

# *The National Service Framework for Renal Services*

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

**DH INFORMATION READER BOX**

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Acute Renal Failure and End of Life Care

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# Foreword



It is a little over a year since part one of the *National Service Framework for Renal Services* was published to deliver fairer, faster and better services and to give people more treatment choices. We are already seeing results from the extra investment going into the NHS for renal services. National survey data show that dialysis capacity is expanding fast and UK Transplant has reported the highest number of kidney transplant operations for fourteen years. These are good early signs that the programme for change is working, improving access and raising quality of care.

We still have some way to go but we are determined to deliver further improvements through part two of this National Service Framework. The *NHS Improvement Plan* together with *Supporting People with Long Term Conditions* set out our priority to improve the care for people with long-term conditions by moving away from reactive care based in acute systems, towards a systematic, patient-centred approach. This document demonstrates how this approach can improve the care of people with chronic kidney disease. Local organisations will also want to consider how they can make integrated care a priority for people living in deprived areas or underprivileged circumstances, especially those who are older or of South Asian or African Caribbean ethnic origin, who are more susceptible to conditions such as cardiovascular disease and diabetes which increase their risk of developing chronic kidney disease.

This part of the National Service Framework breaks new ground for renal services. It considers measures that can be taken, mostly in primary care, to prevent chronic kidney disease developing in the first place, or to slow down the progression of kidney damage when a diagnosis has been made. This builds on part one and on our Public Health White Paper *Choosing Health*. There is good evidence that early interventions, better care and treatment, and life-style changes can not only reduce the risk factors associated with coronary heart disease and diabetes, but also chronic kidney disease.

This document also sets out a programme to address the management of acute renal failure. This is a very serious condition often requiring support from critical care units, with far reaching consequences for many other hospital services. Sadly, the death rate in people with acute renal failure is unacceptably high. It is important therefore to develop co-ordinated strategies both to prevent and treat this condition and, wherever clinically feasible, to prevent survivors from becoming reliant on dialysis or kidney transplantation.

Finally, we aim to support people with established renal failure to live life as fully as possible and enable them to die with dignity in a setting of their own choice.

The standards-based system heralded by *Standards for Better Health* makes it clear that National Service Frameworks are key to supporting improvements in service quality. Together with guidance from the National Institute for Clinical Excellence they are integral to the new system. Some of the terminology is changing: from now on National Service Frameworks will establish 'Quality Requirements', underpinned by the best evidence available, which describe the principles of care that clinicians and others will use to guide their practice. Over the course of the three year planning period NHS

organisations' performance will be assessed not just on whether they are meeting national targets, but increasingly on whether they are delivering high quality services across a range of areas, including National Service Frameworks.

I would like to thank Dr Donal O'Donoghue and Sarah Mullally, and members of the External Reference Group, for their advice on this part of the National Service Framework, and members of the Renal Advisory Group for their support.<sup>i</sup>

A handwritten signature in black ink, reading "John Reid". The signature is written in a cursive style with a long horizontal stroke extending to the right.

John Reid  
Secretary of State for Health

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i Full details of the membership of the External Reference Group and the Renal Advisory Group are included at Annex A.

# Executive summary

## Part one of the National Service Framework for Renal Services

Part one of the National Service Framework (NSF) for Renal Services, published in 2004, established five standards for dialysis and transplantation for people with established renal failure. It stated that by 2014 the NHS will need to deliver:

### Standard one: A patient-centred service

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

Note: this standard applies across the whole of this NSF.

### Standard two: Preparation and choice

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

### Standard three: Elective dialysis access surgery

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

### Standard four: Dialysis

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

### Standard five: Transplantation

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

## Part two of the National Service Framework for Renal Services

Part two of this NSF follows *Standards for Better Health*<sup>1</sup>, which sets out a new framework of standards and promises the NHS fewer national targets. In keeping with this, part two identifies four quality requirements covering chronic kidney disease, acute renal failure, and end of life care. Quality requirements are drawn from and mapped against the core and developmental standards and their domains to be found in *Standards for Better Health*. They are aimed at supporting the NHS locally in delivering those standards in renal services, and helping local health communities to interpret the *Standards for Better Health* in their own service area.

The quality requirements are designed to bring about improvements in the overall health experience for people with kidney disease. They recognise trends in healthcare, supported by the emergence of a new public health agenda, an increasing awareness of the impact of acute renal failure on NHS services, and recent initiatives to spread palliative care beyond cancer into other chronic conditions.

### Quality requirement one: Prevention and early detection of chronic kidney disease

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

### Quality requirement two: Minimising the progression and consequences of chronic kidney disease

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

### Quality requirement three: Acute renal failure

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

### Quality requirement four: End of life care

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

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

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i *Standards for Better Health* is published as part of *National Standards, Local Action*, and is available at [www.dh.gov.uk](http://www.dh.gov.uk)

## Next steps

*The NHS Improvement Plan* makes it clear that in future the NHS will have fewer performance targets, but a stronger emphasis will be placed upon standards and quality requirements by which patients can judge the performance of the NHS. In keeping with this philosophy, local health organisations can use this NSF to inform the delivery of local services.

### Step one: Integrating care pathways

Renal networks can establish links with coronary heart disease and diabetes networks, and consider the scope for integrating the care pathways to manage and reduce the impact of these interacting long-term conditions in primary and secondary care.

### Step two: Early identification of people at risk of chronic kidney disease

Building on care pathways in coronary heart disease and diabetes, primary care can identify people at increased risk of developing or having undiagnosed chronic kidney disease and test their kidney function.

### Step three: Testing kidney function

Local health organisations can work with pathology services and networks to develop protocols for measuring kidney function by serum creatinine concentration together with a formula-based estimation of glomerular filtration rate (estimated GFR), calculated and reported automatically by all clinical biochemistry laboratories.

### Step four: Reducing emergency bed days

Local health organisations setting local plans and targets to deliver the Public Service Agreement on long-term conditions can take this NSF into account in determining how to improve patients' experience and outcomes and reduce emergency bed days.

### Step five: Tackling acute renal failure

Guidance on pre-operative testing from the National Institute for Clinical Excellence needs to be followed in all surgical units. Primary Care Trusts and specialised commissioners can work closely with critical care and renal clinical networks to develop strategies to prevent episodes of avoidable acute renal failure, thus reducing avoidable hospital admissions, and facilitate access to appropriate specialist care.

### Step six: Improving end of life care for people with established renal failure

Renal networks can establish links with palliative care services to improve end of life care for people with established renal failure by using the *Gold Standards Framework*, the *Liverpool Care Pathway for the dying patient* and the *Preferred Place of Care* tools to support all those nearing the end of their life to have choice in their treatment and in where they die.

# Chapter one: Setting the scene

## Introduction

- 1 Part one of the National Service Framework (NSF) focused on key issues for care of patients with established renal failure (ERF)<sup>i</sup>. It looked at preparation for renal replacement therapy (RRT)<sup>ii</sup>, and treatment by dialysis or transplantation. Part two focuses on chronic kidney disease (CKD)<sup>iii</sup> and its identification and management in primary care to minimise its consequences. This part also considers how acute renal failure (ARF)<sup>iv</sup> can be optimally managed, in particular to minimise the risk of people developing CKD. Finally the NSF looks at the care of people with ERF at the end of their lives.
- 2 The requirement that patients become informed partners in their care, with a personal care plan, applies equally across parts one and two.
- 3 This chapter provides the background and context for the quality requirements. Chapter two sets out the four quality requirements and 23 markers of good practice for implementation. In chapter three six steps are identified which will support delivery of the quality requirements and markers of good practice, and help local health organisations in planning and prioritising the implementation of this NSF. Chapter four covers the national programmes which are planned or already under way to underpin implementation and support the development and delivery of local services.

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i ERF (sometimes called end-stage renal failure, ESRF): chronic kidney disease which has progressed so far that renal replacement therapy is needed to maintain life. A glossary of terms is published at [www.dh.gov.uk](http://www.dh.gov.uk)

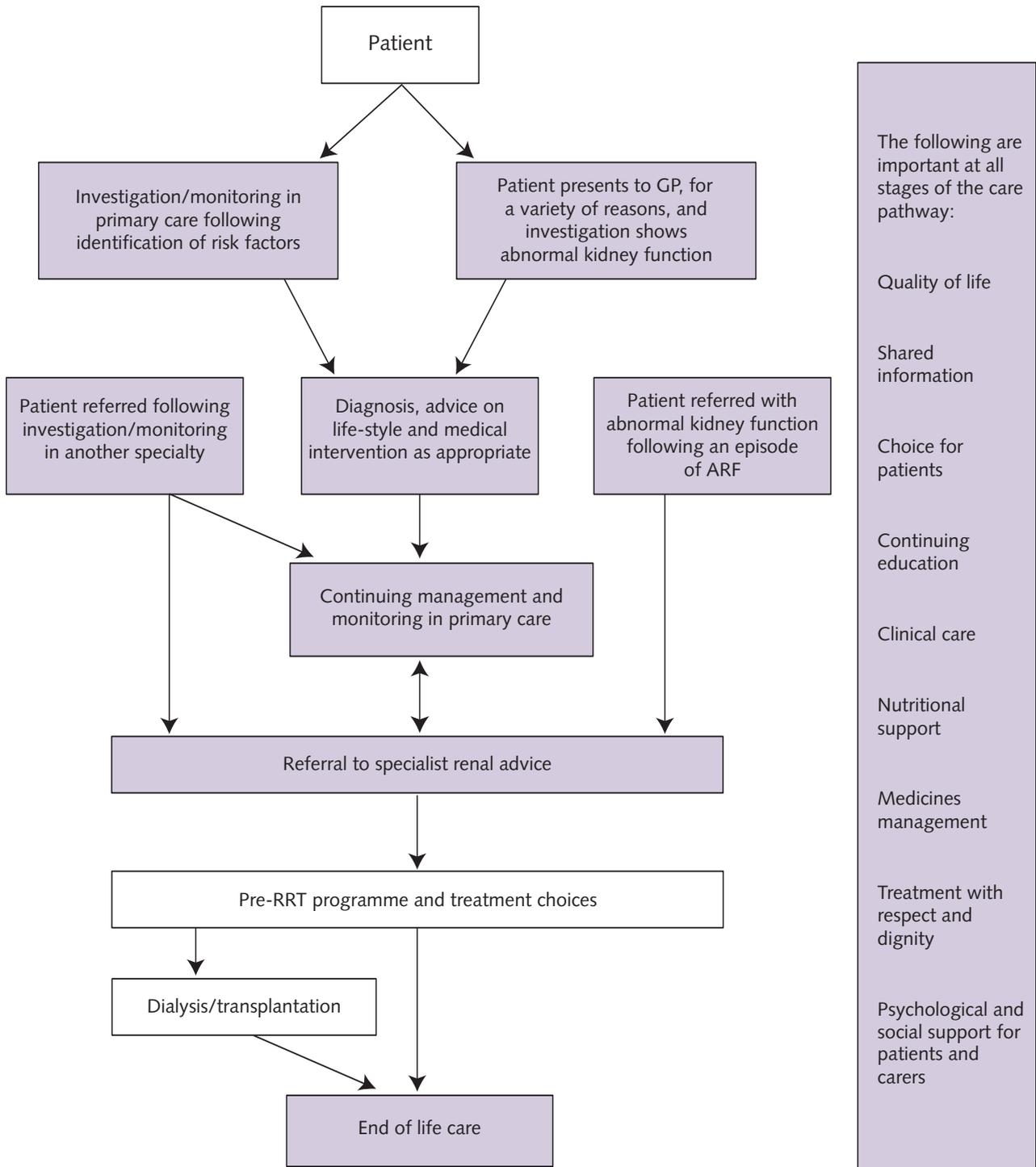
ii RRT: dialysis or transplantation.

iii CKD: kidney disease which develops slowly and is irreversible and usually progressive.

iv ARF: rapid onset of kidney failure caused by injury or illness; often reversible.

Figure one: Care pathway for chronic kidney disease

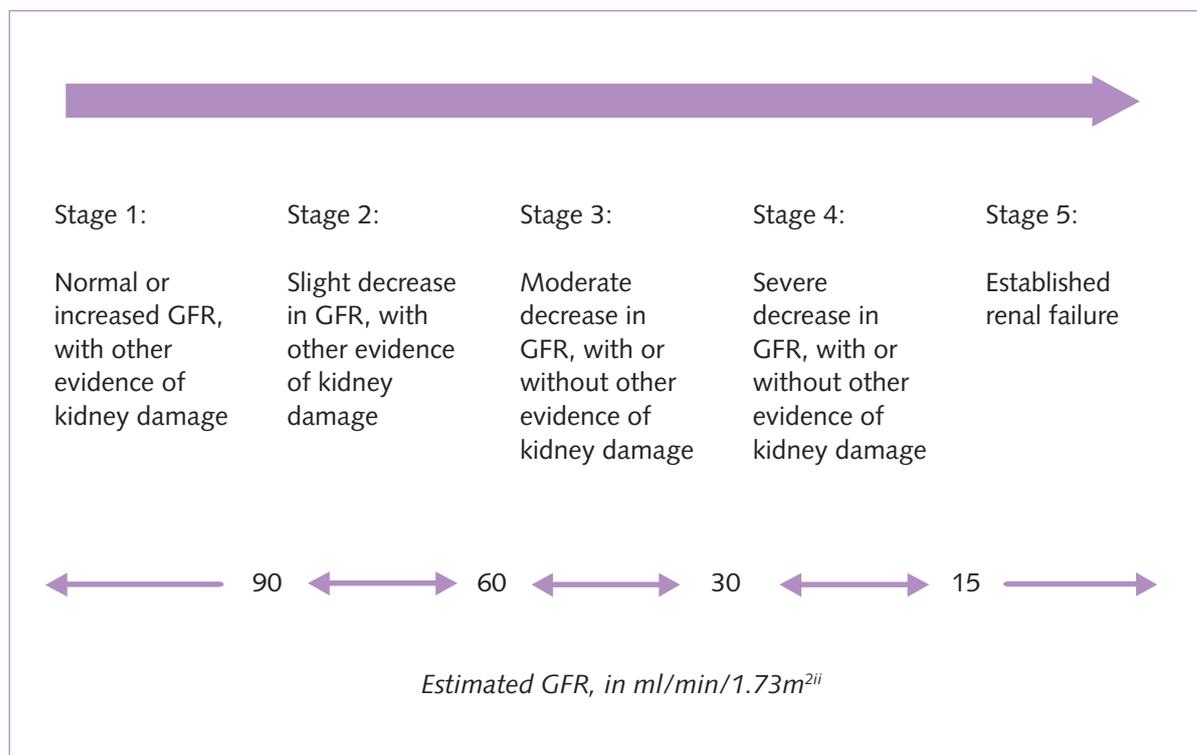
The highlighted areas are covered in this part of the NSF



## Chronic kidney disease

- 4 Chronic kidney disease (CKD) is a long-term condition. It is often progressive. It may involve damage or abnormality in both kidneys, signs of which appear in the blood, urine or in X rays or scans. It may involve a loss of kidney function, with or without other evidence of kidney damage. At its mildest it can be almost undetectable, and for the majority of people with CKD the main risk is cardiovascular disease. However an important minority of people will go on to develop established renal failure (ERF), which is fatal without treatment by dialysis or a kidney transplant.
- 5 The figure below sets out a description of five stages of CKD, using an estimated Glomerular Filtration Rate (GFR)<sup>i</sup> to measure kidney function. It is based on the international classification developed by the US National Kidney Foundation in their Kidney Disease Outcomes Quality Initiative (K/DOQI).<sup>1</sup> Different formulae are used in the calculations for adults and for children and young people.

Figure two: Stages of chronic kidney disease



- 6 An estimated GFR between 60 and 90 does not, on its own, indicate CKD. Only a minority of people with stage 1 or 2 CKD will go on to develop more advanced disease, and symptoms do not usually appear until stage 4. However, early identification of CKD is important as it allows appropriate measures to be taken, not only to slow or prevent the progression to more serious CKD but also to combat the major risk of illness or death due to cardiovascular disease. Early detection also allows timely referral to secondary care. As kidney function deteriorates complications increase, such as anaemia; imbalances of calcium and phosphate, leading to renal bone disease and calcification of the blood vessels; and in children, poor growth and development.

i Glomerular Filtration Rate: the rate at which kidneys filter waste products. It reflects the percentage of normal filtration function remaining. For its use as an indicator of renal function, see quality requirement one.

ii The unit used for estimated GFR.

- 7 Children with CKD most often present in early childhood. Many are not detected because a level of kidney function which is abnormally high for a small child is normal for an adult. Early diagnosis and optimal management are particularly important for children and young people because they will have CKD for life, and long-term consequences such as cardiovascular problems and bone disease will have time to develop.

## How many people have chronic kidney disease?

- 8 Recently international studies have begun to focus on the true prevalence of CKD in the population. A survey of blood samples carried out in the South East of England in 2000/01<sup>2</sup> found the prevalence of diagnosed CKD to be 5,554 per million population (pmp). A large screening study carried out in the United States showed that as many as 5% of adults are in stages 3 to 5 of CKD, and another 5% may have stage 1 or 2 CKD. However this may be an over-estimate of prevalence as it was based on a single measure. Of those in stages 3 to 5 two thirds were over the age of 70, a quarter were known to have diabetes and three quarters had a history of hypertension.<sup>3</sup>
- 9 For older adults, as for small children, a slightly reduced level of kidney function is normal. People with an estimated GFR of more than 60, but with no structural abnormality or any other evidence of kidney disease, are therefore not considered to have stage 1 or 2 CKD, and there is no evidence that they have a higher risk of developing CKD or complications such as anaemia or bone disease.

## Acute renal failure

- 10 Acute renal failure (ARF) is sudden decline in kidney function, often occurring over hours or days. It can occur in people with previously normal kidney function or in those who have background CKD, which may or may not have been previously identified. If it is severe, extra-corporeal therapies<sup>i</sup> such as haemodialysis are required to keep the person alive. It often requires emergency treatment.
- 11 ARF, particularly in those with previously normal kidney function, is not commonly due to disease starting in the kidney, but it is important to identify this quickly as early treatment may slow or even reverse the kidney failure. More frequently injuries and diseases have the secondary effect of damaging the kidneys. Severe infection, particularly septicaemia, and other causes of low blood pressure such as blood loss, are among the commonest causes. ARF can develop post-operatively, particularly if infection occurs. Certain medications may also cause ARF.<sup>4</sup> The characteristics of the illness are those of the primary condition, but ARF itself contributes to the illness, for example by reducing consciousness and causing breathlessness. As well as the rise in concentrations of serum urea and creatinine,<sup>ii</sup> serum potassium<sup>iii</sup> may rise rapidly, risking disturbance to the rhythm of the heart, and the patient's blood frequently shows increased acidity.
- 12 Many people make a complete recovery from ARF, but some are left with CKD or even ERF. Mortality rates are very high, particularly among those who require dialysis, around half of whom die within 90 days of developing ARF,<sup>5</sup> almost always from the primary condition. Evidence on the proportion

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i Extra-corporeal therapies (ie therapies outside the body) include haemodialysis, haemofiltration and haemodiafiltration among others.

ii Serum urea and creatinine: the levels of urea and creatinine in the blood. These are waste products of metabolism which are usually removed via the kidneys.

iii Serum potassium: the level of potassium in the blood. Potassium is usually removed by the kidneys, and too high or low a level can cause a disturbance in the rhythm of the heart.

of patients developing ERF following an episode of ARF varies widely according to the patient groups studied and the setting. For those studied in an intensive care setting it varies from 7%<sup>6</sup> to 40%,<sup>7</sup> and outside intensive care, from zero<sup>8</sup> to 17%.<sup>9</sup>

## How many people have acute renal failure?

- 13 Relatively little is known about the numbers of people who develop ARF, and analysis of the evidence is complicated by varying definitions of the condition. In recent studies those treated for ARF ranged from 209 pmp<sup>10</sup> to 545 pmp.<sup>11</sup> It is clear, however, that the numbers with ARF have risen over the last fifteen years, and it is more frequent in older people and in those with co-existing illness, particularly cardiovascular disease.
- 14 The incidence of ARF in children in the UK, based on referral to regional paediatric renal units, is estimated to be 7.5 pmp per year.<sup>12</sup> The true incidence is likely to be greater as some children with ARF who do not require extra-corporeal therapy are managed by general or non-renal specialist paediatricians.

## End of life care

- 15 Standard one of this NSF states that people are to have access to information that enables them to make informed decisions and encourages partnership in decision making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life. As people reach the end of their life with ERF this approach is equally important, whether they decide not to accept RRT, withdraw from dialysis, or approach death while remaining on dialysis.
- 16 It is proposed that care plans for end of life care in ERF draw on the expertise of palliative care teams, as well as specialist renal skills, to ensure control of symptoms and thus enable a dignified death. Different cultures have different views of death and dying. Individual care plans will need to recognise the physical, psychological, social and spiritual needs of the individual; the importance of effective communication between the agencies involved and the patient, family and carers; and the need for bereavement support.

## Where kidney disease is treated

- 17 Primary and secondary care have complementary roles in the management of CKD, and will be most effective if services are co-ordinated. For example the identification of people with CKD and the management of the disease in its early stages can take place in primary care. This can avoid unnecessary travelling to hospital, reduce pressures on non-emergency patient transport and strengthen the capacity of primary care staff to care for people in their own homes, whether in a rural or urban setting. It may also be combined with the treatment of diabetes and coronary heart disease, and with public health measures to improve diet, reduce obesity and stop smoking. However links with secondary care for those needing complex investigations and those with ERF will enable access to the specialist renal team.
- 18 There is considerable scope for integrating the care pathways for diabetes, coronary heart disease and CKD to manage and reduce the impact of these interacting long-term conditions.

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i RRT for ARF will include many forms of artificial blood purification, but not transplantation.

- 19 People with ARF will be treated in secondary care. Of those who require RRT<sup>i</sup> around half are treated in an intensive care unit (ICU).<sup>13</sup> Many patients may be treated in a ward setting with, for example, fluids and antibiotics, and do not need RRT. Where necessary, access to the specialist renal team will need to be established.
- 20 The care of people at the end of their lives may involve secondary, hospice and primary care services, especially for those who wish to die at home.
- 21 *The NHS Improvement Plan* acknowledges that older people have a relatively high likelihood of chronic disease and long-term conditions. They make heavy use of healthcare services and are majority users of social care. People with CKD are often older, and many have co-existing illnesses. They need packages of care which co-ordinate and personalise their treatment, without requiring them to attend different clinics at different times in different places, as set out in *The National Service Framework for Older People*.

## The evidence base for markers of good practice

- 22 This NSF is based on the evidence currently available, but over the period of its implementation new evidence will emerge and new treatments will develop.
- 23 The evidence base for this part of the NSF was drawn from a range of sources and supported by systematic reviews carried out by a combined team from the NHS Centre for Reviews and Dissemination and the University of Aberdeen.<sup>1</sup> In addition views and experiences were sought from people with CKD, their families and carers; patient groups; professional staff and their associations, and from the private sector and industry.
- 24 The following typology has been used to distinguish the different levels of evidence supporting the markers of good practice underpinning the quality requirements in this part of the NSF:

### Levels of evidence

Level 1: Meta-analyses, systematic reviews of randomised controlled trials, or randomised controlled trials.

Level 2: Systematic reviews of case-control or cohort studies, or case-control or cohort studies.

Level 3: Non-analytic studies, eg case reports, case series.

Level 4: Expert opinion (in the absence of any of the above). This includes the views and experiences of people with renal failure and their carers.

## Conclusion

- 25 This part of the NSF sets out a vision for the modern management of CKD, improved arrangements for people with ARF, and the extension of palliative care to people with ERF who are at the end of their lives. It takes account of the need to:
- ensure the needs of individuals, regardless of race, gender, age, religion or beliefs, disability or sexual orientation, are reflected in care plans
  - achieve equity in the provision of services no matter where people live
  - adopt an integrated approach to primary, secondary and tertiary care services
  - assess the impact of CKD and ARF on other services and on hospital beds.

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<sup>i</sup> The evidence base will be published at [www.dh.gov.uk](http://www.dh.gov.uk)

## References

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### Figure three: Summary of standards, quality requirements and markers of good practice

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

#### Part one of the NSF:

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

##### Markers of good practice

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

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

##### Markers of good practice

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

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

##### Markers of good practice

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

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

##### Markers of good practice

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

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

##### Markers of good practice

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

## Part two of the NSF:

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

### Markers of good practice

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

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

### Markers of good practice

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

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

### Markers of good practice

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

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

### Markers of good practice

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

# Chapter two: The quality requirements

## Introduction

- 26 Since part one of this NSF was published the Government has launched *Standards for Better Health*, which underpins the delivery of high quality services which are fair, personal and responsive to patients' needs and wishes. It recognises the importance of adopting a common framework for all matters related to performance and a common language, so that terms such as 'standards' have a clearly understood, shared meaning. From now on the Department of Health will define standards as a means of describing the level of quality that healthcare organisations are expected to meet or to aspire to. 'Quality requirements' will be established through NSFs. These describe the care which clinicians and others will use to guide their practice.
- 27 Part two of this NSF identifies four quality requirements covering prevention of chronic kidney disease, acute renal failure and end of life care. They are drawn from and mapped against the core and developmental standards and their domains to be found in *Standards for Better Health*, and are aimed at supporting the NHS locally in planning and delivering those standards in renal services.
- 28 Quality requirements will also inform the Healthcare Commission in developing the criteria for assessment and inspection of renal services. The quality requirements in this part of the NSF complement the standards in part one.

## Quality requirement one: Prevention and early detection of chronic kidney disease

### Aim

To reduce the number of people in the population who develop chronic kidney disease.

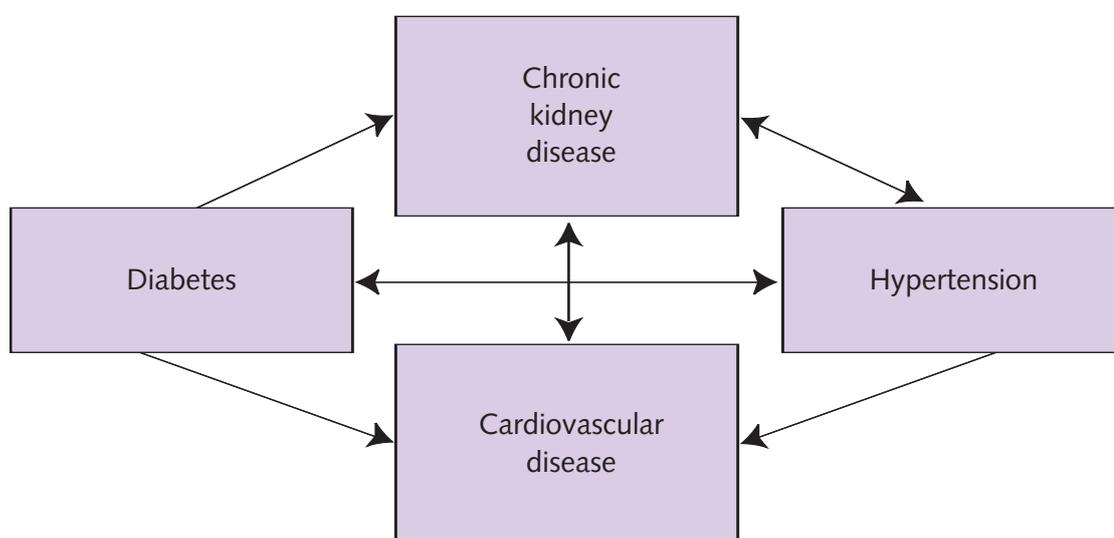
### Quality requirement<sup>i</sup>

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

### Rationale

- 29 The people most at risk of CKD are those with diabetes and hypertension; they are known to have a higher rate of kidney problems than a normal healthy population.<sup>1</sup> CKD, diabetes, hypertension and cardiovascular disease tend to act and re-act on each other in a complex way (see figure four). For example it is well recognised that in some people hypertension may be an early sign of undiagnosed CKD, indicating it is important to check kidney function in this group.

Figure four: Interaction of CKD, diabetes, hypertension and cardiovascular disease



- 30 The chances of developing CKD increase with age,<sup>2</sup> male sex,<sup>3</sup> and South Asian<sup>4</sup> and African Caribbean<sup>5</sup> ethnicity. The close relatives of someone with ERF have a higher risk of developing CKD.<sup>6</sup> People of South Asian origin are particularly at risk of CKD linked to diabetes, as diabetes is more common in this community<sup>7</sup> than in the population overall; similarly people of African and African Caribbean origin have an increased risk of CKD linked to hypertension.<sup>8</sup>

i This quality requirement supports core standard C23 and developmental standard D13b, seventh domain – public health, of *Standards for Better Health*, to have systematic and managed disease prevention and health promotion programmes which meet the requirements of the NSFs, and implement effective programmes to improve health and reduce health inequalities in CKD.

- 31 Other conditions which can lead to CKD are those affecting the urinary tract, especially if they result in recurrent infection and kidney scarring.<sup>9,10</sup> Bladder outflow obstruction can cause CKD<sup>11</sup> (often diagnosed only when it is well advanced), as well as ARF<sup>12</sup>. The most frequent form in adults is benign prostatic hypertrophy.<sup>i</sup> Posterior urethral valves<sup>ii</sup> and other congenital structural abnormalities in children can also lead to problems with bladder and kidney function. On occasion even when urinary obstruction is relieved some people will have persistently abnormal kidney function, requiring follow-up to check it is not deteriorating.<sup>13</sup>
- 32 People with a neurogenic bladder,<sup>iii</sup> who are prone to develop stones, obstruction and urinary infection, are at risk of CKD. The causes vary with age of onset, and include congenital spinal abnormalities (such as spina bifida), spinal cord trauma, multiple sclerosis, and diabetic autonomic neuropathy.<sup>iv</sup>
- 33 Some medicines, especially certain antibiotics and cancer chemotherapy agents, can reduce kidney function or can damage other organs when kidney function is already reduced, sometimes permanently. Advice on such medicines is contained in the manufacturers' guidelines, in the *British National Formulary* and in the Renal Specific Management of Medicines Guidance.<sup>v</sup>
- 34 As the progression of CKD can be slowed or halted in certain circumstances, before dialysis or transplantation become necessary, early identification of kidney disease and timely interventions can be key to prevention. However CKD in its early stages generally produces few if any symptoms; many people are unaware of their condition and could benefit from early identification.
- 35 There is evidence to support the surveillance of people being treated for hypertension, those with diabetes, vascular disease, heart failure or a family history of CKD,<sup>14</sup> especially males of South Asian or African Caribbean origin. However the evidence does not support screening the whole adult population for CKD. One study estimates that 20,000 people over 50 years old would have to be screened to prevent one case of ERF.<sup>15</sup>
- 36 Testing the urine of at-risk populations can help detect CKD, as the presence of excess protein (ie proteinuria), especially with blood, is a marker of kidney disease. Current evidence suggests that the follow-up blood test of kidney function should be a formula-based estimation of the glomerular filtration rate (estimated GFR) rather than the serum creatinine concentration alone, as this varies according to factors such as age, body mass and ethnic origin, and does not always reflect abnormal kidney function.<sup>16,17</sup> In the following groups this is sensibly undertaken routinely during follow-up:
- People with diabetes
  - People with vascular disease (coronary heart disease, stroke, peripheral vascular disease)
  - People with heart failure
  - People with hypertension
  - People with urinary tract obstruction
  - People with neurogenic bladder and people with surgical urinary diversion

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i Benign prostatic hypertrophy: enlargement of the prostate gland, which surrounds the neck of the bladder and urethra in males.

ii Posterior urethral valves: abnormally positioned outflow valves, impeding the outflow of urine from the bladder.

iii Neurogenic bladder: a bladder with impaired function due to abnormal neural control.

iv Diabetic autonomic neuropathy: damage to the nerves arising from damage to the small blood vessels caused by diabetes.

v The Renal Specific Management of Medicines Guidance is available on the Department of Health website, at [www.dh.gov.uk](http://www.dh.gov.uk)

- People taking angiotensin converting enzyme inhibitors (ACE inhibitors)<sup>i</sup> or angiotensin II receptor blockers (ARBs)<sup>ii</sup>
- People taking diuretics
- People with a family history/genetic risk of kidney disease.

37 There is now good evidence that proteinuria can be assessed from a single urine sample (preferably an early morning sample), and can provide a reliable predictor of a fall in GFR.<sup>18,19</sup> Twenty four hour urine collections are therefore unnecessary for this.

38 The Government's Public Health White Paper, *Choosing Health*, aims to make it easier for people to change their lifestyle so they eat more healthily, exercise more and smoke less. Life-style changes that reduce the risk of diabetes, cardiovascular disease and hypertension by improving diet, cutting salt intake, reducing obesity, ceasing smoking, moderating alcohol consumption and increasing physical activity, are also likely to reduce CKD.<sup>20,21,22</sup> Similarly the strict control of blood pressure and blood glucose<sup>23,24,25</sup> as set out in the *National Service Framework for Diabetes*, for example the use of ACE inhibitors, can reduce the development of CKD.

## Markers of good practice

- All people at increased risk of CKD are identified, and given appropriate advice, treatment and support (which is sensitive to the differing needs of culturally diverse groups) to preserve their kidney function. (Level 3)
- People identified as having an increased risk of CKD have their kidney function assessed and appropriately monitored, using estimated GFR. (Level 3)
- Implementation of the NICE<sup>iii</sup> clinical guideline on the management of Type 1 diabetes.<sup>iv</sup>
- Implementation of the NICE clinical guidelines on the management of Type 2 diabetes: renal disease; blood glucose; blood pressure and blood lipids.<sup>v</sup>
- Implementation of the NICE clinical guideline on the management of hypertension in adults in primary care.<sup>vi</sup>

### For children and young people

- For children and young people with potential urinary tract infection, accurate diagnosis and prompt antibiotic treatment, and investigation sufficient to identify structural renal defects and to prevent renal scarring. (Level 3)
- For children and young people with bladder dysfunction, planned investigation and follow-up, with access to urology services with paediatric expertise. (Level 4)

i ACE inhibitors: a class of drug that reduces blood pressure and improves heart function in heart failure.

ii ARBs: a class of drug with a similar function to ACE inhibitors.

iii NICE: the National Institute for Clinical Excellence.

iv *Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults* can be found on the NICE website at [www.nice.org.uk](http://www.nice.org.uk)

v *Management of Type 2 Diabetes – Renal Disease, prevention and early management, Management of Type 2 Diabetes – blood glucose and Management of Type 2 Diabetes – management of blood pressure and blood lipids* can be found at [www.nice.org.uk](http://www.nice.org.uk)

vi *Hypertension – management of hypertension in adults in primary care* can be found at [www.nice.org.uk](http://www.nice.org.uk)

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## Quality requirement two: Minimising the progression and consequences of chronic kidney disease

### Aim

To improve the long-term outcomes for people with chronic kidney disease by minimising the progression and consequences of the disease.

### Quality requirement<sup>i</sup>

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

### Rationale

- 39 Quality requirement one notes that medical interventions and life-style changes can help prevent CKD. Maintaining these can also minimise the progression and consequences of the disease, and are likely to have the greatest impact if applied early. Many people with CKD are already receiving structured care for long-term conditions within primary care, especially for coronary heart disease and diabetes. However the degree of reduced kidney function may not be recognised.
- 40 Studies show that reducing blood pressure in people with CKD reduces the deterioration of their kidney function, whether or not they have hypertension<sup>1,2</sup> or diabetes.<sup>3,4</sup> ACE inhibitors and ARBs are generally more effective than other antihypertensives in minimising deterioration in kidney function, and this effect is most marked when there is significant proteinuria.<sup>5</sup> Such treatment is both clinically and cost-effective.<sup>6,7</sup> For optimal health some people with CKD, particularly those with proteinuria, will need to maintain their blood pressure at a lower level than the general population.<sup>ii</sup>
- 41 For people with CKD and diabetes, who are most at risk of death from cardiovascular disease,<sup>8</sup> measures to reduce microvascular complications are set out in the *National Service Framework for Diabetes*.
- 42 For those with CKD arising from conditions of the urinary tract, continued management is required to minimise kidney damage, especially scarring caused by infection.
- 43 Anaemia is a common consequence of CKD. The National Institute for Clinical Excellence (NICE) is developing a national clinical guideline for primary, secondary and tertiary care on anaemia management in CKD.
- 44 Renal bone disease is an important consequence of CKD, leading to bone pain, muscle weakness and the calcification of blood vessels. Treatment with vitamin D therapies early in CKD may result in improvement of bone disease,<sup>9</sup> and prevent the parathyroid glands from becoming overactive.<sup>10, iii</sup>

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i This quality requirement supports core standard C5a and developmental standard D2a and d, second domain – clinical effectiveness, of *Standards for Better Health*; treatment and care conform to nationally agreed best practice, particularly as defined in NSFs and NICE guidance.

ii Information about optimal blood pressure levels for different groups are given in the guidelines referred to in paragraph 46.

iii Vitamin D is activated in normal kidneys, enabling the body to absorb calcium from food. If this fails blood calcium falls, and the parathyroid glands produce a hormone (PTH) to draw calcium from the bones and restore blood levels. Removal of the glands is sometimes necessary to reduce persistently excess PTH production (a form of hyperparathyroidism).

- 45 As part one of this NSF made clear, around one year is generally recognised as the time needed to prepare a patient and their carers for RRT. However a third of people first reach the specialist renal service less than a month before requiring RRT, and this group has poorer outcomes,<sup>11</sup> including longer hospitalisation and higher early mortality on RRT. While some people do not present until very late, or have acute deterioration without prior history, in up to 50% of cases there is evidence of missed opportunities for earlier referral.<sup>12</sup> Optimal management in primary care, including referral to the specialist renal service at the appropriate stage, could improve outcomes for people with CKD and reduce the organisational pressures on specialist renal services caused by emergency cases.
- 46 *Guidelines for the identification, management and referral of adults with chronic kidney disease* are being developed at the suggestion of the Joint Specialty Committee on Renal Disease of the Royal College of Physicians of London and the Renal Association.<sup>i</sup> These guidelines provide advice on managing CKD in primary care so as to slow its progression, and also on appropriate referral to specialist renal services. The nature of the local renal network, and the level of medical service a GP practice provides, will also be relevant.

## Markers of good practice

- All people diagnosed with CKD have access to care which is sensitive to the differing needs of culturally diverse groups, to maximise the benefits of treatment and minimise the effects of the disease; and have a care plan. (Level 4)
- Use of the best available evidence to inform the management of
  - blood pressure
  - cardiovascular disease and cardiovascular risk
  - urinary tract obstructions and infections in people with CKD. (Level 3)
- In people with diabetes and CKD, interventions to reduce microvascular complications, in accordance with the *National Service Framework for Diabetes*.
- Implementation of the forthcoming NICE guideline on the treatment of anaemia in CKD.
- Referral from primary care to the specialist renal service at an appropriate stage to optimise outcomes. (Level 4)

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i The guidelines are being developed by the Joint Specialty Committee on Renal Disease of the Royal College of Physicians of London and the Renal Association with the Royal College of General Practitioners, the Association of Clinical Biochemists, the Society for District General Hospital Nephrologists, the British Geriatric Society, the Professionals Advisory Council of Diabetes UK, and the National Kidney Federation.

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## Quality requirement three: Acute renal failure

### Aim

To minimise the incidence, consequences and complications of acute renal failure.

### Quality requirement<sup>i</sup>

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

### Rationale

- 47 Acute renal failure (ARF) is potentially fatal but in many cases reversible if appropriately treated. Good practice suggests that people with ARF are identified promptly and investigated to establish whether their kidney failure is caused by a renal condition, which may be amenable to specific treatments, or is the result of another condition such as infection, heart failure or loss of blood and blood pressure. Use of medicines which damage the kidneys may need to be discontinued.
- 48 Development of ARF is associated with a longer stay in an intensive care unit<sup>1</sup> and a longer hospital in-patient stay.<sup>2</sup> One study from the United States has indicated that delayed specialist renal consultation for people with ARF in the intensive care unit (ICU) has a significant association with increased length of hospital and ICU stay.<sup>3</sup> Pre-existing CKD has been identified as the most consistent factor contributing to the development of ARF in people recovering from surgery,<sup>4</sup> but other factors shown to be important include age, diabetes and reduced cardiac function.<sup>5</sup>
- 49 The NICE clinical guideline on pre-operative tests states<sup>ii</sup> those who undergo elective surgery should be assessed pre-operatively. Any factors that indicate a greater risk of developing ARF post-operatively need to be highlighted and managed in the peri-operative period to reduce those risks.
- 50 The risk of malnutrition in people with ARF is high.<sup>6</sup> Nutritional management cannot prevent the loss of lean body mass associated with ARF, but can minimise it.
- 51 Deterioration in kidney function may follow the initiation of treatment with ACE inhibitors or ARBs, especially if people also have renovascular disease, and these medications may need to be temporarily discontinued in people with ARF. However these agents produce long-term protection, and as long as there is not a sustained rise in serum creatinine concentration of more than 30% they need not be permanently discontinued.<sup>7</sup>
- 52 Following an episode of ARF some people recover normal kidney function and some do not. For people in whom CKD is identified, the treatment set out in quality requirement two will apply. The care of those found to be approaching ERF is set out in part one of this NSF, in standard two. For those who recover normal kidney function, evidence is lacking as to whether long-term follow-up is appropriate.

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i This quality requirement supports core standard C5a and developmental standard D2a and d, second domain – clinical effectiveness, of *Standards for Better Health*: treatment and care conform to nationally agreed best practice, particularly as defined in NSFs and NICE guidance.

ii The guideline *Preoperative tests – The use of routine preoperative tests for elective surgery* can be found on the NICE website at [www.nice.org.uk](http://www.nice.org.uk)

- 53 For patients with ARF there are currently various models of care depending on the nature and severity of the primary condition, whether the patient needs RRT, and whether the hospital has a specialist renal service. Care may be managed in a number of settings: in ICUs by specialists in intensive care medicine, or in partnership with renal clinicians; on a renal ward; or on another ward with input from a renal clinician. Wherever patients are treated, there needs to be liaison with the specialist renal service for their continuing management.

### ARF in children

- 54 Unlike in adults, the incidence of ARF in children decreases with age, and is highest in the neonatal and infant age group.<sup>8</sup> The proportion of children with ARF going on to develop ERF has been reported to be between 1%<sup>9</sup> and 7%.<sup>10</sup>
- 55 ARF in babies can be caused by heart failure due to congenital defects, or following heart surgery for such defects; shock due to infection; and shortage of oxygen due to breathing problems. These conditions are in principle reversible if circulation is restored efficiently within a short time. Respiratory failure at birth may result in reversible or non-reversible ARF. ARF requiring immediate urological intervention may also present in the newborn, due to developmental structural abnormalities of the urinary tract. Children with ARF caused by certain types of haemolytic uraemic syndrome<sup>i</sup> may not recover normal kidney function. In older children the incidence of primary renal disease as a cause of ARF is more common.

### Markers of good practice

- Timely identification and referral to renal and critical care services for specialist, culturally appropriate advice and assessment. (Level 3)
- Appropriate pre-operative testing and interventions, in accordance with the NICE guideline on pre-operative testing.
- Involvement of local critical care networks in planning, commissioning and monitoring the delivery of critical care services to acutely ill renal patients. (Level 4)
- Liaison with specialist renal services to facilitate optimal management of people with ARF in the most clinically appropriate setting. (Level 4)

#### For children and young people

- Treatment and care in accordance with *Getting the right start: National Service Framework for Children, Young People and Maternity Services*.

i Haemolytic uraemic syndrome is characterised by fragmentation of red blood cells, blood clots and damage to the lining of small blood vessels, with associated kidney damage.

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## Quality requirement four: End of life care

### Aim

To support people with established renal failure to live life as fully as possible and enable them to die with dignity in a setting of their own choice.

### Quality requirement<sup>i</sup>

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

### Rationale

- 56 Part one of this NSF identified the importance of information and choice for people with renal disease; this will include an assessment of prognosis. This quality requirement concerns those who decide not to undergo dialysis treatment, those who choose to withdraw from dialysis after a period of treatment, and those who are coming to the end of their lives while continuing dialysis. Their right to make choices, and to have a say in where they wish to die, is supported by the Government's Command Paper *Building on the Best: Choice, Responsiveness and Equity in the NHS*. The *Gold Standards Framework*<sup>iii</sup>, the *Liverpool Care Pathway for the dying patient*<sup>iv</sup> and the *Preferred Place of Care*<sup>v</sup> document are tools which can be used to improve end of life care.
- 57 Prognostication, or the estimation of how long an individual has to live, is increasingly accepted as a necessary component of good practice in the care of the dying. Clinicians will need to be prepared to be as accurate as possible should a patient want a prognosis to inform their treatment choices.
- 58 However, it is hard to predict how quickly CKD will progress, especially when it is complicated by co-existing illness and old age. Most people with CKD die of other causes before they reach ERF. However there are helpful data derived from the United States Renal Data System (USRDS) which allow a realistic expectation of survival and projected lifespan to be made, taking into account age, diabetes, and other major co-existing illnesses.<sup>1</sup> Similar data are becoming available from the Renal Association UK Renal Registry.<sup>2</sup> A scoring system developed in the UK identifies and provides survival data for high, medium and low risk patients. In a study of high risk patients, who comprised 8% of all those who started dialysis in a large district general hospital over a four year period and who were identified by functional status, severity of co-existing conditions and age, the majority survived for less than one year.<sup>3</sup> It is clear that for this group dialysis may be palliative rather than rehabilitative.

i This quality requirement supports core standards C13-16 and developmental standards D9 and D10, fourth domain – patient focus, of *Standards for Better Health*; and core standards C17 and C18, and developmental standard D11, fifth domain – accessible and responsive care; information, dignity, respect, access and choice.

ii A definition of palliative care by the World Health Organization can be found at [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/), and NICE's *Supportive and palliative care for people with cancer* is at [www.nice.org.uk](http://www.nice.org.uk)

iii *The Gold Standards Framework* is a GP practice-based system for community palliative care developed by Macmillan Cancer Relief. For more details, see [www.macmillan.org.uk/healthprofessionals/disppage.asp?id=2062](http://www.macmillan.org.uk/healthprofessionals/disppage.asp?id=2062)

iv *The Liverpool Care Pathway for the dying patient* was developed by the Specialist Palliative Care Unit across the Liverpool University Hospitals and the Marie Curie Centre Liverpool. For further details see [www.lcp-mariecurie.org.uk](http://www.lcp-mariecurie.org.uk)

v *The Preferred Place of Care* document is a patient-held record developed by the Lancashire & South Cumbria Cancer Network. For further details see [www.cancerlancashire.org.uk/ppc.html](http://www.cancerlancashire.org.uk/ppc.html)

- 59 A 'no-dialysis' option is not a 'no-treatment' option. Non-dialytic therapy can relieve many symptoms, and maximise the person's health during the remainder of their life. Many patients with ERF will live for several weeks or months without dialysis. Indeed in older patients not undertaking dialysis there may be no significant shortening of life expectancy.<sup>4</sup> Patients need to be reassured that whenever they make a choice, they still retain the right to re-discuss their options with the multi-skilled team and receive full supportive care from the resources of the renal service, even if they choose not to dialyse. The implications of choosing not to undertake dialysis should be shared with patients through the counselling process, to enable them to make an appropriate decision. It is important that patients realise that the decision to take the 'no-dialysis' option is reversible.
- 60 For people with known progressive CKD, there will be time to discuss with the clinical team whether they prefer dialysis or non-dialytic therapy. In these circumstances they may want their relatives, partners or carers present in a relaxed environment. This may include one or more meetings in the patient's home, so that the realities of each approach can be fully explored and a realistic evaluation of the patient's functional capacity made.
- 61 Recent studies have highlighted that most people ideally prefer to die at home. Yet even amongst individuals with cancer, for whom palliative care and related services are better developed, only 25% are able to achieve this aim.<sup>5</sup> The reality is that most people still die in hospital.
- 62 Continuing medical care will need to be modified appropriately to the situation. Thus in a patient with a short life expectancy, dietary restrictions or making great efforts to control moderately raised blood phosphate levels in order to prevent long-term complications may not be sensible. Appropriate drugs are needed to reduce pain and suffering and control symptoms such as nausea and pruritis. Some medical interventions may prolong life but not improve quality of life. It is important that wherever possible patients are involved in decisions about options for medication, and their preferences are noted in the care plan. Continued monitoring of the patient's condition, with appropriate modification of care, and full availability of psychological and palliative support from the renal multi-skilled team, palliative care specialists, primary care and community staff are essential.

### Recognising diversity

- 63 Our attitudes to death and dying are influenced by many factors, and if understood and acknowledged, these influences provide an opportunity for the renal team to provide individually tailored assessments, and high quality care sensitive to the person's needs. They will include, for example, the person's religious beliefs; their cultural background; whether they are single, married, co-habiting or in a same-sex partnership; and if they have family, whether they are close or estranged. As some people and/or their relatives may not have English as their first language, access to interpreters may be required.
- 64 Age raises sensitive issues at both ends of the spectrum. Patients of all ages need a full choice of all types of care. Looking after children and young people at the end of their lives is particularly difficult not only for families, but also for staff, and both may need support.

### End of life care in children

- 65 Dying with kidney disease is less common in children than in adults, and the causes are different. The children most at risk of dying are those who develop ERF in the first few years of life,<sup>6</sup> and the majority of these deaths are associated with co-existing conditions such as congenital abnormalities or major disabilities, which also require special attention by the multi-skilled team. Parents of children with such co-existing conditions will need to be counselled appropriately, and there may be circumstances when

the family believes that the pain and suffering that may be inflicted on their child by dialysis cannot be justified. In some children palliative care may be indicated because of an inability to obtain or maintain the access to the circulation which is needed for dialysis.

## Markers of good practice

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

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# Chapter three: Next steps

## Introduction

- 66 The *NHS Improvement Plan* and *Standards for Better Health* make it clear that in future the NHS will have fewer performance targets, but a stronger emphasis will be placed upon core and developmental standards by which patients can judge the performance of the NHS.
- 67 Chapter two sets out four quality requirements and 23 markers of good practice aimed at better services. This chapter identifies six steps that local health communities and renal networks can use in the planning, development and delivery of local services.

## Policy context

- 68 Both parts of the NSF for Renal Services have been developed with the needs of patients at the centre. In meeting the complex needs of people with CKD it is possible to achieve substantially better outcomes by early recognition and by controlled interventions. But improvements will not come easily unless health organisations work together to tackle the underlying issues associated with ill-health, which will need to take place in the context of the Government's wider strategies for public health and disease prevention.
- 69 Primary Care Trusts (PCTs) and renal networks need to work across both the primary and secondary care fields to set local priorities and local actions on the basis of local accountability agreements, using the quality requirements and markers of good practice in this NSF. In some areas of the country PCTs may need to modernise the process of care to meet the needs of their populations.
- 70 These interactions need to be linked by clinically relevant information systems and continuing follow-up initiated by the best medical practice. Enhanced information systems can facilitate the development of disease registries, tracking systems and reminders, and give feedback on performance. The associated Renal Information Strategy<sup>i</sup> deals with these points in greater detail.
- 71 As both providers and commissioners of services for people with CKD, PCTs and specialised commissioners together with renal networks will be responsible for:
- Planning: developing local implementation strategies to tackle inequalities and to set priorities and provide the resources needed to deliver this part of the NSF over the next ten years
  - Leadership: providing leadership for delivery
  - Local monitoring: ensuring delivery of the NSF
  - Delivery: bringing about marked improvements in the care of patients with chronic or acute kidney disease.

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i Part two of the Renal Information Strategy will be published at [www.dh.gov.uk](http://www.dh.gov.uk)

- 72 Over time, an increasing amount of NHS services will be delivered by independent organisations such as NHS Foundation Trusts, which are not performance managed by Strategic Health Authorities (SHAs). This places particular importance on the role of PCTs as commissioners in securing improvements in service.

## Next steps

- 73 SHAs/PCTs can choose how they phase the process of implementing the quality requirements and markers of good practice, but to help them prioritise their interventions six basic steps are identified. Each step is concerned with making the most of and building on current renal, coronary heart disease, diabetes, cancer and critical care networks and the care pathways they have developed.

### Step one: Integrating care pathways

Renal networks can establish links with coronary heart disease and diabetes networks, and consider the scope for integrating the care pathways to manage and reduce the impact of these interacting long-term conditions in primary and secondary care.

### Step two: Early identification of people at risk of chronic kidney disease

Building on care pathways in coronary heart disease and diabetes, primary care can identify people at increased risk of developing or having undiagnosed CKD and test their kidney function.

### Step three: Testing kidney function

Local health organisations can work with pathology services and networks to develop protocols for measuring kidney function by serum creatinine concentration together with a formula-based estimation of glomerular filtration rate (estimated GFR), calculated and reported automatically by all clinical biochemistry laboratories.

### Step four: Reducing emergency bed days

Local health organisations setting local plans and targets to deliver the Public Service Agreement on long-term conditions can take this NSF into account in determining how to improve patients' experience and outcomes and reduce emergency bed days.

### Step five: Tackling acute renal failure

NICE guidance on pre-operative testing needs to be followed in all surgical units. PCTs and specialised commissioners can work closely with critical care and renal clinical networks to develop strategies to prevent episodes of avoidable ARF, thus reducing avoidable hospital admissions, and facilitate access to appropriate specialist care.

### Step six: Improving end of life care for people with established renal failure

Renal networks can establish links with palliative care services to improve end of life care for people with ERF by using the *Gold Standards Framework*, the *Liverpool Care Pathway for the dying patient* and the *Preferred Place of Care* tools to support all those nearing the end of their life to have choice in their treatment and in where they die.

# Chapter four: How the centre will support local service delivery

- 74 *Shifting the Balance of Power* has seen money, control and responsibility passed to local health services so that the communities they service have greater influence over the way local resources are spent and the way local services are run. Delivery models that have worked well in the past may continue to do so; however some may need to change. The Department of Health is working with SHAs and others on initiatives to support the NHS in implementing this NSF.

## Modernisation programmes

- 75 Part one of this NSF identifies five modernisation programmes to support implementation. These are ongoing.

**Re-designing the workforce:** Two NHS Trusts with their workforce partners are developing and piloting robust local workforce development models for renal dialysis and transplant units, which can be used as a template by other SHA Directorates of Workforce and Learning.<sup>i</sup> This will complement the work on Renal Competency Frameworks, being developed by Skills for Health. The findings of the pilots are due to be published in spring 2005.

**Re-engineering elective dialysis access surgery:** The two sites looking at redesigning the workforce are also looking at different solutions for improving access to, and bringing down waiting times for, elective fistula surgery. Consideration has been given to the appropriateness of treating more patients as day cases and allowing alternative patient management arrangements to evolve.

**Re-designing hospital access (patient transport):** Two action learning sets<sup>ii</sup> have been established on patient transport, working in both urban and rural areas, aimed at making journeys easier for patients receiving haemodialysis.

**Re-designing care plans for partnership and choice:** Work is ongoing to explore how care plans can reflect and facilitate a partnership approach for people with kidney disease. A web-based, personalised care plan tool is being developed for patients.

**Re-designing the built environment:** NHS Estates has issued new Health Building Notes on satellite dialysis units, and is developing those on main renal units and transplant units.

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i Formerly Workforce Development Confederations.

ii Learning sets bring together key individuals in service delivery in small dynamic groups to learn with others by probing, understanding and action. They might be multi-professional and/or multi-agency and can review and implement plans to a positive effect, either nationally or within a specific network, and develop learning tools or good practice guidelines for local use or national roll out.

76 Part two identifies five additional modernisation programmes.

**New action learning sets:** Four sets have been established in the areas of information and prevention in primary care, and the extension of palliative care to renal services. The findings of these learning sets will be widely shared.

**Measurement of kidney function:** Kidney function is more accurately measured using an estimated GFR than by serum creatinine concentration alone, so a change to current practice will be required. Local pilots have been established in co-operation with pathology laboratories to test the changes involved in calculating, reporting and interpreting test results. The centre is supporting the development of practical tools for primary care staff in this area.

## 10 High Impact Changes for Service Improvement and Delivery

77 Good practice guidelines have been developed and published by the NHS Modernisation Agency, *10 High Impact Changes for Service Improvement and Delivery*.<sup>i</sup> This includes Change number 7, for the care and support of people with long-term conditions, enabling them to take greater control of their treatment; and Change number 10, on redesigning and extending the roles of staff, in line with patient pathways. New models for delivering care to those with long-term conditions, as set out in *Supporting People with Long Term Conditions*<sup>ii</sup>, will create a need to utilise nursing skills fully and develop extended roles for nurses working with patients and social care providers in response to complex problems. In a similar way to part one of the NSF where a named person is the first point of contact for the patient who is undertaking RRT, nurses working in these roles can be the named contact for those with CKD who require specialist support in the community.

## Information

78 Part two of the Renal Information Strategy includes the provision of the right information at the right time to support the needs of people with CKD, ARF and at the end of their life. The strategy also covers the delivery of integrated care and shared care as well as the planning and management of monitoring of services for people with kidney failure as described in this document. Delivery of the seamless, co-ordinated care outlined in this NSF is underpinned by advances in information management flowing from the National Programme for Information Technology<sup>iii</sup> and the Renal Information Strategy.

## Measuring success

79 Health organisations will want to review local arrangements for people with CKD and identify gaps in service provision that need improvement to meet the quality requirements set out in this NSF. This will be done in the context of *National Standards, Local Action*, incorporating *Standards for Better Health*, which sets out a standards-based framework for all NHS organisations to use in planning. That document operationalises the Government's Public Service Agreement targets for the NHS and contains broad, overarching core and developmental standards for the NHS to use in planning, commissioning and delivering services.

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i *10 High Impact Changes for Service Improvement and Delivery* is available at [www.content.modern.nhs.uk/cmsWISE/HIC/HIC+Intro.htm](http://www.content.modern.nhs.uk/cmsWISE/HIC/HIC+Intro.htm)

ii *Supporting People with Long Term Conditions* is available at [www.dh.gov.uk](http://www.dh.gov.uk)

iii More information about the National Programme for Information Technology can be found at [www.dh.gov.uk](http://www.dh.gov.uk)

- 80 The Government will not set further national targets beyond the key Public Service Agreement targets. Local health organisations are being given greater autonomy to take local action to improve services for the individuals and communities they serve. This will allow greater scope for locally determined targets and priorities to be matched to local needs. To be successful this will require effective health commissioning, managed through local delivery planning processes, monitored and accountable through the PCT/SHA chain.
- 81 In addition the Healthcare Commission has an important role in monitoring and reviewing quality of care across the NHS, with reference to national standards and National Service Frameworks, and in providing information to local communities about how their local services are doing. The Healthcare Commission is a new organisation and will need to develop processes for inspection and assessment. In monitoring progress towards implementation of the NSF for Renal Services, the Commission may wish to work in collaboration with those providing renal services in determining key measurables for service performance.

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