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<tr>
<td>A summary of progress to date towards achieving the standards and early actions set out in the National Service Framework for Renal Services (NSF), together with a review of the modernisation programme supporting delivery of the NSF.</td>
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**Cross Ref**
The National Service Framework for Renal Services, Part One: Dialysis and Transplantation
The National Service Framework for Renal Services, Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care

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None

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**For Recipient Use**
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Foreword

It is just over eighteen months since I published Part One of the National Service Framework for Renal Services (the Renal NSF) and set up the Renal Advisory Group (RAG) to advise the Department of Health on the development of Part Two of the Renal NSF, and the implementation of Part One.

I asked the RAG to provide me with their evaluation of national progress on the five early actions for the NHS to take identified in Part One. In their evaluation, the RAG noted the progress made by the renal community, including patients and carers, in putting into place programmes which will underpin delivery. They found the reaction of the professional and patient groups was consistently positive, citing the clear vision for development of an effective, efficient and patient-centred service that it provided. I welcome the RAG’s view that enthusiasm is high; it is the willingness of the renal community to champion the Renal NSF and to work with us to engineer change which has proved a hallmark of the success of the Renal NSF.

It is clear that excellent work has been done since publication in January 2004, and we have witnessed a sea change in the recognition of the importance of a patient-centred service offering choice, the role of the multidisciplinary team in optimising outcomes and the perception of vascular access surgery. These early signs are promising. A momentum for change has developed in the renal community with the publication of Part One, the modernisation programme and the appearance of supporting tools like the Information Strategy, the Medicines Management guidance, the Commissioning Toolkit and the NHS Estates Renal Building Notes. The progress shared in this document is reinforced by the publication of Part Two in February this year, which has been warmly endorsed by the renal primary care and other vascular (diabetes, coronary heart disease and stroke) bodies.

The Renal NSF sets out a vision for change and improvement to be met over the next decade, and we all – Government, the NHS and patients – will need to play our part in making it a reality: we cannot rest on our laurels. I would like to thank the Chairs and members of the RAG for giving their time so freely (a list of members can be found at Annex A). I am most grateful for their excellent work, and that of those providing renal services, which is feeding through into real improvements in the care of people with chronic kidney disease.

Rosie Winterton
Minister of State for Health Services
1. Part One of the National Service Framework for Renal Services (the Renal NSF) was published in January 2004, setting five standards for renal services in the areas of dialysis and transplantation, and identifying markers of good practice to support them.

2. As a first step towards achieving the standards, Part One also identified five early actions for Primary Care Trusts, as commissioners, and NHS Trusts to take by 2006:
   - 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\(^i\) appraisal of home haemodialysis
   - implement the National Institute for Clinical Excellence appraisal of immunosuppressive therapy.

3. In addition, Part One committed the Department of Health, with the renal community, to implement a modernisation programme to support the delivery of the standards 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.

4. Part Two of the Renal NSF was published in February 2005, and identified four quality requirements for chronic kidney disease, acute renal failure and end of life care, with markers of good practice to support them. Part Two also set out further initiatives in the modernisation programme underpinning delivery of the Renal NSF.

\(^{i}\) This became the National Institute for Health and Clinical Excellence from 1 April 2005.
Progress Towards Achieving the Early Actions

5. The Department of Health, the NHS and other stakeholders have all contributed to delivering the early actions.

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

6. The UK Renal Registry of the Renal Association was commissioned by the Department of Health to carry out a national survey of renal units. The findings of the survey were published as part of the UK Renal Registry Annual Report, December 2003, and have been circulated by the Department in the form of a CD ROM to support local commissioners in their planning and prioritisation of initiatives to support implementation of the Renal NSF. The UK Renal Registry is working to improve the collection of ethnicity data to support local planning.

7. The Renal Commissioners have produced a toolkit based on current best practice. It aims to support Renal Service Commissioners in the implementation of Part One of the NSF, and is published on the Renal NSF page of the Department’s website.

Step Two: continue to expand haemodialysis capacity.

8. The Department has provided £9 million capital in 2004/5 and a further £14 million in 2005/6 to expand renal services. That money is being used to support the building of new satellite dialysis units and the extension of existing units. Since the Renal NSF was published a number of new units have opened, at Aintree, Castle Vale, Ashfurlong, Stockton, Harold Wood, Doncaster, Boston, Stratford on Avon, Harrogate, Skegness and Farnham Centre. Units have been extended at Kings Mill Hospital Mansfield, the North Middlesex Hospital and Rugby. Building work has begun on new satellites at Wigan, Balsall Heath, St Pancras Hospital, Chandlers Ford (Southampton), the Isle of Wight, Peterborough and Leicester. The NHS has also been working closely with the private sector in building up capacity and improving access. For example, two new private satellite dialysis units treating NHS patients have opened in the North East, in Darlington and Stockton on Tees.

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

9. The UK Renal Registry of the Renal Association continues its roll out of membership. The Registry reports that 49 units are now sending data or have firm plans to submit data by 2006; the remaining two units are in touch with the Registry and are considering the steps they need to take in order to join.

10. The Paediatric Renal Registry has combined with the UK Renal Registry for the collection and analysis of data relating to children’s services, as the first step towards a facility for national comparative audit. Returning data from the paediatric renal units is important in supporting the planning of paediatric renal services.
Step four: implement the National Institute for Clinical Excellence appraisal of home haemodialysis.

11. Data collected by the UK Renal Registry of the Renal Association show that the downward trend in the provision of home haemodialysis has been halted, and there was a slight increase in the number of people undertaking home haemodialysis between 2002 and 2003. The 2004 Renal Registry Report provides a detailed baseline assessment of home haemodialysis provision.

Step five: implement the National Institute for Clinical Excellence appraisal of immunosuppressive therapy.

12. UK Transplant has undertaken a review of the current datasets for organ donation and transplantation, and as a result improvements will be made to the information collected on immunosuppression. This will allow the appropriate use of immunosuppressives to be audited. Revised systems are under development, and implementation of the changes will begin in mid 2006.

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i UK Transplant combines with the National Blood Authority from 1 October 2005 to form NHS Blood and Transplant.
Progress Towards Achieving the Standards

Introduction

13. As noted above the Renal NSF is a ten-year improvement programme and (with the exception of the early actions) it is too soon for more than early signs of progress in the NHS. Most significantly, the publication of the NSF has enabled and empowered a number of stakeholders to launch initiatives, both in partnership with the Department of Health and independently, which are designed to support and facilitate implementation of the Renal NSF 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.

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

14. The Renal Information Exchange Group has been commissioned by the Department of Health to develop a care plan tool for patients, RenalPatientView.

15. The National Kidney Federation was awarded grant funding by the Department of Health for three years to provide advocacy officers to support patients with renal failure. The National Kidney Federation also has grant funding from the Department to develop a web-based series of paediatric information leaflets.

16. The National Kidney Research Fund has received grant aid from the Department of Health for their ABLE (A Better Life through Education and Empowerment) programme of work, which tackles chronic kidney disease in South Asian and African Caribbean communities. Educational and awareness-raising initiatives have been funded in Leicester, West London and Birmingham.

17. The Department sponsored the Tongues on Fire March 2005 Film Festival to increase awareness of chronic kidney disease and kidney transplantation in the South Asian community. The festival is an innovative way to pass key messages of health promotion across to this community.

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.
18. The expansion of renal services referred to in paragraph 8 will increasingly make it possible to give patients a real choice of treatment modality, although evidence is not yet available to illustrate this. A detailed analysis of the models of multidisciplinary care in stage 4 chronic kidney disease, when choice about transplantation and dialysis modalities is best made, has been undertaken by the UK Renal Registry and submitted for peer-reviewed publication.

**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.

19. The Department of Health commissioned the NHS Modernisation Agency to run two projects, at the Royal Devon & Exeter Hospital NHS Foundation Trust and the University Hospital Birmingham NHS Foundation Trust. The projects were designed to map the renal patient pathway; develop and test new ways of working to improve the delivery of vascular access surgery, and facilitate effective renal workforce planning.

20. The UK Renal Registry of the Renal Association is collecting 2004 data on vascular access surgery as part of the UK Renal Registry survey. Results from the survey will be available later this year.

21. A joint working party of the Vascular Society, Renal Association and British Association of Interventional Radiologists has been established to review vascular access provision. The curricula for transplantation training and vascular surgery training have also been aligned so that trainees from either route can now deliver vascular access.

**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.

22. Action Learning Sets have been set up by the Department of Health to identify solutions to problems identified in the Renal NSF. Two of these are exploring ways to improve transport services for haemodialysis patients.

23. Skills for Health was commissioned by the Renal Workforce Group to develop a renal competence framework to cover the patient pathway for dialysis.

24. The UK Renal Registry of the Renal Association continues to monitor dialysis outcomes against the Renal Association clinical standards. The UK Renal Registry will undertake an annual survey of renal units including monitoring clinical outcomes against the Renal Association clinical standards, the facilities and workforce. From 2005, the Renal Association will begin a rolling programme to ensure that the clinical standards are based on current evidence.

25. In January 2005 the first ever GP dialysis unit in England opened at Ashfurlong Medical Centre in Sutton Coldfield. It is the result of a unique partnership between North Birmingham Primary Care Trust, primary and secondary care providers to offer patients a dialysis service close to their homes, so that patients benefit from less travel and inconvenience. The unit has five haemodialysis stations and can treat up to 25 patients a week. GPs run the service, rather than hospital staff, and the unit will help address the shortage of dialysis places across Birmingham.
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.

26. As phase two of the project referred to in paragraph 23, Skills for Health has been commissioned by the Department of Health to develop a renal competence framework to cover the patient pathway for renal transplantation.

27. UK Transplant has published a leaflet entitled *Could I be a living kidney donor?* which is available from kidney transplant and dialysis centres and from the Organ Donor Line. It was written by living donor clinical experts and explains the donation and transplantation process, and how relatives and friends can donate one of their kidneys.

28. UK Transplant also continues to monitor the current kidney allocation scheme. Following a five-year review of the scheme a fundamental review of the allocation scheme was launched in November 2003 through working parties set up by the Kidney and Pancreas Advisory Group. The review considers factors affecting equity of access to the transplant list, equity of access to transplantation and transplant outcome. A major re-analysis has been undertaken, and simulation models have been used to explore the effect of variations on the allocation scheme. Final proposals for a new National Kidney Allocation Scheme have been recommended to UK Transplant by the Advisory Group, and endorsed by the Authority Board. Work is now under way to discuss how the proposals can be implemented whilst minimising any adverse effects on transplant activity within individual centres.

29. UK Transplant published a paper on cold ischaemic time and its effect on graft survival. As a consequence all Trusts with kidney transplant units have been reminded of the need for timely operating theatre availability. UK Transplant, the British Transplantation Society and the British Society for Histocompatibility and Immunogenetics intend to co-ordinate a nationally agreed detailed audit of cold ischaemic times for each centre, and factors influencing these times.

30. UK Transplant has put in place the initiatives in *Saving Lives, Valuing Donors* to support organ procurement and transplantation. This includes launching a number of publicity campaigns to raise awareness of organ donation amongst minority ethnic groups; collaborative engagement with other European transplant organisations following a successful joint bid to secure funding from the European Commission, and a review of non-heart beating and living renal donor co-ordinator schemes which demonstrates that they are particularly successful and cost effective.

31. The Association of British Pharmaceutical Industries (ABPI) Renal NSF task force has established a partnership between some members of the pharmaceutical industry, the NHS and UK Transplant to support projects.
32. The modernisation programme set out in Part One to support delivery of the Renal NSF included:

- 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.

Some of the projects comprising this programme were referred to in earlier sections. While the Renal NSF is for England, a few of the modernisation projects have also been taken forward in partnership with units in Scotland and Wales.

33. Further projects were added in Part Two:

- new Action Learning Sets
- measurement of kidney function.

34. A number of documents have been published supporting the modernisation programme, which can be found on the Department of Health website at www.dh.gov.uk/renal. They are included in Annex B, Sources of Information/Resources.

**Location of workforce projects**

- Workforce/vascular access project – Birmingham, Exeter
- Skills for Health dialysis project – Birmingham, Leicester, London, Stevenage
- Skills for Health transplant project – Aberdeen, Canterbury, Cardiff, Gloucester, Hull, London, Newcastle
35. In keeping with new style working set out in the *NHS Improvement Plan*, the Department of Health commissioned the NHS Modernisation Agency to work with the NHS to deliver the first two elements of this modernisation programme. The NHS Modernisation Agency worked with project teams at the Royal Devon & Exeter Hospital NHS Foundation Trust and the University Hospital Birmingham NHS Foundation Trust. The projects were designed to develop and pilot robust local workforce development models for renal dialysis and transplant units, which can be used as a template by Strategic Health Authority Directorates of Workforce and Learning. The projects also looked at different models for improving access to, and bringing down waiting times for, elective fistula surgery. Consideration was given to the appropriateness of treating more patients as day cases, and allowing alternative patient management arrangements to evolve. A conference in March shared the experiences to date, including the provision of new access nurse roles. A report by the project teams is published on the Department’s website, in which they make available to the renal community both the outcome of their work and also the tools and techniques they found of value.

36. The workforce projects complement the work done by Skills for Health, which was commissioned by the Renal Workforce Group to develop a renal competence framework. Skills for Health is the licensed Sector Skills Council for the entire health sector across the UK, and is the lead organisation charged with developing National Workforce Competence Frameworks for the health sector. A framework providing detailed competencies for staff working within the context of renal dialysis is available. It was developed using the Renal NSF as its starting point and the competencies were tested in dialysis units in Birmingham, Leicester, London and Stevenage. All competencies are mapped to the NHS Knowledge and Skills Framework as part of *Agenda for Change*.

37. In a second phase of this project, Skills for Health is developing a competence framework to cover the patient pathway for renal transplantation. Skills for Health is working with renal and transplantation units in Aberdeen, Canterbury, Cardiff, Gloucester, Hull, London and Newcastle to ensure that the competence framework is fit for purpose.

**Location of Learning Sets**

- **Learning Sets – transport:**
  - Liverpool, Middlesbrough

- **Learning Sets – palliative care:**
  - Birmingham, Manchester

- **Learning Sets – CKD:**
  - Brighton, Leicester

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i Formerly Workforce Development Confederations.
38. Action Learning Sets have been set up by the Department of Health to identify solutions to problems identified by the Renal NSF. Two of these, in County Durham and Tees Valley, and in Cheshire and Merseyside, both of which cover both urban and rural areas, are exploring ways to improve transport services for haemodialysis patients. They will share their learning at the end of 2005.

39. Following the publication of Part Two of the Renal NSF in February 2005 further Action Learning Sets were set up to support implementation. Two based at Leicester and Northampton, and at Brighton, are considering the provision of information and other preventative measures to be taken in primary care, while two in the West Midlands and in Greater Manchester are working on rolling out palliative care services to renal patients.

Location of other modernisation projects

- Renal Patient View – Birmingham, Bradford, Cardiff, Edinburgh, Glasgow, Leeds, Leicester and York
- ABPI living donor project – Preston, Wolverhampton
- Do Once and Share – Leicester

40. The Renal Information Exchange Group represents the renal community in supporting and promoting relevant IT developments. The Group has been commissioned by the Department of Health to develop a web-based, personalised care plan tool for patients, RenalPatientView. This is up and running in Birmingham, Bradford, Cardiff, Edinburgh, Glasgow, Leeds, Leicester and York, with plans to go live in other selected renal units, providing the first direct access for patients to personalised information about their care.

41. The ABPI Renal NSF task force has established a partnership between some members of the pharmaceutical industry, the NHS and UK Transplant to provide educational material on renal transplants and to support live donation in the Preston and Wolverhampton renal units.

42. Do Once and Share is a project under the direction of the National Programme for IT, with the aim of reducing the unknowing duplication of work involving clinicians throughout the NHS. For Renal this work is hosted by the Leicestershire, Northamptonshire and Rutland Strategic Health Authority and based on the East Midlands Renal Network. The project started in July 2005 and will report in January 2006.
43. The aims of the project include testing the blueprint for IT systems in the light of current thinking and clinical practice; identifying the potential for using the National Programme for IT to improve the efficiency of care processes and pathways; involving the renal community nationally through new and existing networks, and sharing work in progress openly and quickly to minimise duplication of effort. Existing strong links between stakeholders (including the multiprofessional Renal Information Exchange Group), and the widespread early implementation and acceptance of IT in clinical care will significantly strengthen this project.

44. The environment in which people are treated affects their wellbeing, and can enhance the therapeutic potential of clinical interventions and the outcome of care. NHS Estates is developing a new series of Health Building Notes (HBN 53) on Facilities for renal services: Volume 1 – Satellite dialysis unit was published in 2004; Volume 2 – Main renal unit and Volume 3 – Transplant unit are due for publication in autumn 2005.

45. A working group has been set up by the Department of Health to facilitate the use of a formula-based estimation of the glomerular filtration rate in measuring kidney function, as recommended in the Renal NSF. It will address practical issues for pathology laboratories, and the information and education needs of technical staff, commissioners and clinicians, especially those working in primary care.

46. Ongoing work to support implementation of the Renal NSF includes the continuing challenge of developing the renal workforce to deliver the vision of high quality patient-centred renal services set out in the NSF; the development by the National Institute for Health and Clinical Excellence of a guideline on the management of anaemia for people with kidney disease, and addressing issues such as morbid obesity in relation to access to transplantation.

Initiatives by the Renal Community

47. Publication of the Renal NSF has encouraged stakeholders, independently of the Department of Health, to initiate work which supports its implementation. For example:

- the British Renal Society has published *Criteria for Success*, which contains multiprofessional criteria for monitoring the implementation of the Renal NSF
- a group including the Royal College of Physicians, the Renal Association, General Practitioners and others has developed guidelines for the identification, management and referral of adults with chronic kidney disease. These guidelines will support the management of chronic kidney disease in primary care as advocated in Part Two of the Renal NSF. They are published on the Renal Association website
- the Renal Commissioners will build on the Commissioning Toolkit which supports Part One to provide a resource for commissioning to underpin delivery of Part Two
- the Renal Association has endorsed a standard method for laboratories to report estimated glomerular filtration rate automatically that will enable harmonisation of laboratory reporting.
Conclusion

48. This report demonstrates how, together – the Government, the NHS, patients and carers, and other stakeholders, including the independent sector – we have grasped the opportunity to change and improve renal services.
Annex A: The Renal Advisory Group

Co-chairs

Dr Donal O’Donoghue, Clinical Director of Renal Medicine, Hope Hospital, Salford

Dr David Colin-Thomé, National Clinical Director for Primary Care, Department of Health (from May 2005)

(formerly Mr Ron Cullen, Clinical Governance Support, Department of Health, who resigned April 2005)

Deputy Chair

Prof John Feehally, Professor of Renal Medicine, Leicester General Hospital

Members

Dr Steve Blades, General Practitioner, Newcastle upon Tyne

Ms Katie Cusick, Performance Manager, Recovery and Support Unit, Department of Health (from July 2005)

Mr Robert Dunn, Living Donor and Carer, Devon

Mr Paul Jennings, Chief Executive, Walsall PCT

Ms Althea Mahon, Consultant Nurse, Renal Unit, Barts and the London NHS Trust

Ms Jan McFadyen, Nurse Consultant, Non-Cancer Palliative Care, South Downs NHS Trust, Brighton and Hove

Mr David Mitchell, Vascular Surgeon, Southmead Hospital, Bristol

Dr Paul Roderick, Senior Lecturer in Public Health, University of Southampton Health Care Research Unit

Ms Sue Sutherland, Chief Executive, UK Transplant (June 2004-July 2005)

Mr Tim Young, Senior Manager, Recovery and Support Unit, Department of Health (resigned July 2005)
## Annex B: Sources of Information/Resources

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