



End Stage Renal Failure -
A Framework for Planning
and Service Delivery

*Towards Equity & Excellence
in Renal Services*

A KIDNEY ALLIANCE REPORT



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FOREWORD - Professor Sir Netar Mallick

End stage renal failure (ESRF) arises from a variety of renal disorders and is fatal if untreated. Dialysis or transplantation reduce the toxic metabolic burden which results when the kidneys fail and preserve life. Transplantation in addition restores other functions of the kidney, including Erythropoietin and Vitamin D production. The quality of that preserved life varies according to the efficiency of the treatment and the co-morbidity of the patient. Studies confirm that the quality of life experienced by the patient is often acceptable despite objective evidence of residual disability.

In the UK between 1993 and 1998 the number of patients with ESRF receiving treatment rose from a prevalence of 396 to 539 per million population (PMP). The incident rate of new patients rose from 67 to 92 pmp. It has proved possible to treat patients who, through age or co-morbidity, have disabilities which would previously have been judged to make the management of their renal disease too intrusive.

This is a success story. However, it is clear from the data in Wales and Scotland and from valid international comparison that, in both quantity and quality, the service provided for the management of renal disease in England still lags behind to an unacceptable degree. The government has laid down criteria by which health services will be judged. These include:

- Health improvement
- Fair access
- Effective delivery of appropriate healthcare
- Efficiency
- Patient/carer experience
- Health outcomes of NHS care

We welcome this framework and present details of our own assessment of the current provision of renal services in relation to it. Our analysis reveals that much of the infrastructure which has been developed to treat ESRF in the UK generally, is sound. However, the analysis also shows that too few patients are receiving treatment, that some of this treatment is inadequate when judged by objective criteria and expert opinion and that there are glaring inequalities in access to services and in the quality of the service across the country.

We have developed a vision of 'Equity and Excellence' in Renal Services which we hope will commend itself to government and its agencies as a goal to work towards if we are to offer a compassionate, yet evidence based service to these patients, who without treatment are mortally ill. We call for timely action to improve equity and quality in renal services which are currently under threat from a negative spiral of rising need, limited access and falling quality.

THE KIDNEY ALLIANCE

The Kidney Alliance was formed jointly by the Renal Association and the National Kidney Federation in 1998 to bring together the patients' voice and professionals committed to renal medicine. The Kidney Alliance is an 'umbrella' body representing all organisations involved in renal services. Its mission:

'to ensure high quality treatment for all patients with kidney failure on an equal and uniform base throughout the UK'.

Under the Chairmanship of Austin Donohoe, much progress has been made including the foundation by the NKF of an All Party Kidney Group of MPs in July 1999. The APKG is committed to improving the understanding in Parliament of kidney disease and transplant medicine and to the care that is available to people with renal failure. Given the timescale of several years before the commencement of work on a National Service Framework, the Kidney Alliance, driven largely by patients keen to prevent any deterioration in the service, judged it would be useful to put forward some service standards and to recommend the structures which will be necessary to deliver them in the new NHS. In so doing, a template for the planning and commissioning of renal services is set out, uniquely, by those working within the speciality in concert with those actually receiving treatment.

The founder member organisations contributing to this Kidney Alliance initiative include:

British Renal Symposium (BRS)
 British Transplant Society (BTS)
 National Kidney Federation (NKF)
 National Kidney Research Fund (NKRF)
 Renal Association
 Joint Royal College of Physicians (London)/Renal Association Committee
 Society of DGH Nephrologists
 Royal College of Nursing
 Kidney Research Unit for Wales Foundation

Representations of nursing, the professions allied to medicine (PAM's) and technical support services are through the British Renal Symposium.

The Kidney Alliance thanks the NKRF and the Renal Association for financing the preparation of this document.

The Kidney Alliance records its gratitude to the External Reference Group which has overseen the production of this document.

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The Kidney Alliance thanks also Dr Alison Armitage, Dr Ken Farrington, Professor David Kerr and David Powell for their help in producing this document.

The Kidney Alliance thanks Jean McManus for secretarial support.

The Kidney Alliance is grateful to many others who have contributed to this document either individually or on behalf of their organisations: Steve Allinson, Ali Bakran, Nick Bosanquet, Andrew Bradley, David Bennett-Jones, Yvonne Bradburn, Sandy Davison, Andrea Devaney, Ciaran Doherty, Peter Drew, Terry Feest, Ram Gokal, Leigh Griffin, Cheri Hunter, Ray James, Don Keir, Donna Lamping, Mike Lavender, Alison MacLeod, Iain Macdougall, Michael Nicholson, Anthony Nichols, Donal O'Donoghue, Claire Phillips, Ed Piele, Steve Powis, Chris Pritchard, Hugh Rayner, Andy Rees, Stuart Rodger, Jenny Scott, Steve Smith, Marianne Vennegeor, David Webb, Es Will, Gwyn Williams.

EXECUTIVE SUMMARY

A The Kidney Alliance, an umbrella body representing all organisations involved in renal services, was formed in 1998 to bring together the voices of patients and committed professionals. The Alliance has produced this document as a forerunner to a National Service Framework for renal services. The driving force has been the need to break away from the damaging culture of reactive management, which has become the habitual manner by which the problems of this rapidly growing service have been addressed, in favour of an approach exemplified by shared ownership of the problems and solutions, responsible investment and planned development. The document is intended for use by commissioners and providers in planning renal services over the next ten years. The initiative concentrates on end stage renal failure (ESRF), which constitutes the largest workload in the renal service and is the area most vulnerable to variations in quality. It also concentrates on the management of adults recognising that the management of children with renal disease will require further specialist attention.

B The first part of the document describes the current status of the service and the important epidemiological and demographic factors which will influence planning and expenditure in the next decade. Together they constitute the main justification for preparing this commissioning framework.

They are summarised as follows:

Increasing Acceptance rates in ESRF and Prevalence of RRT

- Acceptance rates for RRT are rising but there remain geographical inequities.
- The low prevalence rates for RRT compared with Europe reflect continuing difficulties in accessing the service rather than negative attitudes to treating ESRF.
- Since acceptances exceed death rates, the numbers receiving RRT (stock) will not plateau for at least 10 years.
- Since transplant rates are static the number of patients on dialysis will continue to increase.
- Despite the success of transplantation and PD, HD remains the default therapy for all ESRF and the proportion of dialysis patients on HD will continue to increase.

Smouldering Demographic Changes

- Increasing acceptance rates of the elderly and poor access to transplantation in this group is increasing the mean age and co-morbidity burden of the dialysis population. There are consequences for support services such as cardiac and vascular surgery, rehabilitation and social services.
- Increasing acceptance of diabetics increases overall co-morbidity since most have complications including coronary, cerebrovascular and peripheral vascular disease and retinopathy.
- Asian and Afro-Caribbean minorities have 3-4 times the requirement for RRT than whites. These minority groups are still relatively young. As they age the demand for RRT will increase further.

Current problems with the Renal Service

- The slow rate of HD decentralisation into new autonomous centres and satellites has caused congestion in most renal units often severe enough to compromise clinical care.
- Dysfunction in commissioning includes lack of joint working between Health Authorities, a reluctance to accept responsibility for purchasing and crisis management in place of forward planning.
- Lack of a regional perspective on commissioning perpetuates 'blank spots' in the UK which are still without autonomous renal services or even satellite units.

- Difficulties in recruitment and retention of nurses are exacerbated by poor working conditions resulting from congestion and the associated compromises in quality.
- Consultant expansion has not kept pace with the huge rise in RRT stock in the last ten years. The same is true for dietetics, counselling, social work and pharmacy support.

C The document then identifies the building blocks, which are already in place to support continuous quality improvement. Some of these are embodied in new NHS initiatives but some are renal specific.

These include:

- The Renal Association's initiative in clinical standards and audit. A third edition of the document 'Treatment of Adult Patients with Renal Failure - Recommended Standards and Audit Measures' is to be published in 2001.
- UK Renal Registry, which with its electronic downloading of patient specific information, is the key to completing a powerful audit loop with the standards initiative. The UK Renal Registry now covers over 50% of the country and publishes an annual report.

8

D Seven National Service Standards are then described which constitute the core objectives of a strategic plan for renal services for the next decade. Wherever possible, the evidence base for the recommendations is described. Some recommendations reflect the enlightened level of expectation of patients in a modern healthcare system. Other recommendations prescribe the developments needed to reverse the inequities in access to therapy and in quality, which have been characteristic of the UK renal service. These standards could be the basis of performance targets within the new NHS Performance Framework.

The seven National Service Standards are summarised as follows:

NATIONAL SERVICE STANDARD 1

Pre-Dialysis: Retarding Progression and Reducing the Comorbid Burden in Renal Disease

- Diabetic renal disease should be the focus of efforts to reduce the incidence of ESRF by effective glycaemic and blood pressure control, use of ACE inhibitors and cessation of smoking.
- The needs of the Asian community require special attention as they are at particular risk from diabetes and diabetic nephropathy.
- Diabetic patients who develop proteinuria (nephropathy) should be referred for local diabetology/ophthalmology assessment at an early stage. Guidelines for timely referral into nephrology should be agreed locally.
- Efforts to achieve the standards in the National Service Framework for Coronary Heart Disease for reducing cardiovascular risks in the population should be vigorously supported.
- Efforts to implement the recommendations in the National Service Framework for Diabetes should be supported.
- Since Primary Care is well placed to deliver these standards, adequate resources should be made available to allow them to succeed.

NHS Performance

- Health Improvement • Fair Access • Health Outcomes

NATIONAL SERVICE STANDARD 2

Preparation for Renal Replacement Therapy (RRT)

- All patients with chronic renal failure and a plasma creatinine above 150 $\mu\text{mol/l}$ and/or significant proteinuria ($>1\text{gm}/24\text{hr}$) should be referred to specialist nephrology.
- Patients with creatinine $>300\text{ }\mu\text{mol/l}$ should be referred urgently if there is no strong contraindication to further treatment as a significant number will be approaching or will have reached ESRF.
- All patients with ESRF who, after discussion between the multidisciplinary team, themselves and their families, are deemed likely to benefit should be offered RRT.
- Commissioners should audit the number of patients entering RRT as 'late' uraemic emergencies as a first step to developing mechanisms to ensure the proportion is reduced to a minimum.
- Structured education and counselling of patients approaching ESRF involving the multidisciplinary team and other patients and carers should aim for the seamless entry onto RRT using the patient's chosen modality.
- Timely healthy initiation of appropriate RRT demands unimpeded access to the main dialysis modalities, which in turn requires planned expansion of facilities in line with current prediction of need. There should be no 'waiting list' for dialysis nor should any patient be commenced on a therapy known to be inappropriate.
- While it is accepted that the number of transplant centres in the UK will not increase their staffing should allow transplant surgeons, physicians and co-ordinators to carry out clinics in autonomous renal centres to streamline screening of potential recipients and to maximise morale, local organ retrieval, live donation and pre-emptive transplantation.
- Commissioners should be aware that the benefits of erythropoietin therapy in pre-dialysis patients (which is producing cost pressures in the service) are based on increasingly firm evidence.

NHS Performance

- Fair Access • Effective Delivery • Patient/Carer Experience • Health Outcomes

NATIONAL SERVICE STANDARD 3

Vascular and Peritoneal Access

- Trusts with autonomous renal centres should ensure adequate surgical expertise and theatre time is dedicated to vascular and peritoneal access. One weekly theatre session per 120 patients (approximately) on dialysis is needed.
- Service level agreements between the renal service and departments of general or vascular surgery and radiology should stipulate case mix and numbers of operations/interventions required per annum. Arrangements involving transplant surgeons may be possible in some centres.
- Seniority and expertise of surgeons/radiologists involved should be audited together with survival rates of natural fistulae, tunnelled catheters and CAPD catheters.
- Access operations should be timely to ensure the majority of planned (non emergency) patients have functioning, 'permanent' access when dialysis commences. Overall the service should aim to have the percentage of new HD patients with natural arteriovenous fistulae (AVF's) approach the European average of 66%.
- Efforts to reverse the decline in the proportion of HD patients using AVF's should aim to return to the European average for prevalent patients (80%) which will involve cooperation with surgical departments, Trusts and commissioning agencies.
- These initiatives will require an elevation of the profile of access surgery in manpower planning and continuing discussions between the Specialist Workforce Advisory Group (SWAG) and Postgraduate Deans.

NHS Performance:

- Effective Delivery • Efficiency • Patient/Carer Experience • Health Outcomes

NATIONAL SERVICE STANDARD 4

Effective Delivery: Renal Association Standards and Continuous Quality Improvement

- Haemodialysis should be provided thrice weekly for >90% of patients.
- Haemodialysis adequacy should be assessed regularly and should achieve either URR >65% or Stable Kt/V >1.2, in >90% of patients.
- Disconnect systems for peritoneal dialysis should be provided to all PD patients by 2001.
- Peritoneal dialysis adequacy should be measured and the daily fluid volume adjusted regularly to ensure the combined fluid / natural renal creatinine clearance exceeds 50l / week / 1.73m² body surface area or weekly urea kt/v exceeds 1.7. APD or HD should be available for patients who cannot achieve these levels of adequacy.
- Correction of anaemia: Haemoglobin should be maintained >10g/dL in all patients unless there is a specific medical reason. Commissioners should ensure that adequate mechanisms and funding are in place for provision of erythropoietin and iron to achieve this goal.
- All autonomous renal units and their satellites should be linked to the UK Renal Registry within 2 years.
- Service providers should carry out regular audits of their compliance with current dialysis standards and download this data to the UK Renal Registry for national collation and comparison.
- Staffing levels in renal centres should reflect the time necessary to carry out systematic audit.
- Funding bodies and Trusts should support renal professionals engaging in peer review through advisory inspections since they could constitute a powerful aid to continuous quality improvement.
- Wherever possible, Commissioners and Trusts should support improvement of the evidence base for standards of clinical care for ESRF patients.

NHS Performance:

- Effective Delivery • Efficiency • Health Outcomes

NATIONAL SERVICE STANDARD 5

Patient/Carer Experience

- ESRF patients should receive care and support which encourages inclusion of therapy into their overall lifestyle. Treatment should be in comfortable and convenient surroundings and delivered at times consistent with regaining or maintaining employment and maximising rehabilitation into society.
- ESRF patients should expect to access regular HD, CAPD and outpatient review as close to their homes as possible. Access to consultant time, nursing, dietetic, social work, counselling advice and pharmacy support should be equitable irrespective of place of residence or treatment. For the majority, one-way travel time for these services should be less than 30 minutes.
- HD centres should have parking, waiting and changing areas appropriate for 'life-long' attendance.
- RRT patients with intercurrent problems requiring hospitalisation should expect to be admitted to single sex areas in dedicated nephrology wards staffed by nurses trained in renal medicine and dialysis. Nephrology beds should be expanded in line with the expansion of dialysis stock so that the admission of a RRT patient to an 'outlying' ward is exceptional.
- Each patient should have a named nurse responsible for assessment and planning of care.
- Patients and carers, through their local KPAs and the NKF, should expect to be involved in local planning and the setting of Service Level Agreements and to be co-opted onto provider planning committees, onto renal sub groups of RSCGs and onto national initiatives including the setting of Clinical Standards.
- Dialysis patients should be free to holiday in the UK or overseas. This will require investment in the health economies of popular UK destinations. It will require the creation of facilities in all HD units for temporary 'isolation' of patients returning from areas overseas which are high risk for blood borne virus infections.

NHS Performance:

- Fair Access • Effective Delivery • Health Outcomes

NATIONAL SERVICE STANDARD 6

Conservative management of ESRF, Palliative Care and Withdrawal from Dialysis

- Patients with progressive renal failure in whom dialysis is deemed inappropriate or who choose not to start RRT should continue to receive the benefit of the resources available to the renal service to provide a robust support package.
- Service level agreements with funding authorities should recognise the value of anaemia management in alleviating many of the symptoms of ESRF in patients who are not receiving RRT.
- In the terminal phase of ESRF, a management plan, including the preferred location of care, should be agreed with the patient, his/her carer, family and GP. An 'open door' policy for urgent admission to the nephrology ward should be agreed with the Primary Care Team, District Nurses and the local palliative care services.
- Links with Hospices and agencies involved in terminal care should underpin a culture of 'openness' in the renal service in which patients can feel free to discuss withdrawal from dialysis and in which they can feel confident that care will be appropriate to allow death with respect and dignity.

NHS Performance

- Effective Delivery • Patient Carer Experience

NATIONAL SERVICE STANDARD 7

Equity of Provision

- Regions, in conjunction with the UK Renal Registry, should carry out yearly gap analyses to update an NHS register of patients receiving RRT which will allow poorly providing Health Authorities to plan to 'correct upwards' to UK then European levels for their particular population characteristics.
- Elimination of 'blank spots' will require new HD facilities which should be located to balance the need for local services for large towns, economy of scale and travel times.
- Commissioners should recognise that new autonomous renal units may have a greater impact on local acceptance and prevalence rates and Consultant numbers than 'hub and spoke' expansion.
- New facilities developed in the context of Managed Clinical Networks should aim to achieve equity of provision and a Consultant based service with appropriate support services delivering uniform standards of care.

NHS Performance

- Fair Access • Efficiency • Health Outcomes

E The document then describes how some of the new NHS structures, particularly regional specialised commissioning groups (RSCGs), can interface with consortia of Health Authorities and new Primary Care Groups/Trusts to create a framework which will ensure that the National Service Standards are deliverable. Also discussed is the new thinking which will be necessary on the configuration of renal facilities in order to ensure that there is equity of provision and adequate rates of expansion of consultant nephrologists and other professional groups.

F The document then sets out a timeframe for the framework to be put in place and for the delivery of the objectives embodied in the National Service Standards. Since many of the recommended structures flow with the stream of change already taking place in the NHS, some of the timeframes are relatively short. This section also recommends the agencies responsible for the achievement of each milestone. They are summarised as follows:

REGIONAL

Milestones	Responsibilities	Timetable
Commissioning structure operational	RSCG	4/01
Baseline assessment of needs/gap analysis	RSCG	4/01
Regional Implementation and Investment plan	RSCG	4/01
Plan for Consultant expansion	RSCG	4/01
Establish monitoring system	RSCG	4/02

RSCG PRIORITIES REFLECTED IN HEALTH PLANNING

Milestones	Responsibilities	Timetable
HIMPs (Health Improvement Programmes)	HAs	4/02
PCIP's (Primary Care Investment Plans)	PCG/Ts	4/02
SAFF's (Service and Financial Frameworks)	HA to PCT/Trust	4/02
Joint protocols for referral of chronic renal failure	PCT/Trusts	4/02

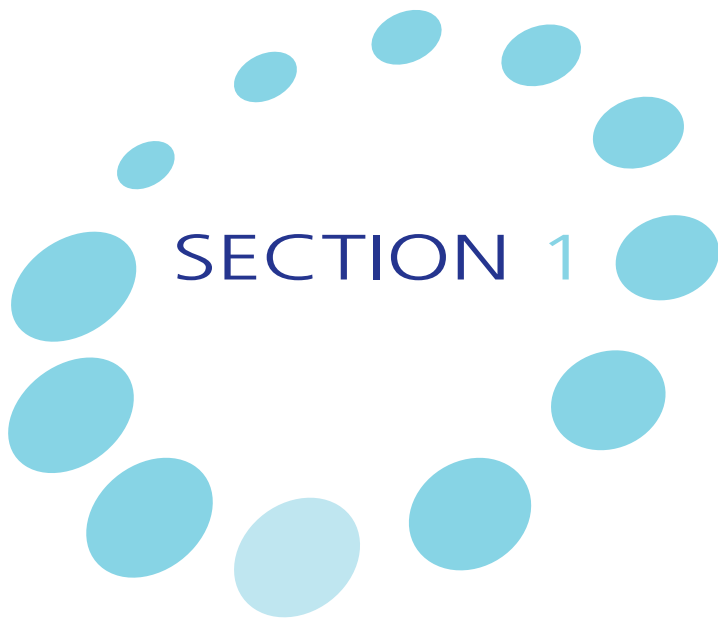
COSTINGS

Milestones	Responsibilities	Timetable
Agreement on template for costing ESRF	NHS Executive	4/02
Establish Benchmarking system for Trusts (25% take up)	RSCG	4/02
Guidelines on the responsibilities for prescribing erythropoietin and immunosuppressant drugs	RSCG	4/02

INFORMATION AND AUDIT

Milestones	Responsibilities	Timetable
Link all renal facilities to National Renal Registry	RSCG	4/02
RSCG reporting framework in place including residence based acceptance and stock rates of RRT	RSCG	4/02
Audit information not available from Renal Registry. Define Audit Plan	RSCG	4/02

G Finally, the appendices detail European comparisons of acceptance and prevalence rates for renal replacement therapy to illustrate the 'gap' which the UK faces to bring its renal services up to European levels. The biggest challenge within this is the achievement of appropriate staffing levels. These are discussed for a number of professional groups in the appendices.



INTRODUCTION

1 INTRODUCTION

This report is intended for use by commissioners and providers involved in planning renal services over the next 10 years. Whilst the Kidney Alliance is unashamedly committed to the provision of excellent and equitable treatment of renal failure in the UK, great care has been taken to ensure that the recommendations contained in this document are realistic, evidence based wherever possible and achievable at acceptable cost. We recognise that the responsibility for achieving these aims will rest with providers and patients as well as commissioners. There is a need for improved efficiency of service delivery, comprehensive staff training and a commitment to continuous quality improvement as well as for increased funding.

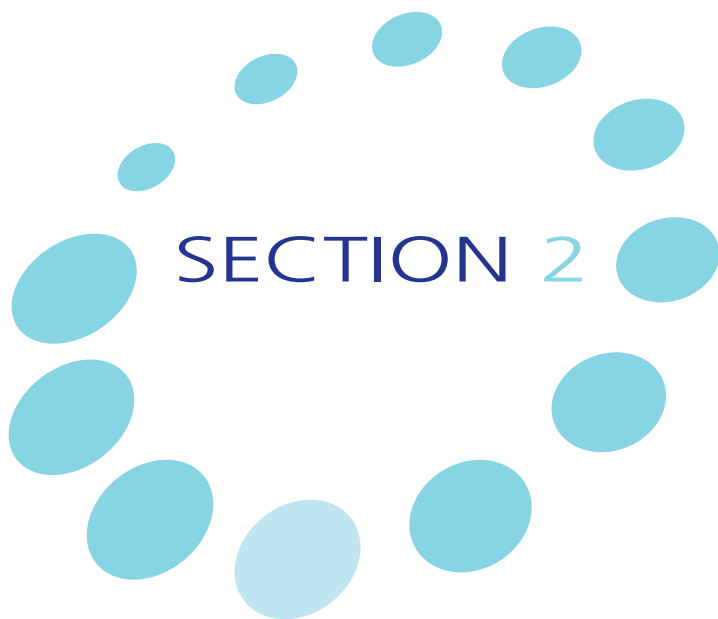
Preparing this document, which we hope will lead the way towards a National Service Framework for Renal Services, has been necessary because the government has chosen, with good reason, to concentrate initially on the much bigger problems of cancer, cardiovascular disease, mental health, diabetes, elderly medicine and critical care. Its contents provide a challenge for everybody involved in renal service provision but we are convinced that implementation of the recommendations will lead to better, more equitable and more efficient patient care.

The first part of the document describes the current status of the service and important epidemiological and demographic factors which will influence planning and expenditure in the next decade. While much has been learned about the preservation of life in end stage renal failure (ESRF) by renal replacement therapy (RRT) since the 1960's, we still have inequitable access and unacceptable variations in clinical standards. We explore the reasons and build on the explanations to construct recommendations for the future.

The report then sets out the National Service Standards to which we would aspire in the modern NHS. These apply not only to patients already with ESRF but also to the attenuation of progression of renal diseases and the reduction of risk factors. The Standards also refer to the need to 'correct upwards' the numbers of patients in those areas of the country which have been historically poorly served where few patients are maintained by dialysis and transplantation compared to the rest of the UK and Europe.

The Structures which will be necessary to make the National Service Standards deliverable are then described. Regional responsibilities are spelt out. Special mention is made of the partnerships which will be required between Regional Specialised Commissioning Groups (RSCGs), Health Authorities, Primary Care Groups/Trusts and Provider Trusts. The report also details the information streams required to enable the Structures to deliver the Standards. Human Resources issues are also addressed. Finally, we outline a timetable for putting these Structures in place with defined responsibilities for each milestone. In adopting this approach, the Kidney Alliance recognises that much work will be needed in the key areas identified in the next few years with refinements which reflect the changes which will emerge as the NHS plan moves forward.

This Kidney Alliance initiative concentrates on ESRF, particularly dialysis, because this constitutes the largest workload in the renal service and the area probably most vulnerable to variations in quality. It also concentrates on the management of adults since we feel the management of children with renal disease will require specialist and focussed attention in a future initiative. We recognise that nephrology departments have wide-ranging responsibilities for all kidney disease which require close links with other specialities such as urology, diabetology, vascular surgery, radiology, cardiology and immuno-histopathology. Acute renal failure, although often reversible, is frequently associated with multiple organ failure and requires high dependency nursing and interface with intensive care. Although transplantation is carried out in relatively few centres the 'work up' and 'follow up' takes place in most renal units. The Kidney Alliance intends to make recommendations on the planning, commissioning and delivery of these services also as we move towards a definitive National Service Framework for Renal Medicine.



THE CASE FOR A COMMISSIONING FRAMEWORK

In this Section, acceptance and prevalence rates of RRT are discussed in detail since they are often the source of confusion. The reasons for the different growth rates for different treatment modalities is also explained and the best available figures are collated to guide Providers, Regions and Health Authorities in planning services into the next five years. The reasons for the inequitable provision of RRT are put forward together with a summary of the areas most under pressure in the service.

The deficiencies identified in this Section constitute the starting points for recommendations and standards set out in subsequent Sections of this document.

2 THE CASE FOR A COMMISSIONING FRAMEWORK

2.1 Acceptance and Prevalence Rates in Renal Replacement Therapy (RRT)

2.1.1 Clarification of Terms

Renal Replacement Therapy (RRT) is a convenient term which comprises all life saving treatments for end stage renal failure (ESRF). It includes dialysis and renal transplantation. **Acceptance** of newly treated patients into the RRT programme is expressed as a rate per million of the population per annum (pmp.pa). The 'per annum' is often implied and acceptance rate is therefore more usually quoted pmp. Since 'pre-emptive' transplantation before patients require dialysis is rare, acceptance into RRT approximates to the acceptance rate for dialysis. The two are often used synonymously.

The **prevalence** of patients refers to the number currently receiving RRT and is usually expressed as a rate pmp. The term 'stock' which equates to prevalence is often used to better emphasise the expansion of numbers receiving treatment which most directly impacts on total cost. Because of the different acceptance and survival rates, for a given percentage expansion of RRT there may be very different rates of expansion (or contraction) of its component parts i.e. transplants and the different dialysis modalities, haemodialysis (HD) and peritoneal dialysis (PD).

2.1.2 Incidence and Acceptance Rates

It is not possible to accurately determine the **incidence** of ESRF in the population which is predominantly a disease of the elderly and a natural cause of death in this age group. Twenty years ago few patients over the age of 60 started dialysis treatment. Since then the numbers of elderly patients accepted for treatment has increased markedly. The second National Renal Registry report¹ showed that at the start of RRT 46% of patients were aged 65 or more and 33% aged 70 or over in England and Wales in 1998. Median age was 63 years.

The acceptance rate into the RRT programme is the main determinant of how many patients are supported on treatment. Rates have been rising and have surpassed the 80 pmp 'target' figure quoted by the Renal Association in 1991². This was a figure based on treatment of patients under 80 years without adjustment for higher incidence in ethnic sub groups.

There persists a commonly held view in some quarters outside the UK that British healthcare professionals are restrictive as to whom they will or will not accept for RRT. In reality it is likely that practitioners in the UK differ little from colleagues abroad in their attitude to the individual patient. The relatively low numbers on RRT in the UK are more likely explained by continuing difficulties in accessing the service (see Section 2.2).

The annual acceptance rate of new patients onto dialysis rose from 67 pmp in 1991/1992 to 82 pmp in 1995, and rose further to 90 pmp in 1998¹. The figure for Scotland was 101 pmp. Between 1990 and 1995, the annual increase in acceptance rate was about 8%³. The West Midlands Regional Audit Group which examines trends in provision across 9 renal units serving a population of 7 million people showed acceptance rate for RRT increasing from 109 to 121 pmp between 1996 and 1999 with a particularly marked increase in those aged over 80 years⁴. Acceptance rate for new ESRF patients in the 1.7 million population of Northern Ireland was 105 pmp in 1999, (Doherty C - personal communication).

There continue to be marked differences in acceptance rates in different areas. Some differences are partly explained by the age and ethnic structure of the population (see Section 2.1.6). While the UK Renal Registry is not yet accurately population based, calculations based on estimated catchment areas show acceptance rates varying from 50 to 150 pmp per year¹.

2.1.3 Transplant and Death Rates

Transplantation is the preferred outcome for many patients reaching ESRF. Organs are in short supply, the numbers of transplants having diminished slightly over the last 10 years⁵. Transplantation rates which rarely exceed 30 pmp per year compare poorly with acceptance rates of new patients. Also a substantial minority of transplant recipients will have lost their transplant kidneys after 10 years. In planning terms therefore it is important to recognise that dialysis remains the default therapy for all end stage renal disease.

The **crude death rate** i.e. the proportion of patients dying per year on the RRT programme is difficult to ascertain but will soon be available from the UK Renal Registry. Estimates would suggest that this is about 20% annually despite the increasing age and cost of the RRT population.

2.1.4 Rising Prevalence

Since acceptance continues to exceed death rate, the stock receiving RRT increases year on year. This has been the case since dialysis was introduced in the mid 1960's and transplantation in 1968-70. In monetary and management terms the rise in dialysis stock is the biggest issue. While second nature to those in the specialty, the concept of rising stock has often proved difficult to appreciate amongst commissioners. This prompted the Medical Director of the NHS to warn in 1996 that "Purchasers should be aware that the total patient population is likely to continue to rise even if there is no further increase in acceptance rate"⁶.

The prevalence rate of RRT patients (dialysis and transplant) in England increased from 396 pmp in 1993 to 476 pmp in 1995³ and rose further to 539 pmp (England, Scotland and Wales) in 1998¹. [Note: these figures differ slightly from those quoted in Appendix II. Only when European countries develop national registries will the figures be entirely reliable]. The prevalence of RRT in Northern Ireland at the end of 1999 was 602 pmp. Despite clear increases, the UK RRT prevalence still lags behind the estimated average (1998) for Germany, Netherlands, Spain, Italy and France of 747 pmp (Appendix II). The percentage of RRT patients with functioning grafts has diminished from 56% in 1988 to 50% in 1998.

Mathematical modelling to estimate future demand for RRT has consistently shown that steady-state (i.e. no growth in prevalence) is not likely to be reached within the next 10 years, and that the overall dialysis numbers are likely to increase by 50% - 100% and HD numbers by 150%⁷. There is considerable experience using a model which was developed in Sheffield⁸. The Renal Review Group in the Northern Region, taking 1998 as the baseline and using the Sheffield model showed an increase of 23% of patients on RRT up to the year 2004⁹. The model showed great sensitivity to the acceptance rate. If this rose from 104 to 120 pmp the numbers of patients on dialysis alone in 2004 would increase by 58%.

Extrapolation from recent activity offers an alternative approach. In an interim report, the Renal Sub-Committee of the Eastern Region Specialities Services Commissioning Group (RSSCG) used provider-based data from the past 5 years to predict growth. They advised Health Authorities to anticipate

continued growth in dialysis stock at an annual rate of between 7% and 10%¹⁰. The West Midlands Regional Audit Group showed patient numbers climbing from 2297 in 1996 to 2809 in 1999⁴. This equates to an annual growth of dialysis stock of 7.4% (simple interest).

2.1.5 Differential Expansion of Dialysis Modalities

Haemodialysis (HD) and peritoneal dialysis (PD) are complementary therapies, the ratio of patients on each varying historically and by provider. While patient preference plays a part, this is often overridden by other factors which include availability of HD stations, technique failure of peritoneal dialysis and the proportion of patients presenting late as 'uraemic' emergencies. The vast majority of late referrals are ultimately treated by HD (see Section 4.2). The availability of automated peritoneal dialysis (APD) which employs machinery to allow overnight cycling of fluids rather than the manual exchanges of continuous ambulatory peritoneal dialysis (CAPD) is a recent development which may allow patients to receive PD for longer.

The relative prevalence of PD in the UK has been declining since its peak in the early 90's. Chief movers have been the availability of satellite haemodialysis and the recognition that in some patients PD provides sufficient dialysis only as long as it is supplemented by natural renal function which declines with time on dialysis. There is a higher rate of transfer from PD to HD in the first two years than HD to PD¹. In addition, 6% of peritoneal dialysis patients (60% of those who died) have a brief period of HD immediately prior to death. These figures emphasise the need for an adequate HD programme to support the PD programme.

The percentage of dialysis patients on HD was 50% in 1993 climbing to 62% in 1998¹. Since 1997 there has been an annual increase of 10% in HD patients, 4% in PD patients and 2.5% in the transplant stock providing an overall 5.3% increase in the total number of patients on RRT. A survey of Eastern Region renal units showed the percentage of dialysis patients on HD climbed from 66% to 69% between 1996 and 1999. HD in the Eastern Region is expanding by 9% pa and peritoneal dialysis stock declining by 2% pa¹⁰. In the West Midlands the percentage of patients treated by HD expanded from 50% to 65% between the years 1995 and 1999. While between 1996 and 1999 the PD population remained static at approximately 1000 patients, HD increased from 1245 to 1806 patients, an increase of 15% p.a. This disparity between HD and PD growth in the West Midlands resulted from an increased proportion of patients choosing HD as their initial modality and a high level of PD technique failure. However, there was a three-fold increase in automated PD (APD)⁴. In Northern Ireland the annual percentage growth in HD during 1995 - 1999 averaged 17.2% with zero growth in PD numbers. (Doherty C - personal communication).

It would be prudent therefore for commissioners to plan for PD prevalence to approach those found in Europe and the United States which are generally less than a quarter of the total managed on dialysis^{11,12}. The corollary is that the planners should accept the inevitable growth of haemodialysis. This remains the default modality for all patients with ESRF: the numbers are increasing despite the successes of CAPD/APD and transplantation.

2.1.6 Smouldering Demographic Changes

Age

Population projections in the UK are for an increase in the percentage over 65. Since ESRF is age related, the ageing of the population will increase need.

Liberalisation of acceptance and poor rates of transplantation resulting from co-existing comorbid disease in the elderly and ageing of patients surviving on RRT are increasing the mean age of patients on dialysis, a trend which is likely to continue. This increases the overall burden of co-morbidity which has major implications for complementary services, particularly cardiac and vascular surgery. Higher numbers of older and more disabled patients will require far more assessments of need for rehabilitative care and support in the community under the 1990 NHS and Community Care Act. Social work input will be significant.

Diabetes

Twenty years ago, diabetics who developed nephropathy were considered to be in the terminal stages of their disease and were rarely accepted for RRT. Diabetics now comprise the most common disease group entering RRT¹. Although rates vary, over 15% of new patients accepted are diabetic and the proportion is likely to increase further given the worldwide epidemic of type 2 diabetes. In the United States the figure exceeds 50%¹². Diabetics who reach ESRF typically have a full house of complications including hypertension, retinopathy (eye disease) and often coronary and peripheral vascular disease.

Ethnic Sub Groups

In the UK, Afro-Caribbeans and Asians from the Indian Subcontinent have higher levels of hypertension and diabetes than the white population which lead to a higher incidence of renal failure and the need for RRT¹³. These populations have three to fourfold higher acceptance rates onto RRT and in some districts comprise the majority of patients treated¹⁴. Their greater need for RRT is accompanied by difficulties in blood group and tissue matching in cross racial transplants and the shortage of donor organs. An important demographic feature of Afro-Caribbeans and Asians in the UK is their relatively young age. The ageing of ethnic minority groups will increase local demand for RRT services significantly^{15,16}. Regions which have high proportions of people from ethnic minorities will need to build in assumptions of growth of dialysis prevalence above 10% per year.

2.2 Historical Basis of Inequity and Congestion

In the 1960's and 1970's, dialysis units and transplant units were established mainly in teaching hospitals. There was little incentive to decentralise and there remained fewer than 60 renal units up to the end of the 1980's. One consequence was that home haemodialysis rather than 'centre' dialysis became the main treatment modality. The need for training resulted in the selection of the relatively young and fit for long term treatment. In contrast there were several hundred units in each of Germany, France and Italy which were established as haemodialysis treatment centres, home haemodialysis being much less developed. As attitudes to age and co-morbidity became more liberal, European units expanded to absorb large numbers of the relatively old and infirm whereas UK units were unable to do this. As a result acceptance and prevalence rates at the end of the 1970's were markedly inferior to that in most other developed countries. On a population basis only a quarter the number of Consultant Nephrologists were employed compared to those other large European countries¹⁷.

The introduction of CAPD in 1980/81 was timely, its simplicity allowing more patients to be treated at home, with minimal capital outlay. Dialysis thereafter expanded rapidly with little increase in the numbers of renal units or haemodialysis stations. By contrast CAPD was greeted with less enthusiasm in the rest of Europe. Eventually though, problems with peritonitis and the recognition that CAPD could be inefficient when patients' natural renal function diminished led to significant numbers of CAPD patients requiring HD as a fallback. This, along with the decline of home

haemodialysis and further liberalisation of acceptance of the elderly onto treatment were the main drivers to the congestion which has been experienced by most British renal units in recent years. It is regrettable that many patients are still channelled into CAPD or forced to remain on it inappropriately due to lack of HD spaces (see Section 2.3.1).

The expansion of HD facilities in the last 10 years has only partially depressurised the over-inflated CAPD programme. Whilst new satellites (usually without local nephrologists or in-patient facilities) of the main tertiary centres have been the main mode of expansion, few new autonomous units (usually two or more nephrologists and in-patient care) have emerged³. The number of nephrologists remains relatively few compared to other European countries.

2.3 Current Problems in the Renal Service

2.3.1 Crisis in Haemodialysis Provision

Services are under intense pressure despite an expansion of satellites from 36 units in 1993 to over 80 now. In a recent survey of provider trusts which achieved >90% response rate (Greenwood R, on behalf of the Kidney Alliance 99/00) 31 out of 56 autonomous centres (55%) reported their dialysis programmes as 'tight, bordering on clinical compromise.' 22 units (39%) reported 'severe congestion resulting in clinical compromise' with 12% centres admitting that thresholds for acceptance had changed with fewer ESRF patients being accepted than in the past. 38% of centres said that more patients than ideal were treated by CAPD with 21% units admitting that CAPD was the only treatment option for new ESRF patients because of exhaustion of HD capacity.

The results showed that the majority of RRT programmes are finding it increasingly difficult to meet the growth in demand. However, another finding was the variation in circumstances. While some units were developing and had the opportunity to meet projected growth others were severely compromised by a lack of capacity and had no obvious way of meeting the problem.

2.3.2 Geographical Areas of Under provision

Given a lack of incentives to decentralise and the difficulty of accessing capital in the NHS it is not surprising that few new autonomous centres (dialysis, inpatient care, local nephrologists) have appeared. Confining expertise and manpower to large metropolitan centres often forces patients to travel many miles to access inpatient care, consultant and paramedical expertise.

It was first shown in 1987 that the chances of receiving dialysis diminish the further patients live from renal centres^{18,19}. The London Implementation Group in 1992 showed prevalence rates for dialysis in some parts of the home counties were less than 120 patients pmp while in some of the Thames regions rates were approaching 300 patients pmp. Perhaps even more alarming was the number of patients with functioning grafts at less than 70 pmp in certain parts of Bedfordshire, Essex, Kent and Sussex compared with prevalences exceeding 200 pmp in more central areas in London²⁰. Data collated in 1991/3 for the 'National Renal Review' which was published by the Department of Health in 1996²¹ showed similar large variations with fourfold differences in stock and threefold differences for acceptance rates in different areas of the Country.

Among Health Authorities in the Eastern Region, dialysis stock rates currently range between 226 and 339 pmp. In Greater Manchester, in 1999/00, the acceptance rate of new RRT patients ranged from 34 to 98 giving an RRT prevalence of 215 versus 319 pmp in contiguous districts (O'Donoghue D - personal communication).

There remain a number of large towns in the UK currently without any dialysis service, e.g. Luton and Colchester. Within Greater Manchester, 5 large towns with large district hospitals i.e. Oldham, Bury, Bolton, Wigan and Trafford have no dialysis facilities. There are still several counties in the UK without autonomous renal services, e.g. Buckinghamshire, Bedfordshire and Cheshire.

2.3.3 Commissioning Difficulties

Linked with the problems of equity are difficulties in the commissioning of RRT. This requires specialist knowledge and an understanding of the issues facing these services. However, individual health authorities often only commission a proportion of the total renal package and may not develop specialist skills or establish constructive relationships with renal service providers. Rapid turnover of health authority (HA) staff who rarely retain responsibility for a particular area for more than a year or two is a further confounding factor.

The Kidney Alliance survey of provider Trusts showed that only 19 of 55 (35%) believed that their commissioners showed an understanding of the planning issues and only 16 (29%) felt that purchasers understood the financial pressures they were facing. The responses to the survey pointed to 6 main issues:

- A lack of joint working and co-ordination between Health Authorities
- A reluctance to accept responsibility for the commissioning of these specialist services
- Uncertainty over funding responsibilities and obligations
- Crisis management as opposed to forward planning
- A general lack of understanding of the issues facing renal services
- Poor access to capital to allow expansion of the haemodialysis base

The commissioning of renal services is currently being reorganised. Renal and supporting nephrology services have been recognised as specialised services which are provided by hospitals to populations larger than that of a single HA. They have therefore been adopted into the remit of Regional Specialised Commissioning Groups (RSCGs). In essence, the strategic plans for the service and the subsequent implementation and investment plans will need to be agreed by a group of HA and Primary Care Trust (PCT) commissioners rather than a single HA/PCT.

2.3.4 Human Resources

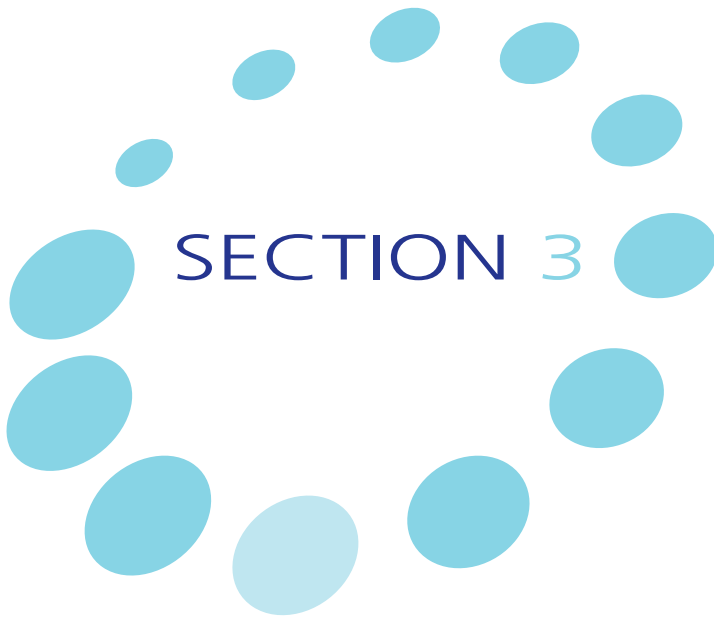
Difficulties in maintaining and developing the renal workforce is another obstacle to progress.

Despite many technical innovations the practice of dialysis is particularly labour intensive with high skill levels required of nurses who, in relation to number of patients, are fewer in number than in the past. Increasingly tasks are being carried out by non-registered practitioners. They in turn must attain high levels of clinical and technical skills which requires substantial investment in education and training. The pressure in the service was reflected in the survey of renal units carried out for the Kidney Alliance in Dec 99/Jan 00. Only 4 of the 55 services stated that recruitment and retention of nurses was not a major problem. Similarly, only nine of the respondents described nursing morale as high whilst 22 described it as poor.

Equally important is the poor rate of Consultant expansion in the last ten years. Although a problem across all medical and surgical specialities, the impact in nephrology is amplified by the huge expansion of RRT stock. (See Section 5.6.2).

Paramedical specialities including social work, dietetics and pharmacy support have all too often been regarded as added luxuries rather than essential components of the multidisciplinary team in workforce planning in provider Trusts. (See Section 5.6.2).

Technical support is an essential component of the service. For home HD patients, although now fewer than in the past, it is common for their most regular contact to be with technical staff. Recruitment and training have been made more difficult in recent years following the disappearance of many of the medical physics departments in NHS hospitals with which technicians were often affiliated. The requirement for more stringent technical standards including water quality calls for urgent reinvestment in the technical service. (See Section 5.6.2).



SECTION 3

EXISTING BUILDING BLOCKS FOR CONTINUOUS QUALITY IMPROVEMENT

This Section explains how the Renal Association Standards initiative combined with the reporting of individualised clinical information to the UK Renal Registry can complete a potentially powerful audit loop in addition to providing accurate demographic and epidemiological data which is necessary for informed planning of future services. This chapter goes on to explain how new Government initiatives in the NHS can be used to implement continuous quality improvement in renal services.

3 EXISTING BUILDING BLOCKS FOR CONTINUOUS QUALITY IMPROVEMENT

3.1 Renal Association Clinical Standards

In 1991 the Renal Association published a document "Provision of services for adult patients with renal disease in the UK" which described the resources and structures necessary to achieve a 'target' annual acceptance rate for RRT of 80 pmp². At the time it was generally assumed that quality was ingrained into patient management provided treatment fell in line with good practice based on the free exchange of scientific knowledge. Challenges included the pursuit of adequate facilities to accommodate growth and sufficient levels of staffing, not only medical and nursing but also dietetics and social work. A further priority was to secure sufficient resources for new developments such as erythropoietin.

The experience in the United States in the 1980s, when systematic reduction in dialysis dose was observed to contribute to high mortality in dialysis patients, eventually changed perceptions of 'assumed quality' on this side of the Atlantic^{22,23}. A faltering European Registry (European, Dialysis and Transplant Association - EDTA) and recognition that European patients were receiving less dialysis year on year raised concerns that measurable targets would be necessary to protect patients from under treatment. In keeping with these concerns, in 1995, the Renal Association published the 'Treatment of adult patients with renal failure; recommended standards and audit measures'²⁴. This was followed by a second edition (1997) which aimed to broaden the evidence base for the recommendations²⁵.

The Renal Association standards initiative not only provided a framework of measurable targets but also recommended good practice over a range of areas in renal medicine. Thereafter, individual units were able to audit their practice against the RA standards as were groups working in co-operation. A third edition of the RA Standards document is in preparation which hopefully will reflect the improving epidemiology and evidence base for the practice of renal medicine. In recent years the RA Standards have become a valuable reference for providers and commissioners.

3.2 The UK Renal Registry

The UK Renal Registry was established by the Renal Association with support from the Department of Health, the British Association for Paediatric Nephrology and the British Transplant Society. It has close links with the Scottish Renal Registry which was established with financial support from the Scottish Office and was one of the first Registries to demonstrate the practicalities of automated data collection. Whilst the initial development of the Registry was financed by grants from the Department of Health and from industry, continuing activity is largely funded through payment by participating renal units of an annual fee per patient registered. In this way it remains an independent source of data and of analysis of national activity in renal disease.

For 20 years many renal units have enjoyed local systematic sequential data collection using clinical computing systems. The potential for electronic downloading of data was recognised by the UK Registry Committee and the UK Registry is unusual in automated collection of sequential quarterly data. Such data includes adequacy of dialysis, haemoglobin, blood pressure and many biochemical variables such as serum albumin, phosphate and cholesterol. The Registry data can help identify reasons for any variations in achieving targets and standards between different units, hence improving practice and generating hypotheses for further investigation. It was apparent during the development of the Standards document of the Renal Association that the evidence base subtending many of the standards was lacking. Evidence from trials and systematic reviews that limit bias are being used to establish standards.

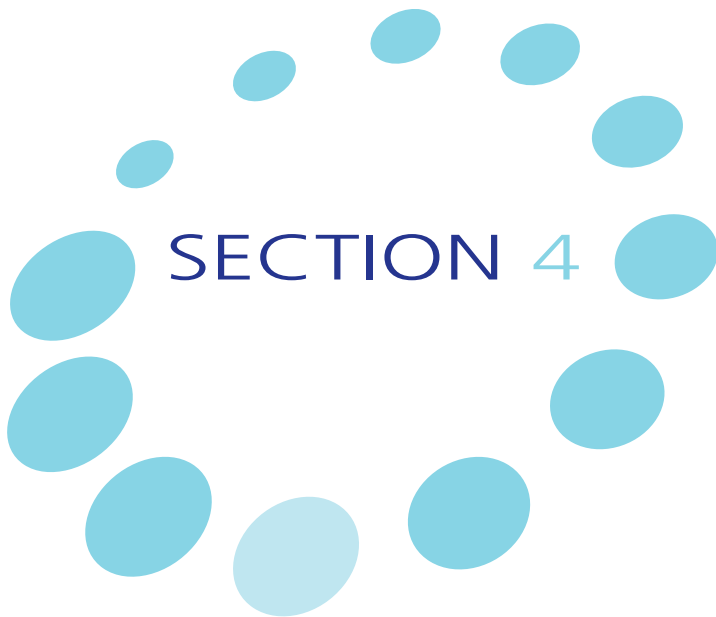
Data from the registry are also important along with studies of targets reached in other countries where factors such as greater resource input may lead to better patient outcome.

The audit and research work of the Registry is essential for 'closing the audit loop' and implementing the recommendations of the Renal Association Standards document. Few, if any, other medical specialities enjoy this facility which makes renal medicine unique in its suitability for automated audit and setting standards of care. In just two years the proportion of the adult population of RRT covered by the UK Registry has grown from 16% to well over 50% and all of Scotland is included. The 1999 report presents data from 15,000 patients on RRT¹. One of the central recommendations of this Kidney Alliance document is that all renal centres and satellites should be linked to the renal registry over a relatively short timescale (see Section 6).

3.3 NHS Initiatives

The development of quality within renal services will be complemented by a number of national initiatives including:

- A national quality infrastructure to support individual services. This includes the National Institute for Clinical Excellence (NICE) which aims to disseminate evidence on best practice throughout the NHS. Opportunities are being pursued to co-ordinate the Renal Association Standards initiative with the activities of NICE.
- A national human resources strategy²⁶ has launched a number of initiatives to link training to service needs and to help staff and services increase their specialist skills. These may be particularly relevant to advanced practice in nursing and the development of the Support Worker role.
- Increasing emphasis in the NHS R&D strategy on assessing the benefits of new and emerging applications of technology. Since renal medicine has a broad technical foundation, this could provide assistance in the development of new initiatives.
- The development of NHS Information Management & Technology (IM&T) strategy through 'Information for Health', 1998²⁷. This places an emphasis on the development of accessible information based on a patient's history and future needs. There may be opportunities to improve local data collection and to interface with initiatives of the UK Renal Registry.
- The introduction of local infrastructure including Health Improvement Programmes (HimPs), Primary Care Groups and Trusts (PCGs and PCTs), and Regional Specialised Commissioning Groups (RSCGs). This infrastructure is aimed at bringing greater consistency to healthcare decision-making and should help to equalise accessibility and quality in renal services.
- The National Plan for the NHS was published by the Government in July 2000²⁸. This sets out a blueprint of how the service needs to be reformed to improve capacity and to increase the number of doctors and nurses. It describes linkages between primary care, hospital and specialised care to ensure patients have timely, accessible treatments. This plan is backed up by significant funding increases which will be spent primarily on extra staff and facilities, additional capacity in the form of extra beds and new equipment and in renovations to existing facilities. Perhaps the aspect of most relevance to renal services is the determination to eliminate the inequities and to ensure that provision and quality of care is consistently high across the country.



NATIONAL SERVICE STANDARDS

The Standards described in this section constitute the core objectives of the strategic plan for renal services into the next 5 years, which aims to ensure that patients with ESRF receive the best medical care. Wherever possible, the evidence base for the recommendations is described. Some recommendations reflect the enlightened level of expectation of patients in a modern healthcare system. Other recommendations reflect the developments which will be necessary to reverse the inequities in access to therapy and quality which have long been characteristic of the UK renal service.

Success in the delivery of standards set out in this document and in the National Service Frameworks will be judged in each Region by the achievement of performance targets within the new Performance Framework mainly by the attainment of the actual milestones and targets set²⁹.

This covers:

- *Health Improvement*
- *Fair Access*
- *Effective delivery of appropriate healthcare*
- *Efficiency*
- *Patient/Carer Experience*
- *Health Outcomes of NHS care*

The National Service Standards described in this Section reflect these broad categories.

4 NATIONAL SERVICE STANDARDS

4.1 Pre-Dialysis - Retarding Progression and Reducing the Comorbid Burden in Renal Disease

4.1.1 Causes of End Stage Renal Failure (ESRF)

Although the management of patients receiving RRT dominates the workload in renal centres, the care of patients with progressive renal impairment is equally important not least because it may be possible in certain situations to retard disease progression. Although RRT is the domain of the nephrologist, management of early renal disease may be managed jointly with Primary Care Teams.

The causes of ESRF in patients starting RRT in England and Wales were recently reviewed³. A similar breakdown in 193 patients referred to a single DGH is also collated below³⁰ as is information from the UK Renal Registry¹.

Cause	England and Wales	DGH	UK Renal Registry
	1995 ³ %	1999 ³⁰ %	1999 ¹ %
Glomerulonephritis	12	20	9
Diabetes	14	15	16
Polycystic kidneys	6	10	6
Chronic interstitial	9	7	9
Hypertension	8	-	5
Myeloma	-	5	-
Other incl. small kidneys, unproven glomerulonephritis, vasculitis, renovascular disease, and uncertain	51	43	55

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Diabetic Nephropathy

Diabetes is the leading cause of ESRF in the western world. Approximately 20-30% of patients with type 1 or type 2 diabetes mellitus will develop overt nephropathy^{31,32}. Although a greater proportion of type 1 diabetics subsequently progress to ESRF, 50-60% of diabetic patients receiving RRT have type 2 diabetes because of the greater prevalence of this type of diabetes in the general population³³. The well-known susceptibility of Asians living in the UK³⁴ contributes to their increased incidence of ESRF¹⁶. A higher proportion of Asian diabetics than white diabetics develop nephropathy³⁵.

The impact is amplified by the associated co-morbidity. Up to 30% of diabetic ESRF patients are blind due to retinopathy³⁶ and almost all diabetics will require laser photocoagulation prior to or during RRT. Peripheral vascular disease is common so that 50-70% of all non traumatic amputations are performed in diabetics³⁷⁻³⁹. Coronary heart disease is accelerated in diabetics and the protective effect of female gender is lost.

Glomerulonephritis or 'nephritis' is a group of conditions in which there is long term (chronic) inflammation mainly involving the part of the kidney which filters the blood - the glomerulus. The kidneys may be involved in isolation or as a part of a generalised disorder of the immune system. Systemic lupus erythematosus (SLE) is a known example. When this occurs early in the disease, renal failure may be postponed or even prevented but success is unusual once progressive renal failure is established. The low figure quoted by the UK Renal Registry¹ is due to counting only biopsy-confirmed cases of glomerulonephritis.

Polycystic kidneys. This is the most common inherited disorder, the chance of transmission being one in two for each child. Throughout life normal kidney tissue is replaced by large cysts which grow at the expense of functioning renal tissue. Families of polycystic patients are often well known to renal units.

Chronic interstitial nephritis. This is a unifying term to include conditions which damage the main body of the kidney by a process of scarring. They include **reflux nephropathy**, a congenital disease in which reflux of infected urine from the bladder back into the kidney early in life can initiate scarring. Prompt treatment and investigation of recurrent urinary infection in small children is the key to successful intervention. The group also includes damage following **obstruction** to the urinary tract. Obstruction due to prostatic disease can occur in men usually above the age of 50 and has important implications for potential future screening programmes in primary care. The group also includes damage due to long term ingestion of **analgesics** (pain killers).

Hypertension. While hypertension superimposed on renal disease can undoubtedly accelerate decline in renal function and accelerated ('malignant') hypertension can cause renal failure, it is less clear whether uncomplicated hypertension causes ESRF. The general view is that it does not⁴⁰. However, the lack of consensus partly explains why the reported prevalence of hypertensive renal failure between countries varies markedly, being as high as 29% in the USA¹². Patients of African descent can experience severe and damaging hypertension which may partly explain the high incidence of renal failure in this group⁴¹. On the other hand it is possible that many patients identified as having hypertensive renal disease actually have indolent nephritis.

Myeloma. This is a cancer of the plasma cells of the bone marrow which impacts on RRT because of its ability to produce ESRF 'acutely'. Since patients may feel well in the early stages of the disease they are often accepted for RRT despite the relatively poor prognosis.

Small kidneys. This is the finding in significant numbers of patients when they first present with signs and symptoms of renal disease or in whom renal impairment is found incidentally. The implication is that indolent disease has been present for a long time. Some will have had or continue to have glomerulonephritis. Biopsy is seldom performed since the implications for treatment are usually minimal.

Vasculitis. This describes a complex group of diseases in which there is inflammation of blood vessels. The kidney is densely endowed with small arteries, the inflammation of which can produce devastating renal disease. Fortunately there is often scope for intervention with immunosuppressive drugs. On the other hand, the symptomatology of these diseases is vague and diagnosis is sometimes missed or delayed.

Renovascular Disease. The arteries leading to the kidney are susceptible to atheroma just as are carotid, coronary and peripheral arteries. The prevalence rises with age. Renal arteries are amenable to angioplasty and stenting. However, the value of these procedures in preventing renal failure is uncertain and is the subject of current controlled trials which will also assess their cost effectiveness.

4.1.2 Retarding Disease Progression

Hypertension There is strong evidence that hypertension accelerates the loss of renal function in patients with chronic renal failure and that treatment of hypertension slows the rate of progression⁴². The deleterious effect of blood pressure may be more important in patients with proteinuria

(see below) in whom lower blood pressures are required to achieve the same protection of renal function. The rate of decline in renal function tends to be faster in hypertensive African Americans compared with hypertensive whites⁴³.

Reduction of Proteinuria. Proteinuria (leakage of protein in the urine) is an abnormal state usually associated with glomerulonephritis although it can occur across the whole range of kidney diseases. There is good evidence to suggest that the higher the level of proteinuria the more rapid the progression of the renal disease^{44,45}. A reduction of dietary protein can reduce proteinuria and lead to a better outcome⁴⁶ but there is diminishing enthusiasm for this approach given the risks of malnutrition and the more powerful and predictable effects achievable with drug therapy; particularly angiotension converting enzyme inhibitors (ACEI).

In addition to lowering blood pressure, ACE inhibitors also lower the filtration pressure inside the kidney which in turn reduces the amount of proteinuria. Meta-analyses have suggested that ACE inhibitors reduce the relative risk of ESRF significantly^{47,48}. In patients with proteinuria, lowering of blood pressure with an ACEI appears to delay progression to a greater degree than with other antihypertensive agents⁴⁹. Dual reduction of blood pressure and proteinuria seems to be the prerequisite for an effective reduction in the rate of progression of CRF.

Diabetic Nephropathy. The main efforts to ameliorate the clinical course of diabetic nephropathy have concentrated on tight control of blood sugar and blood pressure. There is good evidence that good glycaemic control can slow progression of renal failure particularly in the early phases of diabetic nephropathy⁵⁰⁻⁵².

Numerous studies have shown that control of systemic hypertension has a major effect on reducing proteinuria and slowing progression to renal failure in both type I and type II diabetes⁵³. It is now well known that ACE inhibitors can reduce proteinuria over a range of kidney diseases by 40-50%, an effect which may be independent of the blood pressure lowering effect of these drugs^{54,55}. Several studies have shown that ACE inhibitors will reduce proteinuria in both types of diabetes⁵⁶. Furthermore, studies have shown that ACE inhibitors can reduce the risk of death or dialysis in diabetes⁵⁷.

Guidelines on the detection and management of microalbuminuria (small amounts of protein) in diabetics are anticipated in the National Service Framework (NSF) for diabetes.

4.1.3 Co-morbidity Burden in ESRF

While most patients with renal failure have associated hypertension, about one third of patients are without any other discernible disease. In the remainder there is a spread of comorbidities, often florid, which may determine the rate of hospitalisation and survival on treatment. In a recent study of patients starting dialysis in a DGH, 38% had cardiovascular disease, 12% cerebrovascular disease, 24% peripheral vascular disease, 15% respiratory disease and 14% previous or current malignancy³⁰.

Death on RRT is overwhelmingly due to cardiovascular disease⁵⁸. Contributing factors include previous undiagnosed hypertension and smoking which is unusually prevalent in the RRT population. In diabetic and non diabetic patients with renal diseases, smoking is associated with a higher incidence of progressive disease and in men, smoking has been observed to increase the risk of developing ESRF^{59,60}.

Hyperlipidaemia, a well-known risk factor for coronary artery disease also predicts progression in renal failure. There is evidence to suggest that in both diabetic and non-diabetic nephropathies, patients with elevated cholesterol and triglycerides progress more rapidly to renal failure^{61,62}.

4.1.4 Overlap with the National Service Framework for Coronary Heart Disease (CHD)⁶³

The recent launch of the NSF for CHD has broader aims than reducing the burden of heart disease and it is hoped that the incidence of other cardiovascular diseases (especially stroke) will be reduced. It is also hoped that the initiative will encourage systematic approaches which can be applied to other clinical areas. They include the development of registers for chronic diseases and local protocols for referral and treatment. One of the 12 standards in the CHD NSF covers the reduction of risk factors in the population. Given the recognised deleterious effect of smoking, hyperlipidaemia and poorly controlled hypertension in progressive renal disease it would not be unreasonable to expect that significant successes in these areas may well produce a favourable effect on the incidence of ESRF.

4.1.5 Interface with Primary Care

Local solutions will be required to deliver health improvements in patients at an early stage in their disease or in those patients who have not yet developed full-blown renal disease. The NHS and partner agencies should therefore develop, implement and monitor policies that reduce the prevalence of risk factors in the population. Important among these are the reduction in prevalence of smoking and of diabetes through reduced obesity rates. An important target group is the Asian minority. There is clearly a need to engage all stakeholders including those in health promotion and management.

It is hoped that the extra resources which Primary Care will require to impact on the prevalence of coronary artery disease may go some way to ameliorate the burden of renal disease. Primary Care needs good IT systems and close co-ordination with diabetic clinics. Additional resources are needed for the increased use of effective medicines particularly ACE inhibitors in diabetes.

Elaboration of the wider responsibilities of primary, secondary and tertiary care towards the patient with ESRF is included in Section 5.3.

NATIONAL SERVICE STANDARD 1

Pre Dialysis - Retarding Progression and Reducing the Comorbid Burden in Renal Disease

- Diabetic renal disease should be the focus of efforts to reduce the incidence of ESRF by effective glycaemic and blood pressure control, use of ACE inhibitors and cessation of smoking.
- The needs of the Asian community require special attention as they are at particular risk from diabetes and therefore diabetic nephropathy.
- Diabetic patients who develop proteinuria (nephropathy) should be referred for local diabetology/ophthalmology assessment at an early stage. Guidelines for timely referral into nephrology should be agreed locally.
- Efforts to achieve the standards in the National Service Framework for Coronary Heart Disease for reducing cardiovascular risks in the population should be vigorously supported.
- Efforts to implement the recommendations in the National Service Framework for Diabetes should be supported.
- Since Primary Care is well placed to deliver these standards, adequate resources should be made available to allow them to succeed.

4.2 Preparation for Renal Replacement Therapy (RRT)

4.2.1 Early Referral

Patients with renal impairment or significant proteinuria should be referred to a nephrology centre for assessment and to explore the scope for intervention. The Renal Association suggests patients with plasma creatinine above 150 $\mu\text{mol/l}$ and/or significant proteinuria ($>1\text{g}/24\text{hrs}$) should be referred²⁵. Because it is increasingly recognised that patients with a creatinine as low as 300 $\mu\text{mol/l}$ can have ESRF (see Section 4.2.6) it is important that patients with this degree of impairment or worse are referred urgently.

An unplanned start to the initiation of RRT has detrimental consequences for patient outcome⁶⁴. Besides the limited time available to attend to medical complications such as anaemia and bone disease and to make preparations for vascular and peritoneal access, lack of education and information may also exert a negative impact on the prognosis. The percentage of patients with ESRF failure who present or are referred to a nephrologist 'late' varies greatly across Europe. Comparisons are difficult because of the different definitions which are employed. However, one survey which defined 'late' as referral within one month of the necessity for dialysis found the percentage ranged from 10 to 51% in 18 facilities across 7 countries⁶⁵. In Northern Ireland 34% new RRT patients arrive 'late' without prior referral. (Doherty C - personal communication).

There are a number of explanations for the late referral of patients. The evolution of CRF is insidious in the majority, the diagnosis only becoming obvious with the appearance of late uraemic symptoms. This type of late referral can only be avoided by regular screening for renal disease in asymptomatic patients which is costly and of uncertain efficacy. In a smaller group of patients, renal disease is rapidly progressive (e.g. in the context of vasculitis). Late referral may not be avoidable in these circumstances. In other situations the referring physician may not be aware of the severity of the disease or the time needed for adequate pre ESRF care.

Some late referrals may in fact be hidden non-referrals. Khan⁶⁶ in the UK and Mendelssohn⁶⁷ in Canada found that the number of patients with ESRF who are not referred increases with age and co-morbidity. This suggests that some physicians decide that RRT is not appropriate without seeking nephrology advice. A significant proportion of these patients, particularly the elderly, may be referred when their condition deteriorates terminally. In another group of patients ESRF is the consequence of a sudden and unexpected deterioration of pre-existing renal insufficiency. This may be due to iatrogenic diagnostic or therapeutic procedures or prescription of drugs which can upset renal function e.g. non steroidal anti inflammatory drugs (NSAIDs) which are widely prescribed for rheumatic pains.

Late referral is a strong determinant of dialysis modality, only a minority of these patients ultimately being established on PD. Most continue to be treated by HD which is usually the initial life saving treatment in late referral. Late referral also has a negative impact on morbidity and mortality in ESRF with a longer duration of hospitalisation at the start of RRT, a lower number of successfully transplanted patients and a higher mortality⁶⁸.

4.2.2 Selection of Patients

The higher proportion of elderly patients, diabetics and those with other comorbid conditions on RRT has resulted primarily from the relaxation of previously rigid selection criteria, partly conditioned by

increasing medical expertise in the adaptation of available therapeutic modalities, and partly by rising public expectations. These expectations have been fostered by a political climate promoting a more explicit approach to resource allocation. The success of RRT itself has contributed in that patients who were relatively young and fit on commencing treatment have survived into old age with its attendant comorbidities which include those occurring as a result of long term treatment itself.

The approach to patient selection for RRT needs to be flexible and individualised. Hard and fast rules are unhelpful. All patients with ESRF should be considered for treatment and an assessment made of the potential benefits for particular patients in their individual circumstances. It is important to acknowledge the difficulty in obtaining a credible presumption of the patient's subjective perception of his/her likely quality of life. While a 'trial of dialysis' is sometimes advocated, the point at which the trial is deemed to have failed can be difficult to acknowledge and is seldom the same for patient, family, nurse and physician. Withdrawal of treatment after such a trial may be more difficult to manage and at least as stressful for all concerned as withholding dialysis in the first place. In practice there are no objective criteria which can be applied to identify patients who are unsuitable for dialysis.

The working rule is that all patients who are deemed likely to benefit should be accepted for treatment. In a modern era this is seldom a decision which resides exclusively with the doctor. Multidisciplinary input and family involvement is imperative. Just as important is the respect for death with dignity in severely ill patients who should be spared intrusive and inappropriate therapies.

4.2.3 Education, Counselling and Informed Choice of Modality

Education and counselling can be very beneficial in patients whose entry into RRT is 'planned'. Most renal centres approach this in a multidisciplinary fashion aiming to allow patients to come to terms with, and to understand the medical aspects of their disease and also to allow them to make an informed choice of modality. Patients often learn as much from fellow patients within a supportive group as they do from staff members. In addition, patients can be made aware of the wide range of educational material available, much of it having been written specifically for the dialysis patient.

The main dialysis modalities, HD and PD are complementary. Automated peritoneal dialysis (APD) has provided a welcome extension of choice. Patients appropriately appraised of medical and psychosocial constraints should be involved in the choice of their own treatment modality. Limited options for vascular access mitigate against the choice of haemodialysis. The elderly, diabetics (provided retinopathy is controlled) and patients with all but the most severe forms of cardiovascular compromise do at least as well on haemodialysis as on CAPD. Haemodialysis is perhaps the better initial option in patients of above average size in whom CAPD may not provide adequate treatment when their residual function has been lost. On the other hand, PD generally provides more independence and freedom of movement particularly for international travel. APD may offer more powerful dialysis than CAPD and may therefore allow patients to remain on PD longer when natural renal function fails.

The choice of initial modality is as important to patients as is the flexibility to change from one treatment to another according to preference or if medical complications supervene. This requires unimpeded access to all the therapies.

4.2.4 Exploring Transplant Options

A minority of patients with planned entry onto RRT can avoid dialysis by 'pre-emptive' transplantation. The timing of cadaveric transplantation cannot be planned so receiving a kidney before the need for dialysis is usually most practically achieved by live donation. For the majority, however, live donation is not an option and cadaver transplantation usually takes place after a variable time on maintenance dialysis. The demand for renal transplantation in the UK now exceeds 50 pmp. Unfortunately, transplant activity is severely limited by the number of kidneys available to around 30 pmp per year⁶. Patient enthusiasm for transplantation must be tempered by discussion of the risks associated with surgery, chronic immunosuppression and the rejection process. Pre dialysis education should provide an honest appraisal of the chances of receiving a transplant particularly in the elderly.

Screening for potential renal transplant recipients is a time consuming multidisciplinary process involving medical and surgical assessment, histocompatibility testing and radiological investigation. The 1999 Royal College of Surgeons Working Party report on Organ Transplantation identified a number of problems, including a shortage of transplant surgeons, falling organ donor rates and the lack of a national strategy for effective delivery of the service⁶⁹. Currently there are around 28 renal transplant units in the UK and it is generally accepted there is a need for rationalisation to around 20 larger units. The Department of Health recently published plans to modernise transplant services⁷⁰. The UK Transplant Support Services Authority (UKTSSA), established since 1991 was re-named UK Transplant (UKT) in July 2000. It has a new Board, Chief Executive and new responsibilities. UK Transplant plans to orchestrate a national strategy for transplant co-ordinators with the aim of maximising organ donor numbers. The Department of Health is currently developing a commissioning framework for renal transplantation services which is likely to lead to rationalisation of the number of transplant units and an agenda to ensure equitable access to transplant organs for all ESRF patients who are deemed suitable.

The use of kidneys from living donors for transplantation finds its most important justification in the existing shortage of organs from cadaver donors. A second justification is that recipients have better graft survival and quality of life when organs from living donors are used.

It has been suggested that transplant rates can be increased by using donors with non beating hearts. Potential donors are those who have a permanent circulatory arrest either occurring in the intensive care unit or shortly after their admission to an emergency service. The kidneys are cooled while still in the patient using special catheters. If cooling can be achieved within 45 minutes of the arrest the kidneys can be used for transplantation. Additional guidance on the use of non-heart beating donors would be helpful. Also, the issue of elective ventilation needs to be resolved.

If transplant centres are to be reduced and the number of autonomous renal units (nephrology and dialysis) continues to rise (currently 70) it is important that the profile of transplantation does not diminish in non-transplanting centres. This is best achieved by transplant surgeons, physicians and co-ordinators carrying out regular clinics in the autonomous centres.

4.2.5 Vascular and Peritoneal Access

A pre-emptively placed natural arteriovenous fistula (AVF) is the ideal vascular access for the uraemic patient destined for HD. Early placement avoids emergency insertion of catheters and reduces hospitalisation. At least six weeks is required for an AVF to mature. Similarly, a Tenckhoff catheter

for PD should ideally be inserted in time to allow two weeks healing before commencing CAPD or APD. These ideals require time for the multidisciplinary team to co-ordinate surgical review and arrange theatre lists (see Section 4.3.4).

4.2.6 Timely Initiation of Dialysis

The indications for dialysis are clear when patients present with life threatening problems such as severe hyperkalaemia (high potassium level), pulmonary oedema (fluid on the lung) and acidosis (too much circulating acid). The same is not true for 'planned' patients with slowly progressive renal failure. The point at which natural renal function becomes seriously inadequate is often difficult to define. Reliance has traditionally been placed on clinical features of renal failure or fluid overload and biochemical measurements (blood urea, creatinine). Blood urea and creatinine are poor indicators of adequacy in established dialysis patients. Low levels may indicate poor protein intake and wasting rather than adequate dialysis and predict poor survival⁷¹. Kinetic methods which measure the clearances (removal) of urea and creatinine are now the gold standard for the assessment of dialysis adequacy.

The same may be true of low blood urea and creatinine, relative to renal function, in the period before dialysis is started and clearance measurements may similarly have a role in defining the optimum time to initiate dialysis treatment although the evidence base is still slim. Whatever the methodological details, the benefits of initiating dialysis in a timely fashion while patients are still healthy is self evident. To achieve this requires unimpeded access to all available dialysis modalities. There should be no 'waiting list' for dialysis.

4.2.7 Anaemia Management in Pre Dialysis Patients

Over the last few years the benefits of anaemia correction by erythropoietin and iron have become recognised in patients with progressive chronic renal failure in the pre-dialysis phase of their illness. Benefits include improved quality of life⁷², increased energy levels and exercise capacity⁷⁴ and improved cardiac function^{73,74}. Commissioners need to know that a change in clinical practice based on good evidence is taking place whereby more pre-dialysis patients are being treated which translates into a significant cost pressure in the service.

NATIONAL SERVICE STANDARD 2

Preparation for Renal Replacement Therapy (RRT)

- All patients with chronic renal failure and a plasma creatinine above 150 $\mu\text{mol/l}$ and/or significant proteinuria ($>1\text{gm}/24\text{hr}$) should be referred to specialist nephrology.
- Patients with creatinine $>300\text{ }\mu\text{mol/l}$ should be referred urgently if there is no strong contraindication to further treatment as a significant number will be approaching or will have reached ESRF.
- All patients with ESRF who, after discussion between the multidisciplinary team, themselves and their families, are deemed likely to benefit should be offered RRT.
- Commissioners should audit the number of patients entering RRT as 'late' uraemic emergencies as a first step to developing mechanisms to ensure the proportion is reduced to a minimum.
- Structured education and counselling of patients approaching ESRF involving the multidisciplinary team and other patients should aim for the seamless entry onto RRT using the patient's chosen modality.
- Timely 'healthy' initiation of appropriate RRT demands unimpeded access to the main dialysis modalities which in turn requires planned expansion of facilities in line with current prediction of need. There should be no 'waiting list' for dialysis nor should any patient be commenced on a therapy known to be inappropriate.
- While it is accepted that the number of transplant centres in the UK will not increase their staffing should allow transplant surgeons, physicians and co-ordinators to carry out clinics in autonomous renal centres to streamline screening of potential recipients and to maximise morale, local organ retrieval, live donation and pre-emptive transplantation.
- Commissioners should be aware that the benefits of erythropoietin therapy in pre-dialysis patients (which is producing cost pressures in the service) are based on increasingly firm evidence.

4.3 Vascular and Peritoneal Access

4.3.1 Background

Historically vascular and peritoneal access operations were most often provided by transplant teams and sometimes urologists in regional centres. However, the number of surgeons involved in transplantation did not keep pace with the requirement for access surgery save in a few centres. Junior staff, by default, often became the major source of surgical expertise, with limited training and consultant support. As dialysis was decentralised into District General Hospitals (DGH's), the need for access surgery was often underestimated. If local surgeons took on the responsibility, it would often be on a 'grace and favour' basis with no provisions for extra theatre time or sessional commitments. Also, although many DGH's had vascular surgical services, these surgeons were often not experienced in access for HD or PD and were reluctant to take on the extra commitment.

4.3.2 Interfacing Requirements to Available Specialities

Combined renal/transplant units (autonomous transplanting centres) have the option for vascular access services to be provided by transplant surgeons. However, there are currently an insufficient number of transplant surgeons and vascular access in this setting is often poorly provided. Rationalisation to fewer, larger centres may provide the scope for more comprehensive support in these units but at the same time may leave those centres which lose transplantation vulnerable with respect to renal access support.

Vascular surgeons have provided valuable renal access support over the years but their involvement has been patchy, partly because there were alternatives. As the speciality of vascular surgery develops, it is inevitable that renal services will look in the direction of this specialty for support. Following a number of approaches from personnel involved in renal transplantation the Council of the Vascular Surgical Society of Great Britain and Ireland (VSSGBI) circulated the following position statement in their June 2000 Newsletter:

"The VSSGBI supports and encourages training in renal access work and its performance by consultant vascular surgeons. Not all trainees or vascular surgeons will aspire to these skills but the Society strongly endorses this area of work for vascular surgeons, recognising that there is an important need."

It is likely that vascular surgeons working in large departments will be best fitted to provide renal support in the future provided the work is pooled rather than concentrated on one individual. Departments must be provided with enough theatre lists dedicated to renal support and have formal Service Level Agreements (SLA's). The Job Plan of replacement or additional vascular surgeons should ideally include renal support as a core element. The surgical trainees in these departments should receive dedicated training in vascular and peritoneal access. To achieve these aims, discussions need to continue between Specialist Advisory Committees of the Royal Colleges (SACs), the Specialist Workforce Advisory Group (SWAG) and Postgraduate Deans (see Appendix III).

The recently published Health Technology Assessment (HTA) document 'Cost and Outcome Implications of the Organisation of Vascular Services' usefully deals with linkages between vascular surgeons and other services including renal⁷⁵.

In some centres, general surgeons and other surgical sub-specialities have provided support for renal services often on a single-handed basis. There will always be a need for local solutions to the problems of access provision.

Interventional radiology has taken great strides in the last twenty years and a sub-group of radiologists now provide expertise in angiography, angioplasty (including stenting) and thrombolysis all of which are needed for renal support. Interventions with fistulae are often preceded by radiological imaging and the advantages are obvious when radiologists themselves can proceed to angioplasty or the insertion of central lines. Radiology departments however are all working to capacity with demands exceeding their ability to provide. Planned and fully resourced expansion of radiology departments will be required if they are to provide renal support.

4.3.3 Outreach Provision of Expertise

The provision of outreach services in the context of Managed Clinical Networks may be relevant to the planning of renal surgical support (Section 5.8). There are precedents for visiting surgeons successfully providing vascular and peritoneal access services to renal centres without the expertise being available on site. Some visiting surgeons also attend assessment clinics where complex patients can be seen with their X-Rays to discuss the most appropriate operation. These arrangements similarly require dedicated theatre and anaesthetic time.

4.3.4 Service Level Agreements (SLA's)

While individual units may audit and keep records of renal access procedures this information is not regularly pooled and there are no firm data on which to make recommendations about SLA's. However, in a busy autonomous renal unit serving 1 million population supporting 330 dialysis patients with an HD:PD ratio of 2:1 there is currently an annual demand for over 300 operations. Sometimes more than one procedure is carried out at each sitting. In 99/00 106 arteriovenous fistulae, 53 PD catheter insertions and 143 permanent central venous access lines were required (Greenwood R - personal communication). This service is provided by a local general surgeon, the local vascular surgery department and visiting transplant surgeons. The work occupies two theatre sessions per week backed up by 37 'emergency' theatre lists per annum. In a detailed analysis of workload in South Wales, Yorkshire and Newcastle (Appendix IV), it was estimated that for a population of 1 million there would be a requirement for 100 arteriovenous fistulae, 50 PD catheter insertions and 100 permanent central venous access line insertions per annum. The similarity of these figures would suggest that one theatre session will be necessary for approximately 120 patients on the dialysis programme.

While some nephrologists retain skills in bedside insertion of catheters for PD and HD, their contribution is unlikely to affect greatly the level of demand for theatre based surgery as detailed above.

4.3.5 Quality Issues and Audit

The preferred access in any HD patient is a native AVF which produces the highest flows, minimises sepsis and has the greatest longevity. The ideal would be that all HD patients have natural AVF's but all renal units fall short of this. Unfortunately so many veins have been damaged by blood sampling

or cannulation that less than 50% are suitable for AVF's. Thus whilst 70% of AVF's are created at the wrists, no more than 50% are successful. While 30% can go on to have successful access at the elbow, 20% will be dependent on intravenous plastic cannulae tunnelled under the skin or PTFE tubing (grafts) inserted under the skin (Bakran A - personal communication).

The availability of temporary and 'permanent' tunnelled cannulae for urgent venous access has been one of the factors leading to the liberalisation of acceptance of patients for dialysis. Their use in sick patients and in patients presenting late with ESRF, however, has had a negative impact on the number of natural AVF's. Since the life of tunnel catheters is less than natural AVF's, more repeat operations than in the past are inevitable.

The numbers of temporary and tunnelled lines is often symptomatic of congestion in a service with inadequate surgical support. Perhaps not surprisingly the UK is lagging behind most of the large European countries with regard to the proportion of HD patients using natural AVF's.

The Dialysis Outcomes and Practice Patterns Study (DOPPS) is a longitudinal study, currently ongoing, of haemodialysis patients in the USA, Japan and five European countries (UK, Germany, France, Italy and Spain)⁷⁶. After two years data collection in one hundred facilities throughout Europe, results show that for relevant patients, 67% in the UK have functioning AVF's⁷⁷.

The figures for France, Germany, Italy and Spain are 77%, 84%, 90% and 82% respectively.

The European (DOPPS countries) average is 80%. 47% of UK patients start haemodialysis with a functioning AVF, the majority of the remainder starting using tunnelled catheters. The percentages of patients starting HD with an AVF in France, Germany, Italy and Spain are 62%, 83%, 60% and 71% respectively. The European (DOPPS countries) average is 66%.

One of the aims for future organisation of renal services should be to remedy this poor UK performance. Access operations should be carried out in a timely fashion to avoid emergency procedures in planned patients. The prevalence of AVF's and the number of planned patients who start dialysis with permanent access should be audited since their levels reflect the efficiency and effectiveness of the renal service.

NATIONAL SERVICE STANDARD 3

Vascular and Peritoneal Access

- Trusts with autonomous renal centres should ensure adequate surgical expertise and theatre time is dedicated to vascular and peritoneal access. One weekly theatre session per 120 patients (approximately) on dialysis will be necessary.
- Service Level Agreements between the renal service and departments of general or vascular surgery and radiology should be in place which stipulate case mix and numbers of operations/interventions per annum. Arrangements involving transplant surgeons may be possible in some centres.
- Seniority and expertise of surgeons/radiologists involved should be audited together with survival rates of natural fistulae, tunnelled catheters and CAPD catheters.
- Access operations should be timely to ensure the majority of planned (non emergency) patients have functioning 'permanent' access when dialysis commences. Overall, the service should aim to have the percentage of new HD patients with natural arteriovenous fistulae (AVF's) approach the European average of 66%.
- Efforts to reverse the decline in the proportion of HD patients using AVF's should aim to return to the European average for prevalent patients (80%) which will involve cooperation with surgical departments, Trusts and commissioning agencies.
- These initiatives will require an elevation of the profile of access surgery in manpower planning and continuing discussions between the Specialist Workforce Advisory Group (SWAG) and Postgraduate Deans.

4.4 Effective Delivery - Renal Association Standards and Continuous Quality Improvement

4.4.1 Renal Association Standards

It is intended that this Kidney Alliance document should be complementary to the Renal Association's initiatives on clinical standards and audit. The Renal Association, together with the Royal College of Physicians of London, first produced a consensus statement of recommended standards and good practice for treatment of renal failure in 1995²⁴. This was revised and extended and its second edition was produced in 1997²⁵, with a third edition in preparation. The document sets out the standards for clinical practice in renal failure including end stage renal disease. It is being prepared in collaboration with the Intensive Care Society and the British Transplantation Society and includes a section on paediatric nephrology. Since it is largely a consensus document, there is a need to improve the evidence base. The Chairman and members of the Standards & Audit Subcommittee have selected key standards for inclusion in this Kidney Alliance document. They are principally the standards that are most relevant to the planning, commissioning and organisation of service provision for end stage renal disease.

4.4.2 Reporting to the UK Renal Registry

The advent of the UK Renal Registry is one of the most exciting developments of the last few years. Not only will it produce important demographic and epidemiological information, it will also provide the basis for the comparative audit of outcomes in patients with ESRF and patients established on RRT. Given the absence of a statutory reporting mechanism of demographic and outcome information in renal patients it is difficult to systematically improve the service even with accepted clinical standards and targets without employing comparative audit.

The Renal Registry should lead to quality improvements provided renal units 'sign up' to the initiative. RSCGs, with their influence over the allocation of resources, are well placed to request participation in the Renal Registry and are accorded a high priority. If 100% compliance is achieved, Britain will enjoy the same potential as a handful of European countries who already have 100% subscribed National Registries with the added benefit of automated electronic downloading of information.

4.4.3 Audit - Local and Regional

Continuous quality improvement is an important component of clinical governance in provider Trusts. The Renal Association Standards provide a framework for local audit of outcomes. Since RRT has a broad multidisciplinary base, there are great opportunities to test the effectiveness of evolving practice by clinical audit. In order to do this effectively, staffing levels in renal units needs to reflect the time necessary for audit to take place, an activity which is often labour intensive.

Since RRT was initiated, most renal units have maintained contact through sub-regional, regional or even supra-regional discussion/policy groups. Various named Renal Interest Groups, Renal Groups and more latterly Renal Audit Groups, they typically meet several times a year to exchange ideas on management, clinical protocols and on political /strategic issues. There is now a clear opportunity for these groups to input into the RSCGs. Accurate information on activity and staffing levels on the provider side and the historical problems about their region will be well known by these groups. Hopefully regional audit will be given new impetus and authority from working in concert with the

RSCG's. Such initiatives will be in keeping with recent government led initiatives for improving quality and particularly continuing professional development and the requirement for all doctors to participate in clinical audit as part of clinical governance.

4.4.4 Peer Review

Peer review takes many forms. Recently some nephrologists, in concert with the Royal College of Physicians, pioneered the 'inspection' of dialysis facilities by colleagues from another region. Given that practice in renal medicine ranges from the technical to the immunological, the composition of the visiting teams were multidisciplinary. The experience from these initial peer review visits was widely disseminated and published⁷⁸. It was rewarding for both sides with significant educational spin off. Rather than feeling threatened by the inspection, the host Trust often gained a useful foothold in negotiations with purchasers if shortcomings in their service were identified.

Peer review is time consuming and expensive. Recently the Royal College of Physicians paused to reconsider these and other implications. Advisory visits could constitute one of the most powerful routes to continuous quality improvement and are in keeping with the strategic flow of Government thinking. It is likely the Renal Association and the British Renal Symposium will take this initiative forward in concert. There is now a formal peer review process taking place in Scotland which is funded by the Scottish Office.

NATIONAL SERVICE STANDARD 4

Effective Delivery - Renal Association Standards and Continuous Quality Improvement

- Haemodialysis should be provided thrice weekly for >90% of patients.
- Haemodialysis adequacy should be assessed regularly and should achieve either URR >65% or Stable Kt/V >1.2, in >90% of patients.
- Disconnect systems for peritoneal dialysis should be provided to all PD patients by 2001.
- Peritoneal dialysis adequacy should be measured and the daily fluid volume adjusted regularly to ensure the combined fluid / natural renal creatinine clearance exceeds 50l / week / 1.73m² body surface area or weekly urea kt/v exceeds 1.7. APD or HD should be available for patients who cannot achieve these levels of adequacy.
- Correction of anaemia: Haemoglobin should be maintained >10g/dL in all patients unless there is a specific medical reason. Commissioners should ensure that adequate mechanisms and funding are in place for provision of erythropoietin and iron to achieve this goal.
- All autonomous renal units and their satellites should be linked to the UK Renal Registry within 2 years.
- Service providers should carry out regular audits of their compliance with current dialysis standards and download this data to the UK Renal Registry for national collation and comparison.
- Staffing levels in renal centres should reflect the time necessary to carry out systematic audit.
- Funding bodies and Trusts should support renal professionals engaging in peer review through advisory inspections since they could constitute a powerful aid to continuous quality improvement.
- Wherever possible, Commissioners and Trusts should support audit initiatives aimed at improvement of the evidence base for standards of clinical care for ESRF patients.

4.5 Patient/Carer Experience

4.5.1 General Support

The onset of ESRF requires adaptation to major life changes. The patient must cope with new dependencies on doctors, nurses and other agencies and perhaps dependence upon a machine and a restricted lifestyle. The latter can lead to job loss, job changes and pressures on family, sexual and social relationships. In a survey of 24 UK units, 23.5% of all dialysis patients reported two or more areas of difficulty in self care, 68.4% reported that social/personal relations were seriously affected and 29.6% reported that they were unable, or less able, to perform usual activities⁷⁹. Success of RRT is linked to the effectiveness with which these stresses are combated. Lack of adaptation can lead to depression and non compliance with treatment.

Staff attitudes are important. Patients may find it more difficult to adapt when clinicians devote their energies to the technical aspects of care at the expense of personal interaction. There is evidence that loss of independence and disruption of life style can be compensated for by a caring approach by staff⁸⁰. ESRF treatment is intensive and time consuming and it is therefore important that the process is made as convenient and as responsive as possible. Support from the family and carers is critical. Families, partners and friends can amplify anxieties of patients or they can absorb stress and provide a positive influence on the perception of the patient and become their major support.

Patients, families and carers should have their needs assessed on a regular basis to ensure that service and support programmes are targeted effectively. This in turn requires that services should have a sufficient complement of staff to allow time for personal interaction with patients. The care environment should be as comfortable and welcoming as possible. Renal services should strive to provide continuity of care. Minimising staff turnover helps to achieve this aim.

4.5.2 Convenience and Comfort of Dialysis Facilities.

For the majority of ESRF patients, dialysis, once commenced, is for life. Despite the success of independent home treatment, now mainly by PD, the majority of patients require regular 'centre' HD. Ease of access to HD facilities is therefore of major importance. Thrice weekly treatment is the norm and the aim is to make the dialysis day as short as possible. Approximately half the patients on regular dialysis have their own transport, the other half being dependent on ambulance or hospital car services. A recent survey of UK HD units carried out for the Kidney Alliance showed that 4% of patients have a return journey of more than 4 hours for each dialysis session and 36% have a return journey of 2 to 4 hours (Keogh A - personal communication). Except in the most rural areas, a one way journey time of less than thirty minutes should be the aim for the majority. Even if that were achieved, transport dependent patients often have much longer journeys because of the need for a car to pick up several passengers. The placement of new HD facilities must reconcile travel times with the requirements of large towns where most patients live and economies of scale. Good road links and the availability of car parking are important considerations. Proximity to railway stations is also important. These issues are addressed in Section 5.8.

Comfortable waiting areas for patients are needed given that transport dependent patients may have long waits for their travel partners to finish dialysis. There has been a tendency in the past to design renal units along clinical lines. Since medical interventions are not common in routine maintenance dialysis, more emphasis could be given to the hotel ambience. The dialysis day can be made more bearable by comfortable chairs, relatively quiet surroundings, a degree of privacy,

personalised TV/video and friendly administration so that patients can keep in touch with various activities and arrange appointments. It is desirable that consultant led clinics take place in the local facility. Travel to distant centres for routine review is second best. Although there is less need to decentralise PD close to patients' homes, it is generally appreciated if their follow up can also take place locally.

4.5.3 Admission to Hospital

While the number of days RRT patients spend in hospital every year are relatively few (European average 11.3 days⁸¹) the individual patient experience is extremely varied. While it is not uncommon for fit patients to go several years between hospitalisations, some of the more dependent patients need repeated admissions. At any time, approximately 50% of inpatient nephrology beds will be occupied by RRT patients with intercurrent problems. The juxtaposition of patients newly diagnosed with ESRF and RRT patients, some of whom will have serious medical problems, or may be in the terminal phases of their illness demands the highest levels of nursing skill and an environment suitable for the care of patients with the whole range of renal diseases.

RRT patients admitted to hospital should expect to be admitted to a purpose designed nephrology ward staffed by renal trained nurses, some ideally with experience in intensive care and others who are competent in haemodialysis. Patients with acute renal failure often receive dialysis on the nephrology ward as do patients admitted from outlying satellite haemodialysis units. The number of nephrology beds required should keep pace with the numbers supported on dialysis (see Section 5.8). If facilities are inadequate, RRT patients have to be admitted to 'outlying' wards where they will be looked after by nurses who are not renal trained. This should be the exception.

Patients should also expect single sex areas on the nephrology ward with appropriate shower, bathing and toilet areas. Quiet areas for interviewing patients and families should be part of the fabric of the nephrology ward.

4.5.4 Access to Medical, Nursing and Paramedical Expertise

The consultant nephrologist is central to the provision of optimal medical care for the patient with ESRF. Relative to Europe, the numbers of whole time equivalent (WTE) nephrologists remains low. The ratio of RRT patients to the consultants available has climbed so high as to undermine the notion of a consultant based service. The proportion of outpatient contacts made by a consultant is often less than 1 in 3. It is important that consultant contact time with out-patients is at recommended levels (See Appendix IV). Consultant expansion is a complex issue which may relate to the future configuration of renal services. This is addressed in Section 5.6.2.

The role of the nurse within the multi professional team is pivotal as he/she spends substantially more time than any other professional in direct patient contact. He/she is also in the unique position to provide client education, health promotion and act as the patients' advocate within the renal service.

Specialist nursing roles have been developed to increase the effectiveness of pre dialysis education, diabetic care, PD home care and palliative care which translate into an improved quality service. Specialist nurses are essential to provide this service and each patient should have a named nurse in order to ensure continuity.

Future development should include promotion of advanced practice and nurse consultant roles. Development of autonomous roles result in improved care and treatment in that nurses with diagnostics and prescribing responsibilities improve patient management and outcomes.

The tendency to regard paramedical personnel as luxuries rather than essential components of the multidisciplinary team is to be deplored. Their numbers should be expanded in line with the expansion of the RRT population (see Section 5.6).

Drug treatment is key in renal therapy. Pharmacy expertise is proving beneficial in streamlining care, improving compliance and meeting the challenges of clinical governance. Pharmacists now adjust individual patient therapy to minimise adverse events and maximise therapeutic benefit. Renal pharmacists often run medication review clinics and are involved in discharge planning.

Given the devastating personal impact of ESRF, there is a great demand for information about benefits, attendance allowances, insurance etc. While Social Workers are often employed by local authorities, many are seconded whole time into the renal service and become renal specialists. In addition, social workers have traditionally been trained in counselling skills which are increasingly in demand. The practical, economic and psychological needs of patients are addressed often via the more 'mundane' tasks that are needed e.g. Benefits work, arranging community services etc.

Nutritional care is an important part of the management of renal disease. Dietitians are increasingly involved in the prescription and quality assurance of dialysis in the diagnosis and treatment of malnutrition and in the prevention and management of bone disease. Interventions in diabetes and in risk factors for cardiovascular disease are other important areas which bring patients into contact with the renal dietitian.

Link workers with translation skills have been recruited into the multidisciplinary team with great success in certain areas in recent years. These posts can enhance educational activities and may also help to achieve acceptable transplantation rates in ethnic minorities.

4.5.5 Involvement in Local and National Initiatives

From the early days of RRT, local Kidney Patients Associations (KPA's) became established in most renal units. While initially involved in local support and fundraising these groups, through the formation of the National Kidney Federation (NKF), became a significant support group country-wide. Significant contributions are made in many areas including patient education, travel and insurance advice.

More recently the NKF and local KPA's have become involved in the politics of healthcare. There are some recent examples of involvement in contract negotiations between provider and purchaser. The most notable political achievement has been the formation of the Kidney Alliance. The NKF was the chief mover in the formation of the All Party Kidney Group in the House of Commons in July 1999. These initiatives have underlined the great potential for kidney patients to influence the development of services which is in keeping with the ascendancy of the patient voice in modern healthcare systems.

4.5.6 Holiday Dialysis

To take a holiday is a reasonable expectation of patients on dialysis. In common with others, renal patients now enjoy a wide choice of destinations and a holiday break is often an important boost to morale offering a welcome change in routine. Holidays can provide a much needed break also for the patients' family or carer. Historically, however, access to holidays, particularly overseas, has been fraught with difficulties and there are many examples of patients being denied the opportunity. To compound the situation patients may be liable for the costs of dialysis itself if venturing outside the EEC.

Aided by the international organisation of commercial dialysis providers, patients who are established on peritoneal dialysis benefit from the former's ability to deliver fluids to varied pre-determined destinations throughout the world. This is one of the great advantages of the 'independence' of PD patients.

Making arrangements for haemodialysis however is usually more difficult even in the UK. Most HD units are working at or near to capacity which includes those in desirable holiday locations. Often facilities can be overwhelmed by the numbers of requests for holiday dialysis. Hitherto, although money exchanged hands between HA's extra investment to enable NHS units to accommodate holiday patients has not been formally included in planning and commissioning. While a limited number of small private sector initiatives alleviate the situation, holiday dialysis has hitherto failed to attract significant investment from large dialysis companies.

Local initiatives within the NHS are long overdue. It should be incumbent upon health commissioners to assess the size of the problem in their locality and to make adequate provision. While central monies should be made available, the staffing of extra dialysis stations will require careful consideration particularly as the demand will have a seasonal component.

The increase in requests for holiday dialysis impacts on the time commitments of renal unit staff. The process tends to be time consuming partly because of the lack of agreed methods of data transfer between units. This has been helped recently by the publication of a suggested standardised form⁸².

Overseas holidays for HD patients present an extra dimension of difficulty because of the risks of blood borne virus infection. While universal, sterile precautions should be employed in all units to minimise the possibility of virus transmission, guarantees are not possible when patients travel abroad. The problem is particularly difficult in patients travelling to the Asian sub continent. Many renal units have experienced patients returning from these destinations having contracted hepatitis viruses. The alternative to denying patients the freedom to travel, which would be unacceptable, is investment to allow renal centres to 'isolate' patients returning from these destinations for a period of a few months until new infection can be ruled out. In practice this isolation simply requires that patients use dedicated machines in side rooms. Unfortunately this is a luxury that many renal units no longer enjoy, having been drawn into the culture of crisis management which results from inadequate expansion of the haemodialysis base. This will require new units to be designed with enough spacial redundancy to provide temporary isolation facilities for their patients. Haemodialysis expansion should take into account the need to depressurise existing units to permit the development of such facilities.

NATIONAL SERVICE STANDARD 5

Patient/Carer Experience

- ESRF patients should receive care and support which encourages inclusion of therapy into their overall lifestyle. Treatment should be in comfortable and convenient surroundings and delivered at times consistent with regaining or maintaining employment and maximising rehabilitation into society.
- ESRF patients should expect to access regular HD, CAPD and outpatient review as close to their homes as possible. Access to consultant time, nursing, dietetic, social work, counselling advice and pharmacy support should be equitable irrespective of place of residence or treatment. For the majority, one-way travel time for these services should be less than 30 minutes.
- HD centres should have parking, waiting and changing areas appropriate for 'life-long' attendance.
- RRT patients with intercurrent problems requiring hospitalisation should expect to be admitted to single sex areas in dedicated nephrology wards staffed by nurses trained in renal medicine and dialysis. Nephrology beds should be expanded in line with the expansion of dialysis stock so that the admission of a RRT patient to an 'outlying' ward is exceptional.
- Each patient should have a named nurse responsible for assessment and planning of care.
- Patients and carers, through their local KPAs and the NKF, should expect to be involved in local planning and the setting of Service Level Agreements and to be co-opted onto provider planning committees, onto renal sub groups of RSCGs and onto national initiatives including the setting of Clinical Standards.
- Dialysis patients should be free to holiday in the UK or overseas. This will require investment in the health economies of popular UK destinations. It will require the creation of facilities in all HD units for temporary 'isolation' of patients returning from areas overseas which are high risk for blood borne virus infections.

4.6 Conservative Management of ESRF, Palliative Care and Withdrawal from Dialysis

4.6.1 Conservative/Supportive Management of ESRF

Renal Replacement Therapy may not be appropriate for all patients reaching end stage renal failure (ESRF) for many reasons including the presence of overwhelming co-existing medical conditions. While ESRF is a terminal condition, death is usually not a sudden occurrence. More common is a slow decline in general health with malnourishment and wasting related to decreased appetite and progressive metabolic disturbance. Inability to excrete excess fluid and acid, the production of which overwhelms the natural corrective mechanisms, eventually compound the picture.

There is a large potential for alleviating the symptomatology of advanced chronic renal failure using drug therapy particularly diuretics, erythropoietin, iron and hypotensive drugs. The management of patients with progressive renal failure in whom dialysis is inappropriate or who choose not to start dialysis has been raised from the level of frustrating observation to a worthwhile therapeutic endeavour.

Renal units are now managing non RRT patients with the fullest resource package which the renal services can offer. This approach avoids the 'rejection' which may be experienced if the patient is 'not for dialysis' and avoids burdening the GP with medical conditions better managed by specialists. Similar to the experience of patients destined for RRT, the unit liaison team (See Section 4.2) can input education and advice for patients, their carers and families at an appropriate time. Emphasis is put on the control of the symptomatology of renal failure and on providing the appropriate level of psychosocial support. Nutritional advice, counselling, social work advice and pharmacy support can all be brought to bear in a robust support package for conservatively managed patients. Since the general trend is to start people on dialysis earlier while natural renal function is still maintaining reasonable health, the outlook for patients embarking upon conservative therapy rather than RRT can be many months or sometimes even years. Regular outpatient clinic support can augment support packages in the home and community.

4.6.2 Palliative Care

Eventually the support package must give way to palliative care when liaison with a different set of agencies is necessary. Much headway is being made by some centres in integrating care with hospices and the support agencies associated with disease states more traditionally managed in this sector. One of the most distressing side effects of renal failure can be pulmonary oedema (fluid on the lung) which can resemble an asthmatic attack. The nephrology ward has the resources to deal with this complication and an open door policy for urgent admissions of patients known to be in the terminal phases of chronic renal failure can be agreed with GPs, district nurses and hospices.

4.6.3 Withdrawal from Dialysis

Hitherto it has been an unusual occurrence for patients to voluntarily withdraw from dialysis. By contrast, 20% of patients undergoing dialysis in the United States eventually decide to withdraw from dialysis¹². The reasons are varied but commonly there is a breakdown of morale often related to overwhelming medical problems^{83,84}. Failure of successful vascular access for haemodialysis is a particularly wearing complication often requiring multiple hospital admissions and operations. Data

on withdrawal has not been systematically collected in the UK. However the numbers are thought to be less than in the US but are expected to increase as the mean age and co-morbidity burden of the dialysis population rises. (See Section 2).

Improvements in the holistic understanding of the patient experience in ESRF has revealed the major difficulties patients can experience in making the decision to withdraw from dialysis therapy. At this stage in the disease process, the reason for continuing dialysis is often not a spiritual drive to survive. Patients often continue to dialyse for the sake of their families or even for the sake of the renal unit staff whom they perceive will be let down by their decision to withdraw. Other patients require reassurance that their decision will not be construed or recorded as suicide. Simply raising the issue as a discussion point often comes as a major relief to the patient which can pave the way for a constructive discussion on the process and the experience of discontinuing treatment.

When patients withdraw from dialysis, most will be oliguric (little urine reflecting zero natural renal function). The mean survival time is at most 2-3 weeks without dialysis. It is important that the advice and management plan is targeted to allow patients to settle their affairs and come to terms with the needs of their families and carers. Clear lines of liaison need to be agreed between the patient, the GP, community nurses, local hospice and nephrology ward. In this way management is optimised and many of the fears and uncertainties surrounding the process can be removed.

NATIONAL SERVICE STANDARD 6

Conservative Management of ESRF, Palliative Care and Withdrawal from Dialysis

- Patients with progressive renal failure in whom dialysis is deemed inappropriate or who choose not to start RRT should continue to receive the benefit of the resources available to the renal service to provide a robust support package.
- Service level agreements with funding authorities should recognise the value of anaemia management in alleviating many of the symptoms of ESRF in patients who are not receiving RRT.
- In the terminal phase of ESRF, a management plan, including the preferred location of care, should be agreed with the patient, his/her carer, family and GP. An 'open door' policy for urgent admission to the nephrology ward should be agreed with the GP, District Nurses and the local Hospice.
- Links with Hospices and agencies involved in terminal care should underpin a culture of 'openness' in the renal service in which patients can feel free to discuss withdrawal from dialysis and in which they can feel confident that care will be appropriate to allow death with respect and dignity.

4.7 Equity of Provision

4.7.1 Recent Expansion of Nephrology and Dialysis Services

The historical basis of inequities in provision of renal services is discussed in Section 2.2. In the late 1980's, it was recognised that significant decentralisation of dialysis services, particularly HD, would be necessary from the small number of units (<60) which were providing the service. A limited number of new autonomous (dialysis and inpatients) 'single handed' DGH units began to appear. Examples were in Carlisle, Ipswich, Bangor, Stevenage and Gloucester, typically areas where there had been poor RRT provision. Initial experience showed that a nephrologist working alone was unsustainable and junior staffing levels were inadequate. Securing satisfactory surgical support proved just as difficult as it was in the established centres.

By contrast, local recruitment of nursing staff and support workers was generally successful as was the ability to secure technical support, sometimes from commercial suppliers of dialysis and water treatment equipment. Most units found little difficulty linking to transplant centres, the number of local patients with functioning grafts eventually rising with the prevalence of dialysis. Few of the new units found it necessary to refer complex renal cases to the established centres, most being amenable to local management. The ability of the new DGH centres to become truly autonomous i.e. managing all cases of acute and chronic renal failure and all dialysis was aided by 'pairing' nephrologists and the improved distribution of urology, cardiac and radiology services which took place throughout the 1990's.

Appearing in much greater numbers than new autonomous units have been satellite units of the established centres in a 'hub and spoke' configuration. Typically, new consultants are appointed in the hub with 'outreach' responsibility for the satellite. Nurses and support workers are generally recruited and live locally. The majority of satellites (currently 82) do not have resident nephrologists nor local inpatient care although there are exceptions³. Patients requiring inpatient care are admitted to the hub which remains the referral centre for acute renal failure. Most satellite dialysis units have consultant led nephrology outpatient clinics on site or nearby which helps to improve local acceptance rates.

4.7.2 Future Configuration of Services

Traditionally the 'hub and spoke' has been regarded as the ideal service configuration with a typical hub (usually a transplant centre) covering two million population to provide transplantation and dialysis services through its satellites. New thinking is required given the likely reduction in the number of transplant centres and the burgeoning dialysis population. The potential weaknesses of the hub and spoke configuration, if too much resource is concentrated in the hub, include limited senior and junior medical presence, long travel distances for admissions and too many dialysis patients with intercurrent problems temporarily admitted to the hub. Continuing dialysis must take place in the hub which is usually under pressure from local dialysis demand. Excessive congestion in chronic dialysis units can be a disincentive to recruitment and retention of nurses.

Other less obvious weaknesses may be a lower rate of consultant expansion and less effective reversal of inequity of provision if satellites are developed in preference to autonomous centres. In the home counties which were served by London 'hubs' until 1990 dialysis prevalence rates were < 206 pmp²⁰. A recent survey of Health Authorities in the old North Thames Region showed a variation in dialysis prevalence from 226 pmp in one HA served by a satellite dialysis unit

(with 1.0 WTE nephrologists serving a population of 177,000) to 339 pmp in another HA with an autonomous unit (with 3.0 WTE nephrologists serving a population of 978,000).

Equity of access (1999 RRT prevalence 602 pmp) has been achieved in Northern Ireland through development, not of satellite units, but of subregional units. In this model, the subregional units are staffed by consultant nephrologists or physicians with an interest in nephrology. This allows a greater scope of local renal service to be provided, minimising travel inconvenience for patients. The service provided via subregional unit physicians includes local clinics (transplant review, CAPD, general nephrology), inpatient care and access to a nephrologist assessment for local general physicians. In this model, the only services not provided at subregional unit level are transplantation, peritoneal and vascular access surgery, interventional radiology techniques, CAPD training and tissue-typing (Doherty C - personal communication).

In Yorkshire, a policy whereby new satellites are developed into free standing units over a period of a few years has been successfully applied in York and Bradford. There are plans to expand this concept to other major towns. The two units within the Teaching Hospital in Leeds would not have been able to sustain an adequate service without these decentralising developments (Davison S - personal communication).

Therefore a balance has to be struck between the expansion of haemodialysis services by hub and spoke or by the creation of new autonomous units. This reflects the balance between the overall expenditure allocated to renal services, the need for a Consultant based service and to correct under-provision.

4.7.3 Filling in 'Blank Spots' in Service Provision

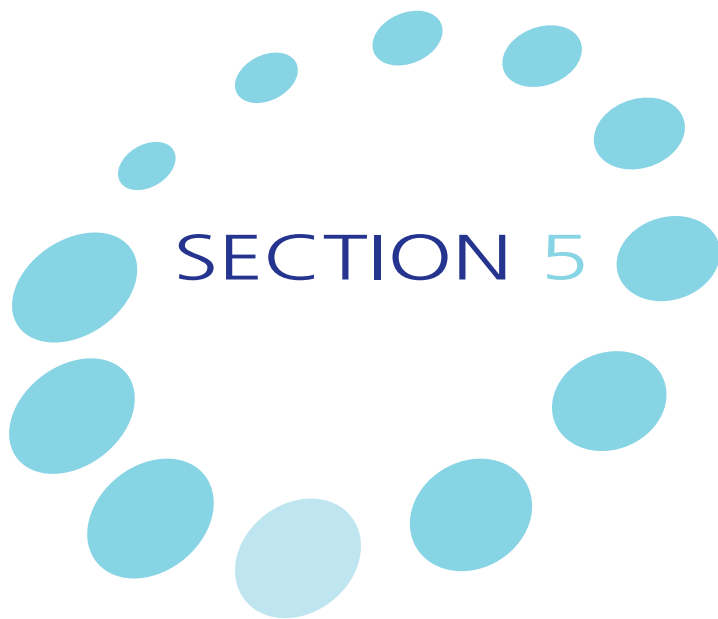
The first requirement is a population based 'gap' analysis where RRT stock can be compared to national norms taking into account local characteristics. Although this might appear straightforward, it may be difficult in practice due to the overlap of providers and HA's. Accurate assessment of transplant stock can also be difficult because of 'loyalty' of patients to the original transplanting centre after change of address. Unfortunately, UKTSSA patient data is not post-coded. Pooling provider based data which is usually more robust is an alternative strategy to identify areas with historically poor provision.

RSCGs have the opportunity to recruit medical, management and financial advice from 'Regional Interest Groups' (see Section 3) to produce an operational/ business plan for reversing the deficit. The options range from introducing satellites, doubling up single handed practices, converting satellites to autonomous units to the introduction of new autonomous units. In all cases, the Managed Clinical Network approach including 'borrowed' management expertise may prove helpful (see Section 5.8). Unless the rate of transplantation increases, approximately two thirds of patients accepted for RRT will be on dialysis. The transplantation rate varies markedly across the country and access to this, the optimal treatment for most patients with ESRF is thus inequitable. For those on long term dialysis, planning must be sensitive to patient and carer needs.

NATIONAL SERVICE STANDARD 7

Equity of Provision

- Regions, in conjunction with the UK Renal Registry, should carry out yearly gap analyses to update an NHS register of patients receiving RRT which will allow poorly providing Health Authorities to plan to 'correct upwards' to UK then European levels for their particular population characteristics.
- Elimination of 'blank spots' will require new HD facilities which should be located to balance the need for local services for large towns, economy of scale and travel times.
- Commissioners should recognise that new autonomous renal units may have a greater impact on local acceptance and prevalence rates and consultant numbers than 'hub and spoke' expansion.
- New facilities developed in the context of Managed Clinical Networks should aim to achieve equity of provision and a consultant based service with appropriate support services delivering uniform standards of care.



STRUCTURES NECESSARY AND ORGANISATION OF SERVICES

In order to deliver the Standards detailed in Section 4, planning of renal services and the determination of Service Level Agreements must be elevated to a higher level than the single Health Authority. This section describes how the new NHS structures, particularly Renal Specialised Commissioning Groups, can interface with consortia of Health Authorities and the new Primary Care Groups/Trusts to create a framework which will ensure that the objectives are deliverable.

This section also describes the new thinking which will be necessary on the configuration of renal facilities in order to ensure that there is equity of provision and adequate rates of expansion of Consultant Nephrologists and other Professional Groups.

5 STRUCTURES NECESSARY AND ORGANISATION OF SERVICES

The 7 National Service Standards detailed in Section 4 can only be met if the necessary infrastructure is in place to support the delivery of treatment and care.

5.1 Regional Framework

Renal services require a consistent, long-term approach across wide geographical areas. The NHS has recognised this and incorporated Renal services into the remit of Regional Specialised Commissioning Groups (RSCGs). These RSCGs need to ensure that an effective planning system is put in place:

- First, the RSCGs should put in place systems that are capable of supporting major service developments. Within these systems, responsibility for establishing and implementing Regional plans for Renal services should be clearly identified.
- There needs to be a thorough baseline assessment of need throughout the Regions which can be matched against current provision. This will then produce a gap analysis which can be used to prioritise development programmes and investment.
- Based upon this analysis, there should be a 3-5 year implementation plan with clear objectives, milestones and responsibilities. This plan should aim to target areas of greatest need and to develop an equitable pattern of service across the NHS. There should be a commitment to review the plan annually to ensure that commissioning dialysis reflects changes in acceptance and transplant rates.
- Linked to this should be an investment plan that explicitly links development priorities with resources. This should include:
 - Analysis of building and equipment needs with a clear mechanism for allocating capital,
 - Targeted revenue allocations to address gaps in provision,
 - Mechanisms for ensuring appropriate allocation of Consultants, Nursing and Paramedical posts within renal services.
 - The RSCG should put in place systems for monitoring progress on implementation of plans, and measuring the performance of commissioners and providers of renal services.

5.2 Partnerships

NHS agencies should work in harmony to meet the standards laid out in this document. Success will depend upon a common approach to the development of services and quality. The RSCGs should oversee joint working at all levels between NHS and partner agencies. In particular, the priorities of the RSCGs must be linked to the priorities of Health Authorities, Primary Care Groups and Trusts (PCGs and PCTs), Hospital Trusts, and other partner agencies. This should be done through the existing NHS planning mechanisms:

- Health Improvement Programmes (HimPs) are local strategies for improving health which combine a range of nationally and locally set targets. HimPs should refer to the Regional renal priorities, especially in areas with low prevalence of RRT, and demonstrate how local health priorities and

development programmes will complement and enable them. Health Authorities should have specific targets aimed at providing health improvement in this area.

- Where and if appropriate in the future, PCGs and PCTs should include in their annual plans and in their agreements with Trusts reference to activities and developments which will impact on renal standards. At the time of writing the PCG/Ts were not expected to do the contracting for RRT. However, PCG/Ts are likely to make a significant impact in improving local diabetes services (see Section 4.1.2). This will be of particular importance in areas with high proportions of ethnic minorities.
- Host Trusts, in preparing renal business plans should demonstrate how they will contribute to the delivery of regional plans and targets. They should be able to demonstrate an understanding of their current baseline with regard to renal services and the key tasks which are required to meet the national service standards.
- Hospital Trusts, PCGs and PCTs should develop shared care protocols to ensure seamless care for renal patients.
- Local Authority Social Services Departments have the responsibility to assess the needs of patients and carers under the Care in the Community legislation and the professional accountability for social work services. The increase in the RRT population will significantly affect the demand for these services and will result in even greater need for Local Authorities to work closely with Provider Trusts.

5.3 Responsibilities of Primary, Secondary and Tertiary Care

Patients with ESRF usually have more frequent contact with dialysis units and transplant services than they do with general practitioners and primary care teams. This imposes a responsibility on all professionals to ensure that patients with ESRF get appropriate care for intercurrent illness and conditions which are not related, or only remotely related, to their renal disease. Renal physicians are not usually trained in primary care and often lack experience in the management of self-limiting illness as well as the breadth of generalist knowledge across other specialities. On the other hand, general practitioners may not immediately grasp the renal implications of occurrently disparate conditions and their management. They do, however, retain 24 hour responsibility for patients on their list unless the patient is actually in a secondary or tertiary treatment centre. There needs, therefore, to be an effective alliance between professionals to provide holistic care for patients.

To place ESRF in perspective, it is instructive to illustrate the numbers of patients encountered. Assuming an RRT prevalence of 800 pmp is reached in the next few years, a PCT covering 100,000 population will have 80 on RRT with 12 new patients a year.

Responsibilities of both renal teams and primary care teams

- To provide effective, speedy two-way communication on all changes in treatment whether instituted by renal units or by primary care
- To consult effectively regarding appropriate secondary care referrals to colleagues in other specialities
- To ensure that each patient has an explicit understanding of who to consult when, about what

Particular responsibilities of renal units

- To keep general practitioners informed about plans for management of end stage renal failure of individual patients including the information that has been provided to patients and their families
- To furnish appropriate protocols and specialist guidance, for example on erythropoietin prescribing
- To keep general practitioners up to date regarding individual patient targets for blood pressure
- To provide effective, immediate specialist consultation for the management of renal emergencies such as pulmonary oedema and for medical conditions with renal implications such as diarrhoea and vomiting which can result in electrolyte imbalance

Responsibilities of general practitioners and primary care teams

- To understand the implications of end stage renal failure for individual patients on their list
- To appropriately flag electronic and manual records in order to maintain safe prescribing and safe health care for patients with ESRF
- To consult appropriately with renal specialists when the management of intercurrent illness has renal implications

It is suggested that it is good practice for local renal units to establish protocols with primary care which take account of features such as the local secondary care provision and the distance patients have to travel to renal units. Usually it will remain appropriate for patients to consult their general practitioner about conditions ranging from influenza to breast lumps and tertiary care should aim not to displace primary care from the important generalist roles. Best practice sees close co-operation between doctors and nurses at all care levels with consultation on appropriate referrals, for example, the renal physicians may know of rheumatologist colleagues with a specialist interest in the management of renal associated arthropathy.

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Communication is particularly important in two situations:

- a) where patients already have continuing, frequent involvement with a specialist unit. The prime example of this is diabetic patients with ESRF who will continue to need specialist diabetes team involvements
- b) patients who need specialist care requiring close co-operation with renal units. The prime example of this is obstetric care. Although it is rare for patients with ESRF to become pregnant they do so occasionally, particularly following transplantation and the management of pregnancy and delivery demands close co-operation between primary care, obstetric units and renal units.

5.4 Local Management

The Resource Management Initiative (RMI) in the late 1980's suggested that discrete clinical services would benefit from self-management and responsibility for their own budgets. The purchaser/provider split embodied in the 1991 NHS Reforms accelerated the movement towards Clinical Directorate structures within provider Trusts. The Home Dialysis Administrator of old became the Business Manager of the Renal Directorate. These changes helped to establish renal services management as a career path for senior nurses and managers. While 'competition' for contracts to provide inpatient and dialysis services has now given way to a more co-operative way of working strict financial management remains important. Responsible and appropriately costed service level agreements (SLA's) between Trusts and commissioners are essential if medical, nursing, paramedical and administrative posts are to be maintained and expanded.

Expertise in renal services management is a valuable resource. While serving provider Trusts well, objective medical/management advice proved difficult to recruit into HA planning in the last decade. This was one of the disadvantages of the 'market' with each provider in quasi competition with its neighbour for dialysis contracts and spheres of influence. With the abolition of the market it should be easier for RSCGs and PCTs to access more objective provider based expertise in planning.

5.5 Information Technology and Audit

Success in meeting standards relies heavily on data collection. Information systems able to provide services and commissioners with measures of progress and performance will be required. Developments need to take place in a number of areas:

- RSCGs and commissioners need to be able to know the incidence of renal failure, demographic trends in the general population and in renal disease. They should have access to the Sheffield model⁸ or similar models to facilitate a consistent national approach to predicting need.
- Information from renal units should be regularly downloaded to the UK Renal Registry which should allow on-line accessing of this data by individual units and pooled data to HAs and RSCGs.
- Investment should be made in information and technology systems to allow services to develop their standards of care and treatment to acceptable levels.
- Programmes of audit and evaluation should be developed across renal services to allow cross-fertilisation of ideas and best practice.

5.6 Human Resources

5.6.1 NHS Workforce Planning Reforms

The renal workforce needs to be developed to ensure there is sufficient skill and expertise to deliver the National Service Standards proposed in Section 4. Until now, planning has tended to have been by different bodies representing many and varied sectional interests, bringing their own narrow perspectives to the table. Since the 1970's there has been progress towards more collaborative working across professional boundaries and more recently greater emphasis on multi-professional teams within both primary and secondary care. However, it is generally accepted that workforce planning mechanisms lag far behind what will be required. 'A Health Service of All The Talents'⁸⁵ sets out a clear agenda for reforms. This proposes a more integrated approach with improved accountability.

'A Health Service for All The Talents' proposes that Trust and Health Authority Chief Executives would take responsibility for local workforce plans which would be linked to HimPs. Regional Workforce Development Directors would manage a budget encompassing the currently separate funding streams (see Appendix III). While such major changes develop, individual Trusts and their new workforce planning bodies - which are expected, subject to a consultation period on the proposed reforms - will be left to arrive at their own, local solutions.

5.6.2 Future Staffing Requirements

Medical Staffing

Consultants are supported by either non-career staff (Associate Specialists, Staff Grades) or career grades (Specialist Registrars, Senior House Officers and pre registration House Officers). The majority of those in training grades will also have duties in general medicine in addition to their commitment to the renal service. There is a commitment to training Specialist Registrars who are expected to attend an academic programme for half a day per week as well as training both within the hospital and outside to fulfil the requirements of the Specialist Advisory Committee (SAC) in general medicine and renal medicine. Each SpR has regular appraisal and assessment with a trainer as well as a record of in-training assessment (RITA) and a penultimate year assessment. All these commitments take registrars and consultants away from clinical service.

The way in which career grade doctors are funded and how their numbers are set are detailed in Appendix III.

The pressures for more consultants in renal medicine are intense for the following reasons:

- Increased numbers of patients on RRT and increased acceptance rates in ESRF
- Reduction in hours worked by all grades of staff as a result of European working time directives
- An increasing requirement for continuous medical education, training and assessment of junior staff, audit and managerial duties

These changes have exacerbated chronic understaffing. Planning for medical staffing is national with the Specialist Advisory Workforce Group (SWAG) taking advice from the Royal College of Physicians and Renal Association on future workforce requirements in nephrology. Predictions of need up to 10 years in the future allow determination of the number of trainees who should be recruited into the speciality each year. The weakness in this system is that there is no means of requiring Trusts to employ the number of nephrologists required. This has resulted in imbalances with an apparent over provision of trained nephrologists for the posts available. SWAG have responded by reducing the numbers of trainees to match the number of posts which Trusts can or will afford rather than the numbers needed. This problem may be solved if budgets for renal services are held or at least carefully directed by Regional Planning Groups.

One suggestion which has been made to deal with the increasing clinical workload in nephrology is the establishment of a new Sub-Consultant grade. While this grade may be suitable for a few doctors who for a variety of reasons have been unable to become fully trained in nephrology and gain the Certificate of Completion of Specialist Training (CCST), it is not appropriate for fully trained nephrologists. Furthermore the establishment of such posts would move us away from the current aim of a consultant based service.

Consultant Numbers

10 years ago it was estimated that there were a quarter the number of nephrologists in the UK compared to France and one sixth compared to Italy on a population basis². The recommendations made at the time by a working party of the Royal College of Physicians/Renal Association that there should be 4 whole time equivalent (WTE) nephrologists per million catchment is now out of date for the reasons stated above.

The Royal College of Physicians (London) taking advice from a joint Renal Association/RCP Committee recently reviewed manpower needs for nephrology (Wilkinson R - personal communication). The figures are derived from independent estimates for a catchment population of one million provided by physicians in South Wales, Yorkshire and Newcastle and are based on analysis of the work programme in all areas of the renal service (for detailed breakdown see Appendix IV).

It is estimated that for a population of 1 million, 65 consultant notional half days (NHD's) are required for direct patient care and 29 NHD's for supporting activities making a total of 94 NHD's per week. This workload would be satisfied by 9.4 WTE nephrologists. If trainees comprise 27% (an approximate average) of the total workforce and there is an Associate Specialist and a Staff Grade then this figure can be reduced to **6.1 WTE per million population**.

This gives a current need of 316 WTE consultants in nephrology for England and Wales. At the moment there are 164 WTE nephrologists which is roughly equal to the number judged to be necessary for the service ten years ago.

With the expected rate of increase in workload, the requirement is estimated to be 390 WTE in 2006 and 439 in 2010.

A survey by the RCP showed that 60% of nephrologists also provide a service in acute general medicine (GIM) and that on average they spend 30% of their time in general medical duties. 1 WTE in nephrology requires 1.4 physicians in post in these circumstances.

The growth rate in consultant numbers of 11.3% per annum over the next four years is required to achieve these recommendations.

Nursing

The role of the nurse within the multi-professional team is pivotal. The scope and content of renal nursing is shaped by many factors but at present difficulty in recruitment and retention of qualified nurses poses a particular problem. In a recent survey carried out on behalf of the Kidney Alliance (Keogh A - personal communication) renal units reported that 26% of all posts for qualified nurses were vacant. In 41% of the units this was causing problems in delivery of service and in a further 38% it had some impact on the service. As satellite units increase in number and size nurses must identify the skill mix required to deliver effective care. A National Strategy is needed. In 1998 a nursing development group was established to standardise nursing skill mix and to provide guidelines. The four key elements to its work are:

- Organisation of patient care
- Competence and development
- Education
- Recruitment and retention

This work, which has the support of the Department of Health, is ongoing and its preliminary recommendations are expected shortly. Meanwhile, 'bottom-up' five year workforce plans from Trusts, feed up to education consortia, which then aggregate plans from Trusts and other employers such as nursing homes and private hospitals. The consortia commission training on the basis of these plans (see Appendix III). Progress is urgently needed since previous structures have failed to

delivery a uniform approach to workforce planning and there are marked differences in the skill mix ratio of registered nurses (RN's) and Health Care Assistants (HCA's). In the Eastern Region for example, the mix ranges from 30:70 to 70:30.

Professions Allied to Medicine (PAM's)

Dietetics

In 'Provision of Services for Adult Patients' (1991), the RCP/RA 'blue book'², it was recommended that 2 dietitians, a Senior 1 with assistance from a Senior 2 would be required for a typical renal unit with 200 patients on dialysis and seeing 70 new patients each year i.e. a dialysis patient: staff ratio of 100. Since that time there have been significant increases in acceptance and prevalence rates for RRT with an increase in the mean age and co-morbidity of patients with ESRF. Dietitians have also become involved in new areas including monitoring the adequacy of dialysis to prevent malnutrition.

The Renal Dialysis Group of the British Dietetic Association (BDA) have recently completed an updated audit of staffing levels (1999). The results are detailed in Appendix V. The survey show that the patient:staff ratio currently averages 128:1 which greatly exceeds the ratio recommended in 1991 where the workload per patient was less. More worrying is the large variation in access to dietetics expertise throughout the country. The dialysis patient:staff ratio varies between 50 and 274:1, i.e. a >5-fold difference in workload.

A survey carried out by the same group in 1999/00 of Trusts advertising renal dietetics vacancies demonstrated lower than usual numbers of applications with frequent acceptance of lower grades who would subsequently require training (Wells L - personal communication).

More work is needed in the context of the new NHS initiatives on workforce planning to better define the needs of the service and to define mechanisms by which appropriate levels of staff can be achieved.

Social Work/Counselling

In 1991 the 'blue book' recommended that a unit with 200 dialysis patients and 600 associated transplant and pre dialysis patients should have 3 WTE social workers. They should be employed at Level 3 due to the complex nature of the work i.e. a dialysis patient:staff ratio of 70:1. Since that time, there has been great increase in the numbers of elderly and disabled in the RRT population who now require support to ensure an adequate quality of life, access to assessment for available resources and empowerment to make the best possible choices in terms of treatment options. In addition, counselling roles have been taken on by social workers without any formal recognition of time necessary to satisfy the most basic needs of the service.

The Renal Special Interest Group of the British Association of Social Work (BASW) recently surveyed the position and the results are detailed in Appendix V. While 76% of renal units had a social work service, the remainder had no specialist renal social work service and 10% of units had no social work provision at all. Perhaps more worrying was the finding that out of the 76% of renal units with a specialist renal social work provision, 38% of posts were supported by charities. It was noted that all were short term contracts designed as 'pump priming' schemes which it was intended that Health or Local Authority would take up - a strategy which does not always materialise.

The ratio of dialysis patient:staff of approximately 175:1 greatly exceeds the recommendations made in 1991.

Social work appears to be one of the most severely under-resourced areas of the renal service, the staffing levels falling far short of those required to provide an adequate service. Elderly, disabled patients, in particular, will not be able to access this vital service unless more resources are made available and the replacement of charitable funding by substantive NHS funding proceeds.

It is important to define service needs accurately in the context of the new workforce planning initiatives. This is work which should be carried out urgently. The analysis in Appendix V constitutes a good basis for this work.

Pharmacy

The UK Renal Pharmacy Group (RPG) are currently developing a best practice standards document, to include minimum standards of service and minimum staffing levels required for different sized renal units.

In 1999 the RPG conducted an analysis of pharmacist staffing levels in renal units. This suggested that the average unit (200 patients) needed 0.5 WTE for pharmaceutical care planning services, 1.0 WTE if providing a transplant service and 1.5 WTE for business service, e.g. commissioning services.

Technical Support Services

Technical support services are as important as they have ever been within the service on account of more stringent quality standards and the renewed interest in home haemodialysis. The critical importance of this highly specialised area was underlined by a study by the Institute of Manpower Studies in 1992⁸⁶. Graduate training schemes for Clinical Technologists of the future are currently being developed by the Institute of Physics and Engineering in Medicine (IPEM). IPEM recognise the specialist nature of renal technology and are working with the Association of Renal Technicians (ART) to produce a suitable scheme.

5.7 Finance

To support the development of renal services there should be a clear financial support structure. This should include:

- A clear responsibility of the RSCG is to ensure allocation of funding aimed at achieving equity of provision and eliminating 'blank spots'.
- A uniform cost structure which allows RSCGs and commissioners to understand the costs of different services, modalities and methods of provision. This information should be freely available to providers of services and other local stakeholders.
- A system of benchmarking which allows Trusts to compare and contrast their costs and financial indicators with their peers.
- A clear process for targeting investment in services to implement the 7 National Service Standards for end stage renal failure.
- Clear guidelines from the RSCG regarding the funding and responsibilities for prescribing expensive medications including erythropoietin and immunosuppressant drugs.

5.8 Organisation of Services

5.8.1 Managed Clinical Networks and Shared Resources

The 'managed clinical network' is a new paradigm for clinical care. The concept was introduced with respect to cancer services in the Scottish Acute Services Review⁸⁷. It recommends the sharing of patients, expertise and resources rather than 'unidirectional centripetal flow' and connection and partnership rather than isolation and self sufficiency, on distribution of resources rather than centralisation. The important roles of nursing and allied professional staff are stressed. The concept may be applicable to renal services. While transplantation is the most obvious asset in renal medicine which must be shared, there are other areas of expertise which are not present in all hospitals which might be shared. Complex interventional radiology and some specialist urology services are other examples as is vascular and peritoneal access.

Technical cover, for example, is well provided in some renal centres but is not available in others. Some centres have highly developed nursing education which is also a resource that can be shared. It may be possible for expertise in different dialysis modalities to be concentrated in particular units. Home haemodialysis centred in one facility serving a Region would be one example of this. There is already an example in London of a private sector establishment training patients from several NHS hospitals for home PD and home haemodialysis. It is conceivable that while a new haemodialysis facility was developing in one centre, peritoneal dialysis services could be supplied by another. Taking the managed clinical network approach may provide a more flexible template for commissioners grappling with the need to redress inequities rather than having to choose between the extremes of hub and spoke and autonomous renal centres.

5.8.2 Infrastructure of Renal Centres

Typically an autonomous renal centre has an inpatient nephrology ward, an outpatient haemodialysis unit and a CAPD unit. Outpatient facilities may be integral or shared with the main hospital.

Dialysis Facilities

In purely structural terms, it is not very expensive to create a new haemodialysis unit. Dialysis machines, once an expensive purchase can now be leased as can water treatment equipment. Conversion costs of existing buildings usually equate to £1K per sq m and a new build £1.5K per sq m. Typically, 4.5 patients with ESRF are managed by one haemodialysis station. Some units who use their facilities more intensively support over 6 patients per haemodialysis station. A 15-station haemodialysis unit will typically occupy 500 sq m, of which a third will be treatment area, a third will be office/outpatient/training area and a third will be for stores and technical support. Storage required for disposable dialysis equipment is often under estimated. A 15-station renal unit will often require 40 sq m and may require a similar space available in the main hospital. Large volumes of sterile fluid are delivered to renal units, usually once or twice weekly in large vehicles. There are important considerations in deciding the locations of renal units.

The requirements for a satellite differ little but in some it is important to include integral outpatient facilities not only for review of dialysis patients but also for local nephrology referrals. Adequate waiting areas for patients and drivers are also necessary given that up to 50% of patients will be transport dependent. Since nurses and support workers tend to be recruited locally, education has to be decentralised from the 'hub' to some extent and there needs to be adequate training facilities.

Quiet areas should be available for counselling and dietetics advice. Finally, satellites need to have good road communications and good parking facilities. A typical 15-station satellite unit will fully utilise 20 car parking places during the main part of the day. CAPD requires discrete training areas and areas for examination / intervention and for patient education. Approximately 30 sq m storage space is required for an average CAPD unit. A CAPD unit adjacent to a nephrology ward is a popular configuration because of the nursing cross cover which is possible for patients who are staying in hospital whilst undergoing training.

Nephrology Beds

The recent Royal College of Physicians review of workload and manpower (Appendix IV) based on data from South Wales, Yorkshire and Newcastle recommends that 36 nephrology beds are required for a team of 6 WTE consultant nephrologists covering a one million catchment population. A facility also functioning as a Regional Transplant Centre requires an extra 8 beds per million population.

In October 1998, a Greater Manchester Renal Project was initiated to manage the change from 3 to 2 inpatient centres and development of the service across a conurbation comprising 13 DGH's and over 25 PCG's in 7 HA's. Detail work which was reported to the National Bed Enquiry recommended 50 nephrology beds and 6 high dependency nephrology beds for each 1.5m population base i.e. 37 beds per million catchment (O'Donoghue D - personal communication). Since approximately half the beds in a typical nephrology ward are occupied by dialysis patients with intercurrent problems, increases in these bed numbers need to be factored in as dialysis prevalence rates increase beyond current levels.

Outpatient Facilities

The Royal College of Physicians review 'Physicians Working for Patients' (Appendix IV) concluded that facilities for 1,800 new and 17,000 follow up consultations per year are required for a one million catchment area. The high number of follow ups results from the fact that the majority of patients diagnosed with renal disease are followed up 'for life'. The numbers include those approaching ESRF and those established on dialysis.

Most renal facilities have two or three general nephrology clinics each week and increasingly nephrologists undertake outreach clinics where there are satellite dialysis facilities and often in DGH's where there are no dialysis facilities. Given the difficulties in expanding the geographical space available for clinics, it is worth considering clinic rooms integral to renal units when new autonomous centres or satellites are being designed. Increasingly, medical staff are joined by nurses and paramedical personnel in outpatient clinics.

5.8.3 The Private Finance Initiative (PFI) and Private Provision of Renal Services

The use of private capital to facilitate the expansion of renal services first took place in Wales in the mid 1980's. At that time the commercial partners were inexperienced in provision of renal services and emphasis was on the acquisition of capital for buildings and machines. It is now ingrained into NHS planning that private capital can be, and is expected to be, sought for new projects which helps overcome the inertia inherent in the NHS where capital is in short supply. Although successive governments have been supportive of the Private Finance Initiative (PFI), privatisation of clinical services rather than buildings and equipment is much more politically contentious.

In the last decade, dialysis equipment manufacturers, in response to business opportunities in the USA and new opportunities in Eastern Europe and Asia, have transformed themselves into service providers. Through a series of acquisitions and mergers there are now a small number of large multinational providers of renal services. The largest, Baxter, Fresenius Medical Care and Gambro have been increasingly active in the UK and a significant proportion of dialysis facilities are now owned and managed by these companies (currently 25% of UK satellites are owned by companies). It has become the norm to provide the whole service including the employment and management of nurses, a model much preferred by the commercial providers.

The transfer of patient care to the commercial sector is likely to continue due to the influence and competitiveness of the large companies and the continuing difficulties in accessing capital in the NHS. Although it has not yet surfaced as a major issue, there are potential training, R&D and clinical governance implications when the management of a major part of the workload of a renal centre is taken over by a commercial company.



MILESTONES AND RESPONSIBILITIES

This final section sets out the timeframe for the structures to be put in place and for the delivery of the objectives described in Section 4. Since many of the recommended structures flow with the stream of change already taking place in the NHS, some of the timeframes are relatively short. This section also recommends the agencies responsible for the achievement of each milestone.

6 MILESTONES AND RESPONSIBILITIES

6.1. Regional

Milestones	Responsibilities	Timetable
Commissioning structure operational	RSCG	4/01
Baseline assessment of needs/gap analysis	RSCG	4/01
Regional Implementation and Investment plan	RSCG	4/01
Plan for Consultant expansion	RSCG	4/01
Establish monitoring system	RSCG	4/02

6.2. RSCG Priorities Reflected in Health Planning

Milestones	Responsibilities	Timetable
HIMPs (Health Improvement Programmes)	HAs	4/02
PCIPs (Primary Care Investment Plans)	PCG/Ts	4/02
SAFFs (Service and Financial Frameworks)	HA to PCT/Trust	4/02
Joint protocols for referral of chronic renal failure	PCT/Trusts	4/02

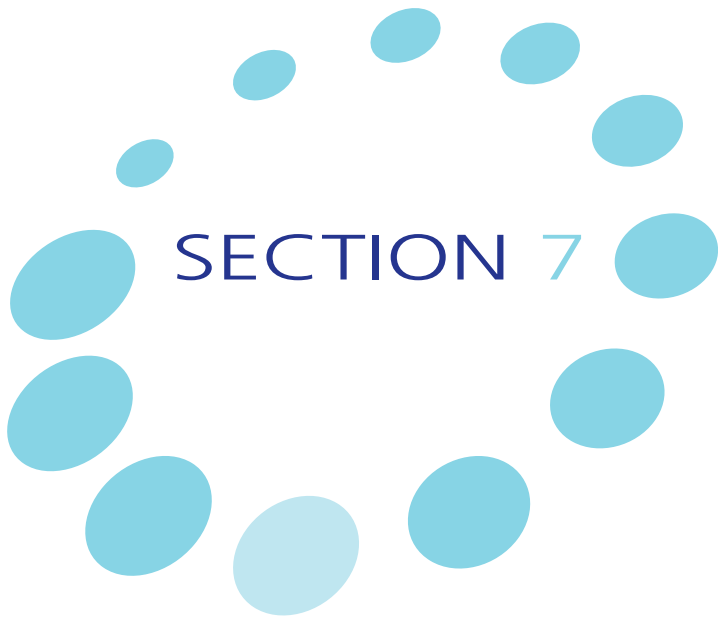
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6.3 Costings

Milestones	Responsibilities	Timetable
Agreement on template for costing ESRF	NHS Executive	4/02
Establish Benchmarking system for Trusts (25% take up)	RSCG	4/02
Guidelines on the responsibilities for prescribing erythropoietin and immunosuppressant drugs	RSCG	4/02

6.4 Information and Audit

Milestones	Responsibilities	Timetable
Link all renal facilities to National Renal Registry	RSCG	4/02
RSCG reporting framework in place including residence based acceptance and stock rates of RRT	RSCG	4/02
Audit information not available from Renal Registry. Define Audit Plan	RSCG	4/02



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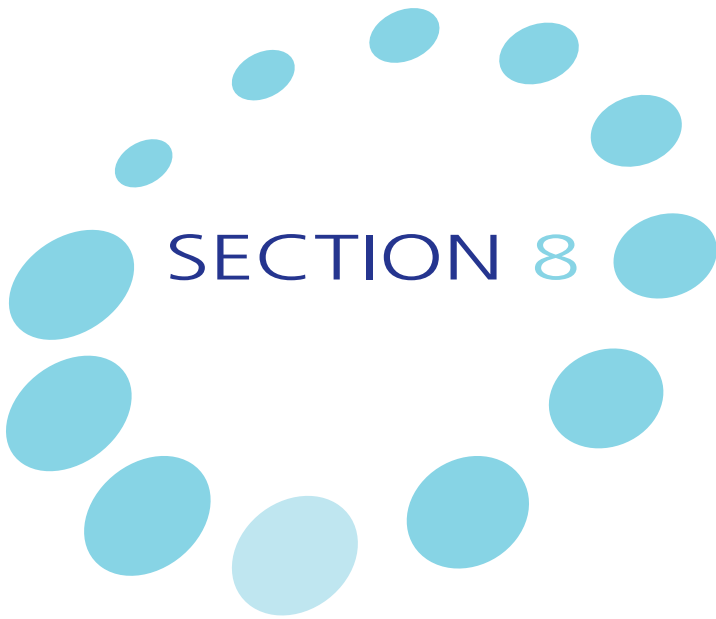
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SECTION 8

APPENDICES

APPENDIX I - ACRONYMS

ACE	Angiotensin converting enzyme
ACEI	ACE inhibitors
APD	Automated peritoneal dialysis
APKG	All Party Kidney Group
AVF	Arteriovenous fistula
CAPD	Continuous ambulatory peritoneal dialysis
CCST	Certificate of Completion of Specialist Training
CHD	Coronary heart disease
CRF	Chronic renal failure
DGH	District General Hospital
DOPPS	Dialysis Outcomes and Practice Patterns Study
EDTA	European Dialysis and Transplant Association
ESRF	End stage renal failure (sometimes end stage renal disease - ESRD - is used)
GP	General practitioner
HA	Health Authority
HimP	Health Improvement Programme
HD	Haemodialysis
KPA	Kidney Patient Association
Kt/V	A measure of dialysis efficiency (Clearance X time divided by Volume)
HCA	Health Care Assistant
HEFC	Higher Education Funding Council
IMT	Information, Management & Technology
MADEL	Medical and Dental Education Levy
MP	Member of Parliament
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NKF	National Kidney Federation
NSAID	Non-steroidal anti-inflammatory drug
NSF	National Service Framework

PAM	Profession allied to medicine
PCIP	Primary Care Investment Plan
PCG	Primary Care Group
PCT	Primary Care Trust
PD	Peritoneal dialysis
PFI	Private Finance Initiative
pmp	Per million population
pmp.pa	Per million population per year
PTFE	Polytetrafluoroethylene (Teflon)
R&D	Research and Development
RRT	Renal replacement therapy
RSCG	Regional Specialised Commissioning Group
RITA	Record of In Training Assessment
RN	Registered Nurse
SAC	Specialist Advisory Committee
SAFF	Service and Financial Framework
SHO	Senior House Officer
SIFT	Service Increment for Training
SLA	Service Level Agreement
SLE	Systemic lupus erythematosus
SpR	Specialist Registrar
STA	Specialist Training Authority
SWAG	Specialist Workforce Advisory Group
UK	United Kingdom of Great Britain and Northern Ireland
UKT	United Kingdom Transplant
UKTSSA	UK Transplant Support Service Authority (now replaced by UKT)
URR	Urea reduction ratio
VSSGBI	Vascular Surgery Society of Great Britain and Ireland
WTE	Whole time equivalent

APPENDIX II - ACCEPTANCE AND PREVALENCE RATES IN EUROPEAN COUNTRIES

Source: Locatelli F, Valderrabano F, Heonich N, Bommer J, Leunissen K, Cambi V. Progress in dialysis technology: membrane selection and patient outcome. *Nephrol Dial Transplant* (2000) 15: 1133-1139.

Note: these data were taken from the following sources for the year 1998: European dialysis and Transplant Association (EDTA) returns, Perilon database, The Registratie Nierfuncievervanging Nederland (RENINE), Membrana GmbH market research report. In 1998 only the Netherlands had a comprehensive national renal registry covering the whole country. The UK Renal Registry now covers over 50% of the country and will shortly be able to provide accurate prevalence data. Meanwhile the figures quoted here should be taken as an approximate guide. The comments are from the above authors.

GERMANY pop 81.7million	No. of Patients (% total)	PREVALENCE pmp	ACCEPTANCE pmp.pa	
Transplant	15,441 (24%)	189	30	Germany has the highest number of patients under treatment for ESRF in Europe. This is mainly due to the very large population of HD patients, supported with a strong transplantation sector, although the proportion of PD patients remains low at 5%. The number of new patients remains high for both HD and transplantation.
Dialysis (All)	49,239 (76%)	602	162	
HD	45,766 (71%)	560	145	
PD	3,473 (5%)	40	17	
All ESRF	64,640 (100%)	791	162*	

NETHERLANDS pop 15.5million	No. of Patients (% total)	PREVALENCE pmp	ACCEPTANCE pmp. pa	
Transplant	4,290 (50%)	277	29	Statistics for ESRF treatment are carefully documented in the Netherlands. The overall treatment rate is relatively low. Transplantation plays the largest part, although the new patient rate is only average. The PD sector is proportionately larger. HD has not developed as far as might be anticipated. Regulations do not allow private sector dialysis facilities.
Dialysis (All)	4299 (50%)	273	81	
HD	3,053 (36%)	197	57	
PD	1,246 (14%)	80	24	
All ESRF	8,589 (100%)	554	81*	

UK pop 58.6million	No. of patients (% total)	PREVALENCE pmp	ACCEPTANCE pmp. pa	
Transplant	15,689 (54%)	268	25	<p>The UK was one of the forerunners in Europe of ESRD treatment. However, in recent years there has been a lack of resources devoted to the therapy and thus, inadequate treatment rates have been noted. The previous high transplantation rate has decreased to below average. The HD sector has been neglected in favour of PD which until recently accounted for half of the patients on chronic dialysis. However, lack of long-term adequacy of PD has prompted an increase in HD facilities, although the number of new patients is still relatively low.</p>
Dialysis (All)	13,484 (46%)	230	87	
HD	8,162 (28%)	139	55	
PD	5,322 (18%)	91	32	
All ESRF	29,173 (100%)	498	87*	

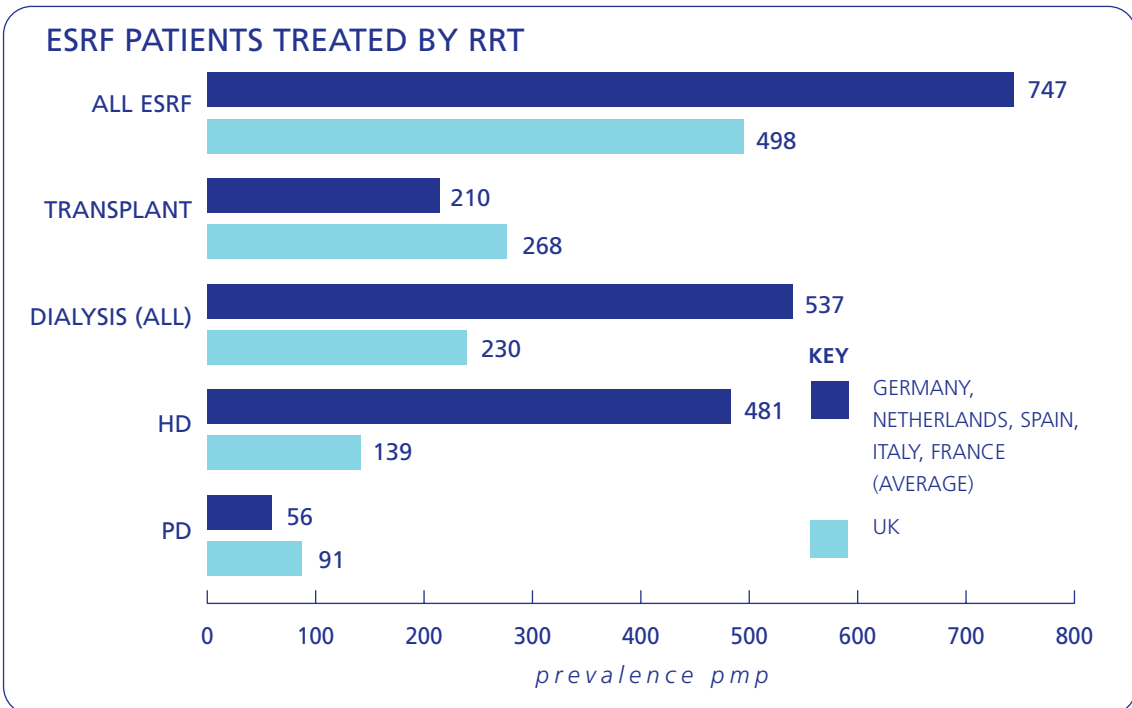
SPAIN pop 39.1million	No. of patients (% total)	PREVALENCE pmp	ACCEPTANCE pmp.pa	
Transplant	11,142 (39%)	285	45	<p>Spain has increased the treatment of ESRF in recent years and overall treatment and new patient rates are relatively high. Most notable is the large number of transplant patients and the continuing high number of new patients of 45 pmp, a result of the conscious decision some years ago to concentrate on organ replacement. HD therapy has been developed and the new patient rate is now similar to that in Italy.</p>
Dialysis (All)	17,804 (61%)	456	120	
HD	16,327 (56%)	418	104	
PD	1,477 (5%)	38	16	
All ESRF	28,946 (100%)	741	120*	

ITALY pop 57.7million	No. of patients (% total)	PREVALENCE pmp	ACCEPTANCE pmp.pa	
Transplant	9,856 (20%)	171	24	<p>The overall treatment rate (prevalence) in Italy for ESRD is the highest in Europe, mainly due to a high concentration on HD (at 593 pmp, this is even higher than that of Germany). This is augmented by a PD penetration rate of 11%. Whilst the transplantation rate is lower than average, the PD sector is more developed.</p>
Dialysis (All)	39,417 (80%)	683	130	
HD	34,214 (69%)	593	104	
PD	5,203 (11%)	90	26	
All ESRF	49,273 (100%)	854	130*	

FRANCE pop 58.1million	No. of patients (% total)	PREVALENCE pmp	ACCEPTANCE pmp.pa	
Transplant	12,255 (33%)	211	28	<p>France has a fairly high overall treatment rate of 634 pmp, predominantly from the HD sector.</p> <p>The overall new patient rate is not particularly high at 111 pmp. For HD, the new patient rate is 89 pmp, significantly lower than in both Spain and Italy.</p> <p>The transplantation rate is now only 28 pmp.</p>
Dialysis (All)	24,553 (67%)	423	111	
HD	21,950 (60%)	378	89	
PD	2,603 (7%)	45	22	
All ESRF	36,808 (100%)	634	111*	

	Germany, Netherlands, Spain, Italy, France Pop 252.1million		UK Pop 58.6 million	
	Patient No. (% total)	Prevalence pmp	Patient No. (% total)	Prevalence pmp
Transplant	52,984 (28%)	210	15,689 (54%)	268
Dialysis (All)	135,312 (72%)	537	13,484 (46%)	230
HD	121,310 (64%)	481	8,162 (28%)	139
PD	14,002 (8%)	56	5,322 (18%)	91
All ESRF	188,296 (100%)	747	29,173 (100%)	498

* To avoid double counting, acceptance for all ESRF includes only those taken onto dialysis since the majority of new transplants are accepted onto dialysis first



APPENDIX III - WORKFORCE PLANNING IN THE NHS

(Modified from: Davies, Health Service Journal, June 2000 6/00)

DOCTORS

Medical students

The medical workforce standing advisory committee decides how many medical students there should be. The Higher Education Funding Council (HEFC) of England and the NHS Executive set long-term targets for medical school student intakes. The General Medical Council and universities decide content of training. The education of medical students is paid for largely by the HEFC. The Service Investment for Teaching (SIFT) helps to provide the clinical facilities in teaching hospitals and DGH's used for student attachments.

Pre-registration House Officers

Postgraduate Deans identify and approve post-registration House Officer posts, with 100% funding coming from the Medical and Dental Education Levy (MADEL) which is held by the Deaneries.

Senior House Officer

Postgraduate Deans agree the number of posts, taking into account educational and service needs, keeping these in line with the needs of the Specialist Registrar grade. 50% of funding comes from MADEL and 50% from Trusts. SHO posts need educational approval from the Royal Colleges with training content set by the Specialist Training Authority (STA) of the medical royal colleges.

Registrars (GP or specialist)

Prospective GPs do one year's GP registrar training with content set by the joint committee on postgraduate training in general practice. Funding is 100% from MADEL and the distribution of GPs is controlled by the Medical Practices Committee.

Prospective consultants/hospital specialists train as Specialist Registrars for up to six years for a certificate of completion of specialist training (CCST), which qualifies them to apply for consultant posts.

Specialist Registrar posts are funded 50% from MADEL and 50% by the employing Trust, and are approved by the STA. The number and distribution of all registrar posts (including GPs) - which, in the case of Specialist Registrars are allocated as national training numbers - are decided by the Specialist Workforce Advisory Group. SWAG is a national body and is a sub-committee of the Advisory Group on Medical Education, Training and Staffing. Specialist Registrars can only stay in post for six months, or in exceptional circumstances 18 months, before gaining a consultant or other permanent appointment.

Consultants

Trusts advertise for consultants according to service need, with advertisements approved by the relevant royal college. Local Medical Workforce Advisory Groups, which are mainly regional, advise Trusts on their current and planned staffing levels. Education consortia, in theory, work through regional education and development groups to advise on numbers and types of doctors needed.

NURSES AND PROFESSIONS ALLIED TO MEDICINE

The focus of planning for all staff, including nurses and everyone from physiotherapists to laboratory staff and clinical psychologists, is at Trust level. For nurses, 'bottom-up' five year workforce plans from Trusts feed up to educational consortia, which then aggregate plans from Trusts and other employers, such as nursing homes and private hospitals. The consortia commission training on the basis of these plans, after the NHS Executive has decided final numbers of training places via regional offices, which collate consortium plans on their behalf. Training is funded from the non-medical education levy or, in the case of pre-registration pharmacists, the Higher Education Funding Council of England. For other staff, national advisory groups provide the 'top down' element of planning.

APPENDIX IV - FUTURE STAFFING REQUIREMENTS - CONSULTANTS

(Source: 'Physicians Working for Patients' Royal College of Physicians of London - draft 2000)

- Nephrology section based on detailed data from South Wales, Yorkshire and Newcastle provided to joint RCP (London)/Renal Association Committee.
- The report describes only the work in nephrology recognising that 60% of nephrologists also provide services in acute general medicine (GIM). Where this is the case the number of physicians required for the renal service is 1.4 x the number of WTE nephrologists.
- The report sets out the work generated by a population of 1 million.

PATIENT CARE

Inpatients

A team of 6 consultants will have responsibility for patients with newly diagnosed renal disease and patients with end stage renal failure either acute or chronic starting dialysis, patients admitted with complications of dialysis or transplantation and for vascular and peritoneal access surgery.

Outpatients

It is suggested that a consultant nephrologist can see 8 new nephrology patients or 15-20 follow up nephrology patients in a 3 1/2 hour clinic sessions (1 notional half day - NHD). He/she can see 6-8 patients for dialysis follow up or 14-16 patients for transplant follow up, or 12 pre dialysis patients.

It is suggested that a junior can deal with 50% the workload of a consultant and when present the consultant has to allocate time for supervision.

Procedures

The procedures and skills which consultants are expected to pass on to their juniors include renal biopsy and temporary vascular access.

On-call

Calls to other units and from outside the hospital are received both during working hours and out of hours. The average time to see a new acute referral is 45 minutes excluding the need for temporary vascular or peritoneal access.

SUPPORTING ACTIVITIES

These include:

- Teaching, training and audit
- Continuing professional development, clinical audit and clinical governance
- Research
- Administration
- Management
- Professional advisory work

FACILITIES NEEDED AND CONSULTANT TIME REQUIRED TO PROVIDE SERVICE TO 1 MILLION POPULATION

Inpatients

A population of 1 million requires 36 inpatient nephrology beds and an extra 8 beds per million population in regional transplant units. 12 NHD's are required per week.

Outpatients

There need to be facilities to accommodate 1,800 new nephrology patients and 17,000 follow up visits which includes patients on dialysis, transplanted or in the pre dialysis phase. New patients require 6 consultant NHD's weekly and the follow ups 35 consultant NHD's weekly.

DIAGNOSTIC AND THERAPEUTIC PROCEDURES

Renal Biopsy

The report estimates the need for 240 native kidney biopsies and 15 transplant biopsies per annum. In a transplant centre the need is 100 per annum (30 per million). Since some are undertaken by radiologists it is estimated that this work requires 1 NHD per week of consultant time.

Access for Dialysis

The report estimates the requirement for 100 AV fistulae and 50 peritoneal dialysis catheter insertions per year, 100 permanent central venous line insertions and 400 temporary central venous line insertions per million of the population per annum. These activities require 2 NHD's per week of consultant time.

On-call

Calls to other centres and departments amount to 700 per annum. This work consumes 3 NHD's per week. In addition, the management of critically ill patients in the ITU requires 2,600 visits per annum consuming 5 NHD's per week of consultant time.

SUMMARY

A total of 65 NHD's are required for patient care.

Most supporting activities have become mandatory. If 6 consultant nephrologists are employed to cover the 65 NHD's required for patient care (assisted by trainees, Staff Grade positions and an Associate Specialist), then 29 NHD's are required for supporting activities.

WORKFORCE REQUIREMENTS

The calculations outlined above indicate a need for 94 NHD's which would be satisfied by 9.4 WTE nephrologists. This would equate to 13.2 consultant physicians if the present pattern of 60% of consultants undertaking GIM (30% of their time) assists.

Approximately 27% of the total staff consist of trainees and in addition Staff Grades and Associate Specialists (typically one for each per million population served) also contribute. If trainees work at 50% of the rate of consultants then they would cover 40% of the work reducing the WTE requirement from 9.4 to 8.1. The Staff Grade and Associate Specialist would reduce the need further by 2 from 8.1 to **6.1 WTE per million population**. This gives a current need of 316 WTE consultants in nephrology for England and Wales.

There are only 164 WTE nephrologists. With the expected increase in workload in nephrology the requirement is estimated to be 390 WTE in 2006 and 439 WTE in 2010. These figures give a current need of 1 WTE nephrologist for 160,000 of the population and by 2004 1 WTE nephrologist per 130,000 of the population.

If calculated in terms of physicians involved in GIM then the current requirement is 442 physicians (1 per 117,000 population) increasing in 2004 to 546 physicians (1 per 95,000 population).

A growth rate of 11.3% per annum over the next 4 years is required to achieve these figures.

APPENDIX V - FUTURE STAFFING REQUIREMENTS - PROFESSIONS ALLIED TO MEDICINE (PAM'S)

(Source:

- 1 *Provision of Services for Adult Patients With Renal Disease in the UK; Royal College Of Physicians of London and the Renal Association, London 1991.*
- 2 *Renal Social Work Provision in the UK (draft). British Association of Social Workers, Renal Special Interest Group, June 2000.*
- 3 *Patient:Dietetic Staff Ratios in known Renal Centres in the UK. April 1999 update of 1996 Audit Report. British Dietetic Association, Renal Dialysis Group, 1999.)*

DIETETICS

In 'Provision of Services for Adult Patients' (1991), the RCP/RA 'blue book', it was recommended that 2 dietitians, a Senior 1 with assistance from a Senior 2 would be required for a typical renal unit with 200 patients on dialysis and seeing 70 new patients a year, i.e. a patient:staff ratio of 100.

This Kidney Alliance document records the increase in acceptance and prevalence rates for RRT since 1991 with an increase in the mean age and co-morbidity burden of patients with ESRF. These changes place greater demands on dietetic services. We also record the need to comply strictly with adequacy standards for dialysis to prevent under-dialysis and malnutrition. Dietitians are necessarily involved in this work. Phosphate control, necessary to maintain bone health, has become more difficult in the modern era owing to shortened dialysis times and the dependence on less toxic but less effective phosphate binders.

The Renal Dialysis Group of the British Dietetic Association (BDA) carried out an audit of dietetic staffing in 1996 and updated this to include patient:staff ratios in 1999. This was presented at the BDA-RDG meeting in May 1999. 63 units were approached and 61 replied giving a response rate of 98%. The results were as follows:

Dialysis Patients	No. Centres	Total Dialysis Patients	Dietitians WTE	Patient:Staff ratio
>400	4	2,172	11.7	186:1
300-399	7	2,601	22.0	118.1
200-299	17	4,165	29.9	139.1
100-199	20	2,928	26.9	109.1
<99	13	761	8.5	90:1
TOTAL	61	12,627	99.0	128.1

This shows that the patient:staff ratio exceeds that recommended in 1991 when the workload per patient was undoubtedly less.

More worrying is the large variation in access to dietetics expertise throughout the country. The patient:staff ratio varied between 50 and 274:1, i.e. a >5 fold difference in workload. Clearly significant resource will have to be invested in recruitment of dietitians in order to bring the patient:staff ratio down to 100:1 which should be regarded as an absolute maximum to achieve adequate service provision.

SOCIAL WORK

The RCP/RA (1991) 'blue book' recorded that the British Association of Social Work and the North Western Regional Health Authority had reviewed workloads and had independently concluded that 1 WTE social worker was needed per 100 standard risk patients on dialysis. Taking into account the fact that high risk (frail, elderly, diabetic, blind) patients and those with special needs require additional time and recognising that they constituted about half the dialysis population, it was recommended that a unit with 200 dialysis patients and 600 associated transplant and pre-dialysis patients should have 3 WTE social workers. They should be employed at Level 3 due to the complex nature of the work .

The Renal Special Interest Group of the British Association of Social Work (BASW) has recently expressed concern about the great variation in provision of services to patients with ESRF throughout the UK. In particular there are concerns about:

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- The rights of patients and their carers to access the service
- The adequacy of service provision
- The variation in funding arrangements and contracts of employment
- The problems caused by short term contracts
- The lack of continuity of service provision
- The part played by charities in funding this essential NHS service

The RSIG of the BASW undertook a survey of renal units between June 1999 and May 2000. 95 units were surveyed and the response rate was 92%. The following information was collated:

Percentage of Renal Units

- | | |
|---|-----|
| • having a specialist renal social work service | 76% |
| • having no specialist renal social work service | 24% |
| • having access to non specialist social work only | 14% |
| • having no social work provision at all | 10% |
| • Total number of specialist renal social work posts identified | 73 |
| • Full Time | 58% |
| • Part time (ranging from 3-30 hr/wk) | 42% |

The sources of funding have become varied partly because units seeking social work services have accepted that Local Authorities may not be able to provide the comprehensive specialist provision they require.

The following is the current situation regarding funding:

Local Authority	10
Health Authority	23
Industry	1
British Kidney Patients Association	16

BKPA/Health Authority	5
BKPA/Local Authority	5
Health/Local Authority	12
Local Authority/Renal Charity/Local KPA	3
Local KPA/Renal Charity	3
Local Authority/Industry	1

Of the 76% of renal units with a Specialist Renal Social Work provision, 38% of posts are supported by charitable funds. These are all short term contracts often introduced as 'pump priming' posts which it is intended that Health or Local Authority will take up - a strategy which does not always materialise.

37% of posts are joint funded in some way, again often on a short term contractual basis with no clear responsibility for the continuation of service provision. 60% of posts are temporary.

Contracts of employment for renal social work are held by Local Authority 81%, Health Authority 15% and industry 3%.

In conclusion,

- The provision of renal social work in UK renal units is patchy and inadequate in some areas.
- Some renal units have no access to social work provision at all
- The large number of posts funded from charity is a cause for concern in this speciality which is of critical importance to the well-being and rehabilitation of patients with ESRF.
- BASW conclude that NHS resources should be made available to fund social work posts in the numbers that are required.
- BASW supports continuation of the arrangement where employment contracts are held by Local Authorities.

The Kidney Alliance notes that the current ratio of dialysis patients:staff of approximately 175:1 greatly exceeds the recommendations made in 1991 (RCP/RA) for a 70:1 ratio despite the increase in the proportion of patients requiring support. Elderly and disabled patients, in particular, will not be able to access the quality of service they require unless their poor staffing levels are reversed to approach towards the 70:1 patient:staff ratio.

Social work appears to be one of the most severely under-resourced areas in the renal service with staffing levels falling far short of those required to provide an adequate service. We cannot hope to achieve some of the key National Service Standards particularly NSS's 2, 5 and 6 detailed in this document unless there are more resources.

NOTES