

*The National Service Framework
for Renal Services*

Part One: Dialysis and Transplantation

January 2004

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The National Service Framework for Renal Services

Part One: Dialysis and Transplantation

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Foreword



This *National Service Framework for Renal Services* is launched at a time of great change in the NHS. *Shifting the Balance of Power* empowers frontline staff and patients in the NHS and gives Primary Care Trusts the role of running the NHS and improving health in their areas. It sets out how the NHS will work in future, with the balance of power shifting towards local communities so they can reconnect with their services and have real influence over their development.

It will be at local level that the improvements in quality flowing from the standards and 'markers of good practice' set out in this National Service Framework will be made. The Government knows this will be an enormous challenge because the number of people with chronic kidney disease is rising in this country and around the world. We can expect the number of people receiving treatment for established kidney failure in England to increase, particularly among black and minority ethnic groups and older people, by at least 50% over the next ten years.

Despite rising patient numbers and increased investment, treatment rates in England are lower than those in many other parts of Europe, including the rest of the UK. There is also wide variation in treatment rates around the country, which cannot be explained by demographic differences.

In the new NHS, Primary Care Trusts, working in collaborative commissioning groups, will be responsible for developing renal services by assessing need and planning for the future. They will be required to forge new partnerships with renal communities to ensure services are equitable and address the needs of those who receive them, particularly the diverse needs of different groups in the community.

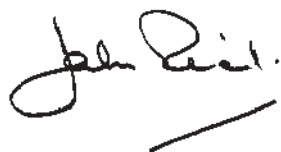
NHS Trusts will continue to provide services, working within delivery agreements with Primary Care Trusts. They will be expected to devolve greater responsibility to clinical teams and to foster and encourage the growth of clinical networks supportive of renal services. Primary Care Trusts will need to ensure children and young people with chronic kidney disease have access to staff with the right specialist skills.

At the same time Primary Care Trusts and NHS Trusts will need to increase capacity and implement standards and markers of good practice to improve equity and quality of care. Together they will want to redesign services so people with established renal failure receive timely intervention for vascular access and responsive patient transport. They will need to offer a real choice of treatment, either peritoneal dialysis; haemodialysis delivered in a main renal unit, a satellite unit or at home; or transplantation if a suitable donor kidney becomes available.

After decades of under investment the NHS is now getting the money it needs. The Government is supporting the expansion of renal services through our capital development programme, with an investment of £60 million between 2000/01 and 2005/06. The NHS is also working closely with the private sector to build up services and improve access and choice. These initiatives are increasing capacity and are accompanied by a significant increase in the use of haemodialysis facilities.

The standards and markers of good practice in this part of the National Service Framework are to be delivered over a ten year period and can be considered together with *Saving Lives, Valuing Donors: A Transplant Framework for England*. Strategic Health Authorities – in leading the strategic development of local renal services – will manage the performance of Primary Care Trusts and NHS Trusts on the basis of local accountability agreements informed by this National Service Framework. The Department of Health will hold discussions with the Commission for Healthcare Audit and Inspection to establish how this performance can be measured nationally to ensure unacceptable variations in services are tackled. We will be turning to the important issues of prevention and end of life care in the next part of this National Service Framework.

I am grateful to Professor Robert Wilkinson and Sarah Mullally, and all in the renal community, especially patients, who have given up their time to help develop this National Service Framework.ⁱ

A handwritten signature in black ink, appearing to read 'John Reid', with a horizontal line underneath.

John Reid
Secretary of State for Health

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

Executive summary

Part one of this National Service Framework sets five standards and identifies 30 markers of good practice which will help the NHS and its partners manage demand, increase fairness of access, and improve choice and quality in dialysis and kidney transplant services.

By 2014 the NHS will need to deliver these five standards:

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.

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.

Next steps

In keeping with *Improvement, Expansion and Reform: the Next 3 Years, Priorities and Planning Framework 2003-2006* this National Service Framework does not prescribe how the NHS should deliver the standards. Instead it sets out five national steps the NHS can take in the current planning cycle (2003 to 2006) that will support delivery of the standards and will improve services.

Primary Care Trusts, in their role as commissioners of specialised services, working with NHS Trusts, other providers and patients, will set priorities for action and agree local arrangements for delivering the five standards and the markers of good practice. Strategic Health Authorities will manage the performance of Primary Care Trusts and NHS Trusts on the basis of local accountability agreements informed by the standards and markers of good practice in this National Service Framework.

The Department of Health will work with the Commission for Healthcare Audit and Inspection to review how the standards and markers of good practice can inform the development of the NHS performance rating assessments.

During 2004 the Department of Health with the renal community will continue:

- the development of Part two of this National Service Framework, focusing on the prevention of established renal failure, primary care, and end of life care
- to support delivery of the standards by a range of modernisation programmes and pilot studies led by the NHS Modernisation Agency, NHS Estates and the NHS Information Authority by:
 - re-designing the workforce
 - re-engineering elective dialysis access surgery
 - re-designing hospital access (patient transport)
 - re-designing care plans for partnership and choice
 - re-designing the built environment.

Between now and 2006 Primary Care Trusts, as commissioners, and NHS Trusts will need to:

- use national data to support planning and to identify local priorities, including the needs of black and minority ethnic groups
- continue to expand haemodialysis capacity
- join the UK Renal Registry of the Renal Association and take part in national comparative audit
- implement the National Institute for Clinical Excellence appraisal of home haemodialysis
- implement the National Institute for Clinical Excellence appraisal of immunosuppressive therapy.

Chapter one: Setting the scene

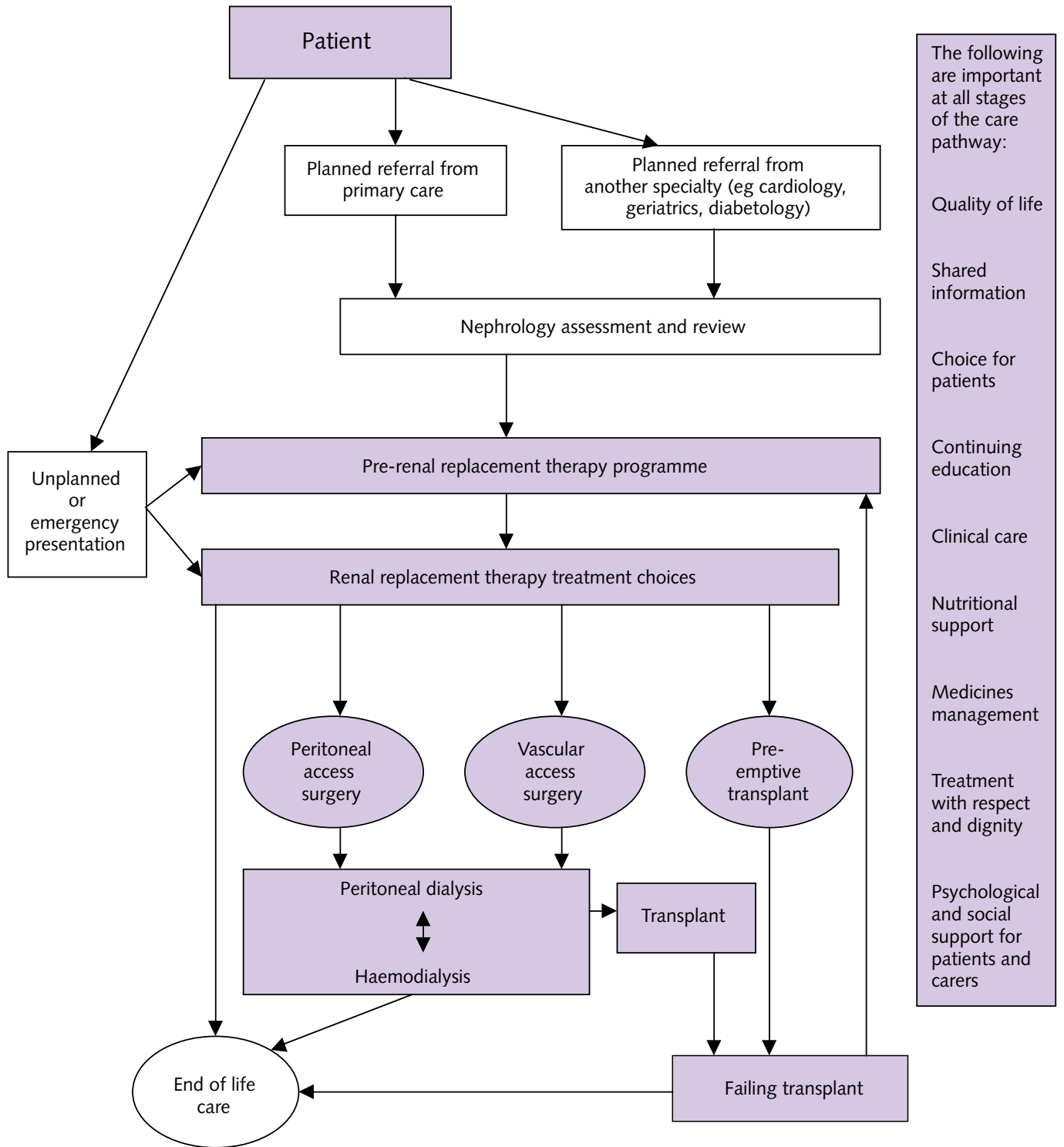
Introduction

- 1 Kidney function is essential to life. Until the 1960s the development of established renal failure (ERF)ⁱ always resulted in death. But the last 40 years have seen significant advances in our understanding of the condition and our ability to treat it, enabling people to survive much longer. A great deal has changed including:
 - the rapid growth in the availability of dialysis treatment
 - the ability to treat older patients who also have other illnesses
 - the development of kidney transplantation, boosted by the introduction of new anti-rejection drugs.
- 2 Another major advance has been the successful treatment of even the youngest infants and children by dialysis and transplantation, with good long-term results.
- 3 This National Service Framework (NSF) will consist of four modules. This document, which is part one of the NSF, includes modules one and two, on dialysis and transplantation. Figure one illustrates the areas of the patient's care pathway which it covers. The remaining two modules will concentrate on preventing ERF, primary care and care towards the end of life. A range of supporting material is being developed including a good practice guide on the implications of this NSF for children. This will be available at www.dh.gov.uk/renal.
- 4 This first chapter provides background information about ERF and its treatment. Chapter two sets five national standards and 30 markers of good practice for implementation. Chapter three describes five steps the NHS can take in the current planning cycle (2003 to 2006) to begin to support delivery of the standards and markers of good practice. Chapter four describes how Primary Care Trusts (PCTs), NHS Trusts, clinical staff and patients will set priorities for action and agree local arrangements for delivering the standards and markers of good practice. Chapter five covers a range of national programmes, including five areas for modernisation, which will support local health communities in delivering the standards and markers of good practice.

ⁱ Kidney (renal) disease which is irreversible and progressive is known as chronic kidney disease. Established renal failure (ERF), also called End Stage Renal Failure, is chronic kidney disease which has progressed so far that renal replacement therapy (RRT) is needed to maintain life. For a definition of all terms, see the Glossary at www.dh.gov.uk/renal.

Figure one: The care pathway for renal replacement therapy

The highlighted areas are covered in this part of the NSF



What is established renal failure?

- 5 ERF is an irreversible, long-term condition for which regular dialysis treatment or transplantation is required if the individual is to survive. If the kidneys fail the body is unable to excrete certain waste products, excess water and salts, or control the body's acidity, resulting in death. In addition kidneys help influence haemoglobin production, blood pressure and bone formation.
- 6 There are many diseases of the kidney that can be treated successfully and do not lead to renal failure. Some conditions are self-limiting, while others may progress so slowly that there is sufficient renal function for the person to live out their normal life span. Even when kidneys begin to fail careful control of diet and blood pressure, and timely intervention to prevent complications, can enable a person to survive in good health for many years.
- 7 When ERF is reached the person is likely to become tired, nauseated, suffer a loss of appetite and be less able to cope with life mentally and physically. Clinical signs include fluid retention, manifest as ankle swelling or breathlessness, pallor and raised blood pressure, and poor growth and development in children, accompanied by falling haemoglobin levels and abnormality of several biochemical indices (including serum urea, creatinine and potassium).¹ At this point renal replacement therapy (RRT), in the form of dialysis or transplantation, is required or the person may die within weeks or months. However many experts believe it is good practice for dialysis to begin before these symptoms become apparent and before the patient feels so unwell. Treatment will last for the rest of the person's life. A description of types of RRT can be found in the glossary at www.dh.gov.uk/renal.
- 8 Since the introduction of RRT some people have enjoyed a near normal life span, surviving in reasonable health for more than 30 years, particularly if they have received a transplant. Nevertheless the rigours of treatment are considerable. For example four hours a day, three days a week are normally devoted to the haemodialysisⁱ process. Those on peritoneal dialysisⁱⁱ will need to carry out dialysis fluid exchanges four or five times a day, or continuously overnight using an automatic machine. People with a transplant must take powerful medicines to prevent their body rejecting the kidney.
- 9 For those on dialysis, particularly haemodialysis, change in diet is also required, especially foods containing sodium, potassium and phosphate, including coffee, chocolate, crisps and many kinds of fruit and dairy products. Intake of fluid may have to be limited. People on dialysis can often become malnourished and need dietary supplements or artificial feeding.
- 10 Regular medication is often required, including epoetin (recombinant human erythropoietin) and iron injections for anaemia, and medicines to prevent bone disease and to decrease cardiovascular risk. Sexual and reproductive problems can include delay in the progression of puberty, impotence^{iii,2} and a reduced likelihood of conception and successful pregnancy for those on dialysis, though both of these improve markedly following transplantation. Problems can arise that require hospital admission, such as complications associated with the vascular access through which haemodialysis takes place, or other illnesses, in particular cardiovascular disease.

i A form of dialysis in which the patient's blood is circulated through a machine which filters out waste products and excess water.

ii A form of dialysis in which dialysis fluid is introduced into the peritoneal cavity in the patient's abdomen, where it draws waste products and excess water out of the blood using the peritoneal membrane as a filter.

iii Guidance on treatment for impotence in men with renal failure who are receiving RRT, in HSC 1999/115 and HSC 1999/148.

Who develops established renal failure?

- 11 Most people who develop ERF do so as a result of chronic damage to the kidneys. This is most commonly caused by diabetes and increasingly by vascular disease which causes narrowing of the kidney's blood vessels, especially among older people. Examples of other causes are hypertension, glomerulonephritis (inflammation of the filters in the kidney) and microscopic vasculitis (inflammation of the small blood vessels). While glomerulonephritis may occur in childhood, most diseases causing renal failure are associated with increasing age.
- 12 Most children with ERF are born with structurally abnormal kidneys. Recurrent infections or obstruction of the urinary tract may increase the rate at which renal function deteriorates. Genetic disorders such as polycystic kidney disease may also cause renal failure, though this may not become manifest until adult life. Other causes of ERF, such as glomerulonephritis, may be acquired throughout childhood.
- 13 Acute renal failure (sudden rapid decline in renal function) may occur following a shock to the kidney such as injury, surgery or severe infection. People with acute renal failure do not always recover full renal function, particularly if they had mild chronic kidney disease beforehand, and may progress to ERF. Acute renal failure will be covered in more detail in the third module of this NSF.
- 14 The risk of renal failure rises sharply with increasing age. In 2001, almost half of all adult patients starting RRT were over 65 years old,³ whereas people over 65 make up only a quarter of the adult population.
- 15 People from the South Asian, African and African Caribbean communities are more prone to developing diabetes and hypertension, which are causes of renal failure, and have higher rates of chronic kidney disease.⁴ These black and minority ethnic populations are now relatively young but as they age the number of those requiring RRT will increase. The prevalence of Type 2 diabetes and diabetic nephropathy is increasing in these communities as well as in the overall population.
- 16 There is increasing evidence that the risk of ERF is greater in socially deprived populations. The reasons are not fully understood but may be that such communities are more prone to develop some of the causal factors (eg renovascular disease, Type 2 diabetes) and have those conditions less well managed.⁵⁻⁷

Number of people with established renal failure and number being treated

- 17 Conventionally the total number of people receiving RRT has been taken as a proxy measure for the prevalence of ERF. However it is generally agreed that in addition there will be people in the general population with ERF which has not been diagnosed, and whose need for RRT has not been recognised. This problem will be covered in the second part of this NSF.
- 18 The Government has invested in expanding overall capacity for treating people with ERF, and this has supported a significant rise in activity. The number of new patients starting treatment and the total number of patients receiving treatment increased from 65 per million population (pmp) and 396 pmp respectively in 1992 to 91 pmp and 547 pmp in 2001. More than 27,000 people were receiving RRT in England in 2001. Around half of these had a functioning transplant, the remainder were on dialysis.
- 19 As more new patients join those already being treated, it is predicted that numbers will rise to around 45,000 over the next ten years. The projected overall growth rate is on average 4.5% to 5% per year, but it is higher (6% to 8%) for hospital based haemodialysis and for older patients. These estimates are based on a number of assumptions including patient survival. Even if the annual rate of people starting

treatment does not increase, there will still be an increase in overall numbers. It will take at least 20 years to reach a position, known as 'steady-state', when the number of new patients starting dialysis treatment is equal to the combined figure of patients leaving dialysis as transplanted patients or through death. Most of the growth in demand will be for haemodialysis for older people.

- 20 Treatment rates for ERF are lower in England than in other comparable countries and this is an indication of unmet need. Figure two presents data for the number of patients beginning RRT and those on treatment in 2001, for which data is available to make comparisons between England and other countries. (These rates are not however adjusted for age, co-existing illness or ethnicity.) Treatment rates in these countries are, like those in England, continuing to rise. Additionally demographic changes will have an impact on the number of people with ERF. The population of England is ageing, particularly in black and minority ethnic groups, and so the number of people with ERF is rising.

Figure two: Treatment rates

Country	New patients starting treatment (pmp)	Overall number of patients (pmp)	Data source
United States	336	1403	(a)
Germany	184	919	(e)
Greece	163	812	(b)
Belgium (Dutch speaking)	160	855	(b)
Spain (Catalonia)	146	1022	(b)
Denmark	138	679	(b)
Italy	136	835	(f)
Austria	136	750	(b)
Sweden	124	735	(b)
New Zealand	119	655	(d)
Wales	105*	641*	(c)
Scotland	101	644	(c)
Netherlands	100	639	(b)
Australia	97	633	(d)
Norway	94	606	(b)
England	91*	547*	(c)

(a) US Renal Data Service

(b) ERA-EDTA Registry

(c) UK Renal Registry

(d) ANZ Data

(e) QuaSi-Niere

(f) Italian Registry of Dialysis and Transplantation (RIDT)

* Estimate from partial coverage of UK Renal Registry

- 21 There is also a variation in treatment rates in different parts of England not fully explained by demographic differences.⁸ The UK Renal Registry of the Renal Association recorded numbers of new patients accepted for RRT in 2001 ranging from 51 to 154 pmp, which highlights the importance of locally based needs assessment. Registry data also shows differences between renal units in the proportion of dialysis patients using haemodialysis compared with peritoneal dialysis that are not explained by patient characteristics.

- 22 An arteriovenous fistula (AVF) is considered the best and most reliable form of access to the patient's blood supply for haemodialysis.ⁱ Yet when compared with other European countries, fewer UK patients start haemodialysis with a permanent AVF and a smaller proportion of the overall number of haemodialysis patients have an AVF. This NSF aims to improve performance in England and pilots for re-designing elective dialysis access surgery, discussed in chapter five, will explore ways of doing this.

Figure three: Haemodialysis patients with an arteriovenous fistula⁹

Country	Patients beginning haemodialysis with an AVF (%)	Overall number of haemodialysis patients with an AVF (%)
Germany	83	84
Spain	71	82
France	62	77
Italy	60	90
UK	47	67

- 23 The number of children and young people in England requiring RRT remains relatively small. In April 2001 there were 529 children under the age of 15 on RRT in the UK, of whom 397 had transplants, 85 were receiving peritoneal dialysis, and 47 haemodialysis. A further 289 young people aged over 15 were being cared for in paediatric units.¹⁰

How can we prevent established renal failure?

- 24 There is increasing evidence that if impaired renal function is detected early, appropriate intervention can delay or even prevent the progression to established renal failure. Diabetes and cardiovascular disease are major causes of renal failure. Moreover patients with chronic kidney disease have increased levels of cardiovascular risk factors such as hypertension and lipid abnormalities which hasten the progression of the kidney disease. The *National Service Framework for Diabetes* and the *National Service Framework for Coronary Heart Disease* identify interventions which are also effective in preventing ERF: control of blood glucose levels for people with diabetes, blood pressure control for patients with hypertension from any cause, and use of ACE inhibitorsⁱⁱ (or angiotensin II receptor blockers that work in a similar way).
- 25 Regular testing of people with diabetes can give an early indication of renal damage, allowing appropriate intervention at an early stage. It is supported by guidance from the National Institute for Clinical Excellence (NICE).¹¹ The second part of this NSF will consider in more detail the opportunities for early detection and prevention of ERF.

How services have been delivered

- 26 Renal services have been a priority for specialised services commissioning since 1998. Traditionally services for people with ERF have been centred around hospital haemodialysis in a limited number of main renal units where renal consultants, inpatient and investigative facilities are based. In the 1970s and 1980s programmes of home haemodialysis and peritoneal dialysis were established. The 1990s saw the development of a 'hub and spoke' model with many main renal units supported by one or more satellite haemodialysis units closer to

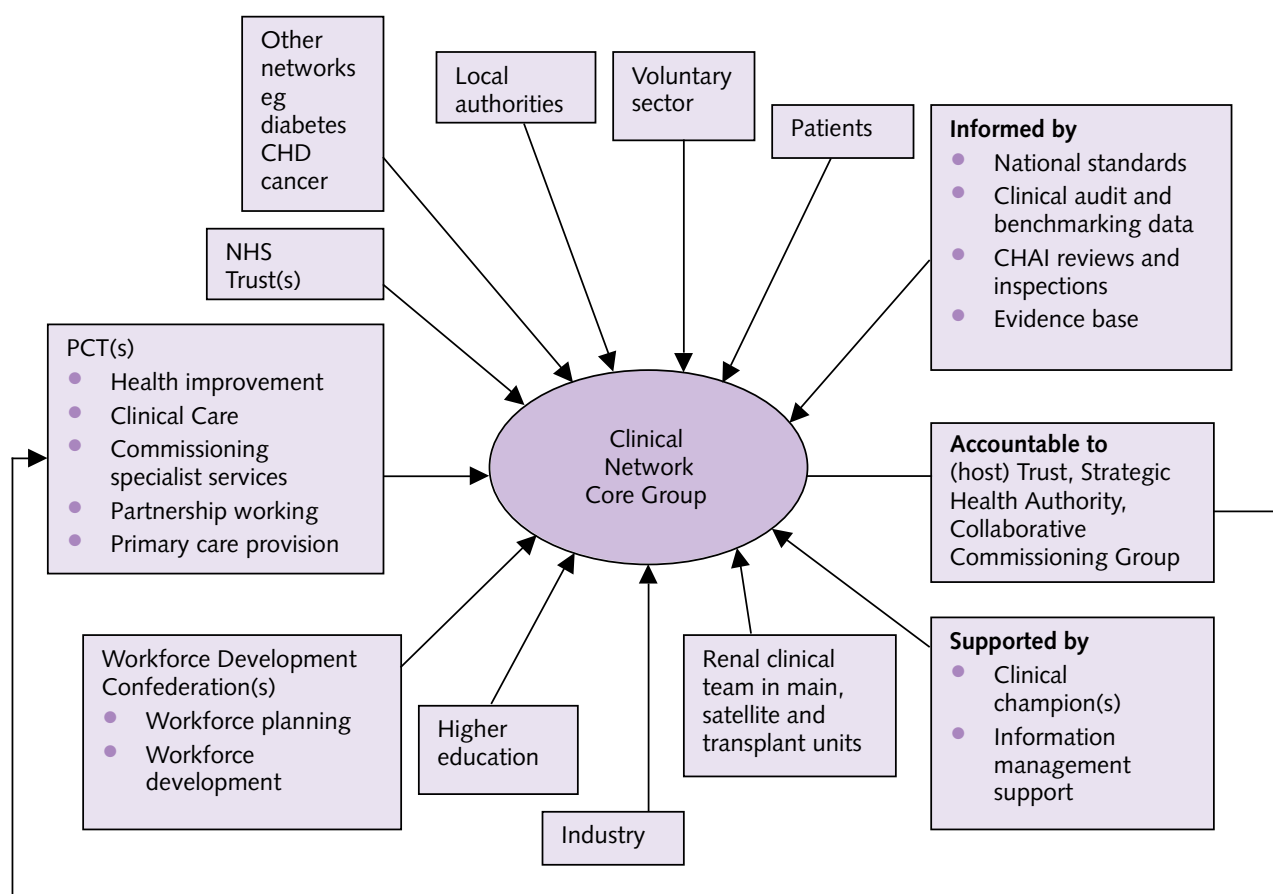
i More detail about dialysis access is given in standard three.

ii Angiotensin Converting Enzyme inhibitors. A class of drug that reduces blood pressure and improves heart function in heart failure.

patients' homes. In some cases the traditional hub and spoke model has evolved into a clinical network, providing the majority of renal care as close to patients' homes as possible.

- 27 Like dialysis services, kidney transplantation in England comes under the arrangements for specialised commissioning, and recently the Government decided that kidney/pancreas transplant operations should be funded through the National Specialised Commissioning programme. There are currently 23 centres in England offering kidney transplants and in future seven of these will offer kidney/pancreas transplantation. All patients require access to kidney transplant centres, which are an important element in any clinical network. The transplant service is at the forefront of high quality care. It operates a busy retrieval and live donor programme to maximise organ procurement, provides treatment regimens that capitalise on the success of a transplant, makes the best use of effective immunosuppressive agents to reduce the likelihood of rejection, and follows up patients for life to enhance the quality of their care.
- 28 This NSF seeks to build on the most successful elements of these models, while providing a more responsive service closer to home.
- 29 In developing renal services health communities can consider putting mechanisms in place to establish a renal network. Such mechanisms:
- engage all stakeholders, including clinical and other staff, commissioners, managers and patients
 - work across traditional service boundaries and models of care
 - have clear lines of accountability
 - demonstrate excellence in leadership and management.
- 30 A network of this type can provide a structure for service planning and delivery, promote seamless care and support staff by targeting resources where they are most needed. The aims of such networks are usually:
- integrated care
 - improved clinical outcomes
 - cost-effective services
 - improved patient experience
 - equity of service provision.
- 31 Experience has shown the most effective networks are inclusive, bringing together all stakeholders, including patients and users of the service. While detailed arrangements should be determined locally, an example of who might be included in a renal network is given in figure four.
- 32 Experience also suggests that an effective network should cover a 'natural' population.

Figure four: Example of a renal network



33 Children with ERF need to be treated by staff with particular skills and expertise. The very small number of children with ERF means they are treated by a small number of specialist centres.

34 A description of a traditional renal multi-skilled team is outlined in The British Renal Society National Renal Workforce Planning Group Report, *The Renal Team: A Multi-Professional Renal Workforce Plan for Adults and Children with Renal Disease*, to be found at www.britishrenal.org.

The impact and cost of established renal failure

Impact on the patient and family

35 Treatment presents social, financial and practical problems for the whole family. It can be difficult for adults to maintain employment. Children requiring treatment may have to travel long distances to specialist units. As well as the time spent on haemodialysis, there is considerable travelling time to and from the dialysis unit, and often additional time spent waiting to be treated or for transport home.¹²

36 Life-style changes are inevitable. Like everyone else, people with ERF will want to have a quality of life that includes work, family visits, everyday pleasures and holidays, but for those on dialysis taking a holiday is only possible with careful planning and preparation. People on haemodialysis will need to have a holiday destination near a dialysis unit with facilities available. For peritoneal dialysis patients, dialysis fluids will need to be delivered to their holiday address.

- 37 Many people with renal failure consider a kidney transplant the best treatment, because individuals feel better than when being dialysed and can lead a near normal life. People with a transplant have greater freedom in their diet and are able to travel and take holidays without the restrictions dialysis imposes. However they still need to take powerful anti-rejection drugs, which may have serious side effects.
- 38 Not everyone can benefit from a kidney transplant, and there is also an increasing proportion of patients starting dialysis who are frail or have advanced vascular disease and may not be healthy enough to have a transplant.

Cost of healthcare

- 39 Treatment is resource intensive for the NHS. The current cost of treating people with ERF has been estimated at 1-2% of the total NHS budget, yet they comprise only 0.05% of the total population. For example NICE estimates that the average annual cost of haemodialysis in a satellite renal unit is £21,000 per patient.¹³
- 40 Dialysis patients often need hospital treatment associated with their RRT, such as surgical procedures for vascular access, or treatment for sepsis, often arising from temporary vascular access. Periods in hospital vary considerably, but on average patients will need to be admitted for between two and three weeks a year. Studies have shown that when people are referred for RRT in the later stages of kidney disease they are less likely to receive interventions that could slow down the progression of their disease, have more hospital admissions and poorer survival.¹⁴
- 41 Transplantation costs about the same as haemodialysis in the first year, which includes surgery as well as immunosuppressive drugs, regular checks and treatment. However the cost reduces considerably in subsequent years, and transplantation is the most cost-effective form of RRT¹⁵ with the best quality of life and independence for patients.
- 42 The projected increase in the number of people requiring RRT will place more pressure on the health economy, renal units and other healthcare resources as greater numbers of older people with co-existing illnesses begin treatment. These resources include: surgery, particularly for vascular access; diagnostic services such as pathology, including immunology, tissue typing and histopathology; radiology; pharmacy and hospital beds.
- 43 The pressure will be greatest in areas with large South Asian, African and African Caribbean communities, and in areas of social deprivation, where demand will rise most steeply.

The evidence base for markers of good practice

- 44 This NSF is intended to be a living document. It is based on the evidence currently available, but over the 10 year period of its implementation new evidence will emerge, new treatments will develop and lessons will be learned.
- 45 The evidence base for this NSF was drawn from a range of sources and supported by systematic reviews carried out by the NHS Centre for Reviews and Dissemination.ⁱ
- 46 In addition views and experiences were sought from people with ERF, including children and their families, patient groups, professional staff and their associations, and from the private sector and industry.

i For details of the evidence base, see www.dh.gov.uk/renal under 'NSF related publications'.

- 47 The following typology has been used to distinguish the different levels of evidence supporting the markers of good practice underpinning the standards in this 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

- 48 This part of the NSF sets out a vision of a patient-centred renal service delivered closer to patients' homes, which takes account of the need to:

- improve access to and choice of services, and reduce inequalities
- ensure a strategic approach to developing integrated services, which fit onto pathways of care
- consider the impact of chronic kidney disease on other specialist services such as surgery, particularly for vascular access; radiology; diagnostic services such as pathology, including immunology and histopathology, and hospital beds
- demonstrate year-on-year improvement, and maintenance of quality and outcomes in those areas not identified as early priorities
- respect the needs of individuals regardless of race, gender, age, religion or beliefs, disability or sexual orientation.

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Chapter two: The standards

Introduction

- 49 In this chapter five standards are set and 30 markers of good practice are identified (see summary at figure five). While it is envisaged the standards will take 10 years to implement fully, PCTs as commissioners and NHS Trusts will need to establish at an early date how far their practice varies from the markers of good practice so they can begin a process of continuous quality improvement. These standards and markers of good practice will be the basis for the Commission for Healthcare Audit and Inspection (CHAI)ⁱ to measure performance in the NHS, and it is expected that PCTs will take this into account in their commissioning.
- 50 These standards apply to all patients. 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. Further information about the impact of renal disease on children, and how services can respond, will be found at www.dh.gov.uk/renal under 'NSF related publications'.
- 51 These standards and markers of good practice build on: the *NHS Plan*; *The National Service Framework for Coronary Heart Disease*; *The National Service Framework for Older People*; *The National Service Framework for Diabetes*; *Getting the right start: National Service Framework for Children, Young People and Maternity Services*; *Saving Lives, Valuing Donors: A Transplant Framework for England*; *The Expert Patient* and *Building on the Best; Choice, Responsiveness and Equity in the NHS*.
- 52 These standards have also been informed by professional guidance including *Treatment of adults and children with renal failure: Standards and audit measures, third edition* published by the Renal Association in 2002, and *Standards for solid organ transplantation in the UK*, published by the British Transplantation Society in 2003.

i From April 2004 the Commission for Health Improvement will be incorporated into the Commission for Healthcare Audit and Inspection (CHAI).

Figure five: Summary of standards and markers of good practice

These standards apply to all patients. 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.

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 with a clear explanation of tests, procedures and results.
- 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*.

Standard one: A patient-centred service

Aim

To optimise the role that people with chronic kidney disease can take in the management of their care.

Standard

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.

Rationale

53 This standard applies across all modules of the NSF.

54 *The Expert Patient*¹ examined the problems that people with a long-term condition, and their families, can meet. These include physical, psychological and socio-economic problems, which can reduce their quality of life and sometimes involve social exclusion. People with long-term conditions can also experience problems with the health and social care systems.

55 Many people with ERF become experts in their own condition. An observation made by doctors, nurses and other health professionals who undertake long-term follow-up of people with chronic conditions is that patients often understand their disease or condition as well as the professionals. For them to own their condition and be able to manage it *The Expert Patient* suggests that, among other things, they will need to know how to:

- recognise and act on symptoms
- make most effective use of medicines and treatments
- comprehend the implications of professional advice
- access social and other services
- manage work and access the resources of the employment services
- access chosen leisure activities
- develop strategies to deal with the psychological consequences of illness.

56 People need information, advice, education and support if they are to be full partners in care. While some people may not wish to be active participants in care, most will want to be involved in decisions and choose which treatment process best suits their needs, and to share responsibility for managing their own condition in partnership with professional staff.

57 Educational programmes have been shown to improve people's knowledge of ERF and its treatment by RRT.^{2,3} Patients will need information on the nature and consequences of renal failure including advice on nutrition, anaemia, hypertension and lipid control, bone disease, exercise and smoking cessation. Additionally interpretation and translation skills may be required where difficulties in understanding and communication may have an adverse impact on patients' ability to make choices, and on the quality of care.

- 58 Good practice suggests that education programmes are most effective when they are tailored to individual needs, both culturally and linguistically, and take account of other influences such as age and disability. For example dietary advice has been identified by patients as being particularly important. It may need to include information on South Asian or African Caribbean foods, or be integrated with other dietary requirements for patients with coronary heart disease or diabetes. It could be presented in large print for elderly people. Patients also value positively presented advice on what they can eat, rather than lists of foods they cannot.⁴
- 59 There is also evidence that patients with chronic kidney disease who choose to undergo an education programme have improved psychological and social outcomes. Studies have shown that information and support enable patients to maintain employment⁵ and to ward off the depressive symptoms that can sometimes arise when people are undergoing long-term dialysis.⁶⁻⁹
- 60 For patients in the care of a multi-skilled renal team, good practice suggests that at each stage of the care pathway the team should identify a named contact for each patient. The named contact might be any one of the range of professionals in the clinical team. Their role is to help the patient navigate their way around the system, to be responsible for ensuring an agreed care plan is in place and to make sure it is regularly reviewed by the clinical team with the patient. The Department of Health will work with other stakeholders to develop guidance on the use of care plans.
- 61 An agreed care plan not only provides the individual with information but can foster a partnership between clinicians and patients and clarify what each will do to reach agreed goals. An agreed care plan would usually identify the person's health and social care needs, how they will be met and who will be responsible. It can set out the social work support required to help patients with problems relating to benefits, work and family matters, and can highlight the need for psychological support and recognition and management of depression.
- 62 People with diabetes who develop renal failure will increasingly (in accordance with the *National Service Framework for Diabetes*) have a fully worked up and agreed care plan, which the renal team will need to integrate with its own care planning.

Special needs of children and young people

- 63 Children and young people with ERF are subject to all the usual pressures associated with childhood and growing up, as well as the challenges of living with ERF. They face a lifetime of treatment. Meeting their individual needs, and the needs of their families, carers and siblings, is key to delivering high quality services. For example, moving from a children's unit to an adult unit can be difficult. Units need robust transition policies in place and skilled staff available, sensitive to the education and social development needs of children and their need for greater independence as young people.
- 64 Equally, optimal management is required to achieve the best growth and development, and to avoid the long-term complications of renal failure. Children and young people with renal failure will inevitably have their education disrupted by frequent hospital treatment, and liaison between the hospital, teacher and the school is essential.
- 65 Children can, with their parents, be engaged as active partners in decisions about their health and care and where appropriate, exercise choice. *Getting the right start: The National Service Framework for Children, Young People and Maternity Services* will set out the principles of care for children and young people in the NHS. The direction of travel is indicated in the *Emerging Findings*, while the first published module, the *Standard for Hospital Services*, covers the care of children in hospital. A good practice guide exploring the implications of this NSF for children is in development and will be found at www.dh.gov.uk/renal under 'NSF related publications'.

Markers of good practice

- Provision of high quality, culturally appropriate and comprehensive information and education programmes. (Level 1)ⁱ
- Education programmes tailored to the needs of the individual. (Level 2)
- Individual care plans, regularly audited, evaluated and reviewed. (Level 4)
- Access to a multi-skilled renal team whose members have the appropriate training, experience and skills. (Level 3)

For children and young people:

- For children and young people, meeting the standards of *Getting the right start: National Service Framework for Children, Young People and Maternity Services*.

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i For an explanation of the levels of evidence, please see page 14.

Standard two: Preparation and choice

Aim

To provide co-ordinated care to patients approaching established renal failure which is responsive to their individual needs and personal preferences, delivered by staff with an appropriate range of skills.

Standard

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.

Rationale

- 66 Because the progression of chronic kidney disease is frequently slow clinicians can often predict the point when the person will need to start RRT. There is evidence that patients known to the renal service for a reasonable length of time before starting RRT have better outcomes, including when case-mix is taken into account. Professional consensus is that the optimal time required to prepare a patient and their carers for RRT is around one year. However a third of people present less than a month before requiring RRT and the outcomes for this group of people are less good than for those who present earlier.¹ For example they frequently require extended hospital admissions and intensive input from the renal team to establish them successfully on RRT.
- 67 Once a person is known to the renal service clinicians can be proactive. They need to establish when they predict RRT will be needed and, with the multi-skilled renal team, prepare patients both medically and psychologically, and minimise the complications of their disease. Some of the interventions may already have begun, and may continue throughout the patient's life. They are likely to include:
- correction of the anaemia associated with renal failure.¹ NICE has been asked to produce guidance on the management of anaemia in renal failure
 - nutritional monitoring and dietary advice. The reduction in nutrient intake associated with ERF begins in the pre-RRT period
 - management of other diseases such as diabetes (in accordance with the *National Service Framework for Diabetes*), peripheral vascular disease (especially in people with diabetes) and cardiovascular disease, and reduction in cardiovascular risk, including blood pressureⁱⁱ and lipid control (in accordance with the *National Service Framework for Coronary Heart Disease*)
 - prevention of the bone disease associated with ERF
 - advice on lifestyle changes such as smoking cessation and exercise. Older patients, in particular, may benefit from therapy/advice to maintain their functional abilities and promote active lives

i Levels of haemoglobin to be achieved may change in the light of future guidance from NICE. Currently target levels for adults and children are recommended by the Renal Association Standards and Audit Subcommittee in *Treatment of adults and children with renal failure, standards and audit measures, 3rd Edition*.

ii Target levels for blood pressure for adults and children are recommended by the Renal Association Standards and Audit Subcommittee in *Treatment of adults and children with renal failure, standards and audit measures, 3rd Edition*, and for adults by NICE in the *Clinical guideline for the management of type 2 diabetes: Renal disease, prevention and early management*.

- immunisation against hepatitis Bⁱ
- liaison with surgical teams to arrange early procedures for vascular and peritoneal dialysis access
- preparation for transplantation, where appropriate
- management of medicines, throughout all stages of ERF. For more information, see *Management of Medicines: A resource document for aspects specific to the Renal NSF*.ⁱⁱ

- 68 It is during this period that the person with ERF can opt for a particular type of RRT. While clinical considerations may determine which options are open (for example peritoneal dialysis may be inappropriate because of previous extensive abdominal surgery) there is no robust evidence showing that one form of dialysis has better outcomes than another.² To make an informed choice people in ERF need to understand what the treatment options involve, and their clinical, psychological and social suitability for the preferred option should be assessed jointly by the team and the patient.
- 69 Patients for whom transplantation is an option should be assessed before being placed on the national transplant list. Currently fewer than 40% of dialysis patients are on the national transplant list,³ and the proportion varies widely from unit to unit.⁴ UK Transplantⁱⁱⁱ has consulted with the British Transplantation Society and the Renal Association to develop protocols for the assessment of adults, and with the British Association for Paediatric Nephrology to do the same for children.^{iv} These will ensure that all patients are assessed to uniform standards.
- 70 Suitable people close to ERF may benefit most if they have a transplant before they need to start dialysis. This is known as a 'pre-emptive' transplant. The guideline published by UK Transplant is that people should be eligible for the national transplant list if dialysis is predicted to start within six months – typically with a GFR^v <15mls/min.⁵
- 71 For the third of patients who begin RRT as an emergency, their first treatment will almost always be haemodialysis via a venous catheter, although they should be offered the choice of all appropriate treatment methods once their condition stabilises, usually before they are discharged from hospital.

Special needs of children and young people

- 72 Care of children will need to take account of their physical and emotional development. Children's physiology differs from that of adults and changes as they grow and develop, for example necessitating changes in dialysis, feeding and medicines prescriptions. They will need chicken pox and BCG vaccinations if they are not immune, as well as their routine childhood vaccinations. Further details on the care of children and young people can be found in *Treatment of adults and children with renal failure, third edition*, published by the Renal Association; and *Medicines Management: A resource document for aspects specific to the Renal NSF*.

i Renal failure can reduce patients' response to hepatitis B vaccine, so immunisation should be carried out early, while plasma creatinine remains relatively low. (For further details see the Good Practice Guidelines for Renal Dialysis/Transplantation Units on the Prevention and Control of Blood-borne Virus Infection (2002), available at www.dh.gov.uk/renal under Renal information).

ii Published at www.dh.gov.uk/renal under 'NSF related publications'.

iii UK Transplant is a Special Health Authority which promotes and regulates organ transplantation.

iv For further details, see the UK Transplant website at www.uktransplant.org.uk.

v GFR is the glomerular filtration rate, ie the rate at which the kidneys filter waste products, and equates to the percentage of normal kidney function remaining.

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. (Level 4)
- Accelerated process with intensive input from the renal team for those who present late to renal units or as acute uraemic emergencies. (Level 4)
- People with ERF given information about all forms of treatment so that an informed choice can be made. (Level 4)
- Patients put on the national transplant list within six months of their anticipated dialysis start date if clinically appropriate. (Level 4)
- Anaemia treated to maintain an adequate haemoglobin level.ⁱ (Level 1)
- Management of cardiovascular risk factors and diabetes according to the National Service Frameworks for Coronary Heart Disease and for Diabetes.

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i Levels of haemoglobin to be achieved may change in the light of future guidance from NICE. Current evidence from randomised controlled trials of dialysis patients supports a correction of haemoglobin to between 9.5 – 11 g/dl; the clinical standard currently recommended by the Renal Association for adults is >10 g/dl, and for children is age related, ranging from 9.5 g/dl to >10.5 g/dl.

Standard three: Elective dialysis access surgery

Aim

To improve the outcomes of permanent vascular or peritoneal dialysis access surgery, minimise complications and maximise the longevity of the access.

Standard

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.

Rationale

73 'Access' has a specific meaning for people who require dialysis. It refers to the place on the body where the needles are inserted on a regular basis (for haemodialysis) or the catheter passing into the abdomen used for the exchange of fluids (for peritoneal dialysis). It is therefore essential that:

- patients have early assessment and investigations to agree the best form of access for their chosen treatment method
- the form of access agreed in the care plan is established sufficiently far in advance to have matured before the start of dialysis, and
- the access site is regularly monitored.

The care plan should set out what is required of the patient, staff and carers to monitor and maintain the site.

74 **Haemodialysis** requires access to the blood vessels, for which surgery is required. An arteriovenous fistula (AVF), formed by connecting a vein to a nearby artery, provides the best long-term vascular access with the fewest complications. AVFs take between one and two months to develop. Because a proportion of wrist (radiocephalic) AVFs fail before dialysis is due to start, time needs to be built into the care plan to undertake a second procedure or revision if necessary.ⁱ An alternative when blood vessels are damaged or in poor condition is for a tube of synthetic material to be connected to blood vessels. This is known as a 'graft'. If someone presents as an emergency or it is not possible to establish mature access before dialysis is required, an intravenous catheter can be inserted, usually into a vein deep in the patient's neck.

75 There is strong evidence to suggest that permanent vascular access should be established as soon as possible. Current best practice suggests this should be six months before starting dialysis. For example, evidence from Europe and elsewhere¹ demonstrates that patients who start dialysis without a properly established and healed access site suffer higher morbidity and mortality. This may reflect their late presentation and greater associated illness, although the effect has also been identified in studies that attempted to correct for these factors.^{2,3} People with central venous catheters have higher infection, thrombosis and hospitalisation rates than those with grafts; and grafts have a higher complication rate than AVFs.⁴⁻⁶ A higher dialysis dose can be delivered through permanent vascular access, and those with

i Pilots to explore innovative delivery in vascular access surgery are being undertaken by the Modernisation Agency.

catheters may need to have the length of their dialysis sessions increased to compensate.^{7,8} Permanent vascular access, particularly an AVF, remains functional for much longer than a catheter.^{9–11}

- 76 **Peritoneal dialysis** requires a catheter to be inserted into the abdomen. Healing may take up to four weeks, and insertion needs to take place in time to allow healing before use to prevent leakage. People need to be involved in decisions about the positioning of their peritoneal dialysis catheters so life-style and cosmetic considerations can be taken fully into account. Time is required to allow for any abdominal surgery, such as hernia repair, to be carried out before catheter placement.
- 77 **Care of dialysis access:** to minimise the risk of complications, the patient and those caring for them need to understand how best to take care of their dialysis access. Regular monitoring by appropriately trained staff can detect problems such as infection, blockage (thrombosis) and narrowing (stenosis), allowing prompt medical, surgical or radiological intervention to keep the dialysis access functioning longer.^{12–17} Delay in dealing with complications can lead to premature loss of the access.

Special needs of children and young people

- 78 Vascular surgery is complex in small children. The choice of vascular access will need to take into account the age and size of the child or young person, as AVFs may not be possible because of the size of blood vessels, or the patient's co-operation with needling of the fistula. Such surgery needs to be undertaken by teams skilled in performing these procedures on children.

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. (Level 2)
- Monitoring and early intervention to minimise complications of the access. (Level 2)
- 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. (Level 4) Temporary access replaced by permanent access as early as possible. (Level 2)
- Proper training for patients, carers and members of the renal team in the care of the access. (Level 4)

For children and young people:

- Dialysis access surgery to follow the principles set out in *Getting the right start: the NSF for Children, Young People and Maternity Services – Standard for Hospital Services*.

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Standard four: Dialysis

Aim

To improve the outcomes for children, young people and adults on dialysis and maximise their rehabilitation, quality of life and survival.

Standard

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.

Rationale

79 Most people with ERF will receive different types of RRT during their lifetime. Many experience both peritoneal dialysis and haemodialysis, perhaps in more than one of their forms. Some will receive more than one transplant, returning to dialysis if the transplant fails while waiting for their next one. The UK Renal Registry of the Renal Association showed that 19.5% of people changed from peritoneal dialysis to haemodialysis during their first two years on RRT, and 5.2% from haemodialysis to peritoneal dialysis.¹ The various forms of therapy are complementary and the best way of managing RRT is by an integrated approach to dialysis and transplantation.

Key elements in clinical care

80 Key elements of high quality care provided in dialysis units can be audited against clinical standards provided by the Renal Association.ⁱ Good practice suggests the following areas are the pivotal points for both the delivery of high quality dialysis treatment and the best possible patient experience and wellbeing.

81 Firstly, for haemodialysis:

- *frequency*: for most patients haemodialysis is a centre-based service that involves treatment three times a week for three or four hours.² For patients using home haemodialysis, more frequent but shorter treatments are also possible and may be more convenient to meet individual needs.
- *adequacy*: the effectiveness of dialysis can be assessed numerically by measuring the clearance of certain molecules from the blood. Two widely used formulae for calculating effectiveness are the urea reduction ratio (URR) and Kt/V ⁱⁱ.³⁻⁶

82 Secondly, for peritoneal dialysis:

- *prevention of peritonitis*: the major risk to physical wellbeing is the development of peritonitis (an infection of the peritoneal membrane). There is mounting evidence that repeated attacks of peritonitis, as well as being associated with considerable morbidity and occasional mortality, are

i Treatment of adults and children with renal failure: Standards and Audit Measures (3rd Edition) August 2002

ii Kt/V : a formula to calculate dialysis adequacy. Current evidence shows that for those on thrice weekly dialysis, outcomes are improved if URR is greater than 65% or Kt/V is greater than 1.2.

linked with early failure of the peritoneal membrane. So the aim should be to keep peritonitis rates below one episode for every 18 patient months, or every 14 patient months in the case of children.⁷

- It has been shown that using *disconnect systems* reduces the risk of peritonitis. The disconnect system is a type of peritoneal dialysis equipment where the dialysis fluid bag and tube are disconnected from the catheter after each fluid exchange.⁸
- *Automated peritoneal* dialysis uses a machine that performs several fluid exchanges, usually overnight. Some patients may prefer this to conventional peritoneal dialysis because it provides more free time during the day for work, schooling or social activities. There is some, albeit currently weak, evidence that peritonitis decreases with automated peritoneal dialysis and continuing evaluation is required. Initially this treatment was more expensive than conventional peritoneal dialysis but this difference is diminishing over time.

83 Thirdly, continuing management of underlying diseases and the risk factors and complications such as those mentioned in standard two:

- *anaemia*: patients with ERF are frequently anaemic, mainly as a result of the lack of production of the hormone erythropoietin naturally formed by the normal kidney.

The treatment of choice is epoetin (recombinant human erythropoietin), with intravenous or oral iron supplementation as necessary.⁹ However patients with certain medical conditions, either temporary or permanent, may be unable to respond to it. Additionally a proportion of patients, more frequently those on peritoneal dialysis, can achieve an adequate haemoglobin level without requiring epoetin particularly if they have sufficient iron stores and are well dialysed. When deciding whether epoetin should be provided in primary care or by the renal unit, the views of the patient should be taken into consideration

- *cardiovascular disease* is the main cause of premature death in patients with ERF, and ERF hastens its progression, so the continued management of cardiovascular risk in people on dialysis represents a special challenge for renal units. The *National Service Framework for Coronary Heart Disease* and the *National Service Framework for Diabetes* set out standards for managing vascular problems where they arise from coronary heart disease or diabetes
- *undernutrition*: malnutrition is associated with poor outcome, and patients on dialysis will need their nutritional status monitored, with appropriate nutritional advice and support provided where necessary
- prevention of renal bone disease eg by control of phosphate levels.

Wellbeing and impact on daily life

Haemodialysis at home

84 Some people prefer home haemodialysis. The benefits summarised in NICE's appraisalⁱ include more flexibility to tailor the individual's dialysis regimen, and freedom from the travel and waiting involved in hospital attendance. Others, however, find it onerous or feel it places too much of a burden on carers who need to support them in the process.

85 While as a general rule children's interests are best served by being in hospital for the briefest possible time needed to provide safe and effective treatment, home circumstances may not be suitable for

i The full guidance on home compared with hospital haemodialysis for patients with end-stage renal failure is available on the website of the National Institute for Clinical Excellence, at www.nice.org.uk.

haemodialysis. This is because life-threatening fluid disturbances and metabolic abnormalities can develop rapidly. Peritoneal dialysis is therefore the dialysis method of choice for most children. It is also preferred by families because it affords maximum freedom for play, education and social activity, and it avoids access surgery and travel to the renal unit for haemodialysis.

Haemodialysis in a unit

- 86 People on haemodialysis have to travel three times a week to their dialysis unit. Haemodialysis patients are disproportionately dependent on hospital transport services, and the time and costs associated with hospital transport are major areas of concern internationally.¹⁰⁻¹²
- 87 Adequate transport is so important to people on haemodialysis that it plays a vital role in the formation of patient views and attitudes towards dialysis. Good transport systems can improve patient attendance,¹³ and shorter travel times can improve patient co-operation if the dialysis treatment frequency needs to be increased.¹⁴ Efficient transport facilities reduce interruption of patients' social life and may therefore improve their quality of life. The development of satellite units and an increased availability of home haemodialysis can be convenient for the patient and also minimise transport costs.
- 88 There is good evidence that for many patients satellite units are as effective as main renal units and often more acceptable and accessible. Satellite units may be attached to primary care centres, or can be located in shopping centres and other public areas. However main renal units will still need to manage patients for whom satellite or home haemodialysis care would be inappropriate.¹⁵
- 89 Renal communities can work up local clinical criteria to determine which patients need to be treated in a main unit. But decisions about the type of dialysis a person receives and where it takes place are best made by the patient as far as possible, with the help of information and advice from the multi-skilled team.
- 90 When undergoing dialysis, people require access to suitable food and drink, for example the NHS Snack Box.ⁱ This may be particularly important for older patients receiving Meals on Wheels or the equivalent, who may miss meals when attending for dialysis.
- 91 The environment where people dialyse is particularly important. Careful attention to the siting and the design of dialysis units is needed so they meet modern requirements, provide patients with good access, including dedicated parking spaces, and have a positive impact on patients' wellbeing. NHS Estates is developing new building guidance for main renal units and satellites, details of which can be found at www.nhsestates.gov.uk.
- 92 For a variety of reasons – work, education, holidays, family visits – it is important that patients can dialyse away from home. For further information, please see www.dh.gov.uk/renal under 'NSF related publications'.

Dialysis while an inpatient

- 93 Patients with ERF undergoing either haemodialysis or peritoneal dialysis are increasingly elderly and often have other illnesses. Some therefore require relatively frequent hospital admissions. When patients are admitted they should, wherever possible, be cared for by health professionals trained in renal medicine because this has been shown to improve outcomes.¹⁶ If they require admission to another specialised unit, eg a critical care unit, close liaison with the renal team is needed.
- 94 Similarly, patients admitted to a renal ward who have other conditions such as diabetes or coronary heart disease will need access to specialist advice from the diabetes or cardiac team.

i For more information about hospital food, see www.nhsestates.gov.uk, select 'Patient Environment' then 'Better Hospital Food'.

Markers of good practice

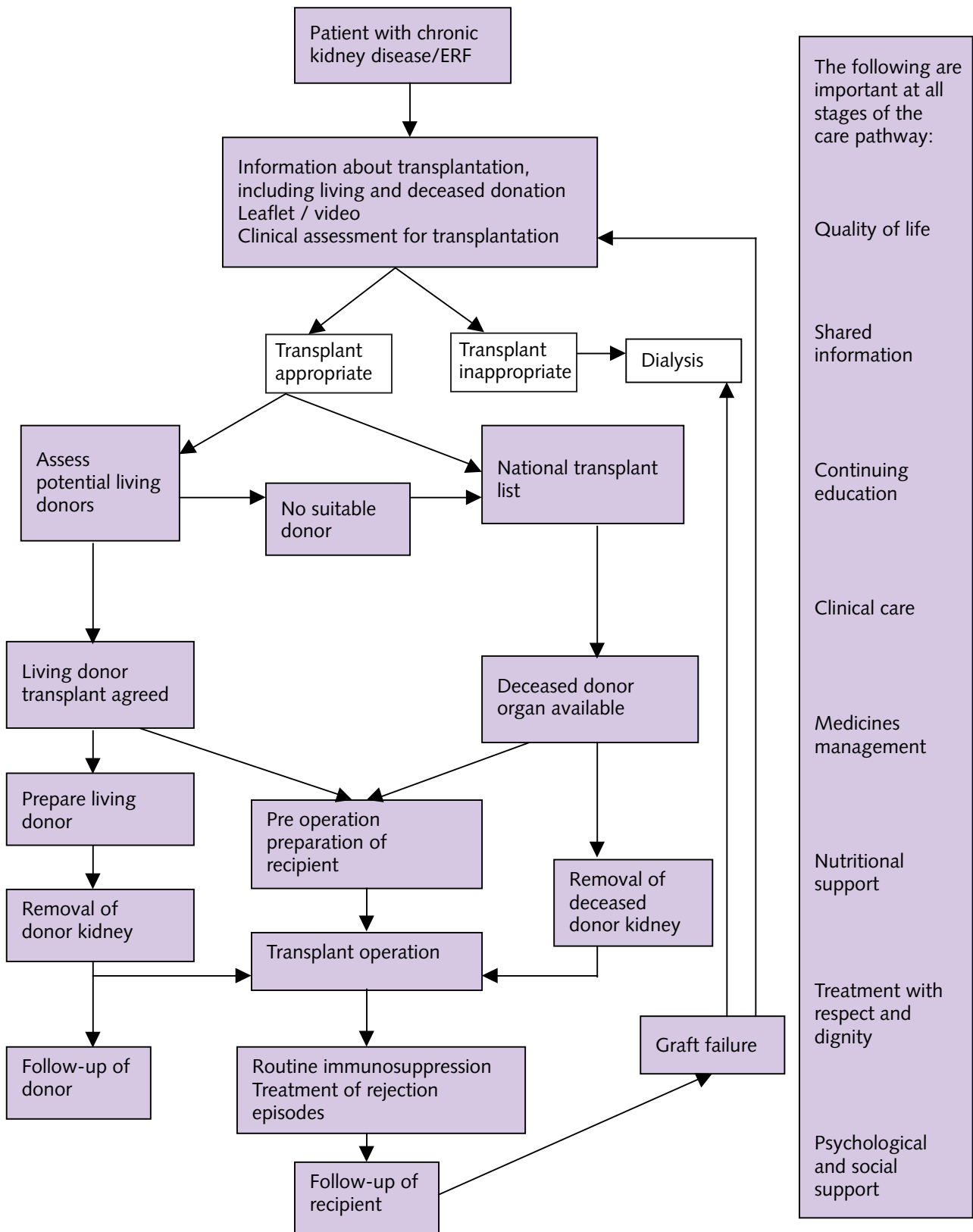
- All dialysis methods available interchangeably for patients, including home haemodialysis and automated peritoneal dialysis. (Level 4)
- Patients receive an adequate and effective dialysis dose. (Level 2)
- Peritonitis rates to be less than one per 18 patient months for adults undergoing peritoneal dialysis, one per 14 patient months for children. (Level 1)
- Patients have their nutritional status monitored and appropriate nutritional support in place. (Level 4)
- Efficient patient transport services available. (Level 3)
- Specialist renal staff, equipment and care available throughout admission, whatever the setting, for patients with established renal failure admitted to hospital. (Level 3)

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Figure six: Care pathway for potential transplant recipients

The highlighted areas are covered in this part of the NSF



Standard five: Transplantation

Aim

To optimise access to and the outcome of a renal transplant for all those who could benefit.

Standard

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.

Rationale

- 95 A successful kidney transplant is the most clinically and cost-effective treatment for many patients with ERF. However a considerable increase in the number of kidneys donated, especially from members of black and minority ethnic groups, will be needed to make this an option for all who could benefit. It can be difficult to find well-matched kidneys for transplantation for smaller population groups. Because many South Asian and African Caribbean patients have a blood group and tissue type which is uncommon in the population as a whole, some may be unable to receive kidneys from the majority of donors.
- 96 There are various guidelines and other documents available to professionals and patients,ⁱ and they have been used to inform this standard. They can aid the assessment, preparation and care of transplant patients.
- 97 The Government's strategy for transplantation, *Saving Lives, Valuing Donors: A Transplant Framework for England*,ⁱⁱ recognises the difficulties of supplying sufficient kidneys to meet demand, and proposes ways to optimise the potential of heartbeating donor,ⁱⁱⁱ non-heartbeating donor^{iv} and living donor programmes.¹ For example, up to 45% of relatives currently refuse permission for organ donation from otherwise suitable patients.² The *Transplant Framework* emphasises the need for people on the organ donor register to tell their family and friends about their wish to donate their organs in the event of their death. An organ donor registration form is included at the end of this document.
- 98 The *Transplant Framework* also forms the basis for local reviews of transplantation services, supported by this NSF.
- 99 Where a kidney is available there are three key stages in the patient's pathway to transplantation:
- psychological and physical preparation

i These include *Treatment of adults and children with renal failure: Standards and audit measures, third edition*, the Renal Association, 2002, and others mentioned in this standard.

ii Further information on transplantation can be obtained from the Transplant Framework and at www.uktransplant.org.uk.

iii Heartbeating donors are those who die while still on a ventilator in a critical care unit. The circulation is maintained until the organs are retrieved.

iv Non-heartbeating donors are normally those who die in hospital following a cardio-respiratory arrest. If steps are taken immediately after death to retrieve or preserve the kidneys they can be used for transplantation.

- pre- and post-operative care
- long-term follow-up.ⁱ

Psychological and physical preparation

- 100 For most patients approaching ERF the concept of transplantation is introduced by the renal team, and a basic description of transplantation is given (see standard two), with discussion of the risks and benefits of a transplant, including information on the types of kidney that may become available and associated problems. Transplantation for patients who present as emergencies is usually delayed until their general condition stabilises.
- 101 Patients who are offered a kidney from a deceased person will need further detailed information about the particular organ available (for example an increased risk of transmitting disease, of the donated kidney not working or only working after a delay), so they can make an informed decision about whether to accept it.
- 102 Some patients will have a potential living kidney donor among their family or friends.ⁱⁱ In this case, the risks and benefits for both the donor and the recipient will need to be discussed with the renal team,ⁱⁱⁱ who can explain that kidneys obtained from living donors have a better long-term survival rate than those from people who have died.^{iv} However the giving of an organ to another will have implications for the donor, the relationship with the recipient, and the feelings the recipient has about the transplanted organ.
- 103 Potential living donors therefore require independent, confidential advice about the risks and implications to make an informed decision about whether to proceed, and this should remain available throughout the donation process. A telephone helpline, trained counsellors, information leaflets or videos (with translated materials available) can be of help to donors, recipients and families.
- 104 Many studies have shown that following kidney donation a living donor experiences very few, if any, long-term complications.³⁻⁷
- 105 Not all people with ERF are suitable for a kidney transplant because of other medical problems they may have. Age in itself is not a barrier to transplantation. However there are extra risks for older people, who are more likely to have other illnesses. UK Transplant applies ethical rules governing the allocation of organs.^v If suitable for transplantation, the recipient will undergo tests including tissue typing and be placed on the national transplant list. People can be placed on the national transplant list six months before their estimated start on dialysis. In some cases people may benefit from a transplant before dialysis begins (see Standard two). Patients need to be aware that their name is registered on the national transplant list. Sometimes it may be necessary for a patient to be suspended or removed from the national transplant list, for example if they become seriously ill or are approaching major surgery. When these decisions are taken the patient needs to be fully involved, to know whether removal from the list is temporary or permanent, and to have that noted in their care plan.

i *Standards for solid organ transplantation in the United Kingdom* published by the British Transplantation Society in July 2003, which includes renal transplantation, can be found at www.bts.org.uk.

ii Organ donation from a living donor not related to the recipient is regulated by the Unrelated Live Transplant Regulatory Authority. For more information, see www.advisorybodies.doh.gov.uk/ultra.

iii *United Kingdom Guidelines for Living Donor Kidney Transplantation*, prepared by a working party of the British Transplantation Society and the Renal Association, are published at www.bts.org.uk. *Interventional Procedure Guidance on laparoscopic live donor simple nephrectomy* will be issued by NICE shortly: see www.nice.org.uk.

iv Figures from UK Transplant show that living donor transplants have an average survival rate of 95% after one year compared with 88% for kidneys from a deceased donor. However recipients of kidneys from live donors are often younger and fitter than those who receive an organ from a deceased donor. This might in part account for the difference in transplant success.

v Information about tissue matching and organ allocation can be found at the UK Transplant website at www.uktransplant.org.uk.

- 106 Some patients with diabetes and ERF may benefit from a combined kidney and pancreas transplant. The results of this combined procedure have improved and a national service based in seven centres will be commissioned by the National Specialist Commissioning Advisory Group from April 2004.

Pre- and post-operative care

- 107 There are some essential pre- and post-operative considerations for a successful transplant operation to restore kidney function. Evidence suggests that to obtain the best results:
- the organ should be adequately matched to the recipient's blood group, tissue type etc (using UK Transplant matching criteria for kidneys from deceased donors) and be in the best possible condition, with short ischemia timesⁱ
 - prophylactic or pre-emptive therapy should be used to control infections
 - NICE guidance should be followed for immunosuppressive therapy and the treatment of acute rejection episodes
 - management of complications and risk factors, such as cardiovascular problems, should continue (see standard two).
- 108 The ischemia time relates to periods between removal of a kidney from the donor and its insertion into the recipient. There is evidence that keeping ischemia times below certain limits is important for the successful outcome of the transplant.^{8–22}
- 109 Infection is a risk in transplantation. It can be transmitted with the organ, and opportunistic infections are potentially more serious because the immune system is suppressed. Patients may need prophylactic treatment, or careful monitoring and pre-emptive treatment to control infections such as cytomegalovirusⁱⁱ.
- 110 Medication to suppress the body's natural immune defence mechanisms is required to decrease the risk of rejection of the kidney once transplanted, and to treat rejection episodes if they occur. Several regimens are currently in use and are under review by NICE. The NICE appraisal is due to be published shortly.ⁱⁱⁱ

Long-term follow-up

- 111 People with a renal transplant will require long-term follow-up. The risk of acute rejection diminishes over time, but there will be a continuing need to monitor the function of the transplant, the risk of complications or infection, and the side effects of anti-rejection therapy, such as skin cancer or impaired liver function.
- 112 Evidence suggests that patients want tests and treatments clearly explained.²³ For transplant patients this is especially true of tests, procedures and results concerning the survival of the transplanted kidney.

i Warm ischemia time is between donor cardiac arrest and perfusion of the kidney with a solution at 4°C. Graft outcome is better if this is less than 30 to 40 minutes, particularly for non-heartbeating donors. Cold ischemia time is between cooling on removal from the donor and insertion into the recipient: evidence suggests if this is below 24 hours it improves the chance of immediate graft function, and overall graft survival.

ii The British Transplantation Society's *Guidelines for the prevention and management of cytomegalovirus disease after solid organ transplantation* (November 2003) are at www.bts.org.uk; and guidance issued by the Advisory Committee on the Microbiological Safety of Human Organs, Tissues and Cells used in Transplantation in August 2000 can be found on the Transplantation page of this website.

iii For further details, see www.nice.org.uk.

- 113 The patient's care plan can be used to agree the role of primary care, and the precautions and life-style changes that will maximise the success of the operation. Giving information and education to people as part of follow-up improves their knowledge of anti-rejection therapy^{24–28} and can diminish weight gain,²⁹ cardiovascular risk factors³⁰ and the incidence of urinary tract infections³¹ following a transplant. People also need to be aware of the risks of not taking their anti-rejection therapy as prescribed.
- 114 Patients with a transplant who are admitted to hospital, whatever the setting, will need access to appropriate specialist advice from the transplant team.

Special needs of children and young people

- 115 Children and young people who have received a transplant will need their immunosuppressive medication carefully monitored, particularly at times of rapid physical change and/or emotional challenge such as puberty, change of school, family circumstances or transition to adult treatment services. They and their families/carers will have particular needs for accessible information and for support to manage their anti-rejection therapy and to cope with any side effects.

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. (Level 3)
- Application of a national matching scheme using criteria agreed through UK Transplant to optimise blood group and tissue matching for kidneys from deceased donors. (Level 2)
- Effective preventive therapy to control infections. (Level 1)
- Timely operating theatre availability to ensure optimal cold ischemia times. (Level 4)
- 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. (Level 1)
- Clear explanation for patients of tests, procedures and results (Level 3) and especially information and education about anti-rejection therapy. (Level 1)
- Specialist advice from the transplant team available for patients with a renal transplant admitted to hospital, whatever the setting. (Level 4)
- Organ procurement and transplantation to follow the principles set out in *Saving Lives, Valuing Donors: A Transplant Framework for England*.

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Chapter three: Next steps in implementing this NSF

Introduction

In keeping with *Improvement, Expansion and Reform: the Next 3 Years, Priorities and Planning Framework 2003-2006* this NSF does not prescribe how the NHS should deliver the standards and markers of good practice. Instead it sets out five national steps the NHS can take in the current planning cycle (2003 to 2006) that will support delivery of the standards and markers of good practice and will improve services.

Policy context

- 116 The aim of the *NHS Plan* is to deliver a health service designed around the needs of patients. The vision is to offer prompt, convenient, high quality services with people exercising greater choice. This NSF has been developed with these goals in mind, so that the range, quality and choice of renal services and users' experience over the next 10 years are improved. The emphasis will be on:
- making measurable progress, particularly in relation to the markers of good practice
 - developing the capacity needed to deliver the NSF in terms of staffing, facilities, equipment and a wider range of providers of services
 - changing the way the whole system works to help staff and organisations deliver on the standards and the markers of good practice, and to ensure that it meets the needs and choices of patients and users.
- 117 Implementing this NSF will need to take place in the context of a number of strategies to prevent illness, promote health, tackle inequalities and improve the quality of treatment and care for conditions that may lead to ERF.
- 118 PCTs are required to set priorities for early local action based on the national priorities. Guidance is published at www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/PlanningFramework/fs/en.
- 119 PCTs in their role as specialised services commissioners can consider setting up renal networks with Strategic Health Authorities (SHAs), NHS Hospital Trusts and the private, voluntary and community sectors providing services for the NHS. They will need to agree local arrangements for delivering the five standards and the markers of good practice over a period of 10 years. Collaborative groups, commissioning specialised services, will be accountable to PCTs for:
- *planning*: developing local implementation plans that tackle geographical and social inequalities in renal services and set the priorities and resources needed to deliver the NSF over the next 10 years
 - *leadership*: providing leadership for delivery
 - *monitoring*: ensuring the delivery of the NSF

- *delivery*: bringing about a marked improvement in patients' experience of renal services and meeting population need for ERF.

120 To do this, collaborative groups commissioning specialised services will need full participation from the range of stakeholders. These include people with renal failure, and parents of children with renal failure; voluntary organisations, including black and minority ethnic community groups; PCTs; SHAs; specialist healthcare professionals; and the Workforce Development Confederations or their successors. People with renal failure will need to be supported in contributing to decisions about the future development of services.

121 In developing local arrangements, PCTs commissioning specialised services can:

- assess population need – key determinants being their population's age structure and ethnic mix and level of social deprivation, in the light of existing provision and use
- take account of the need to improve access to and choice of services, and reduce inequalities
- ensure a strategic approach to developing integrated services, which fit onto pathways of care
- take account of the impact of chronic kidney disease on other specialist services such as surgery, particularly for vascular access, radiology, diagnostic services such as pathology including immunology and histopathology, and the need for hospital beds
- demonstrate continuing improvement, and maintenance of quality and outcomes in those areas not identified as early priorities.

122 All stakeholders will need to draw upon:

- modernisation guidance on workforce; care planning; dialysis access surgery redesign; diagnostic services modernisation; information strategy, at www.dh.gov.uk/renal under 'NSF related publications'; and improving the environment, at www.nhsestates.gov.uk
- the evidence base for markers of good practice, at www.dh.gov.uk/renal
- NICE guidelines and appraisals at www.nice.org.uk
- *The National Service Framework for Coronary Heart Disease; The National Service Framework for Older People; The National Service Framework for Diabetes; Getting the right start: National Service Framework for Children, Young People and Maternity Services and Saving Lives, Valuing Donors: A Transplant Framework for England.*

Early action: steps to take by 2006

123 To begin the process of achieving the standards over a 10 year period PCTs, as commissioners, and NHS Trusts can implement the following steps by 2006:

Step one: Use national data to support planning and to identify local priorities, including the needs of black and minority ethnic groups

The Department of Health has commissioned a national survey of renal treatment facilities in England for 2002. The analysis of these data will be completed in early 2004 and fed back to collaborative commissioning groups. PCTs and NHS Trusts can use these data, local demographic information and international comparative data to support planning and to identify in local development plans the

priorities for access, choice and equity. Future demand for RRT will vary in different areas according to the age, ethnic composition and levels of deprivation in their populations.

Step two: Continue to expand haemodialysis capacity

Collaborative commissioning groups need to identify how they propose to use the three year central capital funding for 2003/04 to 2005/06 to support the expansion of centre- and home-based haemodialysis to meet increasing local demand for dialysis, particularly in satellite units which can provide treatment closer to patients' homes.

Step three: Join the UK Renal Registry of the Renal Association and take part in national comparative audit

All renal and transplant units are expected to participate in national comparative audit and benchmarking, by submitting data to the UK Renal Registry of the Renal Association and UK Transplant. PCTs and NHS Trusts can use these clinical benchmarks to measure their performance against that of others. The Commission for Healthcare Audit and Inspection (CHAI) will work with the Department of Health, Medical Royal Colleges, NHS Information Authority and others, including the Renal Association and the UK Renal Registry of the Renal Association, UK Transplant, the British Association for Paediatric Nephrology and the British Renal Society in setting the criteria for assessing whether the standards and markers of best practice are being met.

Step four: Implement NICE appraisal: assessment for home haemodialysis

Collaborative commissioning groups should already be addressing the recommendations set out in the NICE appraisal of home versus hospital haemodialysis and putting in place the required assessment process. By 2006 they will be expected to have implemented the recommendations in full.

Step five: Implement NICE appraisal: immunosuppressive therapy

PCTs and Trusts are already providing immunosuppressive therapy. They will need to ensure that they do so according to the NICE appraisal once this is published.

Chapter four: Commissioning for success by 2014

Introduction

- 124 This NSF heralds a 10 year programme of change. All the standards are expected to be achieved in full by 2014. The evidence-based markers of good practice set out under each standard provide an implementation guide for collaborative commissioning groups and local renal communities.

Collaborative commissioning groups

- 125 Renal services have been a priority for specialised services commissioning since 1998. These arrangements will continue for the foreseeable future but will be kept under review as the service grows to reflect increasing volumes. *Shifting the Balance of Power: The Next Steps* (January 2002) and *Guidance on Commissioning Arrangements for Specialised Services* (March 2003) made it clear that PCTs are responsible for establishing collaborative commissioning groups for specialised services, as identified in the Specialised Services National Definition Set (available at www.dh.gov.uk/renal). SHAs are responsible for the oversight and performance management of these groups in PCTs.
- 126 Commissioning is a powerful tool in delivering NSF standards and markers of good practice. The key to the success of this document will be for the NHS, through the commissioning process, to introduce systems of care that deliver marked improvements in renal services and patient experience by 2014. The National Primary and Care Trust Development Programme (NatPaCT) within the NHS Modernisation Agency supports PCTs in their role as commissioners. The NatPaCT Competency Framework, a self-assessment and support tool which includes a section on commissioning, can be found at www.natpact.nhs.uk.

Accountability arrangements

- 127 Accountability for local arrangements will be reflected in the annual accountability agreements between PCTs, collaborative commissioning groups and their SHA. Such agreements are regularly reviewed. This will allow specialised services commissioners to ensure that renal services are functioning effectively, with full stakeholder involvement, that there is consistent progress and investment as agreed through the planning process, and that quality improves continuously.
- 128 This NSF, together with clinical guidelines and appraisals commissioned from NICE, and other national standards and audit measures such as those published by the Renal Association, will inform processes for performance review. CHAI will help improve the quality of healthcare by providing an independent assessment of the services provided to patients.

Measuring performance

- 129 PCTs commissioning specialised services, working in collaborative commissioning groups with NHS Trusts, other providers and patients, can set priorities for local action from 2003 to 2006 based on the NSF standards and markers of good practice. Information on performance is essential to assessing the baseline, planning and commissioning and to measuring change towards achieving these standards.
- 130 The Department of Health will work with CHAI to review how the NSF standards and markers of good practice can inform the development of the NHS performance rating assessment.
- 131 NHS services can use comparative information derived from the UK Renal Registry of the Renal Association and UK Transplant, in addition to local information, to inform specialised services commissioning. They can also use it to demonstrate to their community, their SHA and to CHAI in their audit and inspection role that implementation of the NSF is going to plan. Patient surveys will be an important tool in quality assurance.

Chapter five: National support for local action

National modernisation programmes

132 The Department of Health is working with the NHS Modernisation Agency, SHAs and others to develop pilots that will support the underpinning programmes and the modernisation agenda to implement this NSF. These include:

- re-designing the workforce
- re-engineering elective dialysis access surgery
- re-designing hospital access (patient transport)
- re-designing care plans for partnership and choice
- re-designing the built environment.

Re-designing the workforce: Workforce Development Confederations are developing and piloting robust local workforce development models for renal dialysis and transplant units, which can be used as a template by other Workforce Development Confederations. This will complement the work on Renal Competency Frameworks, being developed by Skills for Health.

Re-engineering elective dialysis access surgery: Pilots will look at different solutions for improving access to, and bringing down waiting times for, elective fistula surgery. Consideration will be given to the appropriateness of treating more patients as day cases and allowing alternative patient management arrangements to evolve by using capacity in NHS or Independent Sector Diagnostic and Treatment Centres.

Re-designing hospital access (patient transport): Following a report from the Social Exclusion Unit, *Making the Connections: Final Report on Transport and Social Exclusion*, a project has been set up to tackle the problems of non-emergency patient transport. Action is in hand to establish two patient transport pilots aimed at making journeys easier for patients receiving haemodialysis.

Re-designing care plans for partnership and choice: The Department of Health has facilitated a patient and carer conference to explore how care plans can reflect and facilitate a partnership approach for people with kidney disease.

Re-designing the built environment: The physical environment affects the wellbeing of patients, particularly haemodialysis patients, who attend three times a week. While medical equipment cannot easily be concealed, more can be done to humanise the surroundings where people with ERF are treated, to improve their experience and physical comfort. NHS Estates will issue a new series of Health Building Notes on satellite dialysis units, main renal units and transplant units.

National underpinning programmes

133 There is a range of national underpinning programmes to support delivery of this NSF.

Finance

134 Some parts of this NSF will require additional resources to implement and others will require changes in practice to provide a more effective service for people with ERF. PCTs commissioning renal services should already have carried out an assessment of the population need for RRT and have a plan for meeting increased demand. The extra resources the NHS has received for the three years from 2003/04 to 2005/06 offer realistic scope for achieving this. A three year capital allocation has also been made to support the expansion of centre-based haemodialysis, to expand capacity to meet increasing demand for dialysis and deliver greater choice about how and where people are treated. Additional funding has also been invested via UK Transplant in hospital based schemes to increase the number of organs donated for transplantation.

135 The NHS Purchasing and Supply Agency are able to support Trusts in procuring goods and renal services.ⁱ

Workforce

136 Renal services need to ensure there are enough staff with appropriate skills and experience who are well led, supported and deliver high quality care. The Department of Health's Long-term Conditions Care Group Workforce Team has been established to take a national view on the health and social care workforce pressures and priorities for people with, or at risk of, conditions that require long-term management.ⁱⁱ

137 The renal work programme of the Care Group Workforce Team will be taken forward by the Renal Workforce Group, comprising key stakeholders and reporting to the Care Group Workforce Team. Its work has been informed by The British Renal Society National Renal Workforce Planning Group's publication, *The Renal Team: A Multi-Professional Renal Workforce Plan for Adults and Children with Renal Disease*, which is available on www.britishrenal.org. This document provides the baseline data that supports projections of workforce demand and supply. With information about disease prevalence, it allows the Care Group Workforce Team to understand the possible impact of new roles in health and social care teams in delivering the NSF.

138 The programme includes:

- working with stakeholders to identify and prioritise renal workforce pressures and challenges for the Workforce Development Confederations
- a project undertaken by Skills for Health to develop a competency framework beginning with three areas of renal care – dialysis, the management of progressive and irreversible disease and the preparation of living donors for transplantationⁱⁱⁱ

i For more information, see www.pasa.nhs.uk.

ii For more information, see www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingWorkforcePlanningHome/fs/en.

iii For more information, see www.dh.gov.uk/PolicyAndGuidance/HumanResourcesAndTraining/ModernisingWorkforcePlanningHome/fs/en.

- commissioning two Workforce Development Confederations to pilot the development of robust local workforce development models for dialysis and renal transplant services. The pilots will consider the role of the multi-skilled renal team in the delivery of care in a partnership with a patient with ERF. They will also examine the implications for specialist services such as surgery, particularly for vascular access; diagnostic services such as pathology, including immunology and histopathology; radiology and hospital beds. In particular the pilots will look at workforce demand and supply, recruitment, retention, skill base, new and revised working roles, prescribing roles, education, training and commissioning based on local demography. The output will be a template to be disseminated as a toolkit by other Workforce Development Confederations.

Information strategy

- 139 The provision of the right information at the right time is essential to support the needs of people with renal failure, the delivery of integrated care, and the commissioning, planning, management and monitoring of renal services as described in this NSF. *Information for Health, Delivering 21st Century IT Support for the NHS* and the *Renal Information Strategy* are national programmes which aim to ensure that the information infrastructure, systems and services are developed to do this.
- 140 The *Renal Information Strategy* is published with this NSF (www.dh.gov.uk/renal). It has been developed by the NHS Information Authority and the Department of Health in collaboration with an advisory group including people with renal disease, patient organisations, health professionals, managers from all sectors of the NHS and information experts.

The *Strategy* sets out the national and local approaches required to help achieve the standards in the NSF. Its key components are:

- extending data for secondary purposes (such as epidemiological activity, outcome monitoring and clinical audit) to cover the care pathway. This will support the planning, monitoring and delivery of care
 - supporting the management of renal disease by improving access to information of enhanced depth and quality for patients and healthcare professionals
 - empowering people with renal disease by providing them with access to their personal care plan and health records
 - underpinning integrated care through working with integrated information systems.
- 141 The following key strands of work are already under way:
- improving access to and quality of the renal disease knowledge-base by the development of a Renal Specialist Library via the National electronic Library for Health (NeLH), enhanced content of NHS Direct Online and improved information to support enquiries to NHS Direct
 - inclusion of a specification for renal information requirements within the Output Based Specification for the Integrated Care Record Service (ICRS) which will support the delivery of the standards in this NSF
 - a national review of methods to be adopted for submitting, collating and reporting information for secondary purposes in the light of the requirements for messaging to feed the ICRS
 - development of a model for care plans which can be adopted in advance of ICRS delivering this functionality

- refinement of clinical datasets to extend information collection across the care pathway and to support the production of comparative information and measurement
- work with CHAI, the UK Renal Registry of the Renal Association, UK Transplant and professional bodies such as the Renal Association, the British Association for Paediatric Nephrology, the British Renal Society and the British Transplant Society, to develop national comparative clinical audit data, within a framework of standards for national audit, for national and local use to inform quality improvement processes that aim to improve outcomes for patients
- development of a nationally agreed mechanism to enable patients to monitor their status on the transplant list.

Medicines management

- 142 A resource has been developed on the specific aspects of medicines management which relate to the treatment of chronic kidney disease, such as the management of renal anaemia and hypertension, dose adjustment and nephrotoxicity, prevention of renal scarring, calcium and phosphate management, immunosuppression and others. This highlights examples of innovative practice throughout, with examples of systems that have been set up to help ensure the safe and effective use of medicines. It is published at www.dh.gov.uk/renal under 'NSF related publications'.
- 143 A resource to support implementation of the *National Service Framework for Diabetes*, this NSF and the forthcoming *National Service Framework for Long-Term Conditions* is also being developed, dealing with the general aspects of medicines management. It will provide practical support for PCTs and NHS Trusts.
- 144 There are special issues posed by the prescribing and delivery of medicines to children and young people, and health professionals need an adequate understanding of a child's or a young person's physiology and development. *Getting the right start: NSF for Children, Young People and Maternity Services* will be supported by a strategy for the Management of Medicines that will apply equally to children with ERF.

National Institute for Clinical Excellence (NICE)

- 145 NICE has been asked to develop a clinical guideline for the management of anaemia in renal failure. Further details can be found on the NICE website at www.nice.org.uk.
- 146 Further priorities for appraisals and for clinical guidelines to support delivery of the NSF will be considered for future phases of the NICE work programme.
- 147 Other sources of information on clinical evidence can be found on the website for this NSF (www.dh.gov.uk/renal under 'NSF related publications').

Diagnostic services modernisation

- 148 The Department of Health is working with individual SHAs to develop and implement local strategies for improvement in diagnostic services such as imaging, immunology, histopathology and others. The vision is for diagnostic services designed around patient pathways, which offer choice to patients and faster, more convenient and integrated services. Improvements will be locally driven, responsive to local needs and implemented in the context of local strategies.

Research and development

- 149 During the development of this NSF some gaps in research evidence have been identified, and areas where future research is needed are listed with the evidence base on the website at www.dh.gov.uk/renal under 'NSF related publications'.

Patient and public involvement

- 150 The network of local Kidney Patient Groups and their umbrella organisation the National Kidney Federation play a valuable role in informing patients and influencing local services.
- 151 The Government is currently restructuring the system for patient and public involvement.

The Commission for Patient and Public Involvement in Health

- 152 At the centre is the Commission for Patient and Public Involvement in Health – the independent body which oversees the system. It champions the patient voice at a national level, reporting to Government and Parliament the views and needs of patients. It also supports and facilitates the operation of patient and public involvement forums and the delivery of independent complaints advocacy services. Further details can be found on the Commission's website at www.cppih.org.

Patient and Public Involvement Forums

- 153 There is a Patient and Public Involvement Forum for every NHS Trust and PCT, to influence the day to day management of health services in their area. Membership of forums comprises patients and carers and representatives from local community organisations. Forums feed their reports and recommendations to the management of local health bodies, ensuring that decisions are informed by the needs and experiences of local people. Again, further information is available at www.cppih.org.

Patient Advice and Liaison Services

- 154 To get the best out of their health service people need access to information about local services, and to support and help when things go wrong. Organisations need access to user feedback to ensure services are improved and developed to meet the needs of the people who use them.
- 155 From April 2003 every NHS Trust and PCT should have established a Patient Advice and Liaison Service (PALS). An integral component of clinical governance, PALS have a dual role: providing information and support to individual patients, their families and carers, and acting as a catalyst for organisational and cultural change. The functions and core service standards for PALS are set out in *Supporting the implementation of Patient Advice and Liaison Services: resource pack* which can be accessed on www.dh.gov.uk/publications.

Independent support for complainants

- 156 There is additional support for patients who may wish to complain about the NHS. The Independent Complaints Advocacy Service is available to provide support, advice and assistance to patients and carers who are taking out a formal complaint against the NHS. This service is provided independently of the NHS. Further information is available at www.dh.gov.uk at 'Complaint policy - NHS complaint handling'.

Scrutiny by local authorities

- 157 Elected councillors have the power to scrutinise local health services. Overview and scrutiny committees of local authorities may make reports and recommendations to health service bodies, and request senior NHS officers to attend meetings to answer questions about their decisions. NHS bodies must also now consult overview and scrutiny committees where they wish to make substantial changes to local services. The committees may refer contested proposals to the Secretary of State for Health for a final decision. Further information is available at www.dh.gov.uk at 'Patient and public involvement'.

The duty to consult and involve patients and the public

- 158 NHS bodies are under a duty to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes. The duty means consulting and involving not just when a major change is proposed, but in regular service planning; not just in the consideration of a proposal, but in the development of that proposal; and in decisions about general service delivery, not just major changes. Policy and practice guidance can be accessed at www.dh.gov.uk at 'Patient and public involvement'.

The environment

- 159 The environment in which people are treated should be conducive to dignity and respect, and enhance the therapeutic potential of clinical interventions and the outcome of care. The Health Building Notes on satellite dialysis units, main renal units and transplant units produced by NHS Estates will examine this. For details, see www.nhsestates.gov.uk.

Annex A

Membership of the External Reference Group

Co-chairs

Ms Sarah Mullally, Chief Nursing Officer, Department of Health

Professor Robert Wilkinson, Professor of Renal Medicine at the Freeman Hospital, Newcastle (retired as Chairman September 2003)

Dr Donal O'Donoghue, Clinical Director of Renal Medicine, Hope Hospital, Salford (joined ERG 2002, appointed Chairman October 2003)

ERG members

Mr Ali Bakran, Transplant and Vascular Surgeon, The Royal Liverpool University Hospital

Mr Paul Bates, Chief Executive, Herefordshire Primary Care Trust

Miss Gemma Bircher, Dietetic Manager (Nephrology), Leicester General Hospital

Prof J Andrew Bradley, Transplant Surgeon, Addenbrookes Hospital, Cambridge

Ms Makeda Brown-Dako, Kidney Patient, Bedfordshire

Mrs Maria Da Silva-Gane, Renal Counsellor/Senior Social Worker, Lister Hospital, Stevenage

Dr Julian Dennis, General Practitioner, Collingham, Newark (joined ERG 2002)

Mrs Andrea Devaney, Specialist Principal Pharmacist, Renal Transplantation, Oxford Transplant Centre, Churchill Hospital

Mr Austin Donohoe, Kidney Patient, Northumberland

Mr Robert Dunn, Living Donor and Carer, Devon

Prof John Feehally, Professor of Renal Medicine, Leicester General Hospital (joined ERG 2003)

Prof Terry Feest, Professor of Clinical Nephrology and Chairman of the UK Renal Registry of the Renal Association, Southmead Hospital, Bristol

Prof Ram Gokal, Consultant Renal Physician, Manchester Royal Infirmary

Dr Roger Greenwood, Consultant Nephrologist, Lister Hospital, Stevenage

Ms Maggie Hicklin, Head of Nursing for Children's Services, Guy's and St Thomas' NHS Trust, London (resigned from ERG 2002)

Ms Neerja Jain, formerly Transplant Co-ordinator, University Hospital, Birmingham; now Project Manager, ABLE Programme, National Kidney Research Fund

Mr Ray James, Technical Manager – Renal Services, Barts and the London NHS Trust

Dr Richard Moore, Clinical Director, Nephrology and Transplantation, University Hospital of Wales, Cardiff

Mr Julian Nettel, Chief Executive, St Mary's Hospital NHS Trust, London

Prof Ed Peile, General Practitioner and NHS Fellow in Educational Research, Dept of Primary Care, University of Oxford (resigned from ERG 2002)

Dr Lesley Rees, Consultant Paediatric Nephrologist, Great Ormond Street Hospital for Children, London

Mr Graham Roberts, Manager, Renal Medicine Directorate, Manchester Royal Infirmary

Dr Paul Roderick, Epidemiologist, and Senior Lecturer in Public Health Medicine, University of Southampton

Mrs Carol Sammons, Kidney Patient, Surrey

Dr Elizabeth Scott, formerly Director of Public Health, Leeds Health Authority; now NHS Modernisation Agency

Ms Alison Smith, formerly Director of Renal Nursing, Northern General Hospital, Sheffield; now Assistant Chief Nurse, Sheffield Teaching Hospitals NHS Trust

How do I join the NHS Organ Donor Register?

To join the NHS Organ Donor Register:

- contact the Organ Donor Line on
0845 60 60 400
- or register online at
www.uktransplant.org.uk
- or complete and return the registration form overleaf.

Please make sure your family and friends know your wishes about organ donation

code 658

Organ donation.
The gift of life.



NHS Organ Donor Registration Form

I want to help. Please add my name to the NHS Organ Donor Register.

(If more than one person is registering, please photocopy this form before completing.)

1 My name and address

Surname _____
Forename(s) _____
Date of birth _____
Male/female _____
Address _____

Postcode _____

2 My wishes

I request that after my death:

A any part of my body

or

B my kidneys heart liver
 corneas lungs pancreas

may be used for transplant.

(please tick the boxes that apply)

Signature _____
Date _____

3 My ethnic origin

Please tick the box that applies

White:

British Irish Other

Mixed:

White & Black Caribbean
 White & Black African
 White & Asian Other

Asian or Asian British:

Indian Pakistani Bangladeshi
 Other

Black or Black British:

Caribbean African Other

Other ethnic categories:

Chinese Other

Not stated

Please put this form in an envelope and post it to:

The NHS Organ Donor Register
UK Transplant
FREEPOST (SWB1474)
Patchway
Bristol BS34 8ZZ

You don't need to use a stamp, but doing so helps to conserve our funds.

Once your registration form has been received your name is added to the NHS Organ Donor Register.

Thank you for your help and support.

Transplants save lives

code 658

Data protection assurance

Completion of this form is for the sole purpose of recording your wishes regarding organ/tissue donation on the NHS Organ Donor Register. All information and data that is processed by UK Transplant is in accordance with the provisions of the Data Protection Act 1998. Your details will only be used for administrative purposes by UK Transplant staff or agents and will not be released to any third party without your explicit and written consent.

The data you provide may be processed on our behalf in a country not normally covered by EU data protection law. If so, we will ensure that the data will be protected in accordance with EU requirements.



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34134/*The National Service Framework for Renal Services – Part One: Dialysis and Transplantation* can also be made available on request in braille, on audio cassette tape, on disk, in large print, and in other languages on request.