transplantation
- In-centre dialysis
- Self-care dialysis
- Renal replacement therapies
- Conservative kidney care
- Acute kidney Injury

### Key achievements

- Development of SHA-wide kidney care networks across England
- Support of the implementation of effective care planning through the development of a personalised care plan for all kidney patients
- Development and publication of *End of Life Care in Advanced Kidney Disease: A framework for implementation*[^43]
- Development of robust Reference Costs for kidney dialysis to inform the creation of a national tariff
- Development of a specification for the commissioning of Peritoneal Dialysis
- Creation of an Autonomous Kidney Services toolkit
- Funding of a Specialist Registrar to work on green nephrology

[^43]: [www.kidneycare.nhs.uk/?sID=2&aID=92](http://www.kidneycare.nhs.uk/?sID=2&aID=92)
Projects in progress

NHS Kidney Care works with clinical teams and commissioners of kidney care to look at the services they offer to patients with kidney disease.

Current projects include:

- **End-of-life care in advanced kidney disease**
  
  Kidney communities are acting as development sites to create care pathways and to support staff to deliver high-quality end-of-life care by actioning *End of Life Care in Advanced Kidney Disease: A Framework for Implementation*.

- **Supporting young adults with CKD**
  
  Kidney care networks are developing and will deliver new services to support young adults with kidney disease, with the aim of establishing examples of best practice that can be used to help young adults with other long-term conditions.

For more information, visit [www.kidncare.nhs.uk](http://www.kidncare.nhs.uk), or email [beverley.matthews@kidncare.nhs.uk](mailto:beverley.matthews@kidncare.nhs.uk).
6 Transplantation

National Service Framework standard/quality requirement:

All children, young people and adults likely to benefit from a kidney transplant are to receive a high-quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Key progress to date includes:

- increase in organ donation rates, particularly from living donors
- increase in rates of pre-emptive transplant
- development of an 18-week live donor commissioning pathway.

Organ transplantation is one of medicine’s great success stories. We know that a successful kidney transplant is the most clinically effective and cost-effective treatment for many patients with established renal failure. Kidney transplantation is associated with lower mortality rates, higher quality of life and lower costs than either haemodialysis or PD. However, every year many patients still die while waiting for a kidney or other organ transplant.

There is also an urgent need to address health inequalities. People of Asian or African–Caribbean descent are three to four times more likely than white people to develop end-stage renal failure and need a kidney transplant. However, they are faced with a much smaller number of potentially matching donors.

Encouraging organ donation

The Government is strongly supporting the need to expand organ donation through implementation of the work of the Organ Donation Taskforce, established in 2006, with representatives from the transplant community, NHS Blood and Transplant, and the voluntary sector. The Taskforce has worked to identify barriers to organ donation and address issues affecting donation rates, and has subsequently taken action to increase organ donation.
Organ Donation Taskforce

A report by the Taskforce in January 2008, *Organs for Transplants: A report from the Organ Donation Taskforce*, offered 14 recommendations for the way forward. These recommendations were accepted as a focus for action over the next five years, aiming to achieve a 50% increase in donation, which equates to 700 more kidney transplants.

Significant progress has already been made, although dialysis remains the most common treatment option.

The first annual report of the Organ Donation Taskforce Implementation Programme highlights the progress that has been made in the first year of the Implementation Programme, particularly the changes in structures and arrangements in the NHS, with the move to a centrally managed, and enlarged, network of donor transplant co-ordinators and the appointment of clinical leads for organ donation within hospital trusts.

These changes, coupled with greater public awareness of organ donation, have led to:

- an increase of 11% in deceased donor rates
- an increase of 12% in living donation
- an increase of 6.5% in the number of people on the NHS Organ Donor Register, taking the total to 16.3 million.

In 2008/09, £16.5 million was allocated to the NHS for organ donation and transplantation, with a further £26.5 million allocated for 2009/10. An additional £500,000 was provided from the Department of Health to support implementation programmes and fund national events, including the UK Transplant Games and National Transplant Week.

Increasing transplantation

The total number of deceased kidney donors rose to 859 in 2008/09 from 789 in 2007/08, and the number of transplants increased from 1,453 to 1,570. The number of non-heart-beating kidney donors increased to 275 from 195 in 2007/08, and the number of transplants from such donors increased by 41% to 474.

Living donor kidney transplants are increasing and now represent more than one in three of all kidney transplants. There were 589 in 2005/06, 690 in 2006/07, 831 in 2007/08 and 927 in 2008/09. There is, however, still much work to be done on raising awareness of living donation, particularly among the black population.

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and minority ethnic population which makes up 23% of the kidney transplant waiting list, while representing only 8% of the population.

Extended options for living donation is an important area of progress, and over the last five years there has been much progress, moving away from the situation where most transplants being performed are between close family members (blood relatives). Now, increasingly, extended family individuals (non-blood relatives), spouses, partners and friends are coming forward to donate, and these transplants are equally successful.

In 2008 an 18-week commissioning pathway for living donor transplantation was developed. This pathway plots the patient journey, from a volunteer being identified, through phases of clinical assessment, to rehabilitation after a successful transplant operation.

Bristol Children’s Hospital and Southmead renal unit have been using webcams so that patients can keep in touch with each other.

Living donor transplants in children are usually from a parent or other close family member, so the patient experience can be particularly stressful, with two members of the same family undergoing surgery in a very small time frame. The donor could be the main carer for the child, and as the surgery often takes place in different locations, communication between patients is difficult, visiting may be impossible in the first few days, and both parent and child are often very worried about each other.

Using webcams to keep in touch is a simple innovation that Bristol Children’s Hospital have introduced. They have found that it can make a huge difference to the patient experience. All rooms at the hospital have internet access, so all that was required was the purchase of a laptop for the renal unit at Southmead to make this work.

Following a recent live donor transplant from mother to son, the mother was able to see and talk to her son on the evening of the day of the operation, and they both found this extremely reassuring. This means of communication was a great support to all concerned until the mother was able to come and visit a few days later.

NHS Kidney Care recently sent out questionnaires to gain an overview of current capacity and demand for renal transplantation services. This was to ensure that capacity within the renal transplant centres is sufficient to meet the rise in demand expected from the Organ Donation Taskforce Report (ODTR). The questionnaire was sent to the specialised commissioning groups (SCGs), kidney care networks and provider trusts that have a transplanting centre.
The responses pointed to the need for further partnership work to bring together commissioners and providers for each SCG area, and led to the following four recommendations:

- Kidney care networks should bring specialised commissioners and provider trusts together in each region, establishing working groups to map out capacity issues and develop five-year action plans.

- Specialised commissioners (with responsibility for kidney care) should provide leadership locally to the development of the five-year plans that are agreed, and ensure investments for 2010/11 and beyond are identified and prioritised with their SCGs/primary care trusts for consideration and inclusion as appropriate into investment plans.

- NHS Kidney Care should co-ordinate a national group, with one representative from each of the working groups, to ensure national consistency and enable cross-boundary issues to be addressed.

- The Organ Donation Taskforce Programme Delivery Board should provide resources for dedicated project management through the National Specialised Commissioning Team.

The recommendations are being taken forward on a voluntary and collaborative basis through the Specialised Commissioners for Kidney Care Forum.

**Pre-emptive transplantation**

A marker of good practice in transplantation is pre-emptive transplantation, particularly specifying that patients are placed on the national transplant list within six months of their anticipated dialysis start date, if clinically appropriate. Currently, between 10% and 40% of each transplant centre’s list is made up of pre-emptive patients, and figures are increasing locally year on year.

In 2008/09, 17% of adult transplants were carried out in pre-dialysis patients. Pre-emptive transplants accounted for 25% of all paediatric kidney transplants.

It remains essential to provide clear and culturally appropriate information to recipients and donors at all stages of their transplant if patient choice is to be based on sound information. In recent years we have seen much progress in this area. For example, NHS Blood and Transplant offers nationally available patient-focused advice and educational material, as do many local kidney units and patient organisations.

Local initiatives include the provision of patient leaflets, together with transplant patient information meetings for those considering living donation. These local meetings often take place at the hospital during weekends, to allow donors, recipients and their families to talk to surgeons, clinicians, counsellors and transplant nurses, as well as post-transplant recipients and donors, about the experience.
Summary

Implementation of the recommendations of the Organ Donor Taskforce is already leading to rising numbers of donors and transplants, and several promising initiatives are showing good results. However, sustained progress will be needed to close the gap between supply and rising demand so that as many patients as possible are able to benefit from a kidney transplant. The collection of appropriate data from transplant centres for the UK Renal Registry and NHS Blood and Transplant remains critical for comparative and audit purposes.
7 Acute kidney injury (acute renal failure)

National Service Framework standard/quality requirement:

People at risk of, or suffering from, acute renal failure are identified promptly, with hospital services delivering high-quality, clinically appropriate care in partnership with specialised renal teams.

Key progress to date includes:

- Action learning sets to tackle acute kidney injury
- Acute Kidney Injury Care Initiative (AKICI) conference
- NICE guidance: *Acutely ill patients in hospital: Recognition of and response to acute illness in adults in hospital.*

Acute kidney injury (AKI) (acute renal failure) occurs when there is a functional deterioration or structural change in the kidney. AKI can occur in a variety of settings but is most common in acutely unwell patients in hospital. These patients are often older adults with co-existing illness, particularly underlying CKD or cardio-vascular disease, or those receiving treatments with potentially nephrotoxic drugs. While many patients will make a complete recovery from AKI, others may be left with CKD which may progress to established renal failure.

**Early recognition and prevention of acute kidney injury**

AKI may affect up to 1 in 5 people admitted to hospital. The degree of AKI varies considerably but is most likely in acutely unwell people. Most episodes of AKI occurring in patients where it is a complication of another condition should be appropriately managed by acute physicians. Patients with primary renal diseases, such as acute nephritis, or those who may require renal replacement therapy, need prompt specialist renal input. Close collaboration between kidney and non-kidney departments is vital.

In 2007 NICE produced clinical guidelines for the recognition and treatment of acutely unwell patients in hospital. These guidelines should assist clinicians in recognising deterioration in patients, and provide them with guidance on how to treat these patients appropriately. NICE clinical guidelines on preoperative tests,

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The use of routine preoperative tests for elective surgery,\(^{46}\) published in 2003, state that those who undergo elective surgery should always be assessed pre-operatively to prevent avoidable cases of AKI.

However, evidence suggests that up to 30% of cases of AKI are preventable. The good practice highlighted by the NICE guidance, if implemented fully, should reduce these numbers significantly. Basic clinical care should identify those at risk, and simple investigations can identify AKI at an early stage when treatment is likely to be most effective. These investigations should establish the severity and cause of the kidney dysfunction and help direct therapy to the underlying condition, such as infection, heart failure or drug-induced injury.

Early recognition, together with appropriate and timely management of AKI, is critical if patients are to avoid progression to dialysis and, worse still, multi-organ failure. It has been estimated that 5–20% of critically ill patients develop AKI and the mortality rates are high, especially if renal replacement therapy is required.

**National Confidential Enquiry into Patient Outcome and Death – Adding Insult to Injury: A review of the care of patients who died in hospital with a primary diagnosis of acute kidney injury (acute renal failure)**

The need to tackle AKI was reinforced by the publication of a National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report in June 2009.\(^{47}\) The key findings and recommendations highlighted by the report show that there is much work to be done to ensure that AKI is recognised and prevented.

The key findings of the advisers who reviewed the cases were that:

- only 50% of AKI care was considered good
- there was an unacceptable delay in recognising post-admission AKI in 43% of patients
- 33% of patients had inadequate investigations. The omissions were basic clinical examination and simple laboratory tests
- there was poor assessment of risk factors for AKI
- 20% of post-admission AKI was both predictable and avoidable.

These findings cut across different services and all specialties, including acute medicine and nephrology.

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A multidisciplinary approach

An AKICI conference, convened by NHS Kidney Care, was held at the Royal College of Physicians on 18 March 2009. Representatives from many specialist communities from around the UK were invited to share their own perspectives of AKI and how it impacts on their specialty.

The aims of the conference were for delegates to work collaboratively and consider a range of key issues, including how to work towards a consensus definition for AKI. Improvement in the treatment of AKI has been hindered by the lack of a uniformly accepted definition and a lack of suitably sensitive biomarkers for AKI.

The Department of Health held a workshop in October 2009 with all key stakeholders. The aim was to identify the action that needs to be taken, by when and by whom, to best implement the recommendations from the NCEPOD report.

The Department of Health is drawing up an action plan in response to the recommendations made by NCEPOD. The Medical Director, Sir Bruce Keogh, has taken a special interest in ensuring that services improve, and the National Clinical Director for Kidney Care has been working with SHA medical directors to ensure that appropriate action is taken.

In addition to this, NICE is considering a proposal to develop a clinical guideline specifically addressing the prevention, detection and management of AKI. This would build on the guideline for the recognition and treatment of acutely unwell patients in hospital, and would be specific to patients suffering from AKI. It would require improvements in training undergraduates and postgraduates to prevent, detect and manage AKI. This would address many of the issues raised in the NCEPOD report.

Summary

Prevention and treatment of AKI needs to be a core competency for all clinical staff, wherever they are working and whatever their profession or specialty. To improve AKI identification, management and outcomes, a systematic approach is needed. This would ensure that the possibility of AKI is considered in all acutely unwell patients, that simple basic clinical care is always delivered, and that a co-ordinated approach to AKI management is integrated into the safety and quality culture of local NHS organisations.
8 End-of-life care

National Service Framework standard/quality requirement:

People with established renal failure receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences.

Key progress to date includes:

- publication of *End of Life Care in Advanced Kidney Disease: A Framework for Implementation*
- prescribing guidelines to ensure best practice in the care of kidney patients
- implementation of the Liverpool Care Pathway for the Dying Patient.

The NSF for Renal Services was the first national framework to talk about death and dying. End-of-life care continues to be a critical area of focus in kidney services. It concerns those who decide not to undergo dialysis; those who choose to withdraw from dialysis after a period of treatment; and those who are coming to the end of their lives while continuing dialysis.

Personal attitudes to death and dying are influenced by many factors, including age, religion and culture, and kidney teams must acknowledge these influences and provide the necessary patient-centred assessments and high-quality care sensitive to every individual’s needs. Increasingly, this involves working across specialties and empowering both the patient and the multidisciplinary team with end-of-life care tools.

A strategic approach

In July 2008, the Department of Health published the *End of Life Care Strategy: Promoting high quality care for all adults at the end of life.*48 To support the strategy, the Government has made available £286 million of new funds for the

period to 2011. The strategy included examples of good practice in the area of kidney disease.

National guidelines and initiatives such as the Liverpool Care Pathway for the Dying Patient are being linked more closely with kidney services, and we are seeing more sharing of good practice between units and improvement in quality end-of-life care in many centres. In addition, kidney units are adopting and customising generic tools created for other disease areas, such as the patient-held Priorities of Care document that records personal thoughts and choices about end-of-life care and best practice guidance for cancer patients, and the Gold Standards Framework, which supports more patient control and choice in the community.

### Liverpool Care Pathway for the Dying Patient

The Liverpool Care Pathway for the Dying Patient offers the gold standard in end-of-life care and provides an evidence-based framework for the delivery of appropriate care for patients in the last days and hours of life. Specialist palliative care teams are now training renal teams on the 10-step implementation programme involving delivery of personal care that focuses on the physical, psychological and spiritual comfort of patients.

Prescribing guidelines, *Liverpool Care Pathway (LCP) Guidelines for LCP Drug Prescribing in Advanced Chronic Kidney Disease,* that inform best practice in the care of kidney patients during the last weeks or days of their lives were published in 2008. The guidelines were developed by an expert project group, overseen by the Liverpool Care Pathway Renal Steering Group, and have been endorsed by the Renal Association and the British Renal Society. This document provides clear guidance and advice on medicines management and the control of distressing symptoms. This will help providers of palliative care to respect the wishes of patient and carers in the last weeks and days of life.

### Support for patients, carers and clinicians

In 2008, a Department of Health renal workshop involving patients, carers and clinicians generated themes to focus attention on end-of-life care. Positive outcomes included agreement on the need for clarity in terminology, development of more effective ways of patients and carers working in partnership, collaboration with national initiatives, and expansion of education and training of staff.

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50 [www.endoflifecareforadults.nhs.uk/eolc/CS310.htm](http://www.endoflifecareforadults.nhs.uk/eolc/CS310.htm)
51 [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)
In 2009, the best practice guide, *End of Life Care in Advanced Kidney Disease: A Framework for Implementation* was published. This was an important step in providing guidance to support the service to be able to offer people with advanced kidney disease the very best care in the last years, months and days of their lives. The Framework is about enabling people to achieve high-quality end-of-life care. To achieve this, it explores the kidney-specific issues of end-of-life care, focusing on patients opting for conservative kidney management and those deteriorating despite receiving dialysis.

NHS Kidney Care has been working closely with the Department of Health, and an End of Life Care for Advanced Kidney Disease Project Board has been established to support the NHS to follow recommendations from the Framework, and to support the implementation of the Department of Health’s *End of Life Care Strategy* for renal patients.

Key areas include:

- raising the national and local profile of kidney end-of-life care, developing local agreements with commissioners for conservative kidney management programmes and kidney end-of-life care services
- training frontline staff to recognise the signs of the approaching end-of-life phase and handling communication with patients and their families
- development of care plans for end-of-life care
- co-ordination of integrated care across specialties and across primary and secondary care, and provision of care in all appropriate locations
- rapid access to care
- the use of the Liverpool Care Pathway in the last days of life
- involvement and support of family and carers
- building models of care for local use
- improving education and training of staff and continuing professional development.

Measurement of all these developments will be the key to ensuring that quality personal care is given to every patient. Kidney units will be encouraged to participate in national audits, and networks for research in kidney end-of-life care will be established.

53 www.endoflifecareforadults.nhs.uk/eolc/kidney.htm
The renal team at Lister Hospital in Stevenage has developed a Cause for Concern (CfC) supportive care register. The aim is to identify and support patients who are deteriorating despite dialysis, to offer them the opportunity to discuss future care options and to facilitate collaborative care planning. Communication between the patient and renal, primary care and palliative care teams is the key to enabling a supportive care plan that supports the needs of the patient and their family.

It is a multidisciplinary team approach, and includes link CfC nurses in each haemodialysis unit, home therapies and the in-patient ward. Once the options have been discussed and the goals of care established, a care plan is developed and documented. Regular reviews are built in throughout the pathway. Medical factors, including prognosis, and practical and psychosocial issues, are considered and discussed.

Mrs A was on the CfC supportive care register for 13 months prior to the end of her life. She had been on the haemodialysis programme for six years at the time of the initial discussion and had experienced multiple in-patient admissions for various problems, including issues relating to haemodialysis access. CfC was initiated as after each admission or acute event, it was noted that she did not regain her previous base-line functioning. She had a good network of family and professional social care in the community.

The medical prognosis, her expectations and goals of care were discussed with her and her husband in a sensitive and realistic manner. She welcomed the discussions and participated fully. Her care plan was implemented and documented and contacts were made with the community teams. At a later review, she felt that her quality of life had improved. As this impacted on her goals of care, changes were made to her care plan. All changes were communicated internally as well as to the community teams involved.

Some time later, her medical condition deteriorated. She received end-of-life care support as agreed, and her husband was supported by the team, including bereavement support.

**Summary**

It is hard to predict how quickly CKD will progress, especially when complicated by co-existing illness and old age. The challenge remains in ensuring that patients and their families are involved in all decisions about options for medication and treatment, and that these are recorded in personal care plans. Key elements include timely recognition that the end-of-life phase is approaching; sensitive communication with patients and carers; and joined-up planning and effective multi-professional working across boundaries linking kidney care, primary care, community care and palliative care services.
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Forename(s)*
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My wishes

I want to donate: (Please tick the boxes that apply)
A. any of my organs and tissue □ or
B. my kidneys □ heart □ liver □ small bowel □ eyes □ lungs □ pancreas □ tissue □
for transplantation after my death.

Signature
Date
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Mixed: White/Black Caribbean □ White/Asian □
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Asian or Asian British: Indian □ Pakistani □
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If you wish to amend or withdraw your record from the NHS Organ Donor Register you can do so by calling the Organ Donor Line on 0300 123 23 23, visiting www.organdonation.nhs.uk or writing to us at the address overleaf.