



# KIDNEY HEALTH: DELIVERING EXCELLENCE

A Kidney Health Report  
October 2013



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## FOREWORD

The renal community has a distinguished record of 'firsts' in UK medical practice. When dialysis became established as a long-term treatment for kidney failure in the 1960s relatively few centres were established in the UK compared to mainland Europe. As a result, self-care 'home dialysis' became the most common treatment modality. New ways of working quickly evolved, and the multi-professional team was born. In a Witness Seminar at the Wellcome Trust in 2008, Dr W R (Bill) Cattell commented: "Dialysis, especially in the home, changed the face of British medicine. It introduced the nurse specialist, team work, informality between staff, nurses and doctors and gave patients the chance to have their say. This was a huge change in the manner in which healthcare was delivered in this country'.

During the 1980s public-private partnerships finally led to an expansion of dialysis facilities up to European levels. This trend continued under Labour from 1997, but the commissioning of renal services remained haphazard. The introduction of National Service Frameworks (NSFs) provided strategic direction for important areas of medicine. However, the renal service was 'low priority' until Austin Donohoe, a patient who was Chair of the National Kidney Foundation, initiated a coordinated effort by the whole renal community that eventually led to publication the Renal NSF in 2004 and 2005. Patient influence - another 'first' for the renal community.

The Renal NSF provided a solid foundation of principles from which the renal community could advocate for improved services. It stressed the importance of patient-centredness in decision-making and detailed the infrastructures required for a successful service. Uniquely among medical specialties outside cancer, the NSF recognised that coordinated structured support systems for renal patients approaching the end of their lives were necessary in a modern healthcare

system. The renal community has continued to play a lead role in the development of appropriate end of life care in the NHS.

This new document builds on the NSF and what has been achieved in the last ten years. It projects this experience to identify the challenges ahead. While there are many similarities with past issues, the world is undoubtedly much different as are the hopes and expectations of patients with kidney disease. In this document the renal community has drawn on the maturity and strength gained from former successes to articulate its aspirations for the future and provide the framework for a clear long-term strategy to meet the needs of kidney patients.

**Dr Roger Greenwood**

**Consultant Nephrologist, the Lister Hospital, Stevenage**

**External Reference Group, Renal National Service Framework**



## INTRODUCTORY COMMENTS

Despite obvious improvements in the management of people with chronic kidney disease (CKD) in primary care since the Renal National Service Framework and the introduction of CKD to the Quality and Outcomes Framework, this document identifies significant inequalities in the identification of people with CKD and therefore the management of their condition.

The Royal College of General Practitioners is committed to improve the care of people with CKD. Over the next three years kidney care is one of its clinical priorities with a designated Clinical Champion. The next three years will also see a National Audit and Quality Improvement Programme for CKD in primary care.

As Clinical Champion I see this as an opportunity to work with the UK kidney community to drive forwards the ambitions of this document to develop excellent care for people with CKD in general practice.

**Kathryn E Griffith**

**BM BS MSc FRCP MRCGP**

**RCGP Clinical Champion for Kidney Care**

As a kidney patient I feel privileged to have played a part in developing this strategic document. There are many individuals within the renal community with the experience that only being a patient with a long term condition can bring, perhaps described as 'expert patients' or 'patient champions', who have also contributed. I hope we have helped shape a document for all people with kidney disease, their carers, family and friends, which we can use to demand better care. Much of this care is provided by specialists with expert knowledge of kidney disease

accumulated over many years. We must never get to the point where non-experts are deciding our fate with no knowledge of the complex nature of kidney disease and its treatment. The National Service Framework for Renal Services is reaching the end of its lifespan. Kidney Health: Delivering Excellence describes the ambitions for our future care, a future in which the kidney patient community must play a central role. Strategic documents like this will always draw debate and what happens after its publication will be telling. It will be up to the patient community to take ownership and seek commitment from clinicians, professional bodies and policymakers to make and sustain the improvements in our healthcare that are needed.

For me the ambitions described within this document reflect all parts of my care, past, present and future, and while like many of you I want greater awareness of kidney disease among the general public, my personal favourites are "Self-management" and "Lifestyle on dialysis". Intrinsic to both is patient education. Access to information helps us to take control, share in decision-making and allay our fears. We need knowledge to question, challenge, seek help and help ourselves - this is the power we must use to insist that standards are raised in order to realise our ambitions for the whole kidney pathway.

This document shows the way forward for us all.

**Nicholas Palmer**

**Head of Advocacy NKF National Kidney Federation**

**Kidney Patient: Guys and St Thomas' Kidney Patient Association**

## INTRODUCTORY COMMENTS *continued*

It is sobering to reflect that when my career in kidney medicine began there was scant interest from our professional association in addressing the shortfalls in service provision and service delivery for people with kidney disease in the United Kingdom. Although these deficiencies were highlighted through publications in the medical literature by concerned nephrologists it has only really been in the last 15 years that the whole nephrology community has gradually become involved in driving up the quality, quantity and accessibility of services for people with kidney disease.

We have come a long way since the first part of the NSF was published in January 2004, under the stewardship of the first National Clinical Director for Kidney Care, Donal O'Donoghue. For the first time we began to talk about patient-centred services and set clear standards for delivery of care. Patient choice became the watchword and quality of care a key driver. We have seen substantial improvements in the identification of kidney disease in general practice, and a reduction in late referral to renal services. The incident rates of end-stage renal disease have plateaued, the numbers being transplanted have progressively risen, and the national disgrace which is acute kidney injury is being addressed. We have national professional standards and guidelines and clearly defined

pathways of care for people with kidney disease.

Nevertheless we still have a long way to go before we can be comfortable that we've come to the end of the journey and we need to be very careful that we do not go backwards. Concerns about use of a threshold measure of kidney function leading to possible over-diagnosis need to be tempered with the knowledge that the five-year survival of chronic kidney disease is worse than that of some common cancers. The progress that has been made, in particular with better diagnosis of chronic kidney disease and access to transplantation, should not be compromised. It is perhaps fitting that once again the catalyst for the next stage in this journey is a patient, Fiona Loud. My challenge then to our UK kidney community, to our colleagues in primary care and to our policymakers is to step forward, be counted and stand with Fiona to provide the professional knowledge and leadership to ensure that we complete the journey and do not create unnecessary obstacles for ourselves on the way.

**Dr Paul Stevens**

**Consultant Nephrologist, Kent and Canterbury Hospital.**





## EXECUTIVE SUMMARY

Every day 19 people in the UK will develop kidney failure. Four of them will not have been known to specialist services for sufficient time to prepare for their treatment. They will be on average 65 years old if they are white, or 58 if they are black or South Asian. After 90 days one of them will have died, two will have had a transplant, and the remaining 16 will be receiving dialysis treatment at a cost of over £25,000 per year. Many of these people will be elderly, and some will be young. For all of them, and their families, their quality of life will be severely diminished. Their access to treatment, the education they receive, and their opportunities to become an active partner in their care, will all vary according to where they live. This can and should be improved.

Behind these 19 people are many more who will probably never have to tread this path of dialysis and transplantation, but have a lesser degree of kidney dysfunction that we call chronic kidney disease. The terminology has been controversial, but the fact that they have kidney damage or impairment means they are at increased risk of cardiovascular disease and acute kidney injury. Some will experience a progressive loss of kidney function. They need to know they are at risk so that this risk can be reduced.

Kidney Health: Delivering Excellence is for all these people, those with some element of kidney dysfunction and those whose kidneys have failed. It looks at the opportunities we have to prevent and treat kidney disease, to improve the quality of life for people with kidney failure, and to encourage those who are able to take an active part in their own care.

The National Service Framework has done a great deal to shape services for kidney patients, but has now almost run its course. The healthcare landscape may have changed, but the fundamental needs of patients have not. The ambitions of kidney patients and professionals need articulating once more, in the light of what we have achieved in the last ten years and what we have not.

Kidney Health: Delivering Excellence gives a voice to the ambitions of all those who understand and care about kidney services. It offers a view of kidney care from the whole kidney community, which means people affected by kidney disease and their families and carers as well as the many different groups of healthcare professionals who support and treat them. For people and their families, we describe what they should expect from their service, and for healthcare professionals what they should be providing. But this report must do more than reflect hopes and aspirations. It has the strong support of the patient and professional bodies that serve the needs of people with kidney disease, and should be a force for change, challenging policymakers in Parliament and the Department of Health to create a framework for the delivery of kidney care that meets our ambitions.

We do not presume to propose solutions. Our ambitions are independent of future changes in the structure of the NHS, whilst the solutions may not be. Our report sets the benchmark against which developments in NHS policy, structure, planning and operations can be measured by the kidney community. It must also be used by our community to justify and stimulate new initiatives to address the shortfalls we have identified.

The report walks us through the entire kidney care pathway, from awareness of kidney disease and early identification through to monitoring and treatment, including self-management, transplantation, dialysis and end of life care. The roles of nurses and allied healthcare professionals are highlighted, as are the needs of children and young people affected by kidney disease and those who require highly specialised care. Within the report are important messages for professionals who care for people with kidney disease in all settings, but a number of central themes run through its narrative.

## 1. Perceptions of kidney disease

It is vital that we increase awareness and understanding at all levels. Greater public and professional awareness will prevent some people developing kidney disease and improve the identification and treatment of those that do. Raising the profile of kidney disease and encouraging people without kidney conditions to talk about transplantation will help us to build on the progress of the last five years in this area.

We need to work more closely with professionals outside our field. Treating the cardiovascular diseases as a single family is a laudable aim, but one which must increase the visibility of kidney disease and not lead to a loss of identity. Educating our colleagues working in diabetes and primary care will help to avoid the unplanned starts on dialysis due to late referral that are so harmful. It has been argued by some that too many people are being labelled with a diagnosis of chronic kidney disease. We must counter this and explain that chronic kidney disease is an important risk factor for cardiovascular disease, acute kidney injury and poor prescribing.

## 2. Living with a long-term condition

The need for information is greatest in people who are affected by kidney disease. Patients need to understand their kidney condition, and how this relates to other medical problems they might have, in order to make the choices that are needed to live well with these conditions. People with kidney disease must be offered the help and support they need to manage their own conditions as much as they choose to. Care should be planned with patients, reflecting their choices to help them to live the best life they can.

The professional community has perhaps been too slow to appreciate the importance of quality of life in kidney patients, and how lifestyle is inextricably and uniquely linked to treatment choice in patients with advanced kidney disease. We know how effectively the kidney patient and professional communities can work with one another, and together we now have the opportunity to address these deficiencies.







### 3. Inequality in kidney disease

Inequality is a critical factor throughout the kidney care pathway. Kidney disease disproportionately affects certain groups in the population, who in turn may have poorer access to treatment. Black and South Asian groups in particular have high rates of advanced kidney disease but wait considerably longer for transplants. Nearly one-quarter of people on the transplant waiting list are from black and minority ethnic backgrounds, but only 3% of those on the Organ Donor Register are from these same groups. Health policy, health promotion, research, improvement initiatives and care for individual patients must consider the specific needs of these populations in the context of their culture and religion.

People from socially deprived backgrounds also experience higher rates of kidney disease, but are less likely to receive the best treatment. The factors underlying these relationships are complex, but will not be understood and addressed without action at all levels, from government, public health and the media, through to patient and professional groups, and the staff who work in health and social care.

The care that people with kidney disease receive too often depends on where they live. It is unnecessary and avoidable that the length of time taken to be placed on the transplant waiting list, the time taken to prepare for living kidney donation, and the availability of treatment choices such as home haemodialysis and peritoneal dialysis, are so different between units. Reducing this variation has the potential to save both lives and money.

### 4. Safety in kidney disease

Healthcare systems must provide care that is safe, but people with kidney disease are at increased risk of avoidable harm. Acute kidney injury is a barometer for the quality of care, and probably the most important safety issue in the NHS, accounting in 2011 for 200 times more deaths than infection with methicillin-resistant staphylococcus aureus (MRSA). People who are at risk of acute kidney injury, particularly those with chronic kidney disease, should know they are at risk. Better information and education will help patients and healthcare professionals to reduce this risk. Accurate diagnosis of chronic kidney disease and communication of the diagnosis to patients are therefore needed. Established acute kidney injury must be treated promptly with access to dedicated renal support available whenever it is needed, with the infrastructure and protocols in place to support safe and timely transfers to the right care environment.

Patients with kidney disease are also at greater risk of other adverse consequences of care. As renal function declines the risks to patient safety increase. Kidney patients are vulnerable to avoidable harm due to prescribing errors, inadequacies in infection control practices, dialysis catheter-related related bloodstream infections, and late referral for renal replacement. Improving patient safety in kidney disease therefore needs to be a priority for our health service.



## 5. The need for better evidence

Research is the basis for the understanding of disease and the improvement of healthcare. The kidney community has a strong tradition of research activity, and yet we currently lack a good evidence base for many of the conditions we treat, and where the evidence does exist we are unsure how to apply it consistently. The need for better evidence on how to improve outcomes in chronic kidney disease is an important factor contributing to under-diagnosis in primary care. We can all agree that self-management in kidney disease must be beneficial, but more information on the best way to help patients take control is required. We are beginning to appreciate the significance of quality of life in kidney disease, but how can we measure and improve it? How do we support patients to make treatment choices? What should we do to increase the numbers of living and deceased donors? How do we spread best practice in the prevention and treatment of acute kidney injury?

These questions and more should form the basis of a formal research strategy for our community. This in turn will further our understanding of the mechanisms of disease, provide better evidence on preventing, delaying and treating kidney disease, inform us how best to empower and work with patients, and improve the outcomes and experience of care.

## 5. The costs of care

We must resist in the strongest possible terms any attempts to move the management of patients with end-stage renal disease away from specialist care. It is not possible to provide high quality services which are equipped to meet future changes in demand without the funding to support both capital investment and a skilled multi-professional workforce, staffed at the levels required for safe and compassionate care.

However, achievement against many of our ambitions should be accompanied by costs that are reduced rather than increased. Delaying or preventing end-stage renal disease in even small numbers of patients will recoup the costs of implementing guidelines for the management of chronic kidney disease. The costs of informing, educating and empowering patients should be more than offset by improvements in health status and quality of life and a reduction in avoidable harm. The economic case for increasing transplantation is clear. Acute kidney injury affects up to one in five emergency hospital admissions, and preventing unnecessary episodes could save the health service up to £185 million per year. The cost to the NHS of providing care for kidney disease is undoubtedly high, but delivering care that is better, safer and more patient-focused does not have to be more expensive.

We have witnessed many improvements over the last ten years, but have a considerable way yet to travel before care for people with kidney disease is as good as it could and should be. The progress that has been made in some areas, for example in better identification and referral to renal services, has levelled off. Care across the entire pathway is inconsistent and sometimes unjust. Healthcare professionals are only beginning to appreciate patient care in a broader lifestyle context. Kidney Health: Delivering Excellence describes the challenge for the next ten years and beyond. Now we all need to rise to it.

## SUMMARY OF AMBITIONS

1. **Awareness: People - both healthcare professionals and the general public**  
- understand the factors that increase the risk of kidney disease, and action is taken to reduce these risks.
2. **Identification: All people with kidney disease are correctly identified and monitored.**
3. **Self-management: All people with kidney disease are offered as much information as they would like in order to understand and manage their condition.**
4. **Person-centred care: Care is centred on the person, taking into account individual needs and preferences, quality of life, symptom burden and the presence of co-existing medical conditions.**
5. **Acute Kidney Injury: Avoidable harm related to acute kidney injury is prevented in all care settings.**
6. **Preparation and Choice: All people approaching end-stage renal disease, or moving from one type of treatment for end-stage renal disease to another, understand and are given sufficient time and support to prepare for a treatment that is suitable for them, chosen from the full range of options.**
7. **Equity in Transplantation: Listing for transplantation is based solely on clinical need and suitability, and is not influenced by ethnicity, socio-economic status, or where the potential transplant recipient lives.**
8. **Increasing Transplantation: The number of transplants, from both living and deceased donors, is increased such that all people likely to benefit from a transplant have the opportunity to receive one.**
9. **Living well with a transplant: A person who receives a transplant is enabled to manage their transplant and is supported to achieve the greatest possible benefit from it.**

**10. Dialysis as a specialised service:** Dialysis care (including preparation for dialysis) continues to be commissioned as a specialised service, and is delivered by renal units with the capacity and workforce necessary for all patients to receive high quality dialysis using their chosen method.

**11. Lifestyle on dialysis:** People receive all of the information and education they require to engage fully in the planning and delivery of their dialysis, and are supported to minimise the detrimental impact of treatment on their lifestyle and to self-care if they wish.

**12. Care for children and young people:** All children and young people with chronic kidney disease have unrestricted access to a service specifically designed to meet their needs.

**13. Allied Services:** All people with kidney disease know about, and have access to, a specialist multi-professional team.

**14. Expert care in rare kidney diseases and in pregnancy:** All people with rare diseases affecting the kidney, and women with chronic kidney disease who are contemplating pregnancy, have unrestricted access to expert advice and care wherever they live and whenever it is needed.

**15. Research:** A research strategy for kidney disease is developed, supported by the funding required to design and conduct high quality studies, and used to further understanding of the mechanisms of disease and improve healthcare quality and outcomes.

**16. Conservative care:** All people who opt for conservative non-dialytic management of their kidney disease or choose to discontinue dialysis treatment are supported by a multi-professional team working closely together to ensure a smooth transition to palliative and end-of-life care.





## AWARENESS

### Ambition 1

**People - both healthcare professionals and the general public - understand the factors that increase the risk of kidney disease, and action is taken to reduce these risks.**

#### Key factors

- A clear and consistent message to raise awareness of kidney disease in the general public is delivered and sustained, concentrated on those at highest risk, particularly South Asian and black populations and more deprived socio-economic groups.
- Public health campaigns are enhanced to recognise the importance of kidney disease.
- Inequalities in public health that increase the risks of kidney disease are highlighted and tackled.
- Providers and commissioners of healthcare are educated on the links between cardiovascular disease, kidney disease and diabetes.

#### Commentary

Awareness of kidney disease in the general population is very low. Most people who are at risk of kidney disease do not know this and cannot therefore modify their risk. Clear jargon-free information that people can understand should be developed for the audience at risk and made freely available. This work should build upon existing examples of good practice, for example Kidney Research UK's 'A Better Life Through Education and Empowerment' programme, which sought to raise awareness of kidney disease in black and minority ethnic communities (1).

Several public health campaigns, for example Change4Life and the Food Standards Agency campaign to reduce salt intake launched in 2004, are relevant to kidney disease. An evaluation of the latter indicates their potential effectiveness (2). However, there is a danger that the

importance of kidney disease is lost with generic messaging. Most people will be aware that obesity is a risk factor for heart disease, but few will appreciate the links with the kidney. Although chronic kidney disease is common and harmful, the health promotion within these campaigns is overwhelmingly geared towards prevention of diabetes and cardiovascular disease.

**“ I think this is the most important ambition as prevention is always better than cure... ”**



The National Service Framework for Coronary Heart Disease included a clear call for the NHS to “develop and implement.... policies that reduce the prevalence of cardiovascular risk factors in the population, and reduce inequalities in risks of developing heart disease” (3). Kidney disease disproportionately affects people from more deprived socio-economic groups, and the prevalence of its most important risk factors, including diabetes and smoking, is higher in these groups (4). Ethnicity is a critical factor: there is good evidence that kidney disease progresses more rapidly in South Asian and black populations, resulting in higher rates of renal replacement therapy (5). Obesity is another major, and potentially modifiable, risk factor for the development of kidney disease, in people with and without diabetes (6), and the rising prevalence of obesity is likely to have far-reaching public health consequences. Government needs to highlight and address the social and material determinants of inequalities in health that give rise to a higher risk of kidney disease for particular groups within the population.

The knowledge base in kidney disease has expanded dramatically over the last ten years. However, better education of healthcare professionals is necessary to disseminate this new information. There is now incontrovertible evidence that impaired kidney function (i.e. a reduced estimated glomerular filtration rate, eGFR) and the presence of albumin in the urine (albuminuria) are strong independent risk factors for many important adverse outcomes, including death from any cause, cardiovascular death (7), progressive kidney disease, end-stage renal disease and acute kidney injury (8). A diagnosis of chronic kidney disease also has important implications for patient safety. Training curricula should be updated to reflect this learning. Education of commissioners is equally important. The inclusion of chronic kidney disease within a broader vascular policy and commissioning framework (9) should increase awareness and support better care, but it is important that models developed to manage the cardiovascular diseases as a single family do not result in a loss of identity for kidney disease.

“

***I strongly feel a great deal of education of the general public into kidney disease awareness needs to be done.***

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## IDENTIFICATION

### Ambition 2

#### All people with kidney disease are correctly identified and monitored.

##### Key factors

- People with risk factors for chronic kidney disease are identified and offered testing.
- People identified with chronic kidney disease are monitored regularly as recommended in national guidelines.
- The significance of chronic kidney disease as a risk factor for cardiovascular disease, acute kidney injury and avoidable harm due to poor prescribing, is appropriately recognised and addressed.
- High quality research is conducted to test interventions to reduce cardiovascular risk in people with kidney disease.
- General practice incentives, for example pay-for-performance indicators, for chronic kidney disease are aligned with guidance issued by the National Institute for Health and Care Excellence on the identification and management of chronic kidney disease.
- The NHS Health Check programme, or a similar scheme, is implemented fully.
- The kidney community works closely with allied specialty organisations to improve the detection of kidney disease.

##### Commentary

Large numbers of people with kidney disease remain unidentified. The National Institute for Health and Care Excellence (NICE) Quality Standard 1 mandates that people with risk factors for chronic kidney disease (CKD) are offered testing, and people with CKD are correctly identified (10). CKD is an important risk factor for acute kidney injury (AKI), and detection will also support our ambition to prevent AKI. Once identified, people with kidney disease need to be regularly

monitored as recommended by NICE. This is particularly important because many people with kidney disease do not have symptoms until the disease process is relatively advanced.

The proportion of adults with CKD Stages 3 to 5 recorded on GP registers has reached a plateau of just over 4% (11), against an expected prevalence of at least 6% estimated from epidemiological studies in the UK (12)(13)(14). There are over 42 million people aged 20 and over in England and Wales from the 2011 Census (15), and it can therefore be estimated that there are more than 1 million people with CKD Stages 3 to 5, who have not been correctly identified. The consequence for this “missing million” is that many opportunities to improve outcomes are missed. There is major geographical variation in the identification of kidney disease, with the registered prevalence of CKD Stages 3 to 5 remaining below 2% in some Primary Care Trusts/Clinical Commissioning Groups (11).

The factors underlying the under-diagnosis of CKD are complex. Variability in the awareness of clinical practice guidelines amongst primary care practitioners drives inconsistent care. However, more fundamentally, the kidney community has yet to adequately address the widespread scepticism, particularly in general practice, of the significance of a CKD diagnosis. Many practitioners have understandable concerns over the potentially negative effects of labelling large numbers of asymptomatic individuals with a chronic disease (16). Once CKD has been identified, there may be uncertainties about how best to communicate the diagnosis and its implications to patients. We know that patients with a diagnosis of CKD may experience difficulties that are both practical (for example problems with travel insurance) and psychological. We need to ensure that there is a more appropriate understanding of what CKD means, both inside and outside the healthcare system.

The designation of CKD as a Clinical Priority by the Royal College of General Practitioners for



2013-2016 should allow refinement of the message around kidney disease, emphasising CKD as a cardiovascular risk factor, the use of proteinuria testing to stratify risk, and improving patient safety through better prescribing and avoidance of acute kidney injury. It is vital that these messages are reinforced and sustained. We also need better evidence on how to reduce risk in CKD, particularly in terms of important cardiovascular endpoints.

High quality research is required to fully establish the trade-offs between benefit and harm, even for interventions of proven clinical efficacy. This is particularly so in the case of some types of blood pressure lowering drugs (angiotensin-converting enzyme inhibitors and angiotensin-receptor-blockers), which reduce the progression of renal disease in people with proteinuria, but may increase the risk of acute kidney injury (AKI). The publication by NICE of updated guidance for CKD and new guidance for AKI (17) provides the opportunity to define harmonised research recommendations to address such uncertainties.

It has been argued that labelling a significant minority of the adult population with a diagnosis of chronic kidney disease is an example of over-diagnosis (18). The difficulties are sharpest in older people in whom CKD is extremely common: the prevalence in people aged 75 and over may be as high as 50% (12) and a label of "disease" here may not be helpful. However, the debate should not be focused on semantics or indeed the risks of end-stage renal disease, which are low, but rather on the significance of CKD as a risk factor for cardiovascular disease and avoidable harm (19).

General practice is currently incentivised to identify and treat people with CKD Stages 3 to 5. This needs to be reconsidered. The NICE Quality Standard for CKD covers all CKD stages, including Stages 1 and 2, where the eGFR is preserved but there is another marker of kidney damage, typically albuminuria. This is important because there are many people with CKD Stages 1 and 2 (6% of adult women and 9% of adult men (14)) who are frequently at greater risk of

adverse events, than those with reduced eGFR but no albumin in the urine (7)(8). The latter is widely unappreciated, and close co-operation between kidney organisations and general practice is essential to highlight and reinforce this message, so that these people can be advised and helped to reduce their risk.

The NHS Health Checks programme represents an important opportunity to improve the detection of vascular disease in the population. Estimates suggest that the programme has the potential to detect at least 20,000 cases of diabetes and kidney disease per year (20), but this potential is as yet unrealised. Uptake has been highly variable and in a number of localities checks have been offered to 1% or less of the eligible population. The responsibility for Health Checks was passed to local authorities in April 2013, and we echo calls from Diabetes UK that local authorities are fully funded to deliver the programme, including any necessary follow-up action, and that the scheme is overseen by a national implementation team at Public Health England (21).

Disease prevention and better early management will be helped by the relevant professional and patient bodies speaking with one voice. The kidney community must work with allied specialty organisations to highlight the significance of kidney disease, its determinants and its consequences. Data from the National Diabetes Audit, indicating that urine testing for albumin remains the least frequently completed care process in people with diabetes (22), must be seen as a call to action.

## SELF-MANAGEMENT

### Ambition 3

**All people with kidney disease are offered as much information as they would like in order to understand and manage their condition.**

#### Key factors

- All people with kidney disease are informed of their diagnosis, and the meaning of their diagnosis, at the earliest opportunity.
- Information (which is adapted for kidney disease stage and level of risk) is made accessible online and in hard copy and presented in a way in which people can understand easily, whatever their level of knowledge and education.
- Information is provided in the main community languages for black and minority ethnic patients alongside interpreters where needed.
- People with chronic kidney disease have a current agreed care plan that is appropriate to the disease stage and rate of progression, and recognises the associations between kidney disease and other conditions, including diabetes, cardiovascular disease and depression.
- The multi-professional healthcare team encourages self-management and supports patients to manage their condition as much as they choose.
- High quality research is conducted to determine which aspects of self-management are effective, whether there are differences according age and ethnicity, and the results used to improve quality of patient care.

#### Commentary

Self-care begins at diagnosis. However, healthcare professionals do not always inform people that they have a diagnosis of chronic kidney disease (CKD). This non-disclosure is a significant issue: one study indicated that 41% of patients with CKD Stage 3 from 32 general practices

were unaware of their diagnosis (23). In the Health Survey of England only 1.5% of males and 1.3% of females were aware they had kidney disease (14). Concerns over the validity of a CKD diagnosis and a desire not to induce unnecessary anxiety or “medicalise” the ageing process may play a role in this. There is a need for guidance and help for healthcare professionals on how to communicate the nuances of a CKD diagnosis in an individualised fashion. Informing people of the diagnosis must not create unnecessary harm, particularly in older people in whom reduced kidney function is extremely common, and to whom the use of the words “chronic” and “disease” might result in distress unless accompanied by a sensitive explanation.

There is also an important patient safety element to making people aware of their diagnosis. People need to know they have CKD to be aware of their increased risk of acute kidney injury. They should be advised to talk to their healthcare providers about medicines management if they have significant intercurrent illness, as the temporary cessation of certain blood pressure medications at such times may be beneficial.

The significance of a CKD diagnosis will vary according to many factors, including the stage of disease, rate of progression and primary disease. In many patients, a CKD diagnosis is of more significance as a risk factor than a disease process. It is vital that these aspects are discussed with patients, and that the needs of black and minority ethnic populations, in whom advanced renal disease is more common, are understood and respected. Helpful advice for people with kidney disease is available on the websites of the kidney charities contributing to this report (24)(25)(26).

The practice of medicine has rightly become less paternalistic over the last two decades. The National Institute for Health and Care Excellence Quality Standard 3 emphasises the importance of care planning for people with CKD (10). Within this plan, the healthcare team should be aware of the extent to which a patient is engaging in self-care. Kidney disease frequently

co-exists with diabetes and cardiovascular disease. Patients need to understand these relationships in order to support lifestyle change. The fact that up to one-quarter of people with CKD may have depression (27) is less widely appreciated and should be highlighted to all healthcare professionals who work with patients with kidney disease, so that action can be taken to enable better access to psychological therapy.

Patients should be encouraged to become more involved in their care, with involvement from families or carers if the patient wishes. However, not all people will choose to manage their conditions and others will lack self-confidence or have limited sight, hearing or memory, so self-care is not an option for everyone. Re-assessment with the individual will be important as people's views and perceptions of health change over time.

Renal services in hospitals were at the forefront of the development of multi-professional healthcare teams. Whilst some people with kidney disease will continue to require treatment from renal specialists, the majority of people are managed in primary care. It should not be forgotten that the provision of information to allow patients to make informed decisions is as relevant in primary care as it is in the pre-dialysis setting. The roles of the practice nurse, pharmacist and other allied healthcare professionals have also grown in primary care, and these expanded roles should be supported through training and education.

There is a need for more research to support self-care. Although national guidance recognises the importance of self-management in kidney disease, clear evidence of the benefit is currently lacking. This deficiency should be addressed in well-conducted studies, including outcome measures which are important to patients as well as healthcare professionals. Older people and those from black and minority ethnic groups must be well-represented in these studies.

***“ I have not been offered much insight into my condition, I'm still confused by it all. ”***





## PATIENT-CENTRED CARE

### Ambition 4

**Care is centred on the person, taking into account individual needs and preferences, quality of life, symptom burden, and the presence of other medical conditions.**

#### Key factors

- The ethnicity, religion and cultural background of the patient are taken into account when providing person-centred care.
- Where patients choose, families and carers have the opportunity to be involved in care planning.
- Greater emphasis is placed upon recording and managing quality of life and symptom burden in people with kidney disease, using validated tools.
- Primary care and specialist services treating people with kidney disease work together and communicate effectively, so patients are always seen by the most appropriate person, avoiding duplication of effort and consultations that add no value.
- Clinical practice guidelines and quality markers for kidney disease, diabetes and cardiovascular disease are, where possible, brought together to encourage holistic treatment of people with vascular disease.
- Advances in technology are used for the benefit and convenience of patients and carers, and to support online access for patients to their diagnoses, treatment plans and test results.

#### Commentary

Clinical data concerning the identification and management of kidney disease are freely available from the UK Renal Registry, UK Transplant Registry, the National Clinical Audit and Patient Outcomes Programme (NCAPOP), and the Quality and Outcomes Framework. Such

data are important to improve performance, and the chronic kidney disease (CKD) National Audit is the first programme within NCAPOP to include a specific quality improvement element within its specification.

However, many factors other than clinical performance are important to patients. Person-centred care is the delivery of a system of care that takes into account the individual needs and preferences of the patient and their family/carers. Patient needs include clinical needs, but often are more holistic in nature, and must be seen in the context of an individual's ethnicity, religion and culture, as well as their lifestyle. Patients may depend upon family members and carers for practical and emotional support, and these people should also be involved in discussions about care where patients choose it.

Quality of Life (QOL) is increasingly seen as an important marker of the quality of care in the management of long term conditions. The extent to which patients' perceived physical and mental functioning are affected on a day to day basis by a chronic disease is an especially important marker of care in the management of kidney disease, where even with the best treatment options available, there can be a significant reduction in patients' sense of well-being. QOL is significantly reduced in advanced CKD across all treatment types (28) and strongly associated with both hospitalisation and mortality (29). People with advanced kidney disease (both pre-dialysis and dialysis) experience a wide range of disease and treatment-related physical and emotional symptoms (30) which will contribute to this marked impairment in QOL. Where beneficial treatments for quality of life are available, care is not applied consistently. Despite their importance, data on health-related QOL or symptom burden scores are not yet systematically collected or measured in UK renal centres, and this should be a focus of future activity for the UK Renal Registry. Patients with poor QOL and symptom scores are likely to have

Patient Reported Experience Measures, co-developed between patients and healthcare professionals, are not yet available to address this issue. The development of instruments that are appropriate, valid, reliable, responsive, precise, interpretable, feasible and acceptable (31) should be encouraged and funded.

Person-centred care also means that people are treated at the right time in the right place. People with kidney disease frequently have other long term conditions, and may need advice from both generalist and specialist healthcare professionals. Better integration across both NHS organisations and disease boundaries is vital. There is variation in adherence to referral guidelines in primary care. Patient flows between and within secondary care need to be better described in order to improve. Anecdotal evidence suggests that patients are still being treated in disease “silos”. Even within renal services, practice is highly variable: patients may attend for a single visit in order to define a long-term management plan for primary care, or be followed up in a hospital setting on an indefinite basis, not necessarily with a clear justification. Renal healthcare professionals need to work with colleagues in primary care, diabetes and cardiovascular disease to better define our care pathways.

It is important that we have a description of safe and effective care that transcends NHS structures. Silo management, which is centred on the needs of the healthcare provider rather than the patient, will be perpetuated by clinical practice indicators that are disease-specific. Efforts should be devoted to the harmonisation of clinical targets across the vascular specialties and the development of quality indicators relevant to people with complex medical disease. Technology has a role to play in delivering person-centred care. Technological advances must be utilised for the convenience and benefit of service users and carers. The information technology to offer virtual consultations exists but is under-utilised. The role of Telemedicine in kidney disease, for example remote monitoring to support self-care, is not yet well defined and

can not be seen as a replacement for face-to-face interactions, but should be developed. Information Governance is essential to protect patients, but must also enable information sharing where it is appropriate and beneficial. The Renal Patient View system (32) which can be accessed by kidney patients in secondary care and provides online information on diagnosis, treatment and test results, should be seen as an exemplar for involving people in their own care through the use of technology.

**“ I would also like to see more about listening to what the patient says. ”**

**“ From both my professional work and experience as a patient, I feel that there is a gap in the care given to the chronic renal patient who is not on dialysis or transplanted. ”**

## ACUTE KIDNEY INJURY

### Ambition 5

**Avoidable harm related to acute kidney injury is prevented in all care settings.**

#### Key factors

- Acute kidney injury is highlighted to healthcare professionals, patients and the public as a major preventable public health problem and critical issue for patient safety.
- People at high risk of acute kidney injury, such as those with pre-existing chronic kidney disease, heart failure, sepsis, diabetes mellitus, liver disease, and severe diarrhoea, especially in babies, are identified and action taken to reduce their risk.
- People with established acute kidney injury are treated promptly.
- All patients with established acute kidney injury who may benefit from care within a renal unit are transferred promptly and safely to that unit.
- Renal units are adequately resourced to support people with acute kidney injury.
- Acute kidney injury is a priority topic for the education of undergraduates, postgraduates, practising doctors and other members of the multi-professional healthcare team.
- A robust evidence base is developed to support healthcare professionals treating acute kidney injury.
- Acute kidney injury is recognised as an important risk factor for chronic kidney disease.

#### Commentary

Acute kidney injury (AKI) is a major cause of preventable harm. A 2009 report looking at the processes of care of patients who died in hospital with a diagnosis of AKI found that only 50% of AKI care was considered good. It highlighted poor assessment of risk factors for AKI, an unacceptable delay in recognising post-admission AKI in 43% of patients, poor and inconsistent coding of AKI and inadequate referral to the renal team. Up to 30% of cases were felt to be

preventable (33). It has been estimated by NHS Kidney Care that AKI costs the NHS between £434 million and £620 million per year (34). Preventing avoidable cases of AKI could save the health service up to £185 million per annum, and prevent up to 12,000 unnecessary deaths (35). The risk factors for AKI are well defined, and include pre-existing chronic kidney disease (CKD), increased age, heart failure, diabetes mellitus and sepsis. It can also affect young babies, where it is not well recognised. Even minor reductions in estimated glomerular filtration rate (eGFR) or small elevations in urine albumin are important independent factors that predict the development of AKI: people with stage 3A CKD and a normal albumin:creatinine ratio (ACR) are at almost 5 times greater risk; people with low grade albuminuria (ACR 3 to 30mg/mmol) and an eGFR greater than 60ml/min/1.73m<sup>2</sup> are at up to 3 fold increased risk (36). All healthcare professionals need to be aware of these relationships, which underscore the importance of identifying all people with CKD.

“

***There needs to be greater awareness  
in primary care for prevention.***

”



An assessment for the risk of AKI should form an essential component of any acute medical or surgical assessment. The acute treatment of patients in at-risk groups should be optimised in such a way as to minimise the risk of AKI developing. Primary care also has an important role in the risk assessment and prevention of AKI.

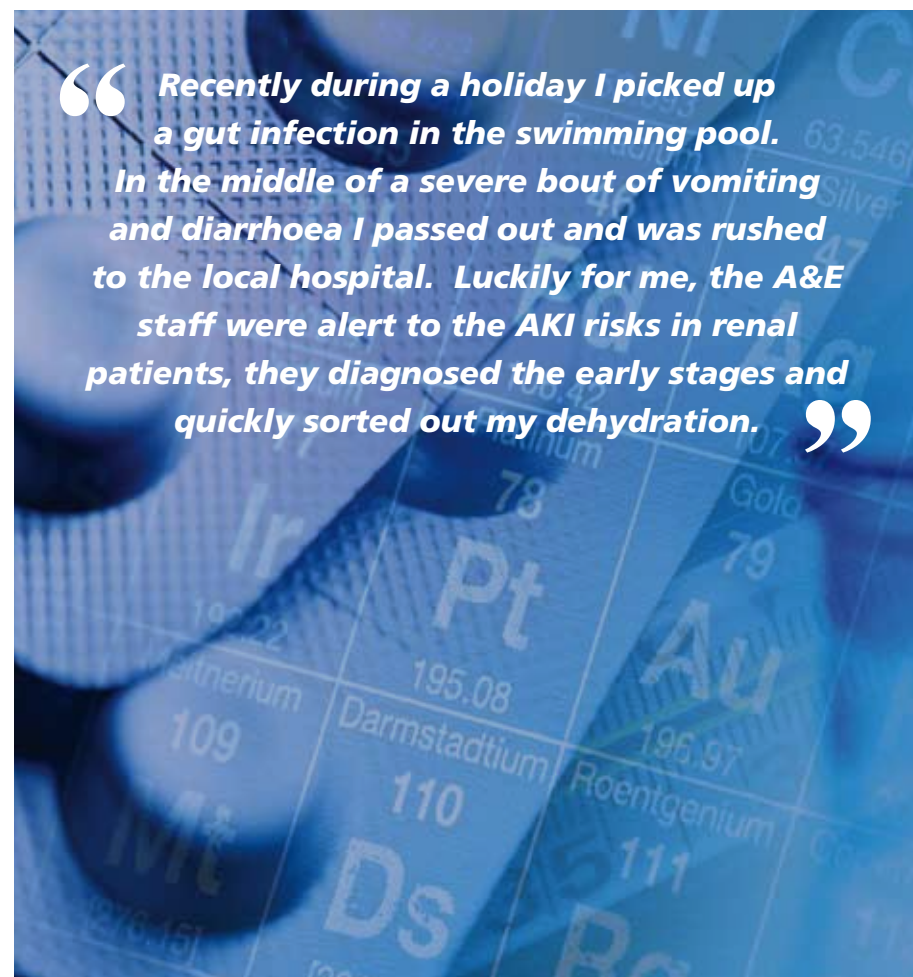
Patients who are at increased risk of AKI should be aware of this so they can take appropriate action to reduce their risk. Some medications, particularly certain classes of blood pressure-lowering drugs and non-steroidal anti-inflammatory agents, the latter available over-the-counter, are associated with an increased risk of AKI, especially in situations where patients may become fluid depleted, or during intercurrent acute illness. NICE Quality Standard 7 mandates that people with CKD who become acutely unwell should have their medication reviewed, and receive an assessment of volume status and kidney function (10).

Established AKI should be treated promptly in accordance with national guidelines. Where AKI is severe, unexplained, complicated, fails to respond to treatment or occurs in the context of pre-existing severe CKD, the National Institute for Health and Care Excellence recommend that a specialist renal opinion should be sought urgently (17), but current practice is variable. It is essential that renal units have a skilled workforce, sufficient capacity and agreed local protocols to allow the prompt and safe transfer of patients who need dedicated specialist renal input.

AKI is a relatively recent priority for the kidney community and awareness of AKI in general practice in particular is extremely low. It must feature prominently in the training curricula of all healthcare professionals. The message that AKI is preventable and harmful needs urgent dissemination to practising clinicians in primary as well as secondary care, and should be supported by the tools required to implement best practice.

The evidence base for the treatment of AKI is limited. High quality research is required to determine the optimal approaches for staging, preventing, ameliorating and treating the

condition. People recovering from an episode of AKI should be regarded as at greater risk of both developing new CKD and of progression of existing CKD. They should be offered information to help avoid future episodes and be monitored in primary care accordingly.





## PREPARATION AND CHOICE

### Ambition 6

**All people approaching end-stage renal disease, or moving from one type of treatment for end-stage renal disease to another, understand and are given sufficient time and support to prepare for a treatment that is suitable for them, chosen from the full range of options.**

#### Key factors

- All kidney units promote the full range of treatments for end-stage renal disease free of institutional bias, including pre-emptive transplantation, home-based dialysis, self-care dialysis and conservative care.
- A multi-professional kidney team sees all patients with advanced chronic kidney disease at least one year before it is expected that end-stage renal disease will develop, and maintains continuity of care for each patient as they move from one treatment type to another.
- Taking into account personal circumstances, the choice of treatment is led by the patient and their families or carers and supported, where people choose it, by discussions with their peers.
- Treatments for end stage renal disease are regarded as complementary, with the healthcare team promoting an integrated long-term approach that best utilises all treatment types.
- High quality multi-professional research is conducted to determine how best to support patients who are choosing a treatment type for end-stage renal disease and whether this varies according to factors such as age and ethnicity, and the results used to improve care for all patients.

- Pre-emptive transplantation (if this is an option) and timely vascular access and peritoneal dialysis catheter insertion services delivered by healthcare professionals with the appropriate skills and experience are available to all patients, so that no-one commences dialysis with emergency access where this is avoidable.
- Patients with end stage renal disease who are referred late to renal services are offered the same information, support and access to treatment types as those people referred early.

#### Commentary

People with end-stage renal disease (ESRD) do not currently have access to the full range of treatments on a consistent basis. Where possible, all suitable patients must be pre-emptively listed or transplanted. Instead, access to pre-emptive transplantation, either from a living or cadaveric donor, is influenced by location. There is also variation between units in their approach to home haemodialysis, self-care dialysis, acute peritoneal dialysis (PD) and assisted PD. Data from the UK Renal Registry indicate that, in 2011, 20% of new renal replacement therapy patients were treated with PD. However, the proportion treated with PD in individual renal centres ranged from 0% to 47%, and was less than 10% in several units (37). The institutional factors that underlie much of this inequity and restrict patient choice need to be highlighted and tackled. All appropriate treatments must be available to all patients irrespective of where they live, so that they can select the option that best meets their clinical and lifestyle needs.

“ **Other patients, who have long experience of CKD, may be able to help kidney patients on their journey, particularly as it starts** ”

Sufficient time is required to prepare for renal replacement therapy (RRT). Late referral for RRT to renal units is a major and avoidable cause of poor outcome. The rate of late referral has reduced significantly since 2006, driven by improvements in the identification and treatment of kidney disease in primary care. It has however changed little since 2009 and remains highly variable across the UK, with more than 30% referred within 90 days of commencing renal replacement in a number of centres (37). Whilst some late referrals will be unavoidable, closer working and better communication between primary and secondary care will help minimise these and reduce unwarranted geographic variation. Preparation for RRT is an exemplar for shared decision making and requires the involvement of an appropriately skilled multi-professional team, including doctors, nurses, dieticians, pharmacists and social workers. The multi-professional team also have an important role in ensuring that any transitions of care experienced by kidney patients are smooth. Patients are at their most vulnerable when moving from one treatment type to another. This can be compounded by a loss in continuity and communication, as the clinical team providing the care within the kidney unit may change simultaneously. Renal units must ensure that effective systems of handover are in place so that patients are clear who their key points of contact and support are.

People with existing kidney disease, particularly those who have experienced transplantation or dialysis, can all be part of the multi-professional team - peer support for newer patients is very important and helpful. Access to other kidney patients, especially when considering choices of treatment, should be supported and made possible by all renal units.

Many people with ESRD will experience more than one treatment type during their lifetime. It is important that decisions to choose a particular treatment are not seen in all-or-nothing terms. Discussions with patients should emphasise, where relevant, a longer term approach, where treatment types are seen as complementary rather than competitive. The advantages

or disadvantages of the various sequences and combinations should be considered in the shared decision-making process, and consideration given to the preferential use of pre-emptive transplantation over any dialysis where this is possible, and of peritoneal dialysis over haemodialysis in those with significant residual kidney function and without significant co-morbidities (38). The needs of patients and their options for treatment should be regularly reviewed with the multi-professional team.

Proven aids to decision making can enhance (not replace) time spent with the healthcare team. Kidney services have been at the forefront of developments in shared decision making and the use of patient decision aids. A programme of multidisciplinary research, co-designed by patients, will provide us with the best information on how healthcare professionals should support patients when they are making decisions about their treatment for ESRD.

Whilst early referral is a pre-requisite, good practice within renal units is vital to ensure a good transition onto renal replacement. There is evidence that shows outcomes are less good in patients starting haemodialysis via a central venous catheter. However in 2011 only 43% of patients commenced haemodialysis with definitive vascular access, and significant variation between centres was apparent (39). This is not explainable solely on the basis of referral practices: the need to provide a flexible, dynamic access service for both haemodialysis and peritoneal dialysis should be regarded as a key target for improvement within renal units.

Patients with ESRD who are referred late to renal services must not be disadvantaged compared with those referred early; they must be offered the same information, education and choices, and have access to an expedited service for definitive vascular access or PD catheter insertion.

## TRANSPLANTATION - Equity in transplantation

### Ambition 7

**Listing for transplantation is based solely on clinical need and suitability, and is not influenced by ethnicity, socio-economic status, or where the potential transplant recipient lives.**

#### Key factors

- Best practice guidelines for the assessment of potential transplantation recipients are followed in all units.
- The achievement of renal units against best practice guidelines is monitored and the results for their units made freely available to kidney patients in a form they can understand.
- High quality research is completed to determine the factors that influence whether patients are placed on the waiting list and/or transplanted, and the results of this research used to increase the consistency and quality of care.
- Progress with transplant work-up investigations and all changes in transplant list status are discussed with patients.
- The system for funding work-up for transplantation is open and transparent so that the commissioning process cannot be a barrier to transplantation.

#### Background

UK Renal Registry and UK Transplant Registry data highlight significant variation in access to the renal transplant waiting list and in rates of transplantation. There are significant differences between units in the proportion of people listed pre-emptively or within two years of commencing dialysis, the proportion transplanted within two years of commencing dialysis, and the median time to listing. These differences are not explainable on the basis of case mix alone (40). Transplantation is a scarce resource and the numbers of people receiving dialysis,

at approximately 26,000 (37), far exceed the 6,300 on the waiting lists for kidney and kidney-pancreas transplantation as at April 2013 (41). It might be argued that those units listing a lower proportion of their end-stage renal disease (ESRD) population are targeting the use of this resource to those most likely to benefit. However this is not reflected in post-transplant outcomes and suggests instead that the processes and philosophies within units are important factors that need to be changed.

There are 52 main renal units in England, of which 20 are transplanting centres. Although guidelines covering the process of assessment for transplantation have been published by the Renal Association and British Transplant Society (42), these guidelines are not universally followed. Patients need to know what the broad criteria are, for example with respect to body mass index and cardiovascular disease, and what to expect during the work-up process, no matter where they live.

Transplant performance data for each renal centre are now available through collaboration between the UK Transplant Registry and UK Renal Registry. The publication of such comparative information, including data on listing, should encourage and enable units to share good practice, raise quality and reduce variation. It is also important that potential transplant recipients and their families are able to see how their units are performing through the publication of summaries in which data is presented in a way that patients can understand.

Health inequalities may be important determinants of variation between units. People from more socially deprived areas have poorer access to the transplant waiting list (43) and are less likely to receive live donor kidney transplants (44). Patients from ethnic minority groups are no less likely to be listed (43), but wait considerably longer to receive a kidney transplant (45). Research is required to explore these issues fully. The Access to Transplant and Transplant Outcome Measures (ATTOM) study has been funded by the National Institute for Health Research (46).

It is vital that outputs from this important work are shared and used to increase the consistency of care. The decision to list someone should always be reached in conjunction with the patient, including a realistic discussion on likely waiting times and the potential for a living donation. The process of work-up for kidney transplantation can be long and is a source of distress for many patients, particularly when multiple tests and opinions, for example on cardiovascular fitness, are deemed necessary. Incidental abnormalities of unknown significance are frequently uncovered, resulting in more testing, waiting and uncertainty. Information on their progress through work-up and any changes in transplant status should be fully communicated to all patients in a timely manner. For example, if a patient is temporarily removed from the transplant list due to an intercurrent illness, they will need to know that their status is being reviewed on

a regular basis. Staff caring for kidney patients and transplant recipient co-ordinators are often not co-located and integration, which includes sharing of data, between these two groups therefore needs to be improved.

Under the current commissioning framework, the funding streams to support the complex process of work-up for transplantation are not clearly defined. This deficiency must be addressed so that this lack of clarity does not delay transplantation (for example if kidney specialists are discouraged from referring directly to other specialists who need to become involved in the work-up process) or even prevent suitable recipients accessing the transplant waiting list.

**“ A job change and house move took me away from a hospital where I was on the transplant list to another where I wasn't placed on the list. ”**

**“ There are ... differences in criteria (e.g. for transplant eligibility) within renal units - this is inequitable and confusing for donors/recipients/renal staff ”**





## INCREASING TRANSPLANTATION

### Ambition 8

**The number of transplants, from both living and deceased donors, is increased such that all people likely to benefit from a transplant have the opportunity to receive one.**

#### Key factors

- The role of pre-emptive kidney transplantation as the treatment of choice for all suitable patients with end-stage renal disease whenever a living donor is available is promoted to patients and healthcare professionals.
- Living kidney donation is widely recognised by the general public as a valuable treatment for end-stage renal disease in patients who are suitable for transplantation.
- Awareness of donation is strengthened in black and minority ethnic communities.
- An individual who donates a kidney is able to do so with appropriate ethical, financial, physical and psychological support, before, during and after the donation process.
- Best practice is adopted in all units to minimise both the risk to donors and the disruption to their lives from the work-up process.
- The commissioning arrangements for living donation are clear, and dedicated funding is available to support donor work-up.
- The number of people making a decision whilst alive to be a deceased donor is increased and a record of their decision is available to healthcare teams whenever it is required.
- Information and support systems are made freely available to help families make consent decisions on behalf of a deceased relative whose donation intentions are not known.
- Best practice guidance for surgeons performing organ retrieval is fully implemented to optimise the proportion of donated organs from deceased donors that are used for transplantation.

### Commentary

Transplantation generally offers both survival and quality of life benefits over dialysis and is cost-effective. This is also true for older recipients with no obvious contraindication (47). Historical data indicate that survival in those who are transplanted is better than in age-matched patients who remain on the transplant waiting list (48).

Living kidney donation offers better graft and patient survival to recipients and the chance to avoid lengthy waits for deceased donor organs, at the expense of small risks to the donor. Pre-emptive transplantation is associated with further reductions in graft loss and mortality as compared to transplantation in people already on dialysis (49) and should be promoted to both patients and healthcare professionals, within and outside renal services, as the optimal treatment in patients who are suitable and have a donor.

For patients with diabetes who are suitable for transplantation of both kidney and pancreas, then simultaneous kidney-pancreas transplantation or living donor renal transplantation may both be regarded as treatments of choice.

There have been significant year-on-year increases in rates of deceased donor transplantation to 19.1 per million population since the 2008 Organs for Transplant report (50) was published, and the number of patients on the active transplant list has declined for the last four years (41). Living donation is largely, and rightly, seen as a success in the UK. It now represents more than a third of kidney donations (41), and we have seen a rise in non-directed altruistic donations.

However, there is a long way to go to before the UK transplantation rates rank favourably with the best-performing countries in Europe. To increase numbers further, we should recognise and promote the success of the living donor programme, but also improve it. The work-up process needs to be streamlined. For example, where recipient and donor are not co-located there can be unwarranted delays in preparation and a lack of clarity on who is driving the process and which unit is paying for it.

Some units have successfully reduced the time taken from referral to activation and made arrangements for donors and recipients to be tested in the same place on the same day (51). This best practice should be shared, and the commissioning arrangements around donation clarified, so payment does not represent a barrier to live donor transplantation.

Living donation is an inspirational example of selflessness. However, some living donors currently feel that the “care follows the kidney” (52). While they do receive an annual review, donors can feel that their needs and expectations are not fully met by post-donation care. The results of monitoring can cause confusion and may not be fully explained. Some may be labelled as having chronic kidney disease. Unlike many transplant patients, live donors are not expert patients and their needs must be more fully understood. Recognising and valuing the contributions of living donors is an important way to improve the donor experience. Guidelines on the reimbursement of living donors for expenses incurred during work-up and surgery (53) should be fully implemented.

We must work more closely and sensitively with the black and minority community to encourage and celebrate live donor transplantation. Peer education programmes have shown real potential for increasing the rates of organ donation, with community leaders able to lead by example as demonstrated in national initiatives such as the National Black and Transplant Alliance (54) and local community events.

Improvements are also needed to support the families of deceased donors in the decision to donate. In 2009, the rate of refusal for donation after brainstem death (DBD) where the deceased’s donation intentions were not known was as high as 50%, with rates of 77% in black and minority ethnic groups where the needs for transplantation are greater (41). Public perceptions of transplantation are generally positive but awareness still needs to grow. A fresh approach is called for if NHS Blood and Transplant is to achieve its goal of increasing consent

rates to 80% by 2020 (55). Systems should be in place so that once an individual has made his or her intentions known this is formalised and accessible on the healthcare record when needed. NICE have listed factors important in decisions to give or refuse consent for organ donation (56) and these factors should closely inform both the work and ethos of Specialist Nurses for Organ Donation. Research is needed to better understand and learn from the experience of consenting. Families considering donation should feel supported but not pressured into doing so.

It is equally important that processes post-consent are improved. As NHS Blood and Transplant recognise, “opportunities for transplantation are lost at all stages of the process from offering to implantation and while there is a valid clinical reason for this in most cases, there are some instances when variation in practice is unexplained” (55). Some centres decline more kidneys than others, and yet patients at centres with higher decline rates not only experience longer waiting times but outcomes that may be below average (57). If all units performed as well as the best, it is estimated that deceased donation rates could be increased to 27 donors per million population. Best practice guidelines for organ retrieval (58) should be implemented fully in all units and the results of comparative audit made freely available to kidney patients.

**“ More awareness in ethnic minority groups and involvement of various faith / communities is required... ”**

## LIVING WELL WITH A TRANSPLANT

### Ambition 9

**A person who receives a transplant is enabled to manage their transplant and is supported to achieve the greatest possible benefit from it.**

#### Key factors

- All the information necessary for patients and their families or carers to prepare for a transplant, physically, emotionally and practically, is provided and discussed within the work-up process.
- Specialists have a long-term responsibility to work with patients to help them manage their transplant and any transplant-related complications.
- Specialist transplant advice is available to patients and other healthcare professionals whenever it is needed.
- Specialists work closely and communicate effectively with other healthcare professionals involved in the care of patients with a transplant, avoiding duplication of effort, so that any other conditions the patient may have are treated safely.
- Clinical practice guidelines for the management of kidney transplant recipients are fully implemented, and renal units' performance against these standards measured and published.

#### Commentary

The quality of life in people approaching kidney failure and in those on dialysis is likely to be reduced. Major restrictions in diet and fluid intake are the norm, and depression is extremely common (27). A kidney transplant is a sudden and major change to the recipient's way of life, and people need to be well prepared in advance for all the potential implications. Patient experience suggests the current system does not prepare people to live well with their transplant as it tends to focus on overcoming the medical barriers to transplantation (52). However

information for patients is also required in many other areas. Patients need to fully understand the possible side effects of their medications, and, after a successful transplant, practicalities such as who will be prescribing them.

The challenge of moving from a severe fluid restriction, which may be as low as half a litre per day, to a need in many cases to drink copious volumes of liquid to maintain hydration should not be under-estimated. People can still experience uncomfortable symptoms post-transplantation and will often have other conditions and so can be disappointed with their outcomes, especially as expectations of transplantation are high. One-quarter of transplant patients may experience clinically significant symptoms of depression (27)(59). This is a frequently neglected area. The right tools to describe the patient experience need to be systematically applied, and the results used to help patients improve their quality of life. Validated and co-designed Patient Reported Experience (PREMs) and Patient Reported Outcome Measures (PROMS) relevant to all patients with kidney disease are urgently needed.

It is essential that kidney specialists have regular long-term input into the care of transplant patients, to help them manage their transplants and to prevent and address transplant-related complications such as infection and cancer, which will not be well-understood by generalists. It is not feasible to prescribe a particular model of care relevant for all localities, but care must be delivered by appropriately accredited healthcare professionals with the appropriate skills and experience at a location with timely and unrestricted access to the full range of necessary diagnostic and therapeutic interventions.

Expert advice from specialists may be required at any time. A patient's transplanted status can influence both routine and emergency care. 24-hour cover from renal units must be available, and both patients and other healthcare professionals need to be aware that this advice should be sought and know how to access it.

Care for other conditions will generally be provided from general practice. Good communication between generalists, specialists and patients is essential. Where prescribing is the responsibility of primary care, it is important that transplant recipients are aware that the specific formulations of the anti-rejection medicines are important and that they should not be switched from one brand of drug to another, or from a branded to a generic version, without prior discussion with their specialist. The potential for the patient's transplanted status to influence the treatment of conditions not directly related to the transplant should always be considered. However patient experience suggests current practice is highly variable (52), and that care tends to be centred on the healthcare system or professional rather than the patient. General practitioners currently collect data on blood pressure and kidney function, for example, to support practice payments under the Quality and Outcomes Framework. Such data are also collected by transplant centres, but not routinely shared, necessitating a repetition of testing and incurring additional and unnecessary costs.

Clinical practice guidelines for the management of renal transplant recipient have been published, nationally by the Renal Association (60) and internationally by Kidney Disease Improving Global Outcomes (61), the latter also with broad relevance to UK practice (62). The greater challenge, to achieve widespread implementation, will be supported by the measurement and publication of performance against these guidelines, so patients can understand the quality of care that their unit is providing.



**“ Patients seem to have to look for help on internet forums, as they don’t seem to get much time from specialists at present. ”**

**“ My GP recently told me, ‘It’s over a year since we had any blood test results for you. The kidney doctors don’t let us have theirs so we need some of our own. ”**



## DIALYSIS AS A SPECIALISED SERVICE

### Ambition 10

**Dialysis care (including preparation for dialysis) continues to be commissioned as a specialised service, and is delivered by renal units with the capacity and workforce necessary for all patients to receive high quality dialysis using their chosen method.**

#### Key factors

- Specialist clinicians provide dialysis care for all modalities, including dialysis preparation, and treat all dialysis-related problems and complications.
- All patients receive dialysis in a safe environment provided by renal units properly resourced and staffed by a skilled workforce committed to delivering high quality care.
- People on long-term dialysis receive the best possible therapy delivered in accordance with national guidance.
- Funding is allocated to permit all renal units to maintain sufficient capacity for their population to dialyse with the flexibility to support personal circumstances.
- Budgeting, capacity and workforce planning take into consideration changes to the future overall demand for dialysis, trends in demand for each type of treatment, and regional variation in demand.

#### Commentary

Dialysis is a highly specialised procedure carried out in patients with many different underlying kidney disorders, with varying and complex co-existing medical conditions. An individual with kidney failure may be treated, at different points in their life, with both haemodialysis and peritoneal dialysis, and receive one or more kidney transplants. Patients receiving treatment for end-stage renal disease (ESRD) frequently experience complications that are unique to their treatment. Specialists with knowledge and experience of the underlying primary renal disease,

dialysis preparation, dialysis techniques, transplantation, and end of life care are essential, supported by a full multi-professional team.

Effective integration of the different elements of specialist care is necessary to deliver quality treatment for ESRD. Therefore no single element can be commissioned separately. Fragmentation of the kidney care service would mean patients losing the continuity of care on which they depend. Delays at any point in the service (caused through uncoordinated commissioning or other reasons) can have severe and far-reaching consequences. Patients who require dialysis depend on it to stay alive. Every time they dialyse, they are receiving life-preserving treatment. Conversely, when a patient is unable to do so, they are put at risk.

Detailed planning, with a longer time-frame than that required to deliver primary care, and significant capital investment in specialised equipment, are needed to procure dialysis services. Primary care clinicians and commissioners do not have the level of knowledge, resources or experience to manage or commission these services. For every 1,000 patients for which a GP is responsible, 100 or more will have chronic kidney disease (all stages). However, only two are likely to be receiving renal replacement therapy or conservative care.

Patients with ESRD must therefore be treated in adequately resourced and properly staffed specialist renal units. Even within such units, current practice is variable. The Renal Association has published clinical practice guidelines that describe standards of care for people receiving renal replacement (63)(64). However centre-specific analyses by the UK Renal Registry continue to demonstrate unwarranted variation in important clinical measures (37). A culture of continuous improvement is needed within units to meet and exceed these standards and deliver best care. This must be complemented by a culture of transparency, particularly between units and patients, to share and co-develop new developments and initiatives. Patient safety must never be put at risk through failings in infection control policy and procedures.

There are clear recommendations on minimum acceptable dialysis frequency and duration, and we must not allow any future changes in the financial environment within the NHS to compromise this practice. It is not acceptable for patients to undergo haemodialysis less than three times per week unless there are exceptional circumstances. On the contrary, we need to develop flexibility around booking of dialysis times and to learn from innovative practice elsewhere in the world.

Capacity is a critical issue for those commissioning and providing dialysis services. Although there have been some improvements, the results of three annual national surveys (2010-2012) conducted by NHS Kidney Care show that provision of haemodialysis varies widely across England, particularly in terms of access to and distance from dialysis units (65). In some areas, there remain gaps between demand and capacity. These shortfalls must be corrected. Furthermore it is expected that the overall demand for dialysis will continue to increase. Although the numbers developing ESRD each year have plateaued in the UK, the total ESRD population continues to grow. In patients aged over 85, these prevalence rates have doubled between 2006 and 2011 (37).

For most patients, dialysis is a long-term treatment that has a major impact on their lives. Dialysis capacity must support the needs of patients changing treatment method, patients requiring renal replacement therapy for acute kidney injury, those training in self-care, and patients who usually dialyse at home needing respite care. Units which are full are not able to offer all treatment options and support their patients. Sufficient capacity is essential to provide the flexibility to support personal circumstances, including work, family commitments and travel. There is a growing need for patients with infectious disease and those returning from high-risk areas to dialyse in isolation. Therefore planning across all elements (including budget, capital investment and workforce) must take into consideration these factors and ensure that there is capacity to meet the needs of all patients wherever they live. Renal units must be allocated the resources to meet these needs and funding must be provided with the stability to permit planning over the long term.



**“ I totally agree (with this ambition), especially as  
I am due to start dialysis in 3-5 weeks’ time and hope it all goes well! ”**

## LIFESTYLE ON DIALYSIS

### Ambition 11

**People receive all of the information and education necessary to engage fully in the planning and delivery of their dialysis, and are supported to minimise the detrimental impact of treatment on their lifestyle and to self-care if they wish.**

#### Key factors

- Dialysis units proactively and regularly encourage all patients to engage fully in their care management, provide training in self-care (or elements of self-care) in haemodialysis units, and offer unrestricted access to home haemodialysis and peritoneal dialysis for those for whom it is feasible.
- The lifestyle of the patient is considered and discussed alongside clinical needs when reviewing and planning changes to care management, optimising the ability to meet commitments such as work, caring for children or other family members and reasonable travel (including holidays) whilst continuing to dialyse.
- Patients are able to attend dialysis sessions in a timely manner either using their own transport arrangements, with prompt reimbursement of reasonable expenses (which must include parking costs), or through a hospital transport service.
- People receiving haemodialysis or training for home therapies who are eligible for hospital transport have access to a transport service that is designed and commissioned as an integral part of care, and centred on their lifestyle and clinical needs.

#### Commentary

At the evidence-gathering meeting for this paper (52), many patients raised concerns that dialysis treatment was being provided with too little involvement of the patient in their care. Whilst the level of involvement desired by patients will vary, support for the engagement of patients

in their own care is frequently inadequate and not offered proactively. Encouraging patients to be involved in their treatment should also promote greater uptake of self-care dialysis, which includes peritoneal dialysis, home haemodialysis and self-care haemodialysis within dialysis units. There are clear benefits from self-care dialysis for those that choose it, related to freedom, lifestyle and control (66). There is evidence that older people may find peritoneal dialysis less intrusive than haemodialysis despite longer treatment times (67). There are barriers to self-care including a lack of understanding and fear of social isolation (68) but these can be overcome by educational interventions (69).

Dialysis for end-stage renal disease (ESRD) is life-saving but also intrusive, demanding and, unless the patient receives a successful kidney transplant, continues until the end of life. Treatment therefore has a major impact on patients' lifestyles and personal ambitions. It is essential that these lifestyle needs are considered when managing dialysis.

Adherence to treatment is closely linked to the way it is provided. Home dialysis should be an available option for any patient who is clinically suitable. Patients may wish to exercise this choice after some time on a different type of treatment. Minimising the impact of dialysis on lives, enabling patients to continue to work, care for children or other family members, and travel is fundamental. For some patients, psychological support is needed and may help patients to continue dialysis if they wish to do so.

The lifelong nature of treatment means transport to dialysis sessions in hospital is much more than a convenience. Patient transport is an essential part of the patient experience. Poor transport can undermine good dialysis care and have a major impact on patients' quality of life. The 2012 Kidney Patient Transport Audit (65) showed that two-thirds of patients who travelled for haemodialysis did so using hospital transport.

While it indicated improvements in transport arrangements since the previous audit in 2010, around one-third of users reported delays of more than 30 minutes in pick-up times on outward and return journeys and journey times of over 30 minutes each way, caused by multiple pick-ups or drop-offs. In some cases, 45 minute journeys could take up to two hours.

Transport must be an integral part of dialysis care and must be organised in a patient-focused way. Funding for patient transport should be clearly identified and detailed specifications, to which patients have had the chance to contribute, should be included within any transport contract.

**“ My father has transport to take him to and from dialysis. I would like some time targets for the timely arrival of transport, to maximise efficiency for renal units, but more importantly for quality of life so the least amount of time is spent hanging around waiting. ”**

**“ Home haemodialysis has given me my whole life back, and I love it ”**



## CARE FOR CHILDREN AND YOUNG PEOPLE WITH KIDNEY DISEASE

### Ambition 12

**All children and young people with chronic kidney disease have unrestricted access to a service specifically designed to meet their needs.**

#### Key factors

- Children and young people with kidney disease have access to a paediatric specialist renal multi-professional team.
- Paediatric renal networks support the delivery of care shared between renal unit and local paediatric teams, to enable access to specialist services as close to home as possible.
- All young people with chronic kidney disease are supported by a transition programme, whether they are already known to paediatric renal services or enter directly into adult services.
- Paediatric and adult renal services work together and communicate effectively to ensure that young people's care is always centred on the patient and their parents and carers.
- Transition is offered to young people with kidney disease at the age of 11 if developmentally appropriate, and continues until the young adult is in their twenties, and is therefore recognised as an important issue for both paediatric and adult services.
- Transition programmes are delivered by a multi-professional team that includes youth workers, which addresses young people's medical, psychological, social, learning and vocational needs, enabling them to become more confident and take control of their condition, whilst addressing the needs and concerns of parents and carers.

#### Commentary

Kidney disease in children and young people is significantly less common than in adults. National care in the UK is delivered from 13 paediatric renal centres so many families have a considerable distance to travel when accessing services at their closest paediatric renal centre. Whilst children do require distinct specialised care from adults, accessing services for children separately from those for adults and the long distances involved, represent an additional significant burden for families.

There is emerging evidence that access to a multi-professional team in children and young people supports better clinical outcomes (70). General paediatricians do not usually have all the competencies or the team support necessary to manage children and young people with kidney disease locally, but the pathways providing specialist care closer to home that have been recommended in previous policy documents (71)(72) have not been fully established.

Structured networks of care providers can provide coordinated, high quality care, delivering as much treatment as possible close to home whilst ensuring the best possible outcome for the child (73). Developing working relationships between local link paediatricians and visiting nephrologists improves access to specialist advice and encourages timely referral.

These paediatric renal networks provide the framework to deliver care shared between specialist and local services, but require investment in network infrastructure to be sustainable (74).

The transition through adolescence can be difficult for all young people, but there are specific issues, challenges and needs in young people with a long-term condition or disability (75)(76) (77). In kidney care, young people who transfer from paediatric to adult services or present directly to adult services often struggle with adjustment issues and problems with denial and concordance. The rate of graft loss in adolescents with a renal transplant is high (78) and associated with poor transition into adult services (79).

Effective transition must be seen as an integral and routine component of the medical care provided to young people with kidney disease. Good transition empowers young people to take a full part in the management of their kidney condition more effectively in the long term, and must be seen as an important area by providers of both paediatric and adult renal services.

Transition programmes should be delivered by a multi-professional team that places the young person at the centre of decision-making and gradually empowers and equips them with the necessary knowledge and skills (80). The provision of young person friendly care in paediatric and adult services (81), for example through age-appropriate clinics for young people and the availability of a service directory with information on lifestyle, useful contacts and links to additional information, can support the most important elements of transition.

***“ This was not done when I got to this age  
- it is very very important as I felt totally lost. ”***

***“ Must also consider the need for support for parents too whilst their child is  
in paediatric unit and in transition ”***



## ALLIED SERVICES

### Ambition 13

**All people with advanced kidney disease know about and have access to a specialist multi-professional team.**

#### Next Steps

- All people with advanced kidney disease (normally chronic kidney stages 4 and 5, including those that choose conservative care and people with transplants, but also others that need it) are made aware of the benefits of specialist allied health professionals, including dietitians, counsellors, social workers, physiotherapists and pharmacists, in improving outcomes and quality of life, and are proactively offered and able to access the full range of services relevant to their needs.
- Advice on diet and lifestyle is offered throughout all stages of kidney disease and support from specialist renal dietitians made freely available for people with more advanced disease.
- All people with advanced kidney disease have access to timely psychological support, which is centred on the patient but also offers help to their immediate family or carers.
- All people with end-stage renal disease have access to social support (which may include support with personal, family, financial, employment and/or social needs) appropriate to their circumstances.
- All staff providing services to patients from black and minority ethnic backgrounds are given basic training so that they have an understanding of the cultural and religious aspects.
- People with kidney disease have prompt access to other specialties where investigation or treatment is required for a co-existing or complicating condition, for example dermatology in patients taking immunosuppressive medication or cardiology in people undergoing work-up for transplantation.

- Healthcare professionals working in primary care are educated so that people with less advanced kidney disease are readily able to access advice on practical (for example advice with travel insurance), physical (for example diet and exercise) and psychological issues.

#### Commentary

Specialist allied healthcare professionals play a vital role in advising, treating and supporting people with kidney disease to achieve better medical outcomes and quality of life. However, many people are not informed about the help that these practitioners offer and are frequently unaware of the psychological and social support services that should be available to them. Access to allied services is inadequate, inconsistent, and is not always coordinated with other aspects of kidney care (52).

People with advanced kidney disease need individualised care plans that include guidance on many lifestyle and medical factors, which can include fluid intake, diet, anaemia management, treatment of chronic kidney disease (CKD) mineral bone disorder, and assessment for suitability for transplantation. Expertise in the medical, surgical, nursing, dietetic, pharmacological, psychological and social issues unique to these patients is essential. This care can only be provided through a multi-professional team of specialists, rapidly able to shift and coordinate care as the patient's needs change. For some of these areas, a proportion of this need is still met by voluntary organisations; this is not sustainable. (82).

Dialysis patients have particular psychological, social and dietary needs but have variable access to support from allied services. It is important that the full range of services is provided by professionals experienced in treating kidney patients. Transplant patients generally receive far less support, despite the potential value of such advice to maintain their graft and their quality of life. Allied care for other people with kidney disease who need it tends to be still more limited.

Pharmacy support is often not integrated into multi-professional care. If it is included, it may be provided by pharmacists with no experience in treating kidney patients. This is very important because kidney patients may require dosage titration of medication due to their impaired kidney function and are at increased risk of medication-related adverse events. Community pharmacists, though not expert in treating kidney patients, can make medicines management safer, but need systems in place so they are aware of a CKD diagnosis and support from specialist pharmacists to do so (83).

Allied services should be provided in the setting of a patient's ethnicity, religion and culture. In particular, the dietary advice to black and minority ethnic group patients should be specific. Staff should be trained so they are aware, for example, of the differences between Muslim patients who are from Bangladeshi and Pakistani backgrounds.

People with kidney disease frequently require advice and treatment from other specialties for conditions that complicate or are otherwise related to their renal conditions. It is a source of frustration and risk, when patients with advanced renal disease are unable to access these services directly at the request of their renal specialists, but have to return to their GP to be referred. Examples of this include dermatology reviews in transplant patients, all of whom are at risk of skin cancer, and cardiology input in people undergoing transplant work-up. Appropriate local pathways must be designed and agreed so care is more streamlined, efficient and safe.

Although their needs may be different from those with more advanced disease, people at an earlier stage of CKD are particularly unsupported, with little help available on practical matters (for example advice with travel insurance), general dietary, lifestyle or psychological issues. Both patients and non-specialist healthcare professionals need access to the educational resources

and tools needed to support patients in these areas. Exercise therapy, which can improve outcomes and increase quality of life in people with CKD (84), is not adequately promoted to patients at any stage of kidney disease. People who do attend a gym are often turned away because they have kidney disease (52), and better alliances between renal teams and external agencies are needed to support improved accessibility.

**“The community pharmacist pointed out a possible bad interaction between one of my ... tablets and another and suggested an urgent discussion with my kidney specialist. Goodness knows how this hadn't been spotted earlier!”**

**“I feel that the encouragement of physical activity I exercise should form part of the lifestyle package for dialysis patients.”**



## EXPERT CARE IN RARE KIDNEY DISEASES AND IN PREGNANCY

### Ambition 14

**All people with rare diseases affecting the kidney and women with chronic kidney disease who are contemplating pregnancy have unrestricted access to expert advice and care wherever they live and whenever it is needed.**

#### Key factors

- All people with rare kidney diseases, which include both inherited disorders and acquired conditions such as vasculitides have access to early accurate diagnosis including the latest genetic and biochemical testing and/or imaging, and regular monitoring. All people with rare kidney diseases have access to expert, coordinated multi-professional (and often multi-specialty) care, where possible in dedicated clinics, supported by effective information technology and disorder-specific care plans.
- All people with rare kidney diseases have access to effective drug treatment for their condition.
- The care of all people with rare diseases affecting the kidney includes the submission of data to a Rare Disease Registry (Renal RaDaR), where the person consents, to improve understanding and treatment of their disease.
- All people with rare kidney diseases have the opportunity to participate in research irrespective of where they live, to improve the future care of their condition, particularly where there is no current evidence base.
- All women with chronic kidney disease (including those treated by kidney transplantation or dialysis) have timely access to expert contraceptive advice and pre-pregnancy counselling.
- All women with chronic kidney disease (including those treated by kidney transplantation or dialysis) have access to expert antenatal care, ideally offered in an experienced combined renal/obstetric clinic so as to optimise outcomes for mother and baby.

### Commentary

Patients with rare kidney disorders and women with kidney disease (particularly more advanced disease) are two groups where expert specialist care is required but current provision is particularly inadequate and inequitable.

Both Rare Disease UK and the Department of Health have reported that the care of patients with rare diseases (defined by the European Union as a condition affecting fewer than 5 in 10,000 people), including those affecting the kidney, is poorly coordinated, and often beset by delayed or mis-diagnosis and inequity of access to centres providing expert clinics (85). The availability of specialist diagnostics (genetic and biochemical), drug treatments and the opportunity to participate in research is limited and dependent on where patients live. Many conditions are genetic in origin and most are diagnosed in childhood. Transition from paediatric to adult care is often uncoordinated and of variable quality, and needs to be improved (76).

Optimal treatment of patients with rare diseases may involve multi-professional care delivered by several specialties. Lack of coordination often results in patients not being seen by the relevant specialists or unnecessarily attending multiple investigative and/or out-patient clinics (often more than 30 visits per year). The result may be expensive, poor quality care leading to unnecessary illness and end organ damage or failure. The Renal Association and British Association of Paediatric Nephrology 'Rare Kidney Disease, an Integrated Strategy' initiative (86) has already led to some improvements. These include the development of national Rare Renal Disease Working Groups, high quality patient information, disease registries, and good practice clinical guidelines in a small number of diseases (87), but much remains to be done.

Patients with very rare kidney diseases will achieve the best outcomes if care for their specific disease is limited to a small number of specialist centres for that disease across the UK. Whilst these 'hubs' may not be geographically convenient to all patients, the use of intelligent IT and disorder-specific care plans should enable effective 'hub-and-spoke' arrangements, with most

care provided by local centres.

Drug therapies for some rare renal conditions are already available, but often acquisition costs are high. A pipeline of drug therapies is being developed. Commissioning coordinated services and funding of these therapies will allow patients to receive the best and most cost-effective care.

The UK Renal Registry has revolutionised audit of outcomes for patients with end-stage renal disease. A greater number of rare renal disease-specific registries covering the entire spectrum of rare renal disorders would help to deliver coordinated care and monitor outcomes, and engage funding bodies and the pharmaceutical industry in much-needed research and development work. Research and drug development are strongly supported by patient groups, but both are limited by lack of access to study these patient groups. The Department of Health recognises the importance that advances in genomic technologies will have on the diagnosis and treatment of patients with rare diseases (88). We must ensure that patients with rare kidney disease are at the forefront of this revolution.

Care for women with chronic kidney disease who need advice on family planning or who are contemplating pregnancy is also very patchy across the UK and often poor. Women with chronic kidney disease (CKD), including those treated by kidney transplantation (or dialysis), are at increased risk in pregnancy. The evidence base for contraceptive advice for these women is limited and experience indicates that it is rarely given.

However, most women can achieve a successful pregnancy outcome if they (and their partners) have access to joint decision making in an expert pre-pregnancy counselling clinic, staffed by both expert renal and obstetric specialists. This allows proper planning for any pregnancy and informed decision-making on proceeding to pregnancy based on the risks for mother and baby.

It also helps with optimisation of the maternal condition for pregnancy, including appropriate changes in drug treatment, genetic advice where relevant and planning for best antenatal care. Women with CKD who are pregnant need intensive antenatal monitoring and are best cared for in established expert joint renal/obstetric clinics with individualised care plans (89). These care plans should include arrangements for post-natal management.

The evidence base on managing pregnancy in kidney disease is extremely limited and women should also be given the opportunity to participate in research to improve outcomes for mother and baby.

**“ ..Relevant information is not available even though changes to medications and other precautions are crucial....having had a transplant at 13 and now married, this is important to make an informed decision ”**

**“ As no-one recognised that I had kidney disease the birth of my first child was beset with distressing complications for me and my daughter. ”**

## RESEARCH

### Ambition 15

**A research strategy for kidney disease is developed, supported by the funding required to design and conduct high quality studies, and used to further understanding of the mechanisms of disease and improve healthcare quality and outcomes.**

#### Key factors

- Priority areas for research in kidney disease, focused on the needs of kidney patients and including the full spectrum of renal disorders, are identified.
- Funding is made available from national bodies to support high quality basic science, applied and translational research into priority areas.
- People with kidney disease are meaningfully involved in the design and conduct of research studies.
- A culture where participation in research is seen as the norm is developed within all renal units, with centres of excellence developing research networks to encourage research within local units, boosting recruitment into multi-centre trials.
- The recognised strengths of the kidney community's registries and databases are used to develop the evidence base for conditions where it may not be feasible to conduct randomised studies.
- The results of research studies are used to identify targets for quality improvement so that research findings are consistently implemented in routine clinical practice, providing better system performance and outcomes for people with kidney disease.
- The role of improvement science in determining which quality improvement strategies are effective within complex healthcare systems is widely recognised and supported through well-designed and evaluated improvement studies.

Research of all types, quantitative and qualitative, basic, applied and translational, provides the foundations upon which advances in healthcare are built. Research, defined as the "generation of new knowledge by addressing clearly defined questions with systematic and rigorous methods" (90) furthers our understanding of disease, allows the development of targeted treatments and supports all clinical developments to improve patient care.

However at present, much of renal clinical care lacks good quality evidence upon which to base practice. Randomised controlled trials are scarce, and we lag well behind other specialties in the culture of recruitment of patients to clinical studies.

A research strategy should be developed to address the most important deficiencies in our knowledge, and the culture to deliver this programme developed within all renal units, supported by centres of excellence. We need high quality research across the entire spectrum of renal disorders outlined in this document. In this way we will increase our understanding of the basic mechanisms of kidney disease and improve clinical care. Better evidence is required to reduce cardiovascular risk, inform patients how to self-manage effectively, measure and improve quality of life, prevent or delay disease progression, prevent, treat acute kidney injury, help people choose a treatment for end-stage renal disease, improve access and outcomes in transplantation, deliver better dialysis, improve the care of children and young people, and treat and support people with rare kidney disorders.

Within these, and other areas of research interest in kidney disease, are important questions of immediate relevance to all five domains of the 2013/2014 NHS Outcomes Framework, which sets out the high-level outcomes that the NHS should be aiming to improve (91). This policy imperative is further supported by a well-developed Kidney Research Consortium (92), a history of meaningful patient involvement in research, a fully integrated team of allied healthcare professionals who care for people with kidney disease, and highly developed registries to

provide evidence for conditions and situations where randomised controlled trials are not feasible. Together this should allow the design of high quality studies that will attract the funding that must be made available to support research in this country.

A sound evidence base is necessary but not sufficient to deliver the best and most cost-effective care to patients. Uptake of research findings into routine clinical practice is also required. The results of research studies should be used where appropriate to identify targets for quality improvement and to close the gap between what is known and what is practised. Quality improvement itself should be supported by the widespread application of improvement science to research effective techniques, strategies and theories that can then be used widely by many teams in different settings to undertake quality improvement well (93).

**“ Research into transition has now taken off, however more needs to be done to see that there is a universal transition framework / guideline for youngsters coping with CKD. ”**

**“ My diabetes was diagnosed four years after my transplant and I am pleased to see that research has shown a link. This will help new patients to look more carefully at pros and cons when making decisions about their treatment. ”**





## CONSERVATIVE CARE

### Ambition 16

**All people who opt for conservative non-dialytic management of their kidney disease or choose to discontinue dialysis treatment are supported by a multi-professional team working closely together to ensure a smooth transition to palliative and end of life care.**

#### Key factors

- Patients and their families or carers are given sufficient information, time and support, to make decisions about non-dialytic and end of life care, which includes, at the appropriate time, discussion about the preferred place of care and place of death.
- All professionals treating patients with advanced kidney disease are trained to initiate and manage discussions with patients and their carers about non-dialytic and end of life care.
- Conservative care is provided by a multi-professional team, including renal and palliative specialists, general practitioners, community nurses, counsellors and social care agencies, who have the required skills and experience and communicate effectively.
- Patients receiving conservative treatment and their families or carers, remain at the centre of care with patients being offered palliative input and symptom management continuously tailored to their needs as they approach end of life, to allow the best possible death.

#### Commentary

Dialysis saves lives. However, dialysis in people with multiple co-morbidities may prolong life for only a limited period and reduce quality of life considerably (94). The concept of a “good life and a good death” should form the basis all renal conservative management. People struggling with the burden of disease face a balance between prolongation and quality of life. In such

situations, treatments can extend life at the cost of quality (95). Renal conservative care involves withdrawing or not embarking on dialysis, whilst carefully and proactively providing all relevant treatments including medication, symptom control and psychological support to ensure the best quality of life and death possible.

All patients should be given the information necessary to make a choice regarding dialysis. Discussing death is never easy for a patient, their family or the clinician, and the healthcare professionals involved need the appropriate training to handle these conversations with skill and sensitivity.

Intensive input from a skilled multi-professional team is as important for conservative care as it is for dialysis treatment or transplantation. Planning alone is insufficient unless the elements of a support network for each patient are put in place. Specialists, including counsellors with renal and palliative expertise, general practitioners and community nurses are all required to provide a patient-focused service, supported by input from social care agencies.

The needs of patients and their families or carers receiving supportive care will change over time. The transition to, but also the maintenance of, high quality conservative care requires flexibility and good communication between all involved parties to ensure that it is smooth. Renal services must have the links and resources in place to keep people who choose non-dialytic treatment or withdraw from dialysis comfortable and provide care right up to their death.

**“ Quality of life should be a key ambition for everyone involved in the treatment of kidney disease and this should include the choice of the kind of care you receive if you become so ill you have literally “had enough” ”**

**“ Multi professional teams include the patients. ”**



## APPENDIX 1 : HOW THIS REPORT WAS PRODUCED.

Kidney Health was an initiative of the Kidney Alliance, which included the following organisations: Association of Renal Managers, British Kidney Patient Association, British Renal Society, Kidney Research UK, National Kidney Federation, Renal Association, Renal Nutrition Group, and the Royal College of Nursing (Nephrology Forum).

The Kidney Health team was assembled in October 2012 to provide advice, guidance and support to the authors of the report. Its membership was drawn from the patient and professional organisations that made up the Kidney Alliance.

The authors gathered evidence and expert comments from a wide variety of sources, spanning the entire kidney care pathway. The sources included people with kidney disease, healthcare professionals from primary care, specialist renal practitioners (medical, surgical, nursing and allied healthcare professionals) and commissioners.

Evidence was obtained in a number of different ways:

- A critical review of the Renal National Service Framework (Parts 1 and 2).
- Original desk research conducted by the authors, or under their supervision.
- Written contributions from a number of patient and professional bodies in renal medicine including the British Association of Paediatric Nephrology, British Kidney Patient Association, British Renal Society, British Transplant Society, Kidney Research UK, National Kidney Federation, Renal Association, and the Renal Nutrition Group.
- An evidence gathering day held on 18th June 2013 (at the Imperial Hotel, Russell Square, London) and attended by over 40 medical professionals, commissioners and patients.
- Subsequent written submissions received from attendees at the evidence gathering day.
- Individual interviews with experts in specific aspects of kidney care.

The evidence was used to create a draft report, which was the subject of a three-week on-line

consultation. 75% of the respondents to the consultation were people with kidney disease. Further comments on the draft were received at a stakeholder feedback meeting held on 19th September 2013 (at Portcullis House, Westminster, London) attended by representatives from the main patient and professional groups.

Comments from the consultation and stakeholder feedback meeting were incorporated into the final document, which was then subjected to a plain English test.

The quotations used in the document were taken from a number of the sources described above.

The paper was co-authored on behalf of the Kidney Health team by Fiona Loud, Policy Director of the British Kidney Patient Association and former Director of the Kidney Alliance, and Dr Hugh Gallagher, Consultant Nephrologist, Epsom and St Helier NHS Trust.



## APPENDIX 2 : ACKNOWLEDGEMENTS

The Kidney Health report was developed by patients and professionals working together throughout.

The Kidney Health team are:

Dr Abraham Abraham, Alan Craig, Dr. Hugh Gallagher, Andrew Greaves, Fiona Loud, Jane Macdonald, Michael Nation, Tracey Rose, Marcelle de Sousa, Carli Wall, Louise Wells.

The Kidney Health team would like to acknowledge the help and support of the following organisations during the preparation of this report:

Association of Renal Managers

British Association for Paediatric Nephrology

British Kidney Patient Association

British Renal Society

British Transplantation Society

Diabetes UK

NHS Blood and Transplant

Kidney Research UK

National Kidney Federation

Renal Association

Renal Nutrition Group

Royal College of General Practitioners

Royal College of Nursing Nephrology Forum

UK Renal Registry

The Kidney Health team is very grateful to the many people who have contributed towards this document as an individual or through their organisations, including:

Lisa Burnapp, Phil Carlick, Ron Cullen, Glyn Davies MP, Professor Azhar Farooqi, Dr Richard Fluck, Dr Roger Greenwood, Dr Kathryn Griffith, Elaine Hanson, Jane Hattersley, Jonathon Hope, Professor Fiona Karet Frankl, Dr Graham Lipkin, Dr Iain MacPhee, Lorna Marson, Dr Christian Martin, Baroness Masham of Ilton, Dr Emma Murphy, Dr Arvind Negra, Professor James Neuberger, Nick Palmer, Dr Paul Stevens, Dr Rebecca Suckling, Dr Charlie Thomson, Dr E Jane Tizard.

The Kidney Health team would also like to thank:

All the attendees at the evidence gathering day, 18th June 2013

All the respondents to the Kidney Health consultation, September 2013

All the attendees at the stakeholder feedback meeting, 19th September 2013

The team would particularly like to acknowledge the contribution of Andrew Greaves.

The team are grateful for editing support from Carli Wall, Shahid Muhammad, Helen Lore, and Celia Heley.

The following organisations have supported this independent report with unconditional grants:

Baxter Healthcare, Fresenius Medical Care Renal Services, Takeda UK Ltd, Shire Pharmaceuticals.



## APPENDIX 3 : GLOSSARY & ABBREVIATIONS

**Acute kidney injury** A rapid loss of kidney function. It has many causes and often occurs as a complication of other conditions (e.g. infection and dehydration). People with pre-existing chronic kidney disease are particularly susceptible.

**Albumin: creatinine ratio** A urine test to determine whether albuminuria is present.

**Albuminuria** The presence of albumin (protein) in the urine. It is a sign of damage to the kidney and helps determine the stage of chronic kidney disease.

**Allied Services Healthcare** services distinct from medicine and nursing. Allied healthcare professionals have a very important role in caring for people with kidney disease.

**Assisted peritoneal dialysis** Where people receive help to perform peritoneal dialysis at home, from either a healthcare worker or carer.

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

**Conservative care** Full supportive treatment for those with advanced kidney failure who decide against starting dialysis or choose to discontinue dialysis.

**Donation after brainstem death** The retrieval of organs for transplantation from a person in whom the heart is still active but after death has been confirmed using tests of brain activity.

**End-stage renal disease** The stage in kidney disease when a person's kidneys fail and dialysis treatment or a transplant is required to sustain life.

**Estimated glomerular filtration rate** A measure of how well the kidneys are cleaning the blood. It is calculated from a blood test and helps determine the stage of chronic kidney disease.

**Graft** A transplanted organ.

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

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

**Information Governance** Set of standards that the NHS follows to make sure that full and accurate records of care are kept and handled securely and confidentially.

**Intercurrent illness** Illness occurring during the course of another disease (e.g. a person with chronic kidney disease developing a chest infection).

**Multi-professional team** A group of people from different professions and agencies who work together to meet the needs of patients.

**Peritoneal dialysis** A treatment for kidney failure which uses the body's natural membrane in the abdominal cavity to clean the blood.

**Pre-emptive (kidney) transplant** A kidney transplant which is performed before the need for dialysis. It offers many advantages to those who are medically suitable.

**Quality and Outcomes Framework** A voluntary incentive scheme for GP practices, rewarding them for how well they care for patients. Chronic kidney disease was included in the QOF in 2006.

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

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

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

**Transition programme** A programme for making all the changes that need to take place as a young person moves from children's services into the adult world and adult services.

**Silo management** Where different conditions that a person has (e.g. chronic kidney disease, diabetes and cardiovascular disease) are treated separately rather than together.

**Vascular access** A method of establishing a point of entry to the bloodstream so that haemodialysis can be performed.

**Vasculitides** A group of disorders where the underlying cause is inflammation of a blood vessel. They are an uncommon but serious cause of kidney disease.



AKI	Acute kidney injury
CKD	Chronic kidney disease
DBD	Donation after brainstem death
ESRD	End-stage renal disease
eGFR	Estimated glomerular filtration rate
HD	Haemodialysis
NHSBT	NHS Blood and Transplant
MRSA	Methicillin-resistant staphylococcus aureus
NICE	National Institute for Health and Care Excellence
PD	Peritoneal dialysis
QOL	Quality of life
RRT	Renal replacement therapy

## APPENDIX 4 : REFERENCES

The National Service Framework for Renal Services was published by the Department of Health in two parts in 2004 and 2005:

### Part 1: Dialysis and Transplantation

([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/199001/National\\_Service\\_Framework\\_for\\_Renal\\_Services\\_Part\\_One\\_-\\_Dialysis\\_and\\_Transplantation.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199001/National_Service_Framework_for_Renal_Services_Part_One_-_Dialysis_and_Transplantation.pdf))

### Part 2: Chronic Kidney Disease, Acute Renal Failure and End of Life Care

([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/199002/National\\_Service\\_Framework\\_for\\_Renal\\_Services\\_Part\\_Two\\_-\\_Chronic\\_Kidney\\_Disease\\_Acute\\_Renal\\_Failure\\_and\\_End\\_of\\_Life\\_Care.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199002/National_Service_Framework_for_Renal_Services_Part_Two_-_Chronic_Kidney_Disease_Acute_Renal_Failure_and_End_of_Life_Care.pdf))

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**Kidney Health : Delivering Excellence**

**The Kidney Health Advisory Group, 2013**

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British Association of Paediatric Nephrologists [www.bapn.org.uk](http://www.bapn.org.uk)

British Kidney Patient Association [www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)

British Renal Society [www.britishrenal.org](http://www.britishrenal.org)

British Transplant Society [www.bts.org.uk](http://www.bts.org.uk)

Kidney Research UK [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

National Kidney Federation [www.kidney.org](http://www.kidney.org)

Renal Association [www.renal.org](http://www.renal.org)