The Renal Team
A Multi-Professional Renal Workforce Plan
For Adults and Children with Renal Disease

Recommendations of the
National Renal Workforce Planning Group 2002

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Renal Association • British Association for Paediatric Nephrology • National Kidney Federation
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British Psychological Society • Association of Renal Technologists • Renal Pharmacy Group
Neonatal & Paediatric Pharmacist Group • Association of Renal Managers
and the Society for District General Hospital Nephrologists.

BRS Mission Statement

The British Renal Society (BRS) is a multiprofessional group created to improve standards of care for renal patients and their families. The BRS provides a forum for the discussion and dissemination of knowledge in the area of renal care.
The BRS is a charity registered with the charity commission for England and Wales and has a primary mission of

- The promotion of good multi professional care for people with renal failure and their families and carers.
- The advancement of education in the area of renal disease and replacement therapy in the UK.
- The provision of funding and facilities for research in the field.

Recommendations for Renal Workforce Planning

Foreword

The British Renal Society established a multi-professional National Renal Workforce Planning Group in January 2001 to prepare recommendations for establishments and staffing levels across each professional group involved in renal healthcare.

This report covers the whole range of specialist renal services including the provision of children's renal services and renal transplantation. The professional staffing recommendations are made for the United Kingdom. They are intended to complement the Renal National Service Framework (NSF) and the Children's National Service Framework for England and the renal standards plans and guidance in Scotland, Wales and Northern Ireland. In addition a workforce plan based on the demand forecast produced for the NSF is included. It is hoped that sufficient information is available to inform local workforce development confederation planning and planning for Scotland, Wales and Northern Ireland.

Patients with renal disease require the management and support of many different healthcare professionals and social service agencies throughout their renal 'journey'. Multi-professional team working is a key theme running through the recommendations enclosed in this report. Integrated working between the renal healthcare professionals, close working relationships with primary care teams and liaison with other healthcare teams and outside agencies is essential for the delivery of high quality renal care. This requires the sharing of skills and competencies between different members of the multi-professional team within the regulatory and accreditation framework. The working party recognises the different models of team working that are in place and the report highlights the need to consider local circumstances and flexibility if equity of access to services and continuous improvement in outcomes is to be achieved.

The purpose of this document is to provide a robust renal workforce plan to support the implementation of the Renal National Service Framework and renal plans for Scotland, Wales and Northern Ireland. It is intended to be of value to:

- The renal community of healthcare professionals, patients and carers, Primary Care, Social Services and external agencies that constitute the individual teams managing renal patients.
- The Workforce Development Confederations, care group workforce teams and commissioners of renal services to inform strategic planning of the renal workforce and assist in the development of a National Renal Recruitment and Retention Strategy.
- Organisations involved in the development and management of renal services based upon patient pathways including Primary Care Trusts; secondary care providers, the emerging renal networks and commercial companies providing renal services.
- The Long Term Conditions Care Group Workforce Team and its Renal Workforce Group in developing the Renal Workforce.

This report should be considered with the Renal National Service Framework, which is a 10-year plan. Renal services are changing, patients' public and professional expectations are increasing and the renal population continues to grow. There is an ongoing technological revolution and working practices are rapidly evolving. There is a need for a regular workforce census, dissemination of evidence based innovative practice and integration of individual professional groups' recommendations into a workforce plan based upon the team skills and competencies required for the management of patients with renal disease. The renal workforce requirements should be regularly reviewed and updated both locally and nationally to ensure that we have the right people, with the right skills in the right places at the right times.

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EXECUTIVE SUMMARY

The report, produced by the renal community, is intended to provide advice and guidance on the workforce requirements to care for adults and children with renal disease. An efficient and effective renal service requires integrated multiprofessional and multi-agency working. The report recommends coordinated planning of the clinical and psychosocial resources required by renal patients.

The wellbeing of many patients with established renal disease by the provision of dialysis and transplantation is one of the remarkable achievements of modern medicine. In the UK, however, there has been historical under provision for renal patients. Although satellite dialysis has increased in the last decade, regional variations remain marked. In many parts of the country the availability of staff with the required skills and competencies is now a limiting factor.

There has been a rapid and sustained rise in the number of adult patients treated with renal replacement therapy (RRT) over the past 2 decades. The acceptance rates, especially in the old age groups continue to rise but remain low in England compared to Scotland and Wales; and low in the UK compared to other European countries. An increasing proportion of patients have associated comorbidities, particularly diabetes and vascular disease. Population projections show that growth will continue until at least 2030. The UK Transplant plan hopes to nearly double transplantation rates but even with this initiative the main workforce requirements will be in maintenance haemodialysis.

The number of children on renal replacement therapy has more than doubled since 1986. The majority have functioning transplants. The complexity of these patients has increased requiring additional clinical skills and support. This report also highlights the psychosocial and educational needs of these patients to support their maturation and growth. Despite the increase, paediatric renal services remain low in volume. The organisation of these services needs to be balanced between the minimum size of the centre to retain expertise against geographical accessibility.

Providing the right staff with the necessary skills in the right place at the right time is a particular challenge for renal services. The guidance in this report is based on the needs of patients and the skills required to deliver them. The need for flexibility and new ways of working to make the best use of skills and knowledge is recognised.

A patient's 'journey' with renal disease can span many decades. High quality care and efficient use of resources throughout this journey require a seamless service. Patients require access to and support from the whole range of renal healthcare professionals and primary care practitioners to differing degrees at differing times and stages of evolution of their renal disease. The importance of involving renal patients and their carers in the planning and delivery of their service has previously been underestimated. The impact of renal disease on patients, families and carers needs to be freely acknowledged. The development of expert patients requires more than providing information and education for patients. Delivery of renal healthcare should be in partnership with empowered patients playing a central role in how their illness is managed. This has implications for workforce requirements and priorities.

Coordinated service delivery requires an integrated multiprofessional team with the range of skills, competencies and responsibilities to manage patients throughout their journey of care and to minimise the institutional, professional and geographical barriers to the timely provision of appropriate care. The placement of vascular access, provision of rehabilitation after commencing dialysis and support during the transition from paediatric to adult services are 3 examples where an integrated approach provides real benefits for patients.

The roles and responsibilities of the individual professional groups within the renal teams is outlined in sections 3 and 4. These sections also provide detailed census information on the current workforce and updated workforce guidance. The workforce plan in section 5 takes account of changing patterns of work, increasing complexity and the demand forecast produced for the National Service Framework in England. Workforce requirements for England and the whole United Kingdom are given. It is assumed that the European working time directive will be implemented and the key assumptions in calculating the renal workforce requirements to 2010 for each professional group are explicitly stated. The plan highlights the need for an increase in specialist renal practitioners and the changing pattern of skills and competencies required.

The report also identifies current gaps in service provision e.g. clinical psychology, pharmacy. Barriers to change are identified e.g. social work funding and the need to develop a competency based registration framework for renal clinical technologists. Of necessity, some of the recommendations are based on incomplete evidence and there are gaps in our knowledge about the renal workforce that should be addressed in future planning cycles. The table below summarises the specialist renal workforce requirements for the United Kingdom to 2010 for adult practitioners in absolute numbers. A more detailed breakdown by England and the United Kingdom current, 2006 and 2010 requirements in both absolute and whole time equavalent (wte) requirements can be found in tables 5.1.5 (a) and (b).

Summary of Adult Renal Workforce requirements for the United Kingdom Total Number of Practitioners

	Adult		
	2001 Establishment	**Current Requirements**	**2010 Requirements**
Renal Physicians	290	512	803
Renal Transplant Surgeons	81	130	130
Renal Transplant Donor Coordinators	87	87	144
Renal Histocompatibility Scientists			
Consultant Scientists	14	48	75
Healthcare Scientists	252	468	734
Renal Dietitians	180	464	738
Renal Social Workers	73	356	555
Renal Clinical Psychologists	7	106	168
Renal Clinical Technologists	225	272	583
Renal Pharmacists	97	425	669
Renal Administrators & Managers	65	165	312
Nurses			
Haemodialysis	2330	2127	4223
Peritoneal dialysis	250	312	524
Ward based (Renal & Transplant)	1834	2958	4760
Healthcare Assistants			
Haemodialysis	876	1441	2860
Peritoneal dialysis	51	65	109
Ward based (Renal & Transplant)	746	1228	1978

The detailed paediatric renal workforce requirements can be found in section 4 and section 5.2.1. the table below summarises the requirements for Paediatric Nephrology, psychologists, play specialists and allied health professionals. Nurses and teachers are not included. With regards to the former detailed standards have been developed for every stage of treatment, both in-patient and out patient. How this translates into numbers for individual units depends on a number of factors including the size and stage of development of the unit. For education services there are many different ways of providing the service, thus defining the service requirements rather than precise work force numbers are important.

Summary of Paediatric Renal Workforce wte requirements for the United Kingdom

	Current workforce	Projected requirements
Paediatric Nephrologists	37.8	72
Dieticians	10.9	25.1
Pharmacists	4.5	31.4
Social workers	10.4	25.1
Psychologists	6.1	12.5
Play Specialists	NK	31.4

The report identifies future work. There is a need to more accurately identify and define the skills and competencies required to manage patients with renal disease at various points along the patient pathway. The detailed workforce implications for non-renal specialist healthcare staff such as histopathology, interventional radiology and virology need to be identified. The requirement for information technology specialists at the unit level needs to be quantified. Currently the rehabilitation needs of renal patients are not adequately quantified. The wider healthcare and workforce implications for both primary care and specialist renal healthcare professionals of early detection of renal disease and implementation of strategy to retard progression and achieve a "preventative dividend" need to be quantified. The National Renal Workforce Planning Group recommends a tri-annual census and review to inform future workforce planning cycles.

We recommend that a national recruitment and retention plan for renal healthcare practitioners is developed in collaboration with the Workforce Development Confederations and as part of the renal NSF implementation strategy in England and the parallel arrangements in Scotland, Wales and Northern Ireland. Local workforce plans should in addition take account of the clinical, cultural and social complexity of their client group. The configuration of renal services, demography, geo political factors, maturity of the renal unit and local factors all need to be considered in regional and individual unit planning.

SECTION ONE

INTRODUCTION

Section 1 Introduction

1.1 The main impetus behind this report was the Kidney Alliance document "End Stage Renal Failure – A Framework for Planning and Service Delivery"[1] that proposed 7 national service standards aimed at improving the quality of renal care and reducing the burden of renal disease. The Kidney Alliance highlighted the multi-professional nature of renal healthcare, the increasing prevalence of renal replacement therapy and the importance of workforce planning.

1.2 Renal disease is a lifelong condition for the majority of patients. Care, support and treatment should be compatible with patients' overall lifestyle and maximise rehabilitation into society. The NHS Plan[2] places the patient at the centre of service design and delivery. The focus of this report is the provision of patient and carer centred services delivered by the multi-professional team throughout the patients' journey of care.

1.3 This report collates the current guidance and workforce planning across each professional group. It also considers the national drivers for change on national workforce planning. The changing clinical demography including the high rates of renal disease in ethnic communities, evolving models of service and the demand forecast for renal services have been reviewed to inform activity projections.

1.4 The National Renal Workforce Planning Group was convened by the British Renal Society and its affiliated organisations representing the whole renal healthcare professional community. The group also contains experts in clinical epidemiology, human resources, management and commissioning. The Department of Health has observer status via its renal team. The report has been produced under the auspices of the Royal Colleges of Nursing, Paediatrics and Child Health, and Physicians with the support of the renal professional societies and the National Kidney Federation representing renal patients.

1.5 A patient's 'journey' with renal disease can span many decades. High quality care and efficient use of resources throughout this journey require a seamless service. Patients require access to and support from the whole range of renal healthcare professionals and primary care practitioners to differing degrees at differing times and stages of evolution of their renal disease. The various components of the renal team and of the renal service should not be viewed in isolation. This workforce planning document therefore covers all aspects of renal healthcare for both children and adults. The recommendations herein assume close working arrangements between renal services, transplant teams and primary care teams based upon patient pathways and shared responsibilities.

1.6 This report builds upon the workforce recommendations in "Provision of Services for Adult Patients with Renal Disease in the United Kingdom" 1991[3], "The Provision of Services in the United Kingdom for Children and Adolescents with Renal Disease" 1995[4] and the "Report of the Working Party to Review Organ Transplantation" 1999[5].

1.7 The complexity of renal healthcare requires integrated multiprofessional and multi-agency working to provide a high quality service. This requires co-ordinated workforce planning and a multi-professional approach to such issues such as patient education, modality choice and rehabilitation. For example, early placement of vascular and peritoneal access avoids emergency insertion of catheters and hospitalisation. This requires co-ordination of theatre lists and adequate time to allow for access maturation. Similarly, rehabilitation after commencing dialysis often requires social work, occupational therapy and physiotherapy working with the clinical members of the renal teams and community agencies.

1.8 Renal and transplant services began to be established in teaching hospitals from the late 1960s onward but there remained fewer than 60 renal units up to the end of the 1980s. In the past decade, renal services have begun to be de-centralised. However the roles of renal healthcare are still not widely understood by many non-renal professionals. It is important that this educational gap is addressed to aid the introduction of preventative strategies and improved services for patients with established renal failure. Multi-professional education by renal professionals and education for renal healthcare workers should be incorporated into the jobplans of renal teams.

1.9 Renal services for children have developed over a similar time period. The incidence of renal failure in children is much lower than in adults and this had led to a different, more centralised pattern of care. The balance between the minimum size of population necessary to maintain expertise against accessibility and geographical restrains has resulted in a small number of regional units[4].

1.10 The National Renal Review conducted in 1992[6] and the subsequent surveys in 1995[7] and 1998[8] continue to show unequal access to care and unacceptable variations in the renal workforce. However the building blocks for continuous quality improvement including The Renal Association[9] and British Transplant Society[10] initiatives on clinical standards and audit and the Renal[11] and Transplant[12] Registries are, however, in place to support local delivery of renal care.

1.11 The importance of academic training opportunities and the invaluable contribution that academic medicine has brought to renal healthcare including long term survival on dialysis, correction of renal anaemia and advances in transplantation highlight the benefits of supporting academic career progression. The evidence base to improve the services for patients with renal disease can only be acquired by investing in a renal workforce that will continue to contribute to basic renal research, implementation of applied research findings and further development of renal health services research.

1.12 Each of the professional groups has reviewed basic factual information on current staffing and activity levels to support the workforce recommendations. Information has been collected from across the United Kingdom and the information has been collated and analysed by each profession. The Workforce Plan is based upon this work, and on the NSF renal demand forecast.

1.13 The views and opinions of the whole renal community have been sought in workshops, via an interactive dedicated website (www.britishrenal.org) and at both uni-professional and multi-professional meetings including the British Renal Society Annual Conference. The recommendations have been developed by this iterative process. Care has been taken to ensure the recommendations contained are realistic, evidence based and achievable at acceptable cost.

1.14 The NHS Plan specifically emphasises the need to increase the flexibility of the workforce, to review skill mix and the importance of breaking down old tribal barriers both within and between professions[2]. Many of the new roles for the healthcare workforce challenge traditional healthcare thinking and raise organisational, professional, human resource and regulatory questions that must be addressed. Many of these issues are considered in "Skill Mix and the Hospital Doctor, New Roles for the Healthcare Workforce" report from the Royal College of Physicians in London in 2001[13].

1.15 Telemedicine links for video consultations, imaging and laboratory data also enable

specialist staff to be involved in discussions with patients and carers from a distance. In many instances this will allow more expeditious advice than could be offered through traditional clinical arrangements.

1.16 "A Health Service of All the Talents" 2000[14] recognises that in the past, workforce planning was not built around service needs and the skills required to deliver them. It aims to build a modern and dependable health service, providing a fast and responsive, high quality service. "Working Together – Securing a Quality Workforce for the NHS" (HSC 1998/162,220998)[15] and "Improving Working Lives" (HSC 1999/218,240999)[16] emphasised the need for modern employment services and the importance of personal professional development.

1.17 This guidance has provided the framework for the Renal Workforce Planning recommendations. The provision of excellent and equitable treatment of renal disease in the UK does require an expansion of the workforce to meet future demands but there is also a need to maximise the contribution of all to standards of patient care and to ensure flexibility to make the best use of skills and knowledge. We recognise that the renal multi-professional team can share skills and can transfer some competencies across professional boundaries. We expect that the Renal Skills for Health Project will identify these relationships further.

1.18 "A Health Service of All the Talents"[14] recommends "thinking about services, workforce and resources together to ensure plans and developments are consistently co-ordinated". The recommendations in this document should therefore be considered with the Renal National Service Framework Standards and Implementation Strategy[17]. This document has utilised the same demand forecast and activity projections of the NSF in an effort to ensure consistency in planning. The report does, however, recognise the different models required in varying geographical locations, flexibility necessary to respond to local circumstances and the variation in workforce requirements depending on the maturity of the particular renal service.

1.19 Primary care services are responsible for detecting and managing early renal disease[1]. The primary care service needs ready access to an adequately staffed and resourced specialist team[18]. It is essential that both of these be well integrated with agreed roles, responsibilities and referral criteria to access specialist advice with an agreed system of audit and evaluation based on patient pathways. This work should also identify the skills and competencies required to manage particular conditions.

1.20 The level of primary care service required in a particular locality to ensure that the provision of renal care reaches the recommended standards will vary. It may be determined by factors such as the incidence and prevalence of renal disease in the local population, the stage of development of local diabetes and cardiovascular disease registries and services and the renal care pathways developed between specialist renal services and local Primary Care Trusts. The pattern of service provision may therefore vary from locality to locality, particularly in the proportion of patients relying entirely on the specialist service, those receiving their planned follow up by General Practitioners and their staff and those receiving "shared care".

1.21 The realisation of a "preventative dividend" and optimal therapy in established renal failure is predicated on developing a successful partnership between patients and carers, primary care and the renal team. Detailed workforce recommendations for non renal specialists have not been made in this report. Further work to develop such recommendations should

be considered in the context of the implementation plan for the National Service Framework 3rd module which includes general nephrology.

1.22 The National Service Framework provides a 10-year plan for England but this workforce planning document recognises that the renal workforce is largely trained within the United Kingdom, the professional regulation spans our national boundaries and that many specialist renal staff move between the countries of the United Kingdom. The development of the Renal NSF and adoption of similar standards and arrangements in Scotland, Wales and Northern Ireland, provides the opportunity to integrate this workforce plan with the needs of patients and carers. The Wanless Report recommended an increase in funding of renal services of £370 million per year by 2010/11 to deliver the renal NSF[19].

1.23 Of necessity, some of the recommendations are based on incomplete evidence and there are gaps in our knowledge about the renal workforce and the roles and responsibilities of renal healthcare professionals in different settings. The impact that expert patients will have on working practices is not known. There is a need to address this gap in our knowledge and we recommend tri-annual reviews of the renal workforce plans on the basis of robust census data and the implementation of evidence based innovative practice supported by health service research findings. This report should provide a foundation for the development of a national renal recruitment and retention strategy.

1.24 Renal healthcare requires close collaboration between renal teams, primary care and other specialist services, particularly renal histopathology, imaging and specialist immunology. In the early phase of renal disease, many patients are jointly managed with diabetes or urology services. Renal failure has complications in every organ system. There is a high incidence of cardiovascular disease, infectious complications and psychiatric morbidity. Social and psychological care needs are currently poorly met. Rapid access to professionals with an understanding of renal healthcare and coordinated management of these complications is highly desirable. We have not examined in detail the workforce requirements of these other specialities.

1.25 The future renal workforce needs to be planned by the Workforce Development Confederations that were established in 2001 and are responsible for Integrated Workforce Planning Across all Healthcare Related Disciplines[20]. This co-ordinated planning needs to be based upon service priorities and linked to other initiatives such as the development of patient pathways to define the skills and competencies required at different phases of illness. Workforce plans for each profession need to provide for continuing professional development if we are to achieve a streamlined, flexible renal workforce working across professional and organisational boundaries.

SECTION TWO

CONTEXT FOR CHANGE FOR ADULT RENAL SERVICES

Section 2 Context for Change for Adult Renal Services

2.1 The History of Renal Service Provision

2.1.1 Modern renal healthcare began in 1960 when technological advances in vascular access established haemodialysis as a life-saving treatment for chronic kidney disease (CKD)[21]. In the UK a national renal network of hospital dialysis units was proposed but service developments lagged behind the rest of Europe and North America[22]. This failure to provide sufficient hospital based services stimulated the development of home haemodialysis in the 1970s[23] and peritoneal dialysis in the 1980s[24] but acceptance rates onto renal replacement therapy, particularly for the elderly remained low[25].

2.1.2 The first successful renal transplant, between identical twins, was reported in 1951. Subsequent development of immuno-suppressive drugs enables transplantation from cadaveric unrelated donors. In 1969, the first year in which statistics are available, 138 renal transplants were performed in the UK[26]. Since then, the renal transplant waiting list has continued to rise inexorably although the proportion of all the end stage renal disease (ESRD) patients in the UK with a functioning graft remained around 50% until the mid 1990s[11].

2.1.3 A review of services in England and Wales in 1975 estimated a need for nearly 8000 dialysis places and 1500 transplants per year. The actual rates were 1900 dialysis patients and only 542 transplants. Marked regional disparities were highlighted. In 1984 the Minister for Health urged Health Authorities to devote more resources to the treatment of end stage renal disease, setting a target for the regional health authorities to accept at least 40 new patients per million of the population (pmp) each year by 1987. Between 1980 and 1990 the acceptance rate onto renal replacement therapy programmes rose from 24.6 pmp per year to 60.7 pmp per year, substantially short of the minimum estimated need in the UK of 80 pmp for the population under the age of 18[27].

2.1.4 The National Renal Review conducted in 1992 again highlighted regional variations in acceptance rates for dialysis and transplantation rates resulting in the issue of national renal purchasing guidelines in 1994[28]. The number of satellite dialysis units doubled between 1993 and 1998[8]. The proportion of patients on hospital and satellite haemodialysis has continued to rise and the proportion on the peritoneal dialysis modalities has fallen to 31% of all dialysis patients in the UK[29]. The proportion of end stage renal failure patients on home haemodialysis is less than 2% in the latest published figures[30] but may increase if the purported advantages of daily haemodialysis are confirmed and following the National Institute of Clinical Excellence Guidance that all potentially suitable patients should be offered the choice of home haemodialysis[31]. The latest UK Renal Registry Report reports that the percentage of patients with a functioning transplant is falling and, despite the increased resources for dialysis, current acceptance rates of around 90 pmp per year still fall behind the perceived need[30].

2.1.5 The funding of renal services was formerly through central allocations but this process changed in the early 1990s to be more locally determined through the commissioning process in order that local health economies agreed overall service priorities for the populations they serve. The commissioning of renal services is guided by the fact that they are defined as specialist under the Specialised Services National Definition Set[32]. This recognises the relatively low volume but complex and costly nature of renal healthcare. Planning and commissioning should therefore be undertaken for a population larger than that of an individual Primary Care Trust (PCT)[33]. In many areas, lead purchaser, and later commissioner arrangements, were developed whereby an individual Health Authority led in commissioning particular services on behalf of the other Heath Authorities in a given region or geographical zone.

2.1.6 This arrangement has now been replaced by lead PCTs being identified and the development of PCT Collaborative Commissioning Groups, which are guided strategically by the newly formed Strategic Health Authorities in overall planning assumptions and performance review[34]. They are also overseen by the Regional Specialised Commissioning Groups (RSCG) through this transitional period. Commissioning agreements for renal services should not only reflect what is currently being provided but should also recognise strategic objectives for the service and commit to longer term financial investment in order that future demand can be met[35].

2.2 Previous Workforce Recommendations

2.2.1 "Provision of services for Adult Patients with Renal Disease in the United Kingdom" published in 1991 by the Royal College of Physicians of London and the Renal Association[3] highlighted the grave shortage of both specialist renal staff and renal facilities. It defined the specialist renal services required for the diagnosis and management of renal disease, provision of dialysis treatment and renal transplantation for those with end stage renal failure and temporary renal support for those with acute renal failure (ARF).

2.2.2 The report identified the treatment facilities required, gave estimates of patient numbers, suggested policies for the organisation of renal services and specified some of the key supporting services.

2.2.3 The multi-professional nature of renal healthcare was recognised. Detailed estimates and recommendations for the medical, nursing, dietetic and social work requirements to manage renal failure services were made. Staffing implications for technicians, business managers, secretaries, Information Technology (IT) support and transplant co-ordination were also noted. These recommendations are summarised in table 2.2.3.

Table 2.2.3
Recommended staff requirements in 1991 for an acceptance rate of 80 new patients pmp per year[3]

Medical	Consultants	330 (150wte)
	Trainees (Registrars and Senior Registrars)	160
Nursing	Renal Wards	1 wte/bed
	Acute dialysis/post op transplant	5.8 wte/bed
	Maintenance dialysis	2.4 wte/2 stations per 12 hours
	Home HD training	3.6 wte/2 stations per 12 hours
	CAPD home support	1 wte/50 home patients
Technical	Sufficient to provide for a 6 day working week and out of hours cover	
Dietetic	2 dietitians (senior 1) with assistance from a dietitian senior 2 per 200 dialysis patients	
Social Work	3 wtes per 200 patients on dialysis	
Business Manager	At least 1 per unit	
Secretarial	1 wte per consultant Plus 1 wte per 100 dialysis patients	
Computing	1 computer manager and staff/unit	
Transplant co-ordinators	At least 2 per transplant unit	

Source: Provision of services for adult patients with renal disease in the United Kingdom

2.2.4 These recommendations, together with the evidence from the National Renal Review[6], formed the basis for adult renal service planning in the 1990s but the predicted growth in total numbers of patients requiring renal replacement therapy proved to be an underestimate[30]. The staffing requirements were based on an annual acceptance for end stage renal disease replacement therapy of 80 new patients per million population per year and did not predict the advances that have enabled an increasing proportion of high-risk patients to benefit from dialysis.

2.2.5 The recommendations for physicians have been revised in "Consultant Physicians Working for Patients" (2001)[36]. Those for other specialist renal healthcare professionals have not previously been updated. In addition both the nature of renal healthcare and a pattern of working have changed considerably over the last decade. The renal multi-professional team has grown and includes pharmacists, psychologists, counsellors and other allied healthcare professionals. The provision of renal healthcare continues to evolve, for instance vascular access radiology has recently emerged as a key component of a modern renal service.

2.3 Changing Demography and Patient Projections

2.3.1 There has been a rapid and sustained rise in the number of patients ('stock') treated with renal replacement therapy in England; at the end of 2000 the rate was estimated to be 554 per million population (pmp)[30]. A review of the Renal Association Clinical Directors Forum in December 2001 identified a RRT stock of 31201 in England and 38082 in the United Kingdom (Table 2.3.1). The main driver to this growth has been a rising acceptance rate, particularly in older age groups: this was only 20 pmp in 1982 but had reached over 90 pmp by 2000[37]. Similarly there have been significant changes in the co-morbidity of patients accepted onto RRT; this is illustrated by changes in the proportions with diabetic ESRD, which rose from 2% in early 1980s to 16% by 2000.

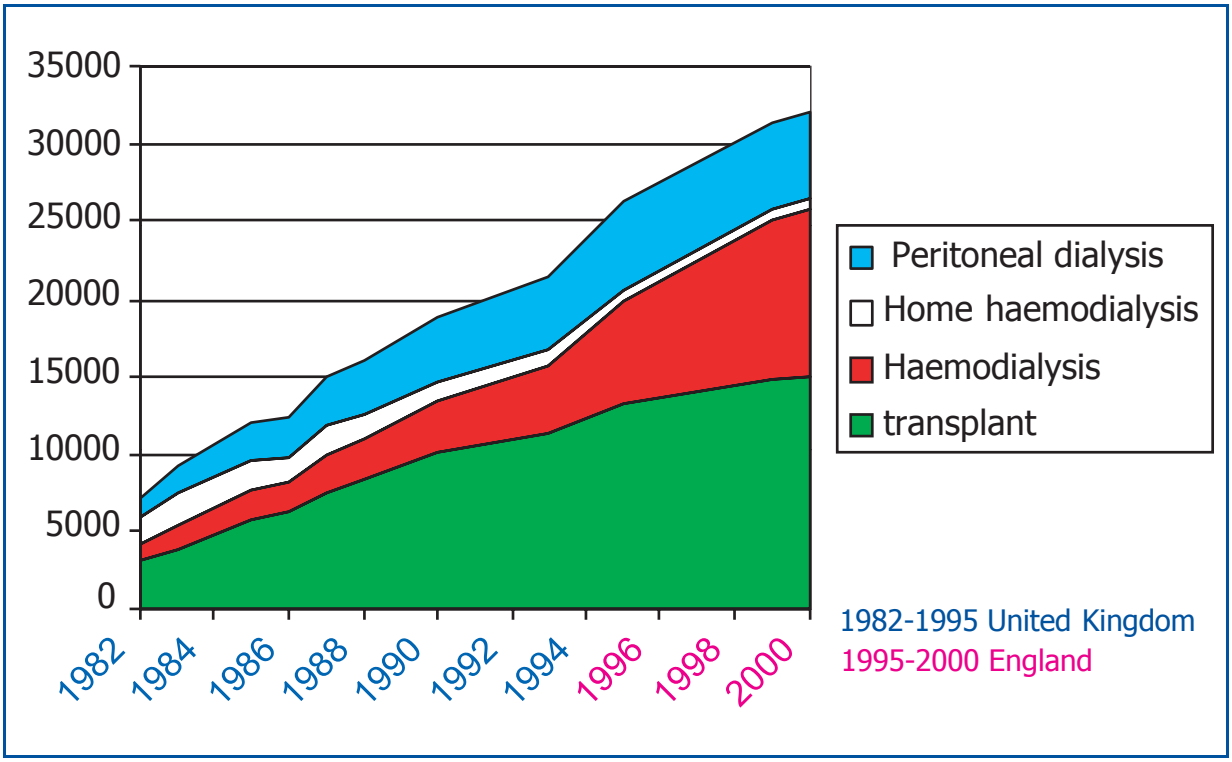
Table 2.3.1
Total numbers of Patients on Renal Replacement Therapy in 2001

	England	United Kingdom
Total Dialysis[29]	15,801	19,082
Peritoneal dialysis	5,034	5,846
Haemodialysis	10,767	13,236
Transplant[38]	15,400	19,000
Total RRT	31,201	38,082

2.3.2 Changes in patient survival, the other factor that could potentially have increased the stock, have been harder to document in England. There is some evidence from the USA on improvements in the early 1990s, which stabilised by the latter half. The rise in acceptance rates is thought to mainly rise from more liberal referral and acceptance policies, which has been documented by periodic attitudinal surveys of physicians and nephrologists. Other factors, which are harder to discern, are better detection of chronic renal impairment, the ageing of the population and trends in Type 2 diabetes.

2.3.3 The pattern of different modes of treatment has also changed significantly in the 1990s. With the falling cadaver organ supply, transplantation, whilst rising in absolute terms has been falling as a proportion of all RRT stock. The main growth has been in hospital-based dialysis, increasingly delivered in satellite units. Peritoneal dialysis, favoured in the 1980s has hardly grown at all recently, recognition that it is inappropriate for many of the elderly on RRT and that dialysis adequacy on PD falls over time[39]. As shown in figure 2.3.3.

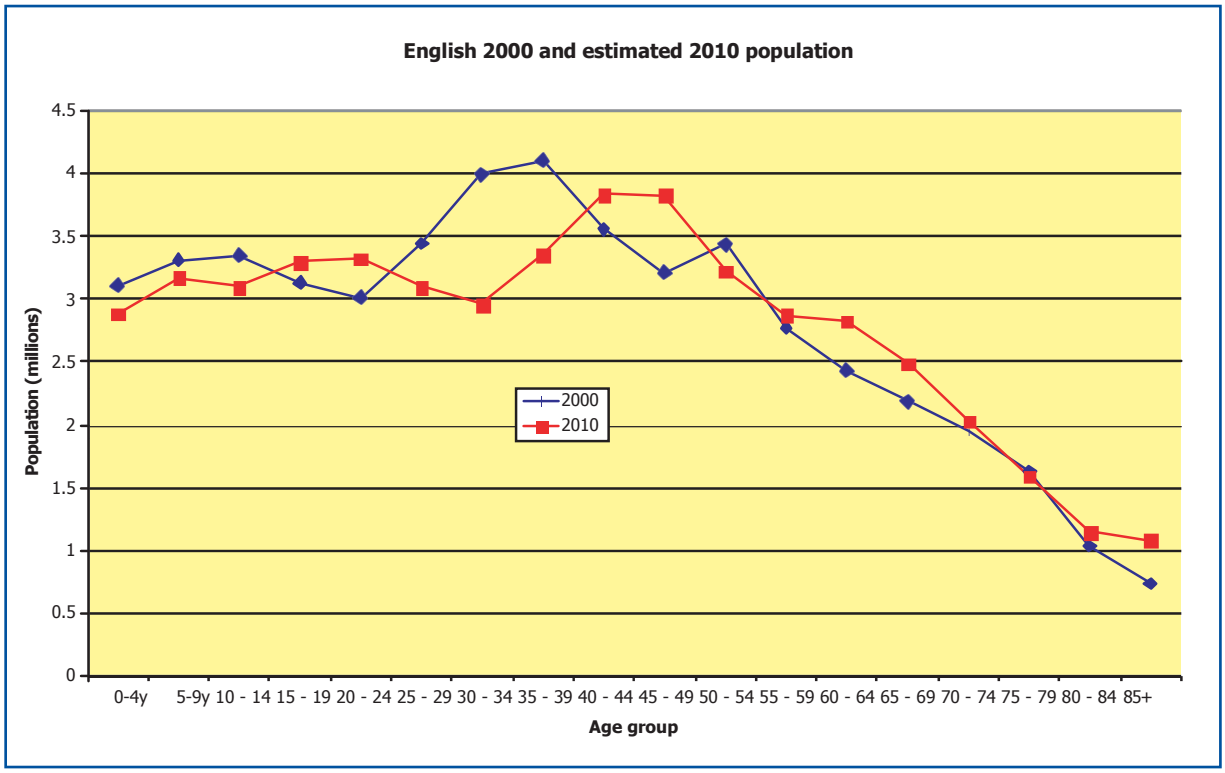
Figure 2.3.3
Renal Replacement Therapy in the UK 1982-1995 and in England 1995-2000



2.3.4 Despite this growth, the acceptance and stock rates in England are lower than in other comparable countries, including Scotland and Wales. For example acceptance rates in 2000 were 129 per million population (pmp) in Austria, 143 pmp in Canada, 175 pmp in Germany, 132 pmp in Spain and 154 pmp in Greece. Countries with higher rates tended to have higher median ages and proportions with diabetic, end stage renal disease (ESRD). These are crude rates unadjusted for differences in the age structure of populations, but they do suggest that the rate in England might be too low, indicating 'unmet need' especially in the elderly and in patients with associated co-morbidity. A significant driver to need for RRT in England is the ethnic minority population (Indo-Asians, African-Caribbeans) who have higher rates of chronic renal impairment, secondary mainly to a higher prevalence of Type 2 diabetes and hypertension[40].

2.3.5 Future acceptance rates for England may be expected to close this gap. They must also take account of population projections (Figure 2.3.5), including the ageing of the ethnic minority populations[41]. Of concern is the rising prevalence of Type 2 diabetes. Recent trends using General Practice Research Database indicated that age adjusted prevalence had increased by nearly 20% in both males and females from 1994-98. Even with a conservative estimate of a 10% increase in prevalence per age group, demographic change would lead to a 44% increase in the overall prevalence of Type 2 diabetes by 2023[42].

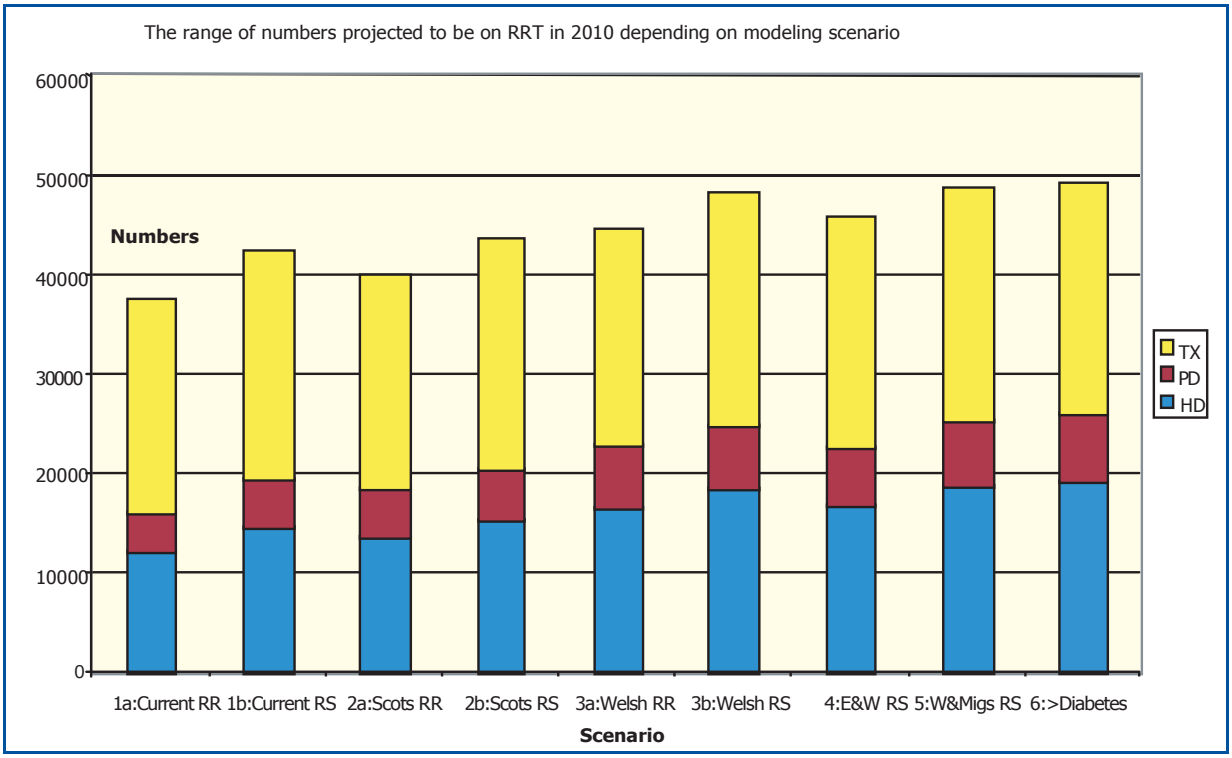
Figure 2.3.5
Total population in England 2000 and estimated 2010 population



2.3.6 A previous simulation model showed that, from 1993, based on acceptance rates of 80 pmp, the steady state would not be reached for 20 years or more and might be two fold higher than in 1993[43]. Key determinants of growth were patient survival and the acceptance rate. Transplant supply determined the proportion of patients with functioning transplants, rather than dialysis. Since that time the donation of cadaver kidneys for transplantation has fallen. However the UK Transplant is introducing measures to increase the numbers for both cadaver and live organs[44].

2.3.7 The effect on future RRT prevalence in 2010 in England of differences in estimating the current acceptance/prevalence rate in 2000 and of the various acceptance rate scenarios is shown in Figure 2.3.7. The estimate of starting acceptance and stock rate based on Registry data or Renal Survey data does affect the future numbers. Even if current age specific acceptance rates in England apply (scenario 1a and 1b) there will be growth in the demand for RRT, due to population change and because a steady state has not been reached. However a more realistic scenario is that there will be continued increase in acceptance rates. The higher acceptance rates in Scotland and Wales in non-ethnic minorities are indicators of a more appropriate coverage of population need for RRT than exists in England. Increasing the acceptance rate to meet need (scenarios 2 to 6) produced, as expected, higher growth in the future prevalence of RRT in England. Including ethnic minority migration has little additional effect as they are mainly in younger age groups. The future prevalence of RRT by 2010 in England is likely to be in the region of 45,000-50,000 cases, a prevalence of about 900-1000pmp.

Figure 2.3.7
Numbers on RRT in 2010 in England for different estimates of current rates and future acceptance rates by mode using pragmatic transplant increase assumption



RR = Renal Registry based 2000 starting numbers (29,000)
RS = 1998 National Renal Survey based 2000 starting numbers (33,000)
Current, Scots & Welsh = Current English, Scots and Welsh take on rates applied to 2010 population.
E&W = Current English young (<54 yrs) take on rates and Welsh elderly 55+ yrs) take on rates
W&Migs = Welsh take on rates with migrants added to 2010 population
>Diabetes = Welsh take on rates with 50% increase in diabetics over 45 yrs

2.3.8 This is an averaged annual growth rate of about 4.5% in England. Even assuming here an increase in transplant supply the largest absolute and relative increase is in haemodialysis with a commensurate increase in workforce requirements and the proportion on dialysis rises with the increase in the estimated acceptance rate. The largest proportional increase is in the over 65s which doubles in the Welsh acceptance rate scenario from 8,000 at start to nearly 16,000 by 2010. Most of these patients will be treated by dialysis.

2.3.9 The future RRT prevalence in the UK can be modelled in the same way. If an averaged annual growth rate of 4.5% is assumed the total UK prevalence of RRT by 2010 is likely to be between 54,000-60,000 cases.

2.3.10 Increasing the transplant supply as planned by UKT is expected to change the number and proportion of patients with a transplant by 2010. The difference between no change and achieving the plan would for example reduce the proportion on dialysis from 58% to 50%. However because of the demand from the existing waiting list and increased input from the rising acceptance rates, organ supply would still be insufficient. The model does not factor in ethnic minority groups directly. Given the shortage of organ donors for the ethnic minority groups the balance between dialysis and transplantation will be differentially higher unless the growth in transplant supply is differentially greater in ethnic groups.

2.3.11 In terms of the split between dialysis modes, using the current age related HD to PD split predicts a predominant increase in HD but also a smaller increase in PD. For example

the Welsh acceptance rate scenario with pragmatic increase in transplant supply predicts by 2010 that the number on HD would increase from 11,568 to 18,361. There is a relative lack of HD facilities in certain areas at present, possibly causing an artificially high number of patients on PD. If HD facilities expand and we assume a higher HD to PD ratio at the start then there is a small impact on future splits of dialysis mode. NICE have examined the role of home haemodialysis[31]. This is not offered by all renal units but has a role for certain low risk patients. Home haemodialysis has different workforce requirements than maintenance haemodialysis.

2.3.12 Changes in patient survival are more difficult to predict. Accurate co morbidity data is not yet available and therefore diabetic ESRD has been used as a proxy. Continued improvements in dialysis care may however improve survival. Rates for morbidity, hospitalization and temporary haemodialysis catheter use are substantially higher in the UK compared to the rest of Western Europe[45]. If similar staffing structures and working practices were adopted in the UK both hospitalization and morbidity for haemodialysis may fall.

2.3.13 Chronic renal impairment is very much more common than end stage renal disease, and its prevalence rises steeply with age[46, 47]. A study from East Kent found that 5500 patients per million population had chronic renal impairment and had not been referred to a nephrologist. This may well be an underestimate, as this study assessed prevalence by relying on samples sent to the clinical chemistry laboratory[48]. An audit of General Practice records of patients aged 50-75years with hypertension or diabetes showed that plasma creatinine had been measured within the last 2 years in 53%; in 11% of this group the plasma creatinine was > 125 µmol/L, giving an estimated prevalence of 110,000 per million in this subgroup of patients[49].

2.3.14 The great majority of patients with mild to moderate chronic renal impairment are not destined to develop end stage renal disease. The risk of cardiovascular disease is higher amongst patients with chronic renal impairment; the question of whether this increased risk is simply due to a high prevalence of recognised risk factors for cardiovascular disease (such as hypertension, smoking, and dyslipidaemia) or is partly attributable to adverse effects of renal impairment per se on the cardiovascular system remains unresolved by recent research. Whichever is the case, these patients are at high risk of vascular events and require active, focussed management.

2.4 Recent Guidance on Workforce Planning

There have been a number of important guiding publications produced in recent years recognising the need for systematic workforce planning in the NHS in order to meet projected staffing requirements.

2.4.1 In the past, workforce planning was not built around service needs and the skills required to deliver them. It did not take a holistic approach looking across primary, secondary and tertiary care or across staff groups and it was not considered responsive to changes or developments. Under A Health Service for all the Talents[14] several key aims are identified:

- To streamline workforce planning and development and ensure that it stems from the needs of the patient and not the professionals.
- To maximise the contribution of all to standards of patient care – removing professional barriers regarding types of care that can be given by different disciplines.
- To ensure flexibility to make the best use of skills and knowledge.
- To enable team working across professional and organisational boundaries.
- To develop new and more flexible careers for staff of all professions.
- To expand the workforce to meet future demands.

The aim identified within this guiding document is to build a modern and dependable health service, providing a fast and responsive, high quality service. It looks to develop a strategy which employs the right people at the right time with the right skills.

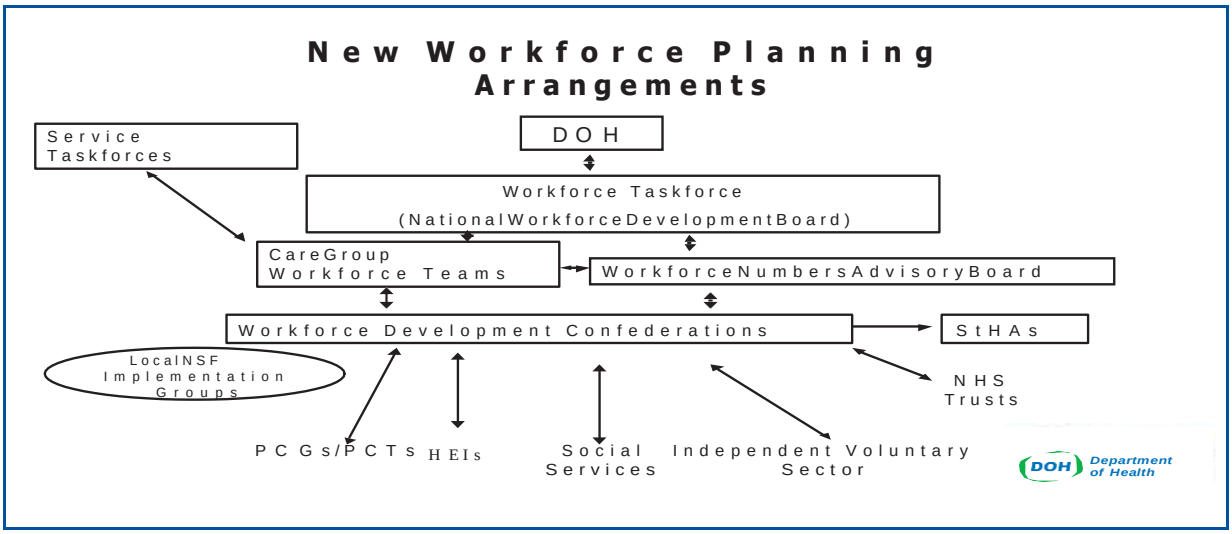
2.4.2 Working Together – securing a quality workforce for the NHS[15] identifies the strategic aim of ensuring that the NHS has a quality workforce, in the right numbers, with the right skills and diversity, organised in the right way to deliver the Government service objectives for health and social care. It integrates human resource planning into the health improvement programmes and clinical governance, recognising that National Service Frameworks (NSFs) should be accompanied by supporting programmes on workforce planning, education and training and personal and organisational development.

2.4.3 Improving Working Lives[16] emphasises the need for modern employment services recognising that staff work best when they can balance commitments to work and life outside. The importance of personal professional development is also recognised. It places human resources within the overall performance assessment framework. It sets out the targets, stages and standards of modern employment practices for our health service.

2.4.4 "A Health Service of all the Talents", 2000[14] recommended new arrangements for workforce development that would support an integrated approach to service and workforce planning. The new workforce planning structures, which rely on a mix of top-down and bottom-up planning, have now been established and include:

- bottom-up planning from stakeholders represented in the Workforce Development Confederations (WDCs);
- top-down planning from the National Workforce Development Board, and the Workforce Numbers Advisory Board;
- planning across the whole service by Care Group Workforce Teams

2.4.5 The diagram below illustrates the relationship between these new structures:



2.4.6 These arrangements are intended to encourage and enable integrated thinking about service, workforce and financial planning in terms both of staff numbers and also of the skills and competencies they need to deliver the service envisaged in the NHS Plan for England. The system needs to co-ordinate all aspects of human resources, including education and training, recruitment, deployment, retention and career progression, whilst remaining as simple and transparent as possible. Above all it needs to be practical and effective for those who do the planning and those who benefit from it.

2.4.7 Workforce Development Confederations (WDCs) are the key local components of workforce planning. Since April 2001, they have replaced the Education and Training Consortia and the Local Medical Workforce Advisory Groups, subsuming their functions. There are now 27 WDCs in all, most of which are wholly coterminous with a single Strategic Health Authority (StHA). The StHAs act as paymasters for the WDCs, who are then accountable to the StHAs for the way in which training funds are used.

2.4.8 All local NHS organisations are required to contribute to Health Improvement Programmes (HImPs) and to develop proper workforce development plans to support them. The role of the WDCs is to bring together NHS and other employers in order to:

- plan the future healthcare workforce;
- plan post registration and other training requirements;
- contract with local education providers;
- work closely with local Higher Education Institutions (HEIs) (who are, for the first time, full members of the Confederations) to develop innovative approaches to education and training, and Learning and Skills Councils to develop joint approaches to training and development for the wider NHS workforce;
- to develop comprehensive plans for delivering workforce increases in their areas;
- to offer long-term support to health authorities, NHS trusts and primary care trusts on related workforce issues such as recruitment and retention.

2.4.9 Given the key role played by WDCs in workforce planning, planning and commissioning of training, and allocation of training funds, it is essential that planners of local renal services understand and are fully engaged in the structures and processes. Also, given that the WDCs' investment plans will be firmly based in the HImP, it is important to ensure that there are strategic plans for renal services which are built into the HImP.

2.4.10 Each of the Care Group Workforce Teams (CGWTs) focus on the workforce requirements - in terms of skills and competencies, as well as numbers - for a specific care group. They take a national view of workforce issues in their care areas, looking across all staff groups and all sectors. Working closely with WDCs they explore and identify different ways of training, educating and deploying staff to deliver improvements in services, and in the working lives of the healthcare teams supporting National Service Framework development and implementation.

2.4.11 Seven CGWTs have been set up, covering the priority areas of mental health, cancer services, coronary heart disease, children's services, services for older people, emergency care, and long term conditions (including diabetes and renal services). The CGWTs are small, expert and action-oriented bodies, made up of individuals who can, through their networks, represent as wide a range of interests, including those of patients and carers, as possible. Each CGWT also has a much broader "reference group" of stakeholders, who will be brought together in various combinations to take forward specific pieces of work.

2.4.12 The Long-Term Conditions Care Group Workforce Team (LTC CGWT) met for the first time on 29 January 2002. It supports the work of the NSFs for Diabetes, Renal and Long-Term Conditions. To do so, it has three Dedicated Workforce Groups. Terms of Reference, key priorities and membership list are available on the CGWT website: www.doh.gov.uk/cgwt.[50] The Renal Workforce has agreed that the National Renal Workforce Planning Group should remain in being as one of its key stakeholder reference groups, andthat this report will be a key source document guiding its work programme in support of the Renal National Service Framework.

2.5 Private Public Partnerships

2.5.1 The private sector plays an important role in the provision of renal care, particularly haemodialysis facilities and in many parts of the UK there are effective working partnerships between commercial companies and the NHS. The first renal unit to be funded through public / private sector collaboration was established in the late 1980s and since that time a significant number of new or expanded units have been developed with private sector support. Over a quarter of all satellite dialysis units are managed by commercial dialysis companies.

2.5.2 Private sector provision remains largely maintenance haemodialysis but recently aspects of both peritoneal dialysis and home haemodialysis have begun to be provided by dialysis companies. Inpatient care, provision of access, transplant and outpatient services have not been included in these arrangements.

2.5.3 There are different funding arrangements for public /private collaboration including:

Fully Contracted-out Service – Capital investment (buildings and land) that remains in the ownership of the private sector partner. The private partner provides machines and maintenance staff, water treatment facilities, technical staff, disposable materials, and other staff (clinical and non-clinical, but often excluding medical staff). The NHS negotiate a 'banded' price based on projected annual activity (usually the number of treatment sessions) and the type of facility, which produces a cost per treatment. If there is significant under/over-activity alternative costing methods may be applied subject to these contingencies in the existing contract.

Sub contracted service – in this situation, the NHS may own the site. In some instances the private partner will provide the entire infrastructure as for a 'fully contracted' service, in other instances the NHS may provide some elements (e.g. equipment, staff). The charging mechanisms will be similar to those for the 'fully contracted' service whereby the NHS negotiates a 'cost per treatment' with the private partner.

2.5.4 In both the above models where nursing staff are employed by the private sector partner, the Units are subject to external Regulation under Part II of the Registered Homes Act (1984)[51]. Issues covered under these Regulations include:

- minimum staffing numbers for the type of unit registered.
- skill mix.
- clinical practice.
- staff training.

2.5.5 In a Private Financial Initiative (PFI), the private sector partner may own the buildings, provide "hotel services" and employ the staff providing these services. The NHS will own the site and lease the building from the private sector partner. The NHS may then provide the service either:

(i) directly: by employing the members of the renal services team (this may require setting up a new service); or

(ii) indirectly: through a Service Level Agreement (SLA) with a neighbouring NHS provider who already has an established service. The SLA will state the clinical and operational management arrangements and the type of service to be provided at the site.

2.5.6 The Care Standards Act 2000[52] sets out a broad range of regulation-making powers covering, amongst other matters, the management, staff, premises and conduct of social and health care establishments and agencies. Section 23 of the Act gives powers to the Secretary of State for

Health to publish statements of national minimum standards that the National Care Standards Commission (NCSC) must take into account when determining whether providers of independent health care have in place appropriate safe guards and quality assurance arrangements for their patients.

2.5.7 The standards comprise core standards, which are common to all organisations, and service-specific ones. Dialysis is a prescribed technique, and service-specific standards detail staffing for dialysis to be that supervision of nursing care is undertaken by a registered nurse with the relevant English National Board (ENB) certificates (ENB 136 or ENB 134 or equivalent).

2.6 Impact of Technology on Renal Service Provision

2.6.1 Optimal health care depends on the availability of good quality information, which is accessible when and where needed. The IT objectives laid out in "Information for Health"[53] emphasize the importance of health care professionals having rapid access to reliable and good quality information in order to support patient care. A second objective is to provide remote and online access to care when possible in order to reduce patient travelling - and this would include the use of telemedicine where appropriate for distant consultation. Further objectives include providing good quality information and advice for patients and on-line access to guidance and evidence base for professionals.

2.6.2 Central to these objectives is the development of the individual electronic health record (EHR), which would include both primary and secondary care contact information. In addition to supporting patient care, the EHR would also feed into aggregated anonymised data subsets for the purposes of governance, public health surveillance and research. The EHR has central components such as electronic prescribing, discharge summaries and letters.

2.6.3 A key objective in "Information for Health" is the use of information for managers and planners to support local health improvement programs, for assessment of performance and for workforce planning itself.

2.6.4 The overall process is now known as "knowledge management" which has been defined as "the task of developing and exploiting an organization's tangible and intangible knowledge assets"[54], which is to be rolled out across the NHS under the direction of Sir John Pattison. This is an enormous task requiring investment in infrastructure and staff training (European community IT driving licence - ECDL) and attitudes.

2.6.5 Several key platforms are well developed to support the process of knowledge management in renal services. These include the Renal Association Standards[9], and the established electronic Renal Registry[30]. Many renal units have already got quite well developed IT in comparison to other specialist services, using a heterogeneity of IT systems.

2.6.6 Developments which may further facilitate the working of renal services include the use of telemedicine to communicate with satellite dialysis units, the use of Wireless technology so that computers can be used on ward-rounds, and hand held technology for community nurses and transplant co-ordinators to use to input data remotely.

2.6.7 Although telemedicine has been used in a wide variety of settings, perhaps its greatest strengths are in remote geographical locations or for specialities that are image based such as radiology or histopathology. In renal medicine it may be potentially applied to reviewing patients at satellite dialysis units by staff members working at the central unit, or alternatively video-conferencing may permit improved staff communication between a number of disparate sites. The technology should be applied cautiously since there is no clear evidence to date of its cost-effectiveness[55].

2.6.8 The appropriate development of suitable renal IT within the context of the NHS strategy[53] will enhance patient care through improved data management, communication, audit, efficiency and a reduction in health related adverse events. This initiative is already well advanced within the renal community; however considerable further development is required. Central to the success of this project is investment in staff training so that health care workers at all levels can interact effectively with the technology. The permissive effect of information technology specialists at unit level on other specialist renal staff IT competencies, in facilitating introduction of new models of care and in performance management is often unrecognized. The full impact on renal healthcare is difficult to predict but the Wanless Report[19] highlights the profound changes in working practice to be expected.

2.7 The Expert Patient

2.7.1 The importance of involving renal patients and their carers in the planning and delivery of service has previously been underestimated. Renal patients and their families bring a unique perspective to the provision of integrated care by highlighting their experience of the patient journey and where improvements could be made. Whilst most NHS patients are treated either within or without an NHS Hospital, on the whole they tend to be visitors. They do not regard the Hospital as anything other than the place to receive treatment, and they do not form attachments. End Stage Renal Disease (ESRD) on the other hand is for life – there is no cure, without treatment the patient will die.

2.7.2 The Hospital renal department quickly becomes a "second home" to the patient, friendships are made and a community is quickly established. The degree of permanency increases the levels of communication between patients, and between patients, carers and medical staff. Over the years this has been very beneficial. Charities, which support the renal unit, are formed - Kidney Patient Associations (KPAs) and money is frequently raised for the unit by the patients. This interchange increases education about the disease and enables patients to make more informed judgements about their own treatment options. There is much to be gained by listening to the renal patient community.

2.7.3 The Expert Patient Programme proposed by the Department of Health[56] will require the renal team to access training and develop its resources to accommodate and support implementation within renal services. Introducing the programme will require more than providing information and education for patients. It necessitates a significant shift in the delivery of health services to enable the development of partnership working with patients empowered to play a central role in how their illness is managed. This will undoubtedly have implications for workforce requirements and priorities.

2.7.4 In addition to individual decision-making, the partnership model will need to extend to accommodate service user representation (e.g. local Kidney Patient Associations or other patient groups) in service evaluations, peer review and audit processes as well as the development of future renal services. Already there are examples across the UK where patients have advised on the service design of new haemodialysis units and have been core members of renal service reconfiguration projects. The production of the Kidney Alliance "End Stage Renal Failure – A Framework for Planning and Service Delivery" is clear evidence of successful partnership[1].

SECTION THREE

RENAL SERVICES FOR ADULTS

Section 3 Renal Services for Adults

3.1 The Importance of Multiprofessional Working

3.1.1 Renal failure has a profound, complex, life-long impact on patients and their families/carers. During the course of their patient 'journey', they will encounter numerous multi-professional staff, who each have a contribution to make to their management and care. Patients' varied needs, physiological, practical, psychological and social, will form a focus for different staff at different times.

3.1.2 In order to optimise clinical outcomes and enhance quality of life, multi-professional staff require a joint perspective on management and care issues, underpinned by recognition of the varied professional skills required, and an ability to work flexibly and in collaboration.

3.1.3 The Department of Health has recently published its framework for lifelong learning in the NHS: "Working Together – Learning Together"[57] (www.doh.gov.uk/lifelong learning). This takes forward the commitments in the NHS Plan for modernising education, training and development. It recognises that lifelong learning and development are key to delivering a workforce with the right skills, knowledge and attributes to support changes in patient care; to take advantage of wider career opportunities; and realise their full potential.

3.1.4 From the patient/carer perspective, they are entering into a partnership arrangement, taking on some aspects of responsibility for their treatment and care, and negotiating some dependency needs. They need open, honest relationships with multi-professional staff, with consistency of information and advice.[58] They require continuity of care, tailored to individual care plans, available to all members of the team. The importance of personal interaction cannot be underestimated, and quality of life will be influenced by the way in which the multi-professional team communicate and operate.[58]

3.1.5 Access to multi-professional staff, especially as needs change is crucial, and good relationships with staff can enhance coping strategies, leading to better compliance and improved medical outcomes[59]. The use of regular review systems, involving patient/carers and key team members, provide opportunities to assess needs, make corporate plans and draw in multi-professional expertise, as required. Patients expect a high level of information exchange, so that all those with whom they come into contact understand their situation and needs.

3.1.6 Given the complexity of issues that need to be addressed in renal care, staff require clarity of information on their changing roles and responsibilities, together with a detailed understanding of the other roles of multi-professional staff. The inter-dependence of multi-professional staff needs to be recognised, to provide integrated renal care. Patterns of working practices need to be tailored to include good collaboration, with clear 'pathways' of patient care and well understood protocols and procedures.[60]

3.1.7 A pro-active role to address shared concerns can result in multi-professional strategies to resolve problem areas. Skills in communication, negotiation, assessment and networking, need to form part of the multi-profession education and training programmes. Staff who develop positive attitudes to their contribution, are more motivated, experience greater job satisfaction and lower stress levels.[61] Mutual multi-professional support in the stressful area of renal care, can enhance the individual staff members ability to cope, providing an improved response to patient/carer needs.[62]

3.1.8 "Working Together – Learning Together" sets out core values and skills required by all staff, derived from those underpinning the NHS Plan, such as effective communication, effective and

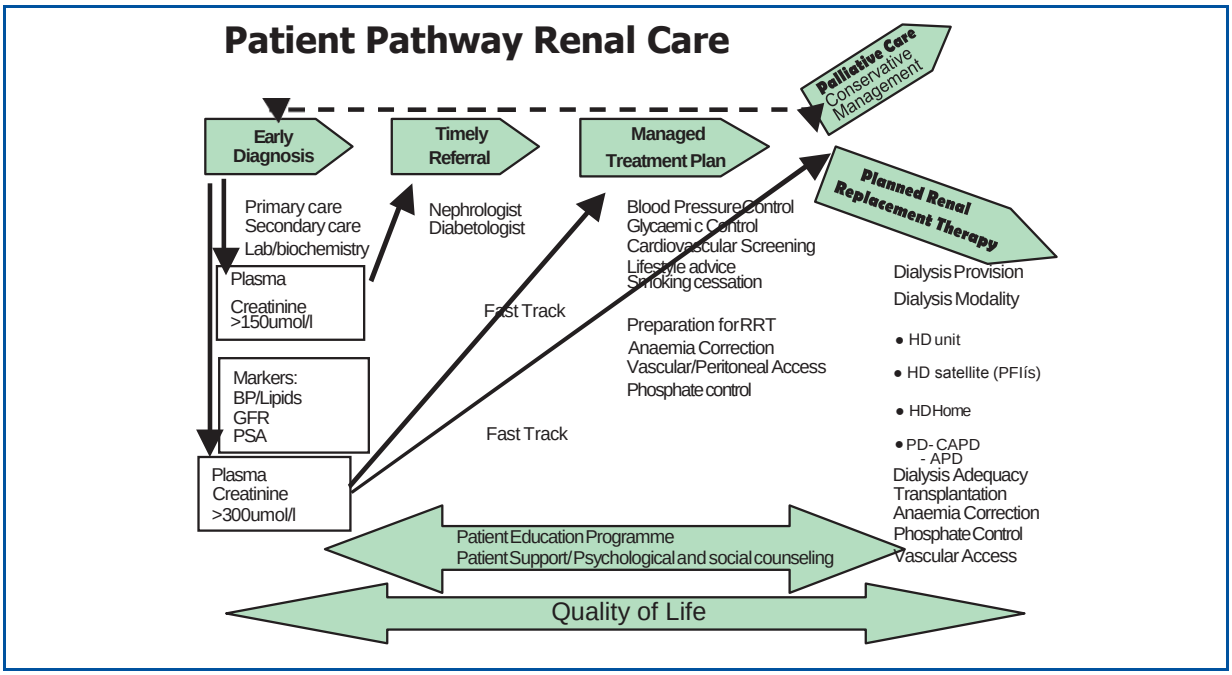
sensitive use of information, teams working and keeping skills up to date. It puts forward the principles which should govern pre-registration education, continuing professional development, leadership and management development, and the concept of the "skills escalator", so that staff without professional qualifications can use NHS Learning Accounts, National Vocational Qualifications and other learning opportunities, to build their skills and careers. The document sets out the work that has already been done and the policies already in place to enable implementation of the Framework, and describes the roles of Workforce Development Confederations and the NHS University in supporting this.

3.1.9 Good multi-professional working is also of importance to service providers, employers and managers, who are aiming for high quality, well managed care at effective cost. Teamwork, the appropriate use of staff, development of additional skills, and the avoidance of duplication, are key issues. Multi-professional working allows a range of professionals to share care responsibilities in innovative ways, across boundaries, and at all levels within health and social care services. A multi-professional team that works well together is likely to maintain team stability, providing continuity of patient care. The provision of a motivated workforce, with a wide-range of clinical and technical skills,[63] who can work collaboratively, and effectively network, is an essential human resource requirement in labour intensive renal services.

3.2 The Patient Pathway

3.2.1 The majority of care for adult patients with renal disease is provided by non-renal specialist staff. Minor forms of renal disease for which specialist care may not be necessary include mild to moderate chronic renal impairment, minor degrees of proteinuria, and asymptomatic microscopic haematuria. Primary care conditions have the key roles in the detection and management of early renal disease in the majority of these patients.

Figure 3.2.1



The Renal Patient Care Pathway from diagnosis to established renal failure (from the Fresenius Medical Care submission to the Renal National Service consultation exercise reproduced with permission).

3.2.2 The major treatable risk factors for progression of chronic renal impairment towards end stage renal disease are hypertension, smoking, obesity, and dyslipidaemia – all conditions which GPs and other non-nephrologists are accustomed to treating. Implementation of the coronary heart disease NSF provides performance targets for these conditions. Primary care based cardio-

vascular risk reduction strategies are helping to define the skills and competencies required by healthcare professionals and generic workers. However, achievement of blood pressure targets in patients with renal disease managed in General Practice has historically been sub-optimal[64].

3.2.3 There is a growing literature on the negative impact of "late referral" of patients with advanced renal impairment[65, 66]. Observational studies have uniformly shown increased morbidity, hospital stay, and cost of treatment in patients starting long-term dialysis who were referred late (usually defined as within 4 months of needing dialysis) compared to those referred to a dialysis unit earlier.

3.2.4 Several factors contribute to this increased morbidity amongst late referred patients, including poorer control of anaemia, bone disease, hypertension, and acidosis, together with often being sicker at presentation, but the dominant factor is lack of sufficient time to prepare the patient for dialysis, particularly if this requires access to the circulation for haemodialysis. It is widely recognised that it may take 6 months or even longer to establish satisfactory vascular access for haemodialysis; during this time the patient is also educated and counselled on the forthcoming need for dialysis, a process which is likely to facilitate an "easy start" when dialysis does commence. Late referred patients are much more likely to start dialysis with a temporary or semi-permanent jugular catheter than with an arteriovenous fistula[67, 68] and use of such access is associated with a greatly increased morbidity, particularly from infection, and with a higher failure rate requiring re-admission to hospital[69].

3.2.5 A recent study in the South West Region, using a case note review including those from referring hospitals and the primary care records, showed that approximately 50% of late referrals were avoidable, the remainder being "unavoidable" – commonly patients presenting with end stage renal disease having had little or no recent contact with doctors[70].

3.2.6 A common conclusion of many of these studies is that the problem should be addressed by increased awareness – amongst general physicians, surgeons, urologists, diabetologists, and general practitioners - of the need for early referral of all patients with renal impairment. However, there are few if any guidelines in the public domain relating to referral of patients with renal impairment and intended for use by these groups. The Renal Association recommends that all patients with a serum creatinine of > 150 µmols/L[9] should be referred to a nephrologist and this recommendation is supported by the National Institute of Clinical Excellence Guidelines on Type 2 Diabetes[71]. The United States of America National Institutes of Health Consensus Conference recommended referral in women with a serum creatinine of >153 µmols/L and in men, with a serum creatinine of >180 µmols/L[72]. The Clinical Practice Guidelines of the Canadian Society of Nephrology suggest referral of all patients whose calculated creatinine clearance is < 30 mils/minute[73]. The British Hypertension Society recommends referral of "all hypertensive patients with elevated serum creatinine or proteinuric"[74].

3.2.7 The K/DOQI clinical practice guidelines for chronic kidney disease were published recently following a comprehensive, methodologically rigorous review of the available evidence[75]. They recommend that patients with an estimated GFR of 30-59 ml/min/1.73 m2 should be managed jointly with a nephrologist, and those with an estimated GFR of 15-29 be referred to a nephrologist. These guidelines are clearly based on the perceived need to avoid late referrals, but imply an assumption that most renal disease is progressive once it has caused a degree of renal impairment.

3.2.8 Progression of renal disease can be confidently predicted in some groups of patients with existing renal impairment, including those with diabetic nephropathy and those with

polycystic kidney disease. Amongst patients with known primary renal disease (e.g. reflux nephropathy, glomerulonephritis), the presence of proteinuria (and, to a lesser extent, hypertension) is strongly predictive of progression towards end stage renal disease.

3.2.9 In such patients with proteinuric renal disease, there is good evidence that antihypertensive and lipid-lowering drug treatment may prevent progression to end stage. The care of all such patients should be shared with a nephrologist, as such treatment is complicated and the treatment goals difficult to achieve, requiring combinations of several different drugs. ACE inhibitors and angiotensin receptor blockers have a particular protective effect in such diseases, over and above their effects on systemic blood pressure.

3.2.10 Patients with polycystic kidney disease and existing renal impairment should also be referred, as they are destined to develop end stage renal disease (unless they die first of a non-renal complication). Neither antihypertensive treatment nor any other intervention is currently known to reduce the rate of loss of kidney function in this condition. Such patients therefore require early counselling and planning for renal replacement therapy.

3.2.11 It is much more difficult to predict progression amongst patients with unexplained mild to moderate chronic renal impairment and minimal proteinuria. Many such patients are elderly and may have atherosclerotic vascular disease. The extent to which atherosclerosis of the renal arteries contributes to renal impairment and to hypertension in such patients is uncertain, as is the role of angioplasty and stenting of the renal arteries in such patients. Most are destined to die of cardiovascular disease with stable renal impairment. Patients with recurrent hypertensive heart failure, refractory hypertension with renal impairment, and those with a marked rise in serum creatinine after ACE inhibitors are most likely to benefit from referral.

3.2.12 The use of serum creatinine concentration as the most widely used marker of renal function contributes to the problem. Because of the reciprocal relationship between glomerular filtration rate (GFR) and serum creatinine, serum creatinine may not rise outside the reference range until the glomerular filtration rate has fallen to half the normal value. The fact that daily creatinine production is proportional to muscle mass means that in those with low muscle mass, (e.g. many elderly patients), an even greater fall in GFR is required before the serum creatinine concentration becomes "abnormal". These problems can be partly overcome by looking at changes of serum creatinine concentration over time within an individual – a progressive rise even within the normal range should raise strong suspicion of progressive fall in GFR – and also by the use of formulae predicting GFR from serum creatinine together with age, sex, and body weight[76]. Although these formulae are not in widespread use, they are simple to use and likely to be incorporated into standard laboratory reports in the relatively near future: graphical reciprocal creatinine plots are an alternative for assessing progressive loss of kidney function but do not get over the problem of underestimation of the severity of kidney damage in patients with low muscle mass.

3.2.13 Once a patient has been referred to a nephrologist with progressive renal impairment, "disease management" is often undertaken primarily by the renal team. This may include antihypertensive treatment, lipid-lowering treatment, treatment of acidosis, use of phosphate binders, calcium supplements, and hydroxylated vitamin D, treatment of anaemia with epoetin or analogues, as well as psychological and practical preparation for dialysis and, where appropriate, transplantation. Renal patients therefore often attend nephrology outpatients more regularly than they would their own GP, and there is a resulting tendency for the renal team to provide some of the services normally provided by primary care.

3.2.14 There is an urgent need to develop the patient pathways for patients with or at risk of renal disease to clarify the roles and responsibilities in early, intermediate and advanced renal disease. The workforce implications of early detection and active management of patients with potentially progressive renal impairment are likely to be significant for both primary care and specialist renal services.

3.3 Renal Physicians

3.3.1 Renal physicians provide a wide range of clinical services for patients with kidney disease. Their roles involve leadership and provision of a renal replacement therapy programme. They provide support for patients who develop renal problems in other units and hospitals, particularly those in ITU, Cardiothoracic Units, Liver and Vascular Units where acute renal failure is common. The service they give patients depends on close collaboration with other colleagues in the renal multi-professional team and in other services. The duties of renal physicians and their various roles and responsibilities are described in detail in Consultant Physicians Working for Patients (2nd edition)[36].

3.3.2 The medical workforce Annual Consultant Census (RCP London)[77] provides detailed information on the current consultant workforce and trends in practice over the last decade. The number of consultants in renal medicine has increased at a rate of 6.4% per annum between 1993 and 2001. The 2001 Census identified 290 consultant renal physicians in post representing 277 wte physicians in the United Kingdom. Approximately half of these renal physicians (55.6%) have a general internal medicine commitment, accounting for 12.7 hours per week. Comparison of contracted notional half days with actual notional half days worked revealed a need for 229 extra wte physicians to provide the current level of service and assuming no change in current workload, an additional 47 wte physicians are required to meet the European Working Time Directive.

3.3.3 The numbers of consultants in post in 2001[77], their contribution to nephrology and the estimated requirements from Consultant Physicians Working for Patients are shown in table 3.3.3. The consultant contribution to nephrology has been calculated from the College Census using a correction factor of 0.71 to account for renal physicians' contributions to general internal medicine, academic activity and part time working for personal reasons[36]. The 2001 requirements are based on the actual workload in South Wales, Yorkshire and Newcastle[36].

Table 3.3.3
Estimated Consultant Requirements

		2001 Actual		2001 Required***	
	Population	Consultant Posts – 2001*	WTE in Nephrology	Consultant Posts	WTE in Nephrology
ENGLAND	50.19	227**	161	429	305
WALES	2.95	13	9	25	18
ENGLAND & WALES	53.14	240	170	454	323
NORTHERN IRELAND	1.68	10	7	14	10
SCOTLAND	5.11	40	28	44	31
TOTAL	59.93	290	206	512	364

* RCP Census 2001[77].
** Includes 1 Consultant in Her Majesty's Forces.
*** Consultant Physicians Working for Patients, 2nd Edition, p240[36]. Consultant requirements for 2001 are based on an estimate of the nephrology needs of a population of one million and take into account the service contribution of trainees and NCCG's and the demands of General Medicine, academic commitments and part-time working for personal reasons.

3.3.4 Renal medical workforce requirements have traditionally been related to the population served (reported as pmp). To provide guidance for future planning and in recognition that the burden of renal disease is influenced by age, ethnicity and the maturity of the replacement therapy programme in addition to the population served, the requirements have also been related to the number of patients receiving renal replacement therapy.

3.3.5 To provide a comprehensive consultant based renal service as detailed in Consultant Physicians Working for Patients would require 1 consultant renal physician per 75 renal replacement therapy patients. This figure has been calculated from the Royal College of Physicians recommended requirements for 2001 in Consultant Physicians Working for Patients[36] and the Renal Association stocktake of patients receiving renal replacement therapy[29].

3.3.6 Currently Non Consultant Career Grade practitioners (NCCGs) provide valuable support to many renal programmes. A survey conducted to inform this workforce planning exercise identified 37 NCCGs in renal medicine in the United Kingdom[78]. Each NCCG provided on average 9.4 sessions per week, the majority of which are devoted to the management of dialysis patients. Over 80% of NCCGs have post graduate medical qualifications and 60% wish to progress to consultant posts.

3.3.7 The demographic profile of consultant renal physicians suggests that around 30% will retire in the next 10 years[77] and it is known that in the region of 2% per annum take up appointments in non-clinical management or industry.

3.3.8 The strength of academic nephrology in the UK has been one of the drivers for the development of renal medicine in the UK. There are benefits at both intellectual and practical levels. In 2001, 21% of renal physicians held academic appointments and contributed an average of 0.5 wte each. The close working relationship between clinical and academic nephrologists is reflected in the high proportion of Specialist Registrars who undertake formal research training as Medical Research Council (MRC), Wellcome Trust and National Kidney Research Fund (NKRF) Training Fellows and the continued strength of academic nephrology will depend on the application of the Savill Report[79]. Accordingly, career paths for academic trainees will need to be developed and supernumerary Specialist Registrar positions created for externally funded trainees. Clinical Lecturer posts will need to be retained, and the demands of modern research on Senior Lecturers time will need to be acknowledged.

3.3.9 These recommendations are based upon Consultant Physicians Working for Patients and the current models of working. It should be emphasised that they are average figures for the UK as a whole and mask considerable heterogeneity across the United Kingdom where physicians are working in teams of varying size. Contributions to general internal medicine and academic activities are variable and the support from trainees, or Non Consultant Career Grades is inconsistent. Local workforce planning will need to consider these factors as well as geographical location, local demography and maturity of the local renal replacement therapy population. Other factors likely to significantly modify the number of renal physicians required include increased detection and referral of patients with established renal impairment as indicated in several recent studies[46,80] and recommended by NICE in patients with Type 2 diabetes[69]. Different models of care are emerging that include joint working with primary care and diabetes colleagues, the development of other renal specialist practitioners and the establishment of consultant renal nurses. The impact of these changes will need to be regularly considered in predicting future workforce requirements.

3.4 Renal Transplant Surgeons

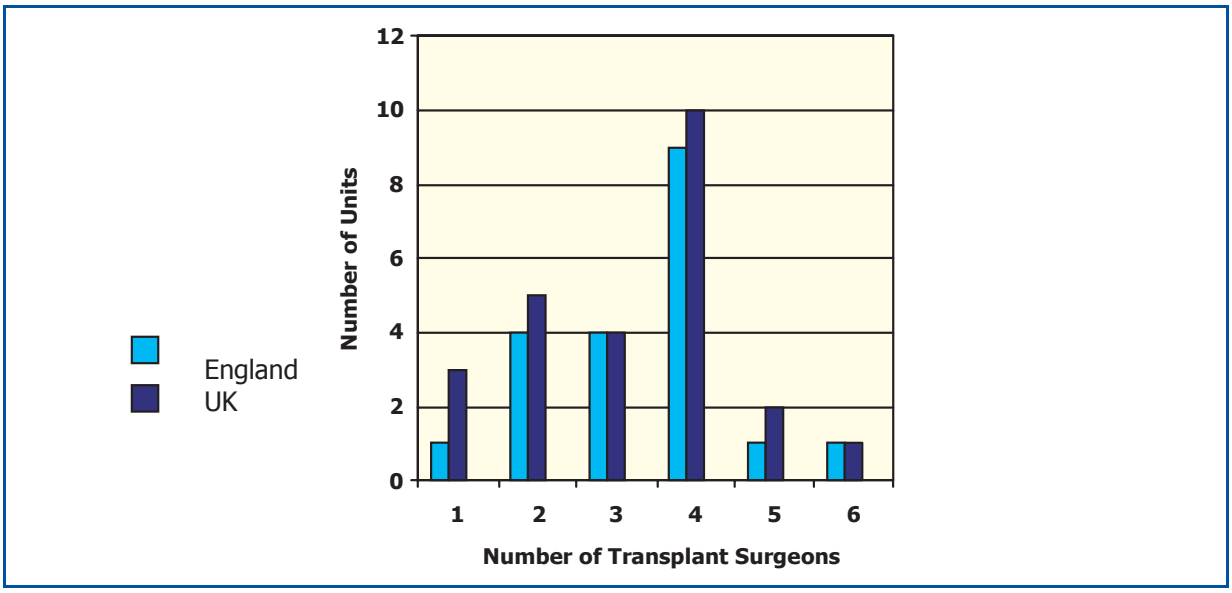
3.4.1 Renal transplantation provides the best quality of life and survival for suitable renal replace-

ment therapy patients. All patients with end stage renal disease should be considered and the British Transplant Society recommends that at least 40% of dialysis patients should be listed for transplantation[10]. Many of the elderly or those with cardiovascular co-morbidity are found to be unsuitable.

3.4.2 Transplant surgeons are responsible for leading and providing a renal transplant service. This involves donor procurement and implantation of grafts. They play key roles in assessing and preparing the patients for transplantation, and in both the peri-operative care and long term management of renal transplant recipients[5]. Transplant professionals are core members of the renal multi-professional team and in addition the transplant surgeons are supported by a theatre team. Renal transplantation is complex and patients and carers often need the skills of all the other members of the renal multi-professional team.

3.4.3 Renal transplant surgery is a sub-speciality of general surgery and of urology. In England there are currently 21 transplant units and 68 consultant surgeons with an interest in renal transplantation of whom only 13 are full time renal transplant surgeons. The remainder have an interest in other sub-speciality areas of general surgery or urology. In the United Kingdom there are 26 transplant centres with 81 transplant surgeons providing 51 wte transplant/renal failure surgeons. An essential component of the work of transplant surgeons is also provision of a dialysis access service, both vascular and peritoneal access. Paediatric renal surgery is performed in 8 units in England by surgeons who also perform adult renal transplantation. Many transplant surgeons also provide parathyroid and general surgery for renal failure and non renal failure patients. The median number of surgeons per unit is 3 with a range of 1-6.

Table 3.4.3
Number of Transplant Surgeons per unit in 2002 in England and the United Kingdom



3.4.4 In most units, transplant surgeons and renal physicians collaboratively provide the pre-operative assessment of the potential transplant recipient and share the inpatient and outpatient peri-operative care of the post transplant patient on an integrated basis with the other members of the renal multi-professional team. UK Transplant, a designated special Health Authority, provide an essential service in organising the distribution of donor organs and has a pivotal role in developing the strategy to increase renal transplantation to 50 transplant pmp per year (30 cadaveric donation, 10 from non heart beating donation and 10 live donations).

3.4.5 The small number of renal transplant surgeons in many of the units, the frequent requirement to be involved in 2 on call rotas (eg vascular surgery and transplantation) and recommendations that donor organ procurement should be consultant led are incompatible with the European working time directive. Live donor donation, non heart beating donation and pancreaticorenal transplantation all need additional dedicated surgical staff.

3.4.6 Surgical trainees are attached to 15 of the 21 units but only 7 units have 5 dedicated renal transplant trainees. In many units cross cover arrangements with renal specialist registrars are in place leaving consultant transplant surgeons unsupported by assistants in the operating theatre and at organ retrieval.

3.4.7 Renal transplantation should only be performed by, or under the supervision of, accredited surgeons. Donor procurement can however be successfully performed by liver transplant surgeons. Assistance in theatre can be provided by non-consultant career grade staff in addition to surgical trainees.

3.4.8 To achieve the planned increase in renal transplantation will require 2 transplant surgeons per million of the population (pmp) providing between 1.2-1.5 wtes in transplant surgery pmp depending on whether or not organ retrieval is consultant lead.

3.4.9 A minimum of 5 transplant surgeons per unit is also recommended[81]. The majority of surgeons will also have an interest in other sub specialities in addition to performing access surgery in the local renal centres. Transplant surgeons should perform a minimum of 15 renal transplants per year. If insufficient surgical trainees are available to provide assistance in theatre and support to organ retrieval, local arrangements should be in place to support consultant renal transplant surgeons in these situations.

3.5 Dialysis Access Services

3.5.1 Access to the circulation or peritoneum in haemodialysis and peritoneal dialysis respectively are essential for dialysis provision. Access is recognised as the Achilles heel of dialysis. The Kidney Alliance has highlighted the need for robust arrangements to ensure the timely creation of vascular access[11].

3.5.2 Dialysis access is best provided by a multi-professional team including surgeons responsible for the creation of access, renal physicians and renal nurses and for the provision of vascular access, radiologists with vascular imaging and interventional skills. Patients require educational material, counselling and frequently psychological and social support in preparation for dialysis access. In certain centres co-ordination has been improved by establishing specific dialysis access co-ordinators and/or multi-professional vascular access clinics.

3.5.3 Peritoneal access is currently provided by surgeons or renal physicians but insertion of catheters by radiologists utilising minimally invasive techniques may develop. Surgeons are likely to continue to provide the bulk of this service. There are a number of techniques for the insertion of peritoneal catheters and long-term catheter survival is predicated on a multi-professional approach to the timing of catheter insertion, discussion with the patient regarding the best location of the exit site and placement of the catheters by skilled and experienced operators working in an appropriately staffed theatre environment. Local anaesthesia is acceptable for many patients if adequate sedation is provided, although some patients do require general anaesthesia. If the patient has hernias, these need to be repaired prior to commencing peritoneal dialysis. Between 2-3 peritoneal access procedures can be performed per session by an experienced operator.

3.5.4 The creation of arterio-venous fistula and grafts is usually provided by vascular or transplant surgeons. Central catheters for haemodialysis are usually placed by renal physicians, access surgeons or radiologists. In a number of units, specialist renal nurses have also acquired skills and competencies in the insertion of central venous lines.The need for pre and postoperative vascular imaging is increasingly recognised and over the past decade the value of thrombolysis, trans-luminal angioplasty and vascular stenting in the preservation of haemodialysis access has become established. A dedicated operating theatre session per 120 dialysis patients has been recommended[1] on the assumption that each operating list could contain up to 3 primary access cases or depending on complexity 1 or 2 secondary access cases under local or general anaesthesia. A case load of 350 vascular access procedures would require 1 wte surgeon but it is recognised that vascular access is likely to be provided by a number of surgeons working as a team, each with vascular access as a component of their job plan.

3.5.5 Close links between the imaging department and the haemodialysis unit are required for optimal and timely management of the long-term haemodialysis patient. Imaging has a substantial role in the selection of the most appropriate sites for fistula formation or graft placement, maintenance of fistula and graft patency, tunnelled dialysis line placement and creation of vascular access via non standard routes[82]. Work is urgently needed to identify the radiological requirements and workforce implications for successful vascular access.

3.6 Donor Transplant Coordinators

3.6.1 Donor transplant coordinators are a vital part of the multi-disciplinary team and must ensure that donor families and the healthcare professionals involved in the donation process receive a seamless professional service.

Table 3.6.1
Key responsibilities of Donor Transplant Co-ordinators

- To maximise the number of potential donors referred within their geographical area of responsibility.
- To promote awareness and disseminate information amongst healthcare professionals and the general public regarding the need for organs/tissues for transplantation.
- Organise all aspects of the organ/tissue retrieval ensuring that donors and their families are treated with dignity and respect.
- Be familiar with current legislation on organ donation and transplantation. Provide advice to colleagues and other healthcare professionals.

3.6.2 The Quinquennial Review of the United Kingdom Transplant Support Service Authority (UKTSSA) in 1998/99[83] recommended the development of a job specification for the transplant co-ordinator role based on best practice and that funding should support this model of good practice to assist the principle of a nationally co-ordinated service. These recommendations were made to address concerns about shortage of donor co-ordinators, onerous on-call commitments with relatively high staff turnover and to help maximise organ donation.

3.6.3 In January 2001 UK Transplant established the UK Transplant Co-ordinators Advisory Group to advise on implementation of these recommendations. The review identified 67 Donor Transplant Coordinators in England and 87 in the United Kingdom; some of these also deal with renal recipients. Detailed job descriptions have been developed[84], training and accreditation recommendations have been made[85,86] and an accountability framework has been suggested[87].

3.6.4 The UKT Coordinators Advisory Group have recommended[88]:

- Each wte donor transplant co-ordinator should care for a minimum of 10 donors per year to gain experience and maintain competencies.
- All donor transplant co-ordinators should work a maximum of 1 in 4 on-call.
- 1 wte living donor transplant coordinator should support 20 living kidney transplants per year.

- The donor transplant co-ordinator requirements for staffing a non heart beating donor programme should be reviewed independently of any other transplant programmes, and be mindful of other local arrangements.

3.6.5 In order to achieve the UK Transplant business case targets for 2001-2006 and assuming the UK population remains static at 60 million, to achieve the above 1.66 wte donor transplant co-ordinators pmp would be required. The establishment of this would be staggered with 1.0 wte established in 2001/02 and 1.66 wte pmp by 2005/06.

3.7 The Histocompatibility and Immunogenetics Service

3.7.1 A Histocompatibility and Immunogenetics (H&I, tissue typing) service that has been accredited by Clinical Pathology Accreditation (CPA) (UK) Ltd is an essential part of a successful renal transplant programme[9]. Crucial to the provision of a quality service are the staffing structure and personnel qualifications within the H & I laboratory. The laboratory must be directed by a Grade C Clinical Scientist or medical consultant with relevant H&I qualifications and experience. Consultant advice should be available outside normal working hours. Other healthcare scientists (clinical scientists/biomedical scientists, medical laboratory assistants, technicians[89]) must have completed a recognised training scheme in order to attain State Registration. The laboratory must provide 24 hour – 7 day cover for the HLA typing and crossmatching of cadaver organ donors[9,10,90].

3.7.2 The core responsibilities of the H&I laboratory is to provide HLA typing, antibody screening and crossmatching services to support the renal transplant programme.

Table 3.7.2
Components of the renal Histocompatibility and Immunogenetic Service

- HLA typing of patients in renal failure
- Detection and definition of HLA specific antibodies
- HLA typing and crossmatching of cadaver kidney donors
- HLA typing and crossmatching of potential living kidney donors
- Testing as required in order to comply with the Human Organ Transplants Act (1989)
- Clinical advice
- Education and Training
- Audit
- Research and development

3.7.3 The role of the staff in the H&I laboratory continues to develop as the tests available become increasingly complex and practice advances. There are currently 21 H&I laboratories in the UK supporting renal transplant programmes. The majority also support other organ transplant programmes, stem cell transplant programmes or the blood transfusion service. In the UK the service is provided by 151 wte Healthcare Scientists plus 14 Consultant Grade Scientists. The recent British Society of Histocompatibility and Immunogenetics staffing survey shows current staffing levels per 300 patients on RRT to be 0.09 wte Consultant Clinical Scientists plus 1.55 wte Healthcare Scientists.

3.7.4 The British Society of Histocompatibility Immunogenetics recommend 0.25 Consultant Clinical Scientists/Medical Consultant plus 2.32 wte Healthcare Scientists per 300 RRT patients to deliver a service consistent with the British Transplant Society and Renal Association standards, to comply with the working time regulations and to achieve the increase in cadaveric and living donor transplant rates in line with the Department of Health and UK Transplant objectives. The following staffing structure is recommended:

Table 3.7.4
Recommended staffing levels

- 1 wte Healthcare Scientist per 300 patients in RRT plus
- 0.6 wte State Registered Healthcare Scientist per 300 patients in RRT to support cadaver donor transplantation plus
- 0.72 wte State Registered Healthcare Scientist to support living donor transplantation plus
- 0.25 wte Consultant (Grade C) Clinical Scientist or Medical Consultant per 300 patients in RRT

In order to provide a viable out-of hours service, a laboratory must employ a minimum of 4 appropriately qualified Healthcare Scientists.

3.7.5 The British Society for Histocompatibility & Immunogenetics (BSHI) have a well established training scheme for new graduates entering the profession that leads to the BSHI Diploma in H&I. Guidelines for post basic training as a pre-requisite for State Registration have been developed and BSHI have highlighted an urgent need for higher specialist training posts to support the expansion of transplant programmes.

3.8 Renal Nurses and Healthcare Support Assistants

3.8.1 Renal nursing involves a wide range of activities supporting patients throughout their various care pathways and providing continuity during an individual patient's career with renal disease. The named renal nurse is often the key link professional for their patient to the system of care provided by the multi-professional team. The role involves patient and carer education, support and advocacy. In addition nurses require the clinical skills and competencies to manage renal patients in different stages of their illness and on particular renal replacement therapy modalities. Healthcare assistants work within the nursing team in skilled roles, usually within a discreet area of practice.

3.8.2 "A Health Service for all the Talents"[14] and "Agenda for Change"[91] describe the changing roles and aspirations of nurses. They provide a vision of a skills and competency based practice, flexible careers and an holistic approach to patient needs. Renal patients needs and expectations are also changing. Implementation of competency based frameworks for education and development of renal nurses and healthcare assistants will help address these needs. The nursing competency ladder is shown in figure 3.8.2 and an example of the competencies for peritoneal dialysis nursing can be found at www.britishrenal.org

Fig 3.8.2
The Nursing Competency Ladder

Level 8-10	Senior registered practitioner
Level 4-7	Intermediate registered practitioner
Level 4	Newly registered nurse NVQ Level III
Level 0-4	Health Care Assistant

3.8.3 Specialist practice roles are well established in renal nursing and include anaemia management, counselling, vascular access, transplant liaison and low clearance management. The skills required to practice at an advanced level include clinical practice, communication, teaching, problem solving and leadership[92]. In many units specialist nursing posts have been created in a reactive fashion to address service pressures. Not all posts are part of the funded nursing establishment. The modern career framework and the changing needs in practice will facilitate the emergence of further specialist nursing roles. Although it is not at present possible to make national recommendations for specialist nursing workforce levels, because of the different local models of service delivery, there is a need to provide the higher

education and development needed to undertake these roles and facilitate innovative practice developments.

3.8.4 Consultant nurses will play a key role in enabling an effective workforce culture and in the NHS modernisation[93]. Focussing on practice development, research and evaluation will help to create a learning culture that is patient centred, evidence based and continuously improving[94]. This initiative is likely to have a profound impact on renal workforce requirements over the next decade.

3.8.5 A comprehensive survey of renal nursing was undertaken by the British Renal Society in 2001 to provide baseline information. Summary of the levels of staffing in adult renal units in the United Kingdom is shown in the table below:

Table 3.8.5
Adult Renal Nursing Staffing Levels in England 2001 (BRS Survey 2001)

	No of units	**Skill mix** (qualified/unqualified)	**Nursing staff:patient ratio***
Maintenance HDx	70	2.7:1	1:5.1
Peritoneal Dx**	69	5:1	1:24
Renal wards*** (includes renal transplant wards)	70	2.5:1	1.2:1

* includes healthcare assistants
** includes community HD support in some units
*** equates to nursing staff to occupied beds

3.8.6 Haemodialysis nursing requires the skills and competencies to manage both the technical aspect of the haemodialysis process and the holistic care of patients receiving this form of renal replacement therapy. In the past, all patients commenced dialysis in central units and a proportion of stable patients were subsequently transferred to satellite units without resident medical staff or co-located renal inpatient services. The majority of patients wish to dialyse close to their homes and most (greater than 80%) are now considered suitable for satellite dialysis such that the staffing levels and skill mix should reflect the patient case mix.

3.8.7 A staff to patient ratio of between 1-3 and 1-4 during dialysis with a skill mix of between 70% qualified:30% unqualified and 50% qualified:50% unqualified is recommended for both in-centre maintenance haemodialysis units and satellite maintenance haemodialysis units. The staffing ratios and skill mix should be assessed locally in relation to both case mix and patient dependency; and recruitment and retention. Table 3.8.7 below illustrates "added value" of the higher staffing and skill mix ratios to patient care.

Table 3.8.7
Haemodialysis nursing ratios and roles
Staffing Ratio

Skill mix	**1:3**	**1:4**
70:30	Patients of all complexity Nurse lead clinical review Training of nursing staff and healthcare assistants	Management of moderately complex patients Limited training and development opportunities
50:50	Managing patients of moderate complexity Task orientated/reduce trouble shooting	Basic maintenance haemodialysis for stable patients Protocol driven task orientated Limited training opportunities

To provide for an 18-station unit with 3 patient shifts per day, staffing levels as shown in the table below would be required.

Haemodialysis

18 station dialysis unit, 3 patient shifts per day. Patient to staff ratio 3:1, 70:30 registered to unregistered. 20% added to WTE for annual leave, sickness and training		
No of staff per shift	Level of skills	WTE
1	8-10	4.5
3	4-7	13
1	4	4.5
1	0-4	4.5
	TOTAL	26.5

18 station dialysis unit, 3 patient shifts per day. Patient to staff ratio 4:1, 50:50 registered to unregistered. 20% added to WTE for annual leave, sickness and training		
No of staff per shift	Level of skills	WTE
1	8-10	4.5
2	4-7	4.5
2	4	8.5
1	0-4	4.5
	TOTAL	22

This level of nursing support equates to a nurse (or healthcare assistant) to Maintenance Haemodialysis (MHD) patient ratio of between 1:4 and 1:5. This does not include the management of patients during their inpatient episodes when many dialysis patients require a higher level of support, nor does this provide for the training and community support for home haemodialysis patients.

3.8.8 Peritoneal dialysis is performed by patients (and/or carers) in the community. In most units the community dialysis team provides training and support for patients and carers at home, in nursing homes, district general hospitals or when patients are admitted to non-renal wards. To provide patients with comprehensive renal nursing care, a staff to patient ratio of up to 1:20 is recommended depending on geographical factors and travelling times. This would then enable training of patients at home or in hospital, monthly nursing visits and support at home, quarterly nurse led multi-professional clinic visits, troubleshooting, management of anaemia, ongoing patient education, performance monitoring and audit. Community dialysis nursing teams often also help support home haemodialysis patients who in addition require technical support at home.

3.8.9 Inpatient care for patients receiving renal replacement therapy or with significant renal disease is frequently due to dialysis related problems, the complications of renal failure or associated medical comorbidity. These episodes are best managed in a multi-professional renal ward environment by a team that can provide continuity and holistic care. The Royal College of Physicians have identified a requirement for 37 specialist renal beds per million of the population based on 2001 acceptance rates and practice[36]. Renal ward nursing involves acute general medical care, dialysis support and management of the inter-current illness. In many units surgical care skills are also required for patients undergoing dialysis access surgery or other surgical procedures in replacement therapy patients. Rehabilitation is a major requirement for all age groups managed on the renal wards.

The staffing levels required to manage renal inpatient care depend on the levels of dependency of patients and their nursing needs (Table 3.8.9).

Patients with a need for high level nursing care, eg single organ acute renal failure or replacement therapy patients with a severe inter current problem, can be managed in either a dedicated renal high dependency unit (HDU) or a general HDU/ITU that can provide intermittent renal replacement therapies. The staffing levels on renal wards need to be appropriate for the nursing needs of renal patients throughout the full 24 hours. Patients with dual or multipleorgan failure usually require ITU level of nursing support.

Table 3.8.9
Nephrology inpatients

Level of nursing need	Level of skills	Ratio (staff to patient)
Low	4-7	1:4
Medium	6-8	1:3
Increased	8-10 or 7	1:2
High	8-10	1:2 or 1:1

A typical 28 bedded renal ward and a renal ward with 22 beds plus 6 renal high dependency beds, staffed according to these principles, would require 35 wte and 46 wte respectively with a staffing structure as indicated in Table 3.8.10.

3.8.10 Renal transplant nursing care involves general surgical care, pre-transplant management (this includes dialysis and optimisation of fluid balance), immediate post-operative care and management of the complications of immunosuppressive drugs, rejection and chronic kidney disease. The Renal Association guidelines[9] recommend at least 4 beds pmp for renal transplantation but additional beds are needed to manage live donors and if access surgery is performed from these beds. The staffing levels and skills required reflect recipient dependency, high dependency needs in the early post-operative period and the skills to be able to manage the dialysis process and post transplant complications. The staffing ratios are similar to those for renal wards.

Table 3.8.10

Nephrology Ward of 28 beds	
Nursing staff	34.00
Clerical support	1.00
Level of skills	**wte**
8-10	3.00
6-8	15.00
4-7	6.00
0-4	10.00
Ward Clerk	1.00
TOTAL	**35.00**

Nephrology Ward of 22 beds + 6 Renal HDU	
Nursing staff	45.00
Clerical support	1.00
Level of skills	**wte**
8-10	5.00
6-8	20.00
4-7	8.00
0-4	12.00
Ward Clerk	1.00
TOTAL	**46.00**

Transplant Ward of 22 beds	
Nursing staff	24.50
Clerical support	1.00
Level of skills	**wte**
8-10	4.5
6-8	14.00
4-7	4.00
0-4	2.00
Ward Clerk	1.00
TOTAL	**25.50**

A "typical" 22 bed renal transplant ward providing transplant and renal related surgery would require 25.5 wte with competency levels as shown above in table 3.8.10.

3.9 Renal Dietitians

3.9.1 Patients with renal disease have complex and changing dietary requirements depending on the degree of renal impairment, co-morbidity, modality of treatment, medications and inter-current events. Dietary modification can assist in management of hypertension and cardiovascular risk factors, improving phosphate control and optimising nutrition. Individualised dietary advice, in the context of the home environment, from specialist Dietitians working as part of the multi-professional team improves outcomes. This can be particularly challenging in patients from different ethnic and cultural backgrounds.

3.9.2 The Renal Nutrition Group in 1998 published "Setting Standards and Achieving Optimal Nutritional Status for Adult Renal Patients over 18 years Old"[95,96] which details the role and standards/guidelines for renal Dietitians (Table 3.11.2). The development of dietetic prescribing[97,98] in the management of hyperphosphataemia, vitamin and nutritional supplementation is likely to become established in the near future.

Table 3.9.2
Components of the Renal Dietetic Service[1]

- Assessment of nutritional status
- Developing and implementing a plan of nutritional care
- Providing a nutritionally adequate diet
- Patient and staff education
- Monitoring of nutritional targets/standards
- Production of educational materials
- Audit and research

3.9.3 In March 2001 there were 180 posts in the UK (142 in England), providing 146.7 wte in the UK. This equates to 1 wte per 260 RRT patients with a range of 1:140-675 patients.

Table 3.9.3
Renal Dietetic Workforce in the UK (March 2001)

Grade of Dietitian	WTEs in UK	%
Chief I	0.1	0.06
Chief III	11.2	7.6
Chief IV	1.55	1
Senior I	109.65	75
Senior II	23.8	16
Basic grade	0.4	0.3

3.9.4 The national shortage of Dietitians[99,100] has led to problems with recruitment within renal dietetics as recently highlighted by a survey carried out in 1999/2000 by the Renal Nutrition Group[1]. This survey cited the lack of career progression as an important factor which could be addressed by the development of dietetic consultant posts[2,14].

3.9.5 The Renal Nutrition Group have reviewed the dietetic workforce requirements and produced recommendations based on modality of therapy and, for inpatients, dependency of care, detailed in Table 3.11.5. Trained renal dietitians should manage dialysis and low clearance patients but the dietetic management of transplant recipients with stable function and many patients with general nephrological disorders can often be delivered by non-renal specialist dietetians. Dietetic assistants[101] also have an important role in supporting the renal dietetic team but are not qualified to advise patients on diet modifications.

Table 3.9.5
Renal Nutrition Group (UK) Recommendations for Dietetic Services

RRT Programme	New patients	Reviews
Pre dialysis / nephrology	1 hr for 1st appointment	6 hrs per year
Haemodialysis patients	2 hrs for 1st month	8 hrs per year
Home HD patients		3 hrs per year
CAPD patients	2 hrs for 1st month	4 hrs per year
Transplant recipients	3 hrs for 1st 3 months	2 hrs per year

Inpatient care

Recommendation for renal inpatient beds should be: -	
Renal ward	78 hrs per bed per year
Renal HDU/ITU	0.05-0.1 dietitian per bed per year[102]

3.9.6 These recommendations would equate to a requirement for 1 wte Senior I dietitian for 135 haemodialysis patients and 1 wte Senior I dietitian for 270 peritoneal dialysis patients on the assumption that 65% of time was devoted to renal replacement therapy patient contact time. A 28 bedded general ward would require 1 wte Senior II and 1 wte Senior I dietitian.

3.10 Renal Social Workers

3.10.1 Renal social workers care for the needs of patients at the interface of health and Social Service, addressing the practical, economic, social and psychological problems of patients and carers helping those with end stage renal disease to cope with chronic disease, disability and eventually death and bereavement. The main roles and responsibilities are detailed in the British Association of Renal Social Work Job Description[103]

Table 3.10.1
Renal Social Work

(a) Major responsibilities	(b) Areas of work
Statutory responsibilities The provision of information Advocacy and liaison Promoting patient choice and empowerment Participating in training, clinical governance and research Counselling	Pre-dialysis assessments Support to dialysis patients and carers Facilitating links with community services Post transplant adjustment to life post dialysis Supporting conservative management options Supporting palliative care options

3.10.2 Renal social workers should be part of the hospital social work team and have close links with other hospital and community based social workers and care assessors who also provide an important contribution to social work support for renal patients. Renal social work is often based at regional centres, covering large geographical areas. Even at District General Hospital (DGH) level, the catchment area may cover several Local Authorities. Renal social work therefore has to liaise with, and engage many community based services, often having different procedures, protocols and charges in relation to community care services. An extensive knowledge baseand negotiation skills are therefore essential to work with such a wide ranging variety of staff and skill mix within the community served by the hospitals.

3.10.3 There are no national guidelines for social work in healthcare and there is increasing concern that social work provision, as provided by Local Authorities, will increasingly focus on statutory responsibilities alone. The McLennan Report, the Social Services Inspectorate Report 1998[104], emphasises the importance of holistic care and the Kidney Alliance Report 2001, expresses concern that social work appears to be one of the most under-resourced areas in renal services, with staffing levels falling far short of those required to provide an adequate service[1]. The continuing crisis in renal social work provision almost invariably leads to inadequate specialist social work access for renal patients because 'crisis work' and statutory responsibilities take priority. Responsibilities for the funding and management of posts are unclear and ad hoc, with no national formula.

3.10.4 The Renal Special Interest Group of the British Association of Social Workers (BASW) conducted a survey of all renal social work posts in the UK and identified 54.9 wte renal social workers equating to 1 wte per 348 dialysis patients[105]. The ratio is 1 wte per 370 dialysis patients in England[4]. The survey established that 14% of renal units have no specialist renal social work support, 42% of posts are part time and 60% of posts are temporary.

3.10.5 The BASW Renal Special Interest Group[105] have reviewed the data from the survey and adjusted the recommendations from the Royal College of Physicians[3] in line with the National Job Description[1]. To provide an adequate renal social work service requires 1 wte post: 70 dialysis patients. This equates to 1 wte post:140 RRT patients. This includes pre-dialysis, transplant and palliative care work, taking into account the increasing number of high-risk patients, who are frail, elderly, have co-morbidity, or serious social problems. Each wte post should relate to a caseload of 30 active cases at any one time, and provide sufficient time for supervision, team meetings, collaborative work, staff development and participation in training and educational activities. Posts should take into account the geographic, socio-economic and ethnic distribution of the population served.

3.10.6 The NHS Plan[2] refers to "breaking down barriers between health and social services", recognising that cooperation in providing social care is vital, and social work expertise is integral to health promotion and chronic disease management.

3.10.7 Funding responsibilities for posts needs to be urgently addressed on a national basis. There is great concern about the temporary nature of posts and the heavy dependence on charitable funding (38%). The BASW Renal Special Interest Group recommends that, health commissioners reimburse the costs of renal social work provision to Health Trusts, by patient service agreement, and that Health Trusts purchase the service from the Host Local Authority. Thus, enabling social workers to work in the context of health in a multi-professional way providing links with the Local Authority, appropriate professional accountability, management and access to Local Authority resources for patients and carers.

3.11 Renal Clinical Psychologists

3.11.1 There is huge variation in the availability of clinical psychology support for patients with renal failure. Clinical psychologists working in adult renal services appear to be clustered in the South West, South Wales, Midlands and N. Yorkshire. There are currently 7 clinical psychology posts (2.5 wte) with dedicated renal time in the United Kingdom. This equates to 1 wte post: 15000 RRT patients. In units with renal clinical psychologists the range is 1 wte: 822 patients to 1 wte: 2205 patients. These posts represent qualified clinical psychologists and exclude assistant psychologists and other applied psychologists (e.g. health and counselling psychologists). In units without formal clinical psychology service provision, occasional referrals are made to clinical psychologists in community mental health or physical disability services. Renal social workers and renal counsellors provide significant aspects of psychological and social support but, to provide an effective high quality service, clinical psychology, social work and counsellor expertise needs to be available as part of the renal multi-professional team.

3.11.2 Clinical psychologists are essentially 'applied psychologists' and draw on a range of theoretical and scientific, evidence-based approaches in their delivery of care. Their roles in renal units are complementary to those of the renal social worker and counsellor. They offer psychological assessment and intervention for renal patients, their carers and families as well as clinical supervision for direct care staff, training on aspects of psychological care and consultation as well as conducting research, audit and service evaluations.

3.11.3 The major role of clinical psychologists in supporting renal programmes is in the provision of evidence based psychological assessment/interventions[106]. This involves work with patients with specific mental health problems drawing on a range of theoretical perspectives, e.g. cognitive – behavioural, psychodynamic, systemic. Problems might include anxiety, depression, specific phobias, trauma reactions, difficulties in adjusting to and coping with care regimes and treatments, associated behavioural and habit problems, as well as difficulties people encounter in their home, work and hospital relationships as a consequence of renal problems and treatment. These services are provided to renal patients and their carers in a number of settings.

3.11.4 As an appropriate response to the high demand for psychological services in renal units in the face of very limited human resources, another significant role of the clinical psychologist is to develop and supervise the delivery of appropriate routine psychological care by all renal unit staff. This may be via ward based clinical supervision with direct care staff, training courses e.g. managing challenging behaviour, understanding why patients find it difficult to change their behaviour, patient focussed clinical consultancy to multi-professional teams, as well as promotion of and participation in unit-wide initiatives e.g. promoting a patient-centred framework of care, developing patient networks. They are also involved in developing population specific psychological interventions e.g. specialised assessments for living-related donor families.

3.11.5 Specific professional recommendations for adult renal clinical psychology services do not currently exist. The British Psychological Society – Division of Clinical Psychology recommends that workforce planning be based on both population size and population needs[107]. Recommendations from other areas of physical healthcare such as HIV/AIDS, oncology and cystic fibrosis have made recommendations using various formula e.g. 0.5 wte per medical consultant, minimum of 3 wte per cancer centre and 0.4 wte per 50 patients for each specialist cystic fibrosis centre[108,109]. Caseload and complexity in renal healthcare shares some similarities with these other services so provide some guidance. These recommendations are for appointments to the Consultant Grade (Grade B) to provide the seniority that is necessary to establish and co-ordinate appropriate psychological care systems.

3.11.6 Based on current available evidence and information provided by clinical psychologists working in renal services it is recommended that clinical psychology needs would be met by a minimum of 1 wte clinical psychologist per 1000 RRT patients in units with adequate renal social work and renal counselling workforce. In the absence of such support, requirements would increase to a minimum of 1 wte per 500 RRT patients. This level of resource would enable provision of direct work with patients, staff support and consultancy, staff training, research and audit to fulfil clinical governance requirements.

3.11.7 There is currently a dearth of research to formally describe the range and evaluate the severity of the psychological difficulties experienced by patients within the renal population. The recommendations for renal clinical psychology support should be reviewed in subsequent workforce planning cycles based on co-ordinated national and local surveys of psychological needs[110] (see figure 3.12.6).

3.12 Renal Counsellors

3.12.1 There is, as with clinical psychology, a huge variation in the availability of counsellors within renal units. Counsellors working in renal units appear to be found mainly in London, the South East, East Anglia, Midlands and Belfast. There are 16 identified counselling post with dedicated renal time in the United Kingdom. These posts represent qualified counsellors, psychotherapists and include one cognitive behaviour therapist.

3.12.2 Counsellors provide a wide variety of services and interventions, this is often dependent upon their individual contracts and job descriptions which tend to have evolved locally within individual renal units rather than having guidelines at a national level. The work often involves crisis management, counselling related to emotional distress, bereavement and loss, enhancing patients ability to understand in order to make informed decisions and collaboration with multi professional teams regarding treatment planning and working with patients with competing health problems.

3.12.3 The major role of counsellors in renal programmes is in direct work with patients. Counselling involves more than support to help meet the psychological or social needs of patients and carers. It is a specific activity involving information giving, implications counselling, supportive counselling and psychotherapeutic counselling. The first two levels are often seen as a routine part of renal care for all patients. Formally defined counsellors, who tend to have more theoretically informed approaches, can provide the latter. Their roles are complimentary to those of the renal social worker (section 3.10) and clinical psychologists (section 3.11) and they deal with a similar range of problems encountered by renal patients, their carers and their families.

3.12.4 Counsellors involved in living donor programmes support informed decision making, exploring changes within family relationships, guilt and overt/covert pressure to receive/donate, and support/counselling post transplant surgery in both successful and unsuccessful outcomes.

3.12.5 The British Association of Counselling and Psychotherapy (BACP) has produced an 'Ethical Framework for Good Practice in Counselling and Psychotherapy' but specific recommendations for renal services have not been made[111].

3.12.6 The psychosocial needs of individuals affected by renal disease need to be quantified to identify their frequency, range and complexity. The skills and competencies to address these needs can then be defined. In parallel a more detailed census of the current workforce providing counselling support needs to be undertaken. (See figure 3.12.6) Recommendations on renal counselling requirements can then be incorporated into future workforce planning cycles.

3.13 Renal Clinical Technologists

3.13.1 Haemodialysis is an advanced technology requiring high specification dialysis and water treatment equipment. Renal technologists provide "traditional" equipment management (maintenance, calibration and repair) and Quality Management and Controls Assurance[112]. The multi-professional role of the technologist includes education and advice for patients and staff, advice on the design, installation and commissioning of new dialysis facilities and often administrative and/or IT support[113].

Table 3.13.1
Breakdown of time spent on activity (ART survey 2001)

Activity	Average time spent %	Range %
Equipment Management	72.2	35 – 94.5
Water Treatment	8	0 – 20
Administration	10.1	0 – 28
Computing/IT	2.2	0 – 22
Education	4.1	0.5 – 20
Health & Safety	1.7	0.5 – 5
Research and Development	1.7	0 - 14

3.13.2 As with other groups, Renal technologists play an important, but often unrecognised, part in modern healthcare[89]. The NHS Plan[2] and Making the Change[89] sets out a challenging agenda and modernisation programme that requires the skills and experience of scientists and technicians. The Association of Renal Technologists recommends a staffing structure for clinical technologists, outlined in Agenda for Change[91], which is supported by the development of a competency based registration framework.

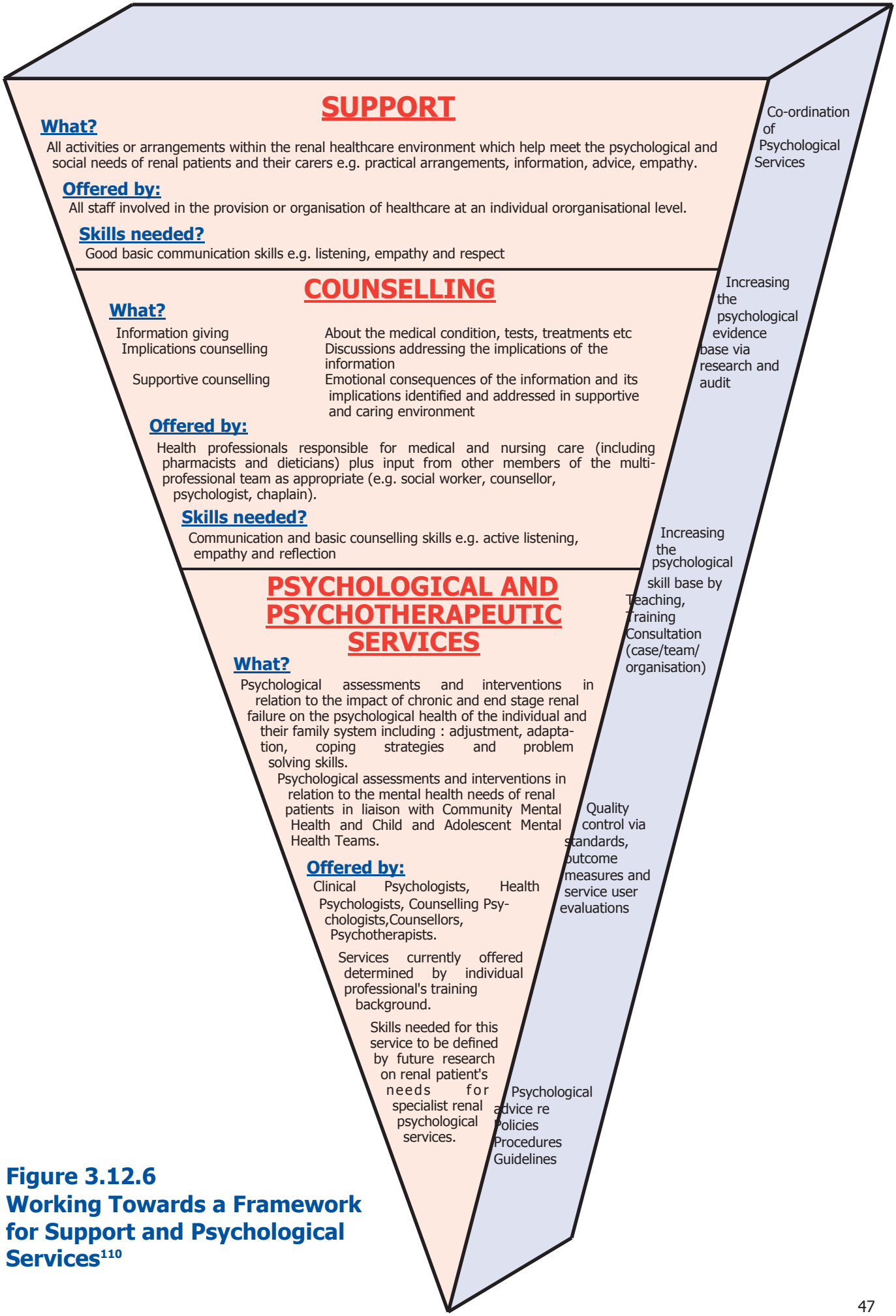


Figure 3.12.6
Working Towards a Framework for Support and Psychological Services[110]

3.13.3 Technical backup from suitably trained technologists is considered to be of critical importance in the provision of regular dialysis for a RRT programme. An important aspect of their role is carried out in the clinical area. Technologists provide advice and support during dialysis to nursing staff and home patients. The Kidney Alliance Report[1] has highlighted shortage of technical staff. The Association of Renal Technologists' (ART) Survey in 2001 identified poor promotional prospects and inadequate access to education and training as significant factors responsible for the shortage of technical staff. Currently there are some 180 renal clinical technologists in England which gives an approximate ratio of 1 wte technologist:60 haemodialysis patients (including unit, satellite and Home Haemodialysis).

3.13.4 Adequate staffing levels need to be considered on the basis of a range of local factors including the number of home haemodialysis patients, total number of haemodialysis patients and number of dialysis stations operating in main and satellite units. The contribution of renal technologists to other aspects of service delivery and development also needs to be considered. A ratio of 1 wte clinical technologist: 50 unit based haemodialysis patients is recommended as a minimum requirement. Where a home-based haemodialysis programme exists, the ratio should reflect this and a ratio of 1: 20 home patients is recommended as a guideline. Dialysis is provided over a 6-day working week and technical support is also required out of hours for emergencies[3]. This will require a minimum of 3 technicians.

3.13.5 The introduction of Modernising Regulation[114] should enable better definition of career pathways, which may assist in recruitment, and retention of staff. The training and education of clinical technologists working in renal healthcare should include physiological measurement techniques as well as medical engineering. The introduction of a diploma level course for renal technologists and a graduate training scheme with renal technology as a recognised speciality conforms to Modernising Regulation.

3.14 Renal Pharmacists

3.14.1 Patients with renal disease or on renal replacement therapy require a large number of medications[115,116]. The alteration in drug excretion (as a consequence of renal failure) and the complexity of therapeutic regimens increases the risk associated with these medicines[116,117]. Medicines management by renal pharmacists is a core function of renal healthcare[117].

3.14.2 The pharmacist has a principal role in risk minimisation, therefore ensuring the appropriate medicine is delivered to the patient at the right time, in the right way and of the right quality at the best price[117]. Pharmacists have key roles as patient educators, in discharge planning and in medicines review schemes[116,118]. The introduction of new agents, development of protocols, education of other healthcare professionals and financial risk assessment also require pharmacy support[119]. Recent legislation allowing pharmacists to prescribe, either as independent or dependent prescribers will also affect the level and type of service provided by pharmacists[98].

Table 3.14.2
Components of the Renal Pharmacy Service[120]

- Clinical pharmacy service to wards, dialysis and transplant unit.
- Pharmacy lead outpatient medication review
- Formulary and guideline development
- Provision of medicines information to patients, renal staff and non renal pharmacists
- Education and training of other clinical staff
- Clinical governance to manage medicines' risk
- Monitoring analysis of medicines' use, costs and patient outcomes
- Clinical trials and evaluation of therapeutic agents and regimes
- Strategic planning and service development

3.14.3 There are currently 97 posts, providing 34 wte in the United Kingdom for renal pharmacy support[121]. This equates to 1 wte per 1120 RRT patients. This survey highlights large variations in renal pharmacy with no specialist pharmacist support in some units and up to 2 wte renal pharmacists in others.

3.14.4 The standards of pharmaceutical care for renal patients have been developed by the UK Renal Pharmacy Group[122] and these include:

- Standards for prescription review
- Standards for inpatient discharge planning
- Standards for patient medication counselling
- Standards for renal medicine information
- Standards for training of renal pharmacists

3.14.5 Provision of a comprehensive medicines management service as detailed in Table 3.14.2 and to the standards outlined in 3.14.4 require 1 wte renal pharmacist per 250 RRT patients. In transplant units additional pharmacy support of 1 wte per 60 transplants per annum is required.

3.14.6 In large units (with greater than 800 RRT patients) economies of scale can be achieved such that renal pharmacy requirements would be 3 wte for a non-transplanting unit or 4 wte for a transplanting unit. These recommendations are based upon a detailed analysis of the average number of hours per week to deliver the various components of the renal pharmacy service seven days per week. A review of the skills and competencies required for the various roles should be undertaken. This would help clarify the role of pharmacy technicians and pharmacy assistants in supporting renal patients. Development of career pathways for specialist renal pharmacists is likely to be of help in recruitment and retention of staff.

3.15 Renal Unit Administrators and Managers

3.15.1 Dialysis involves complex logistics that require the co-ordination of patients, staff and consumables for an efficient service. Renal unit administrators support this process and patients benefit when administrators are core members of the renal multi-professional team. The importance of the Administrator-Patient relationship, particularly for home patients, in facilitating flexible and uninterrupted high quality patient care is often underestimated.

3.15.2 A standard renal unit administrator's job description does not exist but the majority of administrators have a range of responsibilities as indicated in table 3.15.2.

Table 3.15.2
The roles and responsibilities of renal unit administrators

1	Stock control, monitoring and procurement of dialysis consumables
2	Contract monitoring
3	Liaison with Local Authorities and agencies for community dialysis patients
4	Patient holiday dialysis arrangements
5	Reporting of financial and statistical information to relevant organizations

3.15.3 A survey conducted for this workforce planning exercise identified 65 renal unit administrators in the UK from a range of professional backgrounds – nursing, technical and ancillary and clerical. This equates to 1 renal unit administrator per 382 dialysis patients.

3.15.4 From analysis of the current workload and review of best practice, the Association of Renal Managers recommends a ratio of renal unit administrators to dialysis patients of 1:150 to provide an efficient, timely and responsive service for patients commencing and maintained on dialysis.

3.15.5 The general management of renal services is configured differently in individual Trusts. A dedicated general manager often shares responsibility with senior clinical staff supported by the renal unit administrator. The roles and contributions vary from time to time and team to team. In this model, the renal manager will have responsibilities for strategic planning and development, service provision and delivery, financial and budgetary control and the implementation of national and local health policies. The model of service and management issues differs from site to site and it is not possible to provide a national recommendation for renal general manager workforce requirements. However, strategic and operational management of complex processes across geographic, professional and institutional boundaries is required for a patient centred service. Sufficient time and resource for these activities should be made available within the departmental or directorate job plan.

3.16 Occupational Therapy and Physiotherapy

3.16.1 The ability of renal patients to maintain independence and to function optimally often requires assessment and support from occupational therapists and physiotherapists. The increasing age and complex co-morbidity of patients with renal disease is often compounded by late referral. The consequent malnutrition, prolonged hospitalisation and the impact of unplanned dialysis requires intensive rehabilitation. Delays in establishing permanent vascular access and maintenance on inappropriate modalities of dialysis can lead to similar problems and rehabilitation needs. In addition, recurrent episodes of illness and hospitalisation related to infection, surgery and cardiovascular disease are persistent causes of muscle wasting which requires continuing rehabilitation support.

3.16.2 Occupational therapists' assessment of patients' needs for aids in the community is an increasingly frequent pre-requisite to enabling patients to make informed choices about the modality and location of dialysis treatment. For many self-care patients, both peritoneal and haemodialysis, occupational therapy recommendations can improve training and extend technique survival. In patients receiving maintenance haemodialysis occupational therapy input can enable patients to remain independent in their homes.

3.16.3 Exercise rehabilitation interventions in chronic renal disease have been shown to improve physical functioning and quality of life[123]. In addition, exercise during haemodialysis may improve dialysis efficiency.[124]. However, few units offer patient advice or exercise/fitness programmes. Many patients with co-morbid vascular disease, diabetes or commencing dialysis late with malnutrition require physiotherapy provision to regain activity and independence.

3.16.4 There is an urgent need to quantify the occupational therapy and physiotherapy needs of renal patients and to consider the most appropriate models of care. Access to these services is variable and often dependent upon on a "grace and favour" basis with no provision for the extra commitments required.

3.17 Conservative management of ESRD

3.17.1 In the past, attitudes to frail, elderly patients with chronic uraemia, and those with co-morbid conditions, resulted in few referrals to renal teams for consideration for treatment. Now, with a far better understanding of the benefits of renal medicine and patients' rights, referrals are increasing, resulting in difficult decision-making for all concerned. Of those referrals, some patients will be unsuitable for dialysis, and others may choose not to dialyse. Renal medicine has the potential for therapeutic management of conservative treatment, and will be increasingly required to meet this sensitive area of service provision[1].

3.17.2 The rights of patients to information and full discussion of their condition and treatment options, should facilitate informed, decision-making. Those patients unsuitable, medically for dialysis, and those who choose conservative management for their renal failure, need to be assured of continued support. They have a right to expect co-ordinated and planned care, which respects their wishes, and is aimed at alleviating symptoms, promoting independence for as long as possible, assisting with care options at the end of life, and providing emotional support for them and their families/carers, in an appropriate and culturally, sensitive way.

3.17.3 Once a patient has been given good information and is aware of their options, the multi-professional team can assess their physical and psychological and social needs. Possible future care options can be explored, including funding issues, and liaison with potential sources of support in the community can be identified e.g. nursing and domiciliary support services, nursing homes, hospices and voluntary agencies, specialising in the support of the terminally ill. Shared care arrangements between specialist units and primary care services, can provide continued monitoring and promote well-being. Good liaison and communication is vital, if the multi-professional team is to help the patient/carer make the best possible use of available resources, in the statutory, private and voluntary sectors. The avoidance of unnecessary and disruptive admissions to acute hospitals, may be made possible by an integrated approach[125]. Continued outpatient clinic reviews, to stabilise and maximise renal function, and an agreed policy of admission in difficult cases of symptom control, may be necessary. Many patients are readmitted, and die in hospital, due to lack of information, poor symptom control, lack of support for carers, lack of appropriate home nursing aids, and financial/practical care problems[126].

3.17.4 Good renal, palliative care depends on understanding the needs of the dying and their carers. A joint, holistic approach is necessary, with the ability to respond in a multi-professional way to patient's physiological, practical, emotional and financial needs. Traditional ambivalence about coping with death can hamper appropriate responses from professional staff, unless good training and support are provided to help shift the focus from "curative" work to a compassionate, monitoring role[125]. Adequate preparation, co-ordinated care, and continued

support are the key issues to well-planned care, according to the patient's wishes. The needs of relatives/carers can be met by open discussion, advice and the opportunity to ventilate feelings and anxieties. Bereavement counselling is essential[127].

3.17.5 Providing conservative management of renal failure has considerable workforce implications, in terms of staffing levels, skills required, and appropriate training to undertake sensitive, urgent work. Advocacy and liaison work across professional and inter-agency boundaries requires time and collaborative working practices[128]. However, the gains in terms of best practice, patient choice, and carer's support, are immense, making the inevitability of death more acceptable, minimising distress, and supporting quality of life for as long as possible.

SECTION FOUR

RENAL SERVICES FOR CHILDREN AND YOUNG ADULTS

Section 4 Renal Services for Children and Young Adults

4.1 The Challenge for Multiprofessional Teamwork

4.1.1 The diagnosis of a chronic renal illness, particularly one which is going to lead to the need for renal replacement therapy, impacts on every aspect of a child or young person's life. Like throwing a stone into water, the ripples created by this diagnosis spread out to include parents and carers, siblings, extended family, educational and social networks. An assumed future based on the child's past social, emotional and intellectual development is challenged and replaced with one of uncertainty about everything, a psychological state recognised as potentially leading to stress and anxiety. In this sea of uncertainty the paediatric renal team becomes a focus for the child and family to seek specialist support, advice and guidance in relation to emotional, social and educational issues in addition to the medical care on which the child's well-being is dependent.

4.1.2 The need for multidisciplinary resources within the paediatric renal team has been historically recognised[4]. Since this report further legislation, guidance and research[129,130,131] has supported the rights and needs of children and young people to access services which will enable them to fulfil their developmental potential and maintain a reasonable quality of life whilst managing a chronic medical condition. The challenge for the paediatric renal team is how to meet those needs as part of an integrated and co-ordinated model of service provision which is part of a network including primary, secondary and tertiary healthcare systems, locality and specialist social work systems, mainstream and hospital based education systems and voluntary agencies. To meet these needs, in partnership with the child and family system, the paediatric renal team will need to:

- Participate in a shared philosophy of working in partnership with children, young people and carers which reflects multi-agency as well as multi-disciplinary philosophies for service provision
- Be party to shared protocols, guidelines and agreed care pathways
- Contribute to effective communication between all points of the network
- Identify and communicate what resources are available within the team and how to access them
- Provide and develop services which are evidence based and reflect multi-disciplinary audit and research on service user needs as well as efficacy of interventions and treatments
- Show evidence of service user involvement and feedback in future service developments within the framework provided by the external peer review process

4.1.3 To achieve the above, workforce planning has to include sufficient resources within the team to

- Respond to the social, psychological and educational needs of the child and family system in addition to the clinical needs resulting from the child's medical condition as part of an integrated package of care. This may require:
    - Direct work with the child and or family
    - Consultation with other professionals within or without the renal team
    - Liaison within or without the renal team
    - Referral on to or accessing services without the renal team
- Enable all members of the multi-disciplinary team to have time to address the processes which lead to effective team functioning (e.g. attending multi-disciplinary meetings which analyse and review service delivery systems, contributing to multi-disciplinary audit and research)
- Value and invest in the continuing professional development and clinical supervision needs of all members of the multi-disciplinary team[132].

4.2 Context for change

4.2.1 The numbers of patients with end stage renal disease cared for in Paediatric Units continues to increase (tables 4.2.1 and 4.2.2).

Table 4.2.1
Stock of children on RRT in the United Kingdom 1986-2001

Year	Total number of children of ESRD management	Percentage change Since 1986
1986[4]	263	
1992[4]	429	+63%
2001[30]	818	+211%

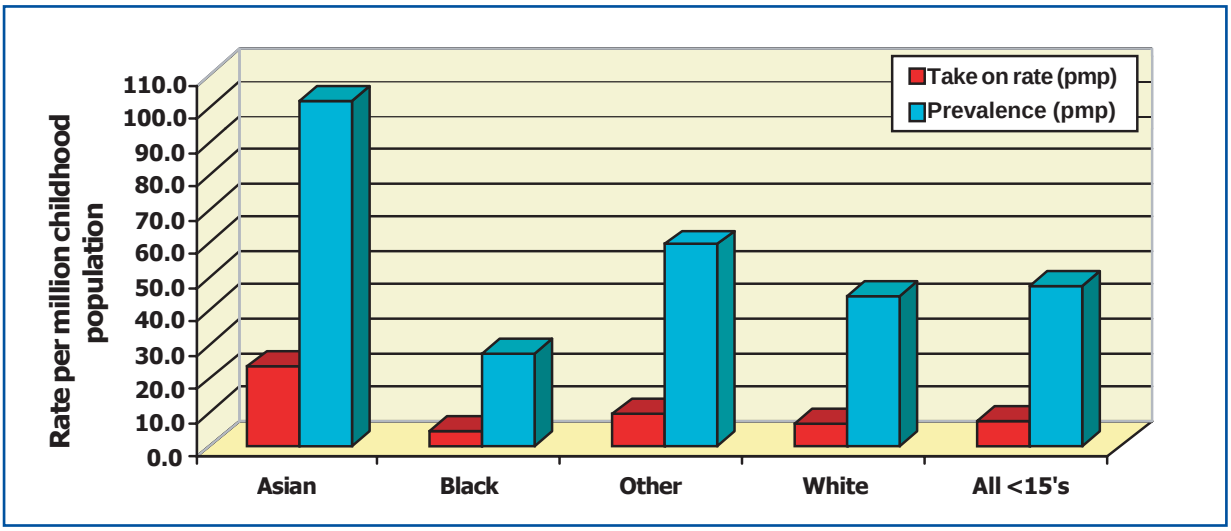
Table 4.2.2
Stock of children on RRT April 2001 by treatment modality[30]

Age	No	%	HD	CAPD	CCPD	Tx
0-1.99	11	1.3	0	0	11	0
2-4.99	58	7.0	14	2	14	28
5-9.99	152	18.5	10	1	22	119
10-14.99	308	37.6	23	8	27	250
15+	289	35.3	22	3	34	230
Total	**818**	**100**	**69**	**14**	**108**	**627**

4.2.2 The complexity of these patients has also increased significantly. At the time of the 1995 report the majority of patients had renal failure with no other complicating factors. A number now have had previous transplants of other organs. Many have other medical or developmental disabilities. The majority of patients have disease from early in childhood which predicts for higher psychosocial morbidity.

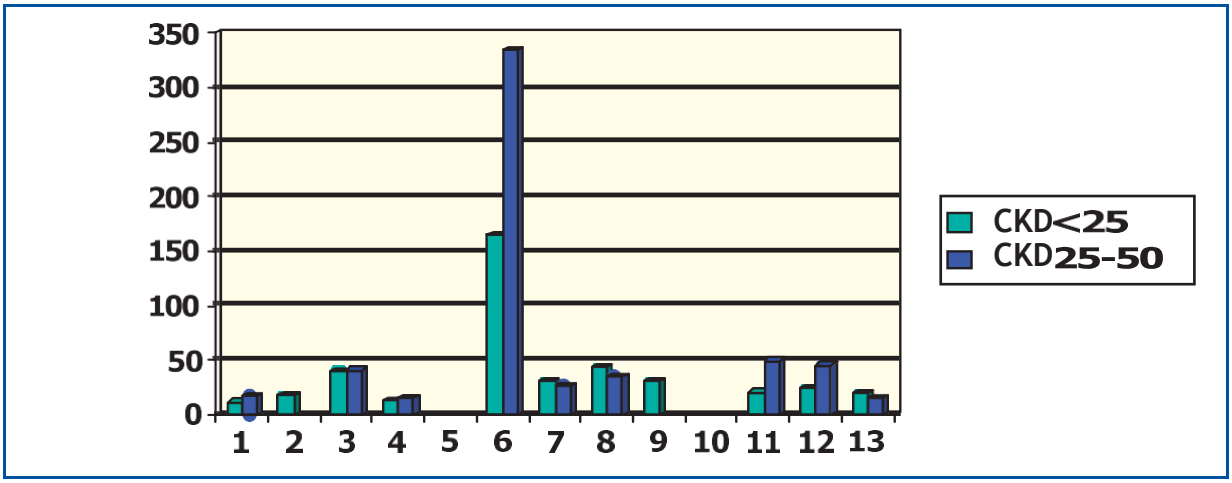
4.2.3 There is significant increase in the incidence of ESRD in some ethnic minority groups[30].

Figure 4.2.3
Prevalence of ESRD in children and take on rate of new patients broken down according to ethnicity[30]



4.2.4 Intensive management of pre-end stage renal disease in children has improved growth and rehabilitation[133] and may delay the onset of end stage renal failure. Many of these children have congenital renal disorders and intensive management involves major input throughout the whole of childhood. The British Association of Paediatric Nephrologists (BAPN) Audit in 2001[132] showed one Unit was treating many more pre end stage renal disease patients than all the other Units (see figure 4.2.4). It is highly probable that the higher number of patients treated in this one centre is more representative of the workload of pre-end stage renal failure.

Figure 4.2.4.
Number of pre-end stage renal disease patients followed at each centre



4.2.5 Considerable numbers of children with chronic renal problems, both renal failure and others, are now surviving into adult life. There are significant risks of problems, including transplant loss, as these patients move into adult services[134]. Specialised transitional services for this group of patients are poorly developed.

4.2.6 Despite the significant increase in numbers on end stage renal failure management in children these remains high cost, low volume activity. Organisation of services needs to balance the minimum size of centres necessary to maintain expertise against geographical accessibility[4]. Future workforce requirements should be based on each units needs to be able to provide a comprehensive 24 hours a day service.

4.3 International Comparisons

4.3.1 Access to and the delivery of paediatric nephrology services vary widely throughout the world. This is in part due to the different patterns of paediatric care in each country and also to the economic status.

4.3.2 The prevalence of ESRD is difficult to compare accurately due to the different ages included within the definition of paediatrics in different countries. However, some comparative figures are presented in table 4.3.2.

Table 4.3.2
Prevalence of end stage renal disease in children per million child population (pmcp)

Year	Country	Prevalence of ESRD (pmcp)	Comments
1999[11]	UK	53.4	0-18 years. Some 16-18 year olds are managed in adult units and are not included
1996[135]	USA	58.75	0-19 years
1990[136]	France	37	Less than 16 years of age
1999[11]	UK	47.5	Less than 15 years of age

4.3.3 Currently there are 37.8 WTE paediatric nephrologists in the UK plus 4 vacant posts (see below). This approximates to 2.7 WTE pmcp (total population under 18 years 14,000,000).

4.3.4 Some comparative numbers from other countries are presented in table 4.3.3. Thus there are approximately twice as many paediatric nephrologists pmcp in the USA[135]. In Europe the picture is very variable and the number of paediatric nephrologists in the UK approximates to the median number in Europe[137]. However, in many European countries specialist paediatric practice extends into secondary and primary care. Thus, in addition to the 842 paediatric nephrologists, there were 1087 paediatricians with an interest in nephrology[137]. If account of these posts is included the number of paediatric nephrologists in the UK is one of the lowest in Europe.

Table 4.3.4
Number of paediatric nephrologists per million child population – International Comparisons

Year	Country	No of Paediatric Nephrologists	PMCP	Comments
2002	UK	37.8	2.7	See table 4.4.2 for more details
1995[135]	USA	383	5.3	
1998[137]	Europe	842	1.4-15 (below median 5.9)	Data from 40 countries
1998[137]	Europe	1,929	3.2-34 (below median 13.51)	Paediatric Nephrologists + Paediatricians with an interest in nephrology

4.3.5 The above figures show an under provision of medical staff for paediatric renal services. A review of paediatric renal services which is to be published[132] shows an even greater inequality in access to all other members of the multiprofessional team.

4.3.6 There is debate currently about the numbers of units that are required to allow equality of access to balance with the base population that allows adequate experience for all members of the multidisciplinary team, an appropriate number of nephrologists and training facilities. In Europe in 1990 a median of 1.4 centres pmcp provided a 24 hour service with a median of 4 paediatric nephrologists per centre[137]. In the UK the current provision is 1.09 centres pmcp providing 24 hr cover with a median of 3.25 WTE per unit[132]. Therefore it is significantly less than the provision in Europe 12 years ago.

4.3.7 The national comparisons show Paediatricians with a special interest in nephrology undertake a far greater workload in nephrology than currently occurs in the United Kingdom[137]. Currently there are only 3 or 4 such Consultants in the United Kingdom. There is considerable scope to increase the number of such Consultants, particularly in teaching centres which do not have a nephrology/dialysis or nephrology/dialysis transplant centre. Such posts could take on a significant workload in non end stage renal disease management and support other specialities within their own centre.

4.3.8 The American Society for Pediatric Nephrology, in conjunction with other nephrology societies has assessed the number of paediatric nephrologists that will be required by 2010[135]. The number of patients with ESRD under the age of 19 in 1996 was 5244 and the expectation is that the figure would rise to 5970 by 2010. The workforce analysis predicted a need for 9-12 trainees per year in paediatric nephrology but this was thought to be an underestimate due to the increasing roles expected of the Nephrologist, the "contraction" of clinical career due to onerous on call commitments and the move of some into less clinically active roles. The recommendation of the Ad Hoc Committee for Pediatric Nephrology Work Force was for 18-20 entries in to the training programme per year[135].

4.3.9 There is a worldwide crisis in recruitment to paediatric nephrology with many unfilled posts in the USA, Europe and UK. This is creating a vicious circle in which the onerous on call commitments are exacerbated by the vacant posts which are a further disincentive to trainees opting for paediatric nephrology training. Many of the on call demands are generated by the need to support other specialties and are not captured in workload data, which relate only or predominantly to the ESRD population.

4.4 Paediatric Nephrologists

4.4.1 Paediatric Nephrologists provide a wide range of clinical services for children with kidney disease. This occurs within both tertiary referral centres and by offering support to surrounding secondary services. This support includes telephone advice, management protocols and shared care clinics. Within the tertiary centre the Paediatric Nephrologists offer support to many other specialities particularly Paediatric Intensive Care and Neonatal Intensive Care.

4.4.2 The strategy for provision of services has been set out in 3 previous reports[4]. Currently tertiary paediatric nephrology is delivered by 13 centres in the United Kingdom, 10 in England, one each in Scotland, Ireland and Wales. 10 of these centres currently provide a comprehensive service including dialysis and transplantation whereas 3 offer dialysis only.

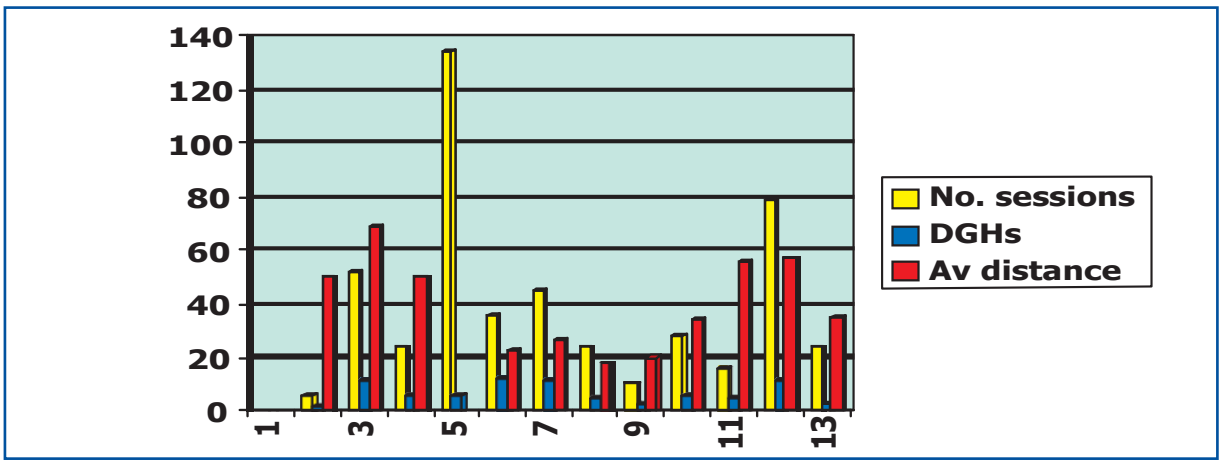
4.4.3 The terminology to describe the different units is not agreed and can be confusing. Furthermore, the function of different units has changed and will continue to do so in the future. In this report we have used the following terminology:

- Nephrology/dialysis/transplant centres
- Nephrology dialysis centres
- Nephrology centre
- Secondary service with Link Paediatrician

4.4.4 Nephrology/dialysis/transplant centres, and nephrology/dialysis centres will be staffed by Paediatric Nephrologists. Nephrology centres will be staffed by Consultants with a special interest.

4.4.5 Lack of Consultants significantly affects equity of access to Paediatric Nephrology services. Provision of clinics in district hospitals, which is an essential element of taking the service to the patients and their families, illustrate this. Some centres were not able to support any shared care clinics whereas one unit was able to support 134 sessions in a year, that is a monthly clinic.

Figure 4.4.5. Number of shared care clinics[5]



4.4.6 The effectiveness of shared care clinics would be further increased by the identification of a Link Paediatrician. Such a paediatrician might have a number of other link clinical roles in other specialties and it would not be possible to train in all areas so at appointment they might have no experience of nephrology. The role of such an individual would be limited initially but would grow as they, supported by the Paediatric Nephrology team, gained clinical experience. They might, other duties permitting, wish to attend specialist renal clinics to broaden their experience. Their roles would include:-

- Attending the nephrology shared care clinic
- Ensuring that the secondary service was familiar with local care pathways and that they met the needs of the local population
- In discussion with the Regional team they would filter referrals to the Shared care clinics
- Taking referrals from colleagues of more complex cases which otherwise might need to go to the Specialist Unit
- Attending an annual Paediatric Renal Network meeting

4.4.7 The numbers of consultants in post in May 2002 and estimated requirements for consultants are shown in table 4.4.7. This data is taken from a survey conducted by Dr Mark Taylor in May 2002.

Table 4.4.7
Consultant Numbers in October 1994, and May 2002 and Estimated Consultant requirements in 1995 and 2002

Centre	Consultant Whole Time Equivalents (plus Academic Appointments)				
	Consultants in post October 1994 +(Academ)	Target suggested in 1995 report[4]	May 2002 Actual NHS + (Academ)	Proposed target	Deficit against target
Birmingham	3	5.0	2.8	6.0	3.2
Bristol	3	4.0	3.6(0.4)	5.0	1.4
Leeds	2(1)	4.0	2.5(0.5)	5.0	2.5
Liverpool	2	4.0	3.0	5.0	1.5
London GOSH	3(2)	6.0	3.8(2)	7.0	3.2
London Guys	2(2)	6.0	3.5(0.5)	7.0	3.5
Manchester	3	5.0	4.0	6.0	2.0
Newcastle	2	4.0	3.5	5.0	1.5
Nottingham	2	5.0	2.0	6.0	4.0
Southampton	0	4.0	2.0	5.0	3.0
N'Ireland	1	4.0	1.5(0.5)	5.0	3.5
Scotland	2	4.0	4.0	5.0	1.0
Cardiff^	2	4.0	1.6(0.4)	5.0	3.4
Totals	**27(5)**	**59**	**37.8(4.3)**	**72.0**	**33.7**

4.4.8 The American survey previously referred to, identified that the majority of Paediatric Nephrologists had a substantial academic role[135]. In contrast in May 2002 there were only 4.3 whole time equivalent academic Paediatric Nephrology posts in the United Kingdom and this was a reduction from the numbers in October 1994. The burdens of clinical work severely limit the research activity of the other Consultant Paediatric Nephrologists. Education, audit, clinical governance, management and administration are all increasing the pressures on consultants' time[138].

4.4.9 Table 4.4.7 also includes the numbers of consultants the BAPN report in 1995 suggested[4]. Despite the aspiration for 59 consultants between 1995 and 2002, an expansion of 32 posts, there were only 10.8 new posts (and a small reduction in academic posts). There are a number of reasons for this lack of consultant expansion including:

- The numbers were never actively endorsed by the college or the department
- Drivers for consultant expansion have been largely issues of capacity. Children with acute or chronic kidney disease require immediate treatment and hence paediatric nephrology has not benefited from consultant expansion to meet capacity problems

This uncertainty has also affected recruitment; there are currently a number of unfilled consultant posts.

4.4.10 To ensure that the present problems are resolved and the inherent difficulties in planning in a small specialty it is essential that planning takes place on a national basis. The establishment of the National Training Grid has been a great advance but unless this is matched by a linked, planned expansion of consultant posts there is a danger that the output of trainees will increase but they will not have posts to go to.

4.4.11 There will be more University Departments of Child Health and/or Paediatric Intensive Care Units (PICUs) than there are nephrology/dialysis+/- transplant units. These units could be the focus of new nephrology units staffed by Consultants with a special responsibility for nephrology. Such consultants could not only support the other specialties within their centre but, in collaboration with thenephrology/dialysis/+/- transplant centre could develop managed clinical networks. This would allow for more care to be returned closer to patients' homes. Additional training positions would be required for these consultants.

4.4.12 The development of modular training programmes would allow trainees to access different levels of nephrology training. Training could then be tailored to the needs which range from secondary paediatrician, through link paediatrician to full time paediatric nephrologist.

4.5 Renal transplantation in children

4.5.1 As in adults, renal transplantation provides the best quality of life in children. There are added advantages of improved growth and psychosocial development, and conservation of peritoneal and vascular access for the future. Advantages of transplantation in paediatric patients are so great that it is an agreed standard that pre-emptive transplantation (transplantation before dialysis) should be undertaken whenever possible in children[9].

4.5.2 Paediatric renal transplantation is performed by the adult Renal Transplant Surgeons with support from the Paediatric Nephrology team.

4.5.3 Between 1986 and 1995 1,252 cadaveric renal transplants were performed in patients under 18 years of age. The numbers each year range from 96 to 148[139]. In subsequent years there has been no increase in transplantation in thispopulation age group and it seems unlikely the number of transplants in the paediatric age range will increase and it is possible there might be a small decline because of better preventative measures in pre-end stage renal failure and fewer graft failures.

4.5.4 125 of these transplants were performed in 21 non-paediatric centres. The remaining transplants were performed in 13 paediatric centres. Of these 13 paediatric centres 4 were performing greater than 10 transplants per year, 8 were performing 5-10 paediatric transplants per year and one was performing less than 5 paediatric transplants per year[139].

With the increasing number of Transplant Surgeons (see section 3.4), many of whom now have no previous or current experience of paediatric surgery, there is a need to re-consider the strategy for provision of paediatric renal transplantation.

4.6 Dialysis access services for children

4.6.1 Peritoneal access in paediatric patients is usually obtained by either a General Paediatric Surgeon or a Paediatric Nephrologist[132].

4.6.2 Central venous access in paediatric patients is usually placed by a General Paediatric Surgeon or occasionally a Paediatric Nephrologist[132].

4.6.3 A small number of children, often those who are difficult to transplant and have failed peritoneal dialysis, will end up on chronic haemodialysis. In these patients a planned strategy for management of vascular access is essential to their long-term survival both in childhood an adult life. A strategy for establishing vascular access in these children needs to be agreed which draws on expertise in the vascular surgical field.

4.7 Paediatric Renal Nursing

4.7.1 The roles of paediatric renal nurses do not differ fundamentally from those of their adult counterparts (see 3.8) but there are the added dimensions of growth and development, and support for the family including siblings[140].

4.7.2 A comprehensive survey of paediatric renal nurse staffing was undertaken by a multi-professional group under the auspices of the British Association for Paediatric Nephrology in 2001 to provide baseline information. This is summarised in table 4.7.2.

Table 4.7.2
Paediatric Nursing Staffing Levels127

	Nursing Staff: patient ratio	
	Common ratios	**Exceptions**
24 hour on call service	Provided by 4-9 staff (median 5.5)	Only 7 units were able to provide 24 hour cover
Haemodialysis <5 years of age	1:1	Occasionally 1:1.5 or 1:2
Haemodialysis >5 years of age	1:2 to 1:3	Occasionally 0.8:1 or 1:1
Home peritoneal dialysis case loads	<10 cases 5 units 10 –20 cases 5 units >20 cases 2 units	Data not available for one unit
Respite nursing service	Provided by only 1/13 units	
Baby sitting service	Provided by only 2/13 units[a]	

a. Funded by charity but staffed by nurses in their own time

4.7.3 Paediatric Nephrology Wards and dialysis units should be managed on a day-to-day basis by an Registered Children's Nurse with ENB 147/136[140]. There should be a minimum of two Registered Children's nurse per shift[141]. Ideally all nurses should possess this qualification. Similarly qualified nurses should be available for clinical support and advice at all times, on site or on-call to provide specialist advice, support and extra-corporeal treatments. Staffing requirements for inpatients are set out in table 4.7.3.

Table 4.7.3
Nurse staffing requirements for children's renal services

Treatment	Staff ratio
General paediatric nephrology beds	1:3 to 1:4
Acute dialysis/filtration/plasma filtration	1:1
In centre chronic haemodialysis < 5 years of age (and some patients with special needs) > 5 years of age	 1:1 1:2
Immediate post operative care of transplants	1:1 (for 48 hours for > 5 year olds; for 72 hours for < 5 year olds)

4.7.4 The responsibilities of Specialist nurses include preparation, training, community liaison and follow up. Caseloads for specialist nurses are given in table 4.7.4. In smaller units these roles may be combined.

Table 4.7.4
Case loads for specialist paediatric renal nurses

Patient group	Caseload
Pre-dialysis patients	1:3
Home peritoneal dialysis	1:1
Transplantation (outpatient follow up)	1:5
Respite care (including liaison with local facilities)	1 per centre

4.8 Paediatric Renal Dietetics

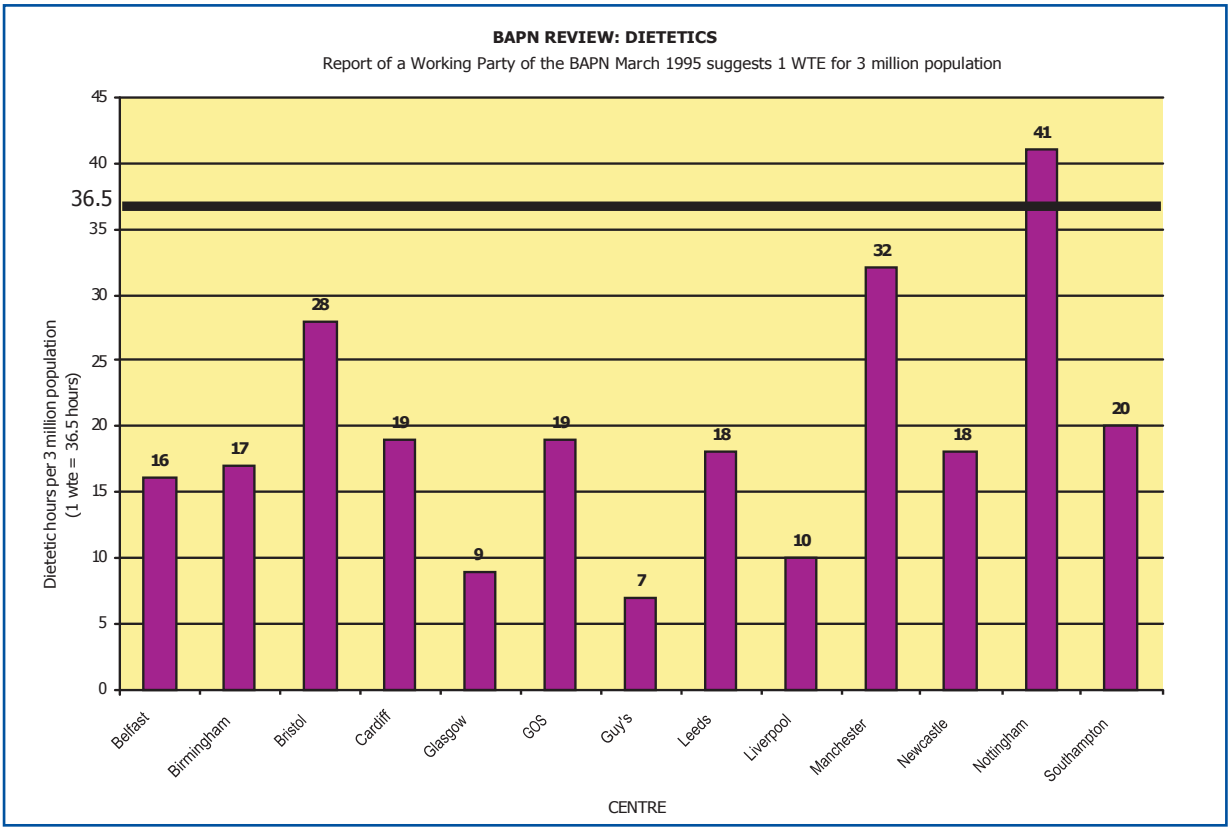
4.8.1 Paediatric dietitians working within the multi-professional renal team provide the specialised nutrition & dietetic service to all paediatric patients with renal disorders requiring dietetic support and to their carers. This includes preventative work in the pre-dialysis population, the nutritional management of the dialysis, and the transplant populations together with input into acute renal failure management and nephrotic syndrome with intensive nutritional involvement in congenital nephrotic syndrome.

4.8.2 Poor growth is well recognised in infants and children with renal impairment[133,142]. Input from a paediatric renal dietitian is essential to prescribe, monitor, and maintain satisfactory standards of nutritional care for each child because of the changing needs for growth and development[9,143]. The paediatric renal dietitian needs to interpret growth parameters when developing and implementing a nutritional care plan[144]. Recommended energy and protein intakes need to be aimed for using appropriate age related supplements. Where the infant or child does not meet their nutritional requirements and/or maintain an adequate growth velocity, especially in infants, supplementary feeding via nasogastric or gastrostomy tubes must be considered[145,146].

4.8.3 The paediatric renal dietitian liaises and works with the multi-disciplinary team members to discuss patient needs and support concordance especially with prescribed therapy as related to nutrition[147]. Liaison with schools and other health professionals including health visitors and community paediatric nurses is essential to providing holistic care.

4.8.4 The Report by the British Association for Paediatric Nephrology 1995[4] recommenced 1 WTE dietitian per 3 million population. In May 2001 there were 18 dietitians (10.9wte) providing the service to the patients at the 13 paediatric renal centres. The majority of posts were Senior I (72%) with only 25% holding the higher posts at Chief III. Only one unit met the 1995 recommendation; the majority of units correspond to half or below of this recommendation[132] (see Figure 4.8.4).

Figure 4.8.4
Dietetic workforce in 2001[132]



4.8.5 This under provision has resulted in a limitation to the service provided to those not on regular dialysis therapies. Specialist renal dietetic services can only be provided to local clinics by one unit. There are also limitations to practice development as a result of staffing shortages (Table 4.8.5).

Table 4.8.5
New or different ways of working in which the profession could develop

Working Practice	Barrier(s)
Evidence based practice. Clinical standards which can be audited against.	Poor evidence base in many paediatric dietetic renal areas. Staffing resources to undertake audit.
Dietetic Consultant posts.	Recruitment – candidates having sufficient knowledge and experience in this specialised area.
Dietetic prescribing e.g.; phosphate binders.	Staffing experience and resources to monitor. Establishment of competencies.
Dietetic led clinics e.g.; peripheral clinics, Pre dialysis and growth clinics.	Staffing resources.
Research role to improve evidence base.	Staffing resources.
Increased dietetic input into pre-dialysis clinics.	Organisation of consultant led clinics, staffing resources.
Shared care clinics; skill sharing	Time for development of shared care protocols. Time for training and liaison with local dietitians

4.8.6 A staffing level of 1 wte per 2.5 million population is recommended to provide a full service to all paediatric patients with renal diseases requiring dietetic support. This would enable dietitians to function as members of the multiprofessional team, undertake clinical governance and audit and provide support in the community and to local clinics (Table 4.8.6)

Table 4.8.6
Recommended staff levels for paediatric renal dietitians

Unit	Million Total Population	Current Dietetic Staffing		Recommendations For 1 WTE for 2.5 Million Population	
		WTE	Actual Hrs	WTE	HOURS
Belfast	1.68	0.25	9	0.7	26
Birmingham	5.5	0.8	30	2.2	81
Bristol	4	1	37	1.6	58
Cardiff	2.4	0.4	15	1.0	$36^{1}/_{2}$
Glasgow	5.1	0.4	15	2	73
GOS +	11.65	2	74	4.7	170
GUYS +	9.05	0.6	22	3.6	132
Leeds	3.6	0.6	22	1.4	53
Liverpool	3.1	0.3	11	1.2	44
Manchester et.	5.3	1.55	57	2.2	81
Newcastle	3.1	0.5	$18^{1}/_{2}$	1.2	45
Nottingham et.	5.5	2	74	2.2	81
Southampton	2.8	0.5	$18^{1}/_{2}$	1.1	41

NB: 1 wte = 36.5 hours

◆ These two units provide a quaternary service and the data for frequency of review needs further consideration in proposed staffing levels.

et. These two units are currently providing a widespread service to all Paediatric patients with renal disorders requiring dietetic support but report limited time for non-clinical activities.

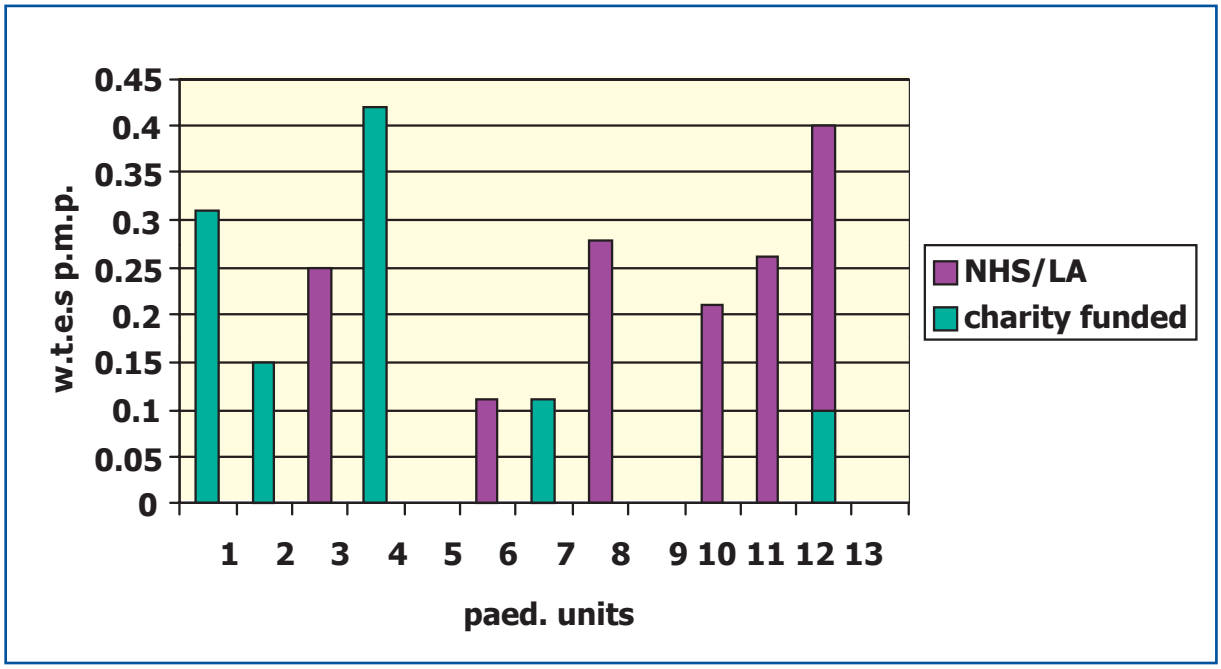
4.8.7 Future workforce planning should consider the roles of dietetic assistants, catering assistants and local dietitians (without specialist renal paediatric expertise) in the provision of service.

4.9 Paediatric Social Workers

4.9.1 The responsibilities of the paediatric renal social worker are similar to those of their adult counterparts (see section 3.10). Each new patient and their family circumstances should be assessed as soon as possible after the diagnosis to plan ongoing support and counselling throughout the illness. Any statutory duties such as child protection issues, need to be identified as soon as possible. The costs and strain on family life need to be freely acknowledged and information to families to enable them to gain maximum support needs to be given[145]. Social workers should work in the context of the multiprofessional team, liaising with community-based services and contributing particularly to the psychosocial aspects of the care plan.

4.9.2 The BAPN review revealed that 3 units had no social work provision[132]. Details of the staffing levels are given in figure 4.9.2. All the social workers in post are appointed at level 3 grade, the top of the practitioner Social Work Grading.

Figure 4.9.2 Social work provision[132]



4.9.3 Funding of current posts is perceived to be insecure. Charitably funded posts are usually for short term contracts and even Local Authority (LA) posts are under threat because of the wide geographical area paediatric renal units serve. Travel restrictions are imposed on certain units making it difficult to support patients receiving treatment at a distance. These issues are similar to the barriers encountered in adult renal social work and need urgent attention.

4.9.4 The BASW Renal Special interest group has looked at the staffing levels for paediatric services[105]. The recommendation is that is for a caseload of 30 cases for each social worker (approximately 0.4 WTE per million population). The practitioners should be qualified level 3 grade social workers with relevant experience in health and child care settings and ideally have counselling qualifications.

4.10 Paediatric Clinical Psychology

4.10.1 Clinical psychology aims to reduce the psychological distress and to enhance and promote psychological wellbeing by the systematic application of knowledge derived from psychological theory and data[149]. As part of the multiprofessional renal team, a comprehensive clinical psychological service would comprise psychological assessments, formulations, interventions and evaluations for:

- Children and young people with chronic and end stage renal disease
- Siblings and carers
- Health and social care system around the child or young person

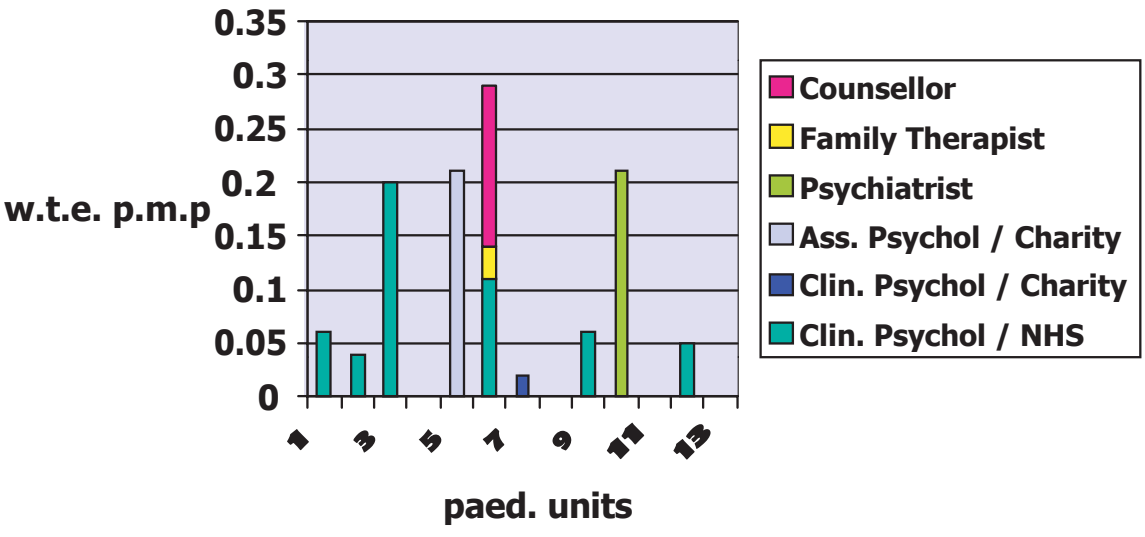
4.10.2 This service would aim to enable children, young people and their carers to have the necessary skills and abilities to cope with their emotional needs and daily lives in order to maximise psychological and physical wellbeing whilst learning to adapt to the impact of the renal illness; to develop and use their capacity to make informed choices with regard to treatment options; to have a sense of self worth, self understanding and self respect; to be able to enjoy good social and personal relationships and to share commonly valued social and environmental facilities[149]. The key roles and components of the paediatric renal psychology service is shown in table 4.10.2.

Table 4.10.2
Key roles and components of the paediatric renal psychology service

Roles	Components
Assessments	• Psychometric • Interview • Direct observation
Formulations	• Integration of assessments • Evaluation and synthesis of psychological data • Framing the issues – linking theory to practice
Interventions	• Psychological therapies • Mediation and facilitation of communication • Psychological training, support and liaison with other Healthcare and psychological practitioners
Education and Research	• Multiprofessional audit • Development of psycho social outcome measures • Applied psychological research

4.10.3 Historically, there has been a shortfall of clinical psychologists across all specialisms in the NHS. Over recent years this has been addressed by increases in training places. However, infrastructure deficiencies, organisational barriers and an inadequate evidence base remain significant challenges to developing a workforce for children with chronic renal disease. There is currently marked variation in the provision of psychological resources to paediatric renal units (figure 4.10.3)

Figure 4.10.3
Paediatric renal psychological workforce (in wte) in the United Kingdom 2001[132]



4.10.4 This BAPN review[132] identified that psychological services are provided by a range of professionals. In addition social workers, play specialists, teachers and nurses contribute to the psychosocial support and management of children and their carers. However, the variation in service provision has led to a crisis intervention model of care rather than proactive integrated involvement of clinical psychologists as part of the multiprofessional team in some units.

4.10.5 Specific guidance for workforce planning in such a specialised area as paediatric renal services is not currently available from the division of clinical psychology or the faculty for children and young people. National occupational standards for applied psychologists are currently in the consultation process[150]. Review of the guidance offered in the recent information leaflet published by the division[151], the Guidelines for Clinical Psychology Services[152] and Continuing Professional Development[153] (CPD) suggest a minimum requirement of 0.3 wte clinical psychologists pmp divided as follows:

- A minimum of 0.2 wte pmp of appropriately qualified and experienced clinical psychologists is needed for direct clinical work with children and young people with chronic and end stage renal disease as part of the multiprofessional team
- A minimum of 0.1 wte pmp is indicated for consultation, training, giving and receiving clinical supervision, CPD, audit and service evaluation with links to other psychologists working in paediatric renal services to enable peer review and multi-centre audit and research.
- Additional session(s) for research will depend on local and national needs and priorities.

4.10.6 This review has identified the need for further research and audit to inform the future workforce planning cycles of the:

- Psychological needs of the paediatric renal disease population and their carers.
- Core competencies and the skills required to meet these needs.
- Outcome data from psychological interventions and different models of care.

It is envisaged that provision of the minimum renal paediatric clinical psychology resource recommended above coupled with more detailed needs assessment will enable significantly better provision of psychological support by a range of practitioners resulting in better clinical and psychological outcomes than is currently achieved.

4.11 Play Specialists

4.11.1 Play is at the very centre of a healthy child's life. From the earliest age, playing helps children to learn, to relate to other people and to have fun. When children or teenagers are admitted to hospital, they are at their most vulnerable. They are not only ill, but are also separated from their friends and familiar surroundings. Due to the nature of treatment for renal patients, many children face isolation, lack of opportunity for developing social skills or forming and maintaining relationships. Play specialists can provide opportunities for group activities to building patients' confidence and to help overcome these difficulties.

4.11.1
The role of play specialists[154]

- organising daily play and art activities in the playroom or at the bedside provide play to achieve developmental goals
- helping children master and cope with anxieties and feelings
- using play to prepare children for hospital procedures
- supporting families and siblings
- contributing to clinical judgements through their play-based observations
- teaching the value of play for the sick child
- encouraging peer group friendships to develop
- organising parties and special events
- Assisting in rehabilitation and recovery

4.11.2 Provision of play activities is required daily, including evenings and weekends. Opportunities for play are required in the inpatient, outpatient, daycase and community setting. Much of the preparation is community based. The play specialist is a core member of the paediatric renal team.

4.11.3 To provide for combined community and hospital roles 0.5 wte hospital play specialist pmp is required to manage the current level of paediatric renal activity.

4.12 Paediatric Education

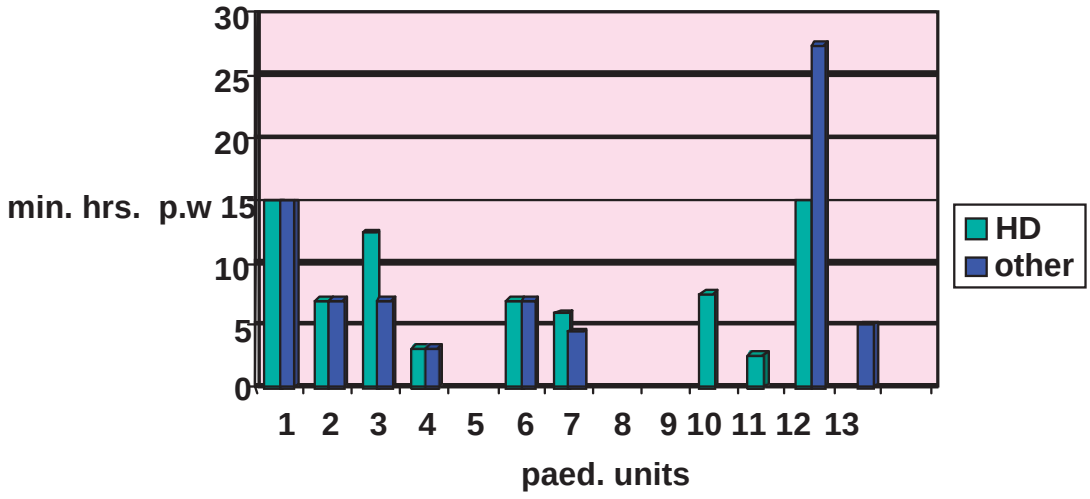
4.12.1 Hospital Schools are historically staffed on total past numbers of pupils that will therefore include all medical conditions. Teachers are appointed by their Local Education Authority to work in the hospital generally. Supply and demand of an ever changing pupil population will mean that the teacher in charge may move staff around the hospital to meet the needs at any given specific time. Renal inpatients will receive education in line with that available in the specific hospital. The key roles of teachers are outlined in table 4.12.1.

Table 4.12.1
The role of teachers in multiprofessional teams

- Delivery of a broad and balanced curriculum
- Liaison with mainstream schools
- Provision of advice on statutory requirements e.g. code of practice and statementing procedures
- Advice and support to patients and parents
- Provision of input into the psychosocial development plan via the multiprofessional team
- Provision of distance learning support and advice, e.g. the Anytime, Anywhere Learning programme (AAL)

4.12.2 Patients receiving haemodialysis have additional needs; they attend for dialysis 3 days a week. For the majority this will be for months or years until a successful transplant, but a minority remain on maintenance haemodialysis for many years. They will be of varying ages and a wide range of educational abilities. The teacher: pupil ratios for haemodialysis patients varies from 1:1 to 1:10 with the average being 1 teacher: 5 or 6 pupils. The number of hours teaching per week for haemodialysis patients and other renal patients is shown in table 4.12.2. In addition to the limited number of hours teaching in some units, teachers are only sessional and this causes further problems due to lack of continuity.

Table 4.12.2
Teacher-pupil contact time available in paediatric renal units



(No data available from units 5, 8 and 9)

4.12.3 The Department of Education has recently published a document "Access to Education for Children and Young People with Medical Conditions"[131]. Whilst this does not give advice on staffing levels it does give clear guidance on the level of educational provision that should be made available. Local Education Authorities should now carefully review staffing levels in hospitals, schools and teaching units to meet these guidelines. This will have to include the mix of staff skills and competencies to take account of specific needs e.g. foreign language learning and also allow time for teacher input into both the psychosocial care plan and liaison with schools.

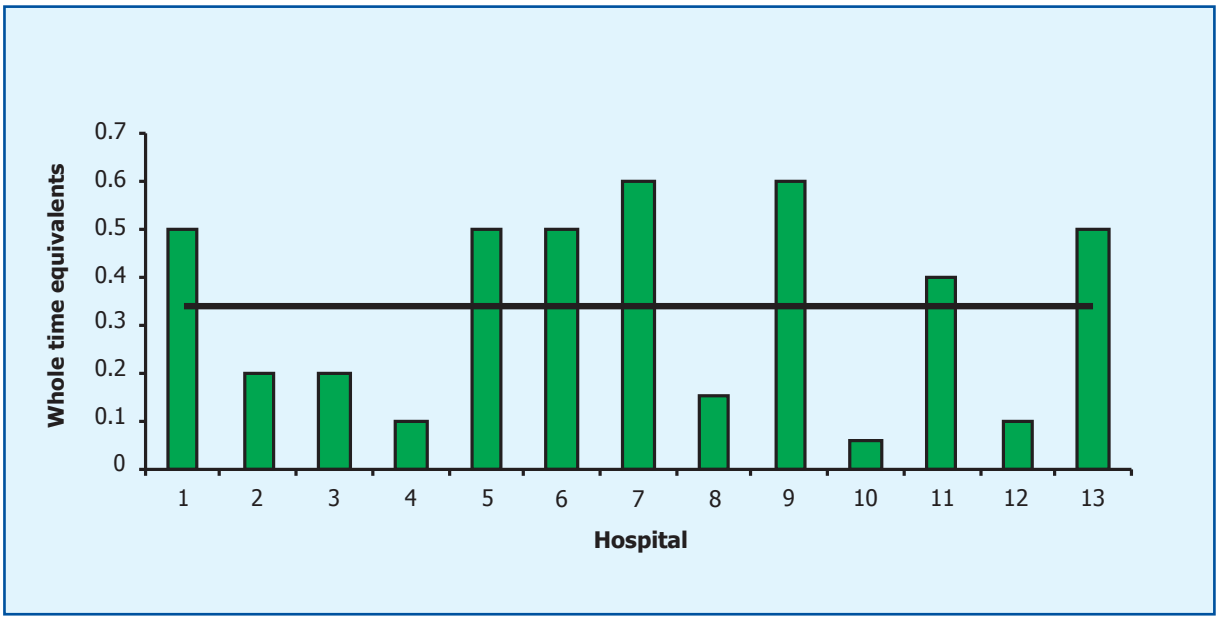
4.13 Paediatric Renal Pharmacy

4.13.1 Medicines management in children with renal disease must take account of both altered pharmacokinetics due to renal disease and the problems of prescribing in paediatrics. These complex patients require experienced pharmacist input to both prescribing for the individual and the multiprofessional delivery of the care plan.

4.13.2 The key components of the renal pharmacy service are outlined in section 3.13. In addition the paediatric environment requires specialist skills in formulation assessment (many medicines are not in a suitable form for children), drug handling in paediatric renal impairment and strategies to improve concordance[119,155,156,157,158,159]. Furthermore, centralised intravenous additive services[160,161,162,163] are already provided by pharmacists in half of all the renal centres.

4.13.3 There are currently 13 posts, providing 4.5 wte in the United Kingdom, an average of 0.35 wte pharmacists per site (figure 4.13.3).

Figure 4.13.3
Distribution of Pharmacy Workers



4.13.4 New initiatives and professional developments as recommended in the NHS Plan[2], pharmacist led prescribing and medication review clinics are limited by insufficient staffing. These limitations have consequences for the other members of the paediatric renal team and result in increased prescription errors and unnecessary clinical risk. In turn many renal pharmacists receive insufficient pharmacy technician Medical Technical Officer (MTO 3 level) support. The consequence is a reduction in pharmacy – patient contact time.

4.13.5 To provide a complete renal pharmacy service for paediatric patients suitably trained and experienced (usually Grade D or above), pharmacists need to be integral members of the renal multiprofessional team. The recommended staffing levels and implementation schedule for pharmacy technicians is shown in table 4.13.5.

Table 4.13.5

Level of Service	Pharmacist	Pharmacy Technician	Implementation date
Basic service	0.1 pmp	0.05 pmp	Immediately
Full service	0.2 pmp	0.1 pmp	2006
New professional developments	0.3 pmp	0.2 pmp	2008

4.14 Other Paediatric renal team members

There is no specific discussion of the paediatric requirements for Donor Transplant Co-ordinators, Histocompatibility and Immunogenetic service, Renal Clinical Technologists and Administration and Management. These are essential to paediatric renal services but are usually provided from the adult service (see sections 3.6, 3.7, 3.12 and 3.14) or with regards to administration and management within the management structure of the paediatric unit. It is important that secure, appropriate local arrangements are made to support the paediatric renal service.

SECTION FIVE

WORKFORCE PLANNING PROJECTIONS

Section 5 Workforce Planning Projections

5.1 Adult Renal Services Work Force Requirements

5.1.1 This section provides a specialist work force plan for Adult Renal Services up to 2010. It is based upon the detailed review of the current renal work force described in section 3 (Table 5.1.1) and increasing prevalence of renal replacement therapy outlined in Section 2.3.

Table 5.1.1
Total number of specialist renal healthcare practitioners and wtes in 2001 in England and the United Kingdom

	England		United Kingdom	
	Total	Renal WTE	Total	Renal WTE
Renal Physicians	226	161	290	206
Renal Transplant Surgeons	68	42	81	51
Renal Transplant Donor Coordinators	67	50	87	59
Renal Histocompatibility Scientists				
Consultant Scientists	12	8	14	9
Healthcare Scientists	180	111	252	151
Renal Dietitians	142	118	180	147
Renal Social Workers	56	43	73	55
Renal Clinical Psychologists	6	2	7	3
Renal Clinical Technologists	173	173	225	225
Renal Pharmacists	66	28	97	34
Renal Administrators & Managers	55	43	65	50
Nurses				
Haemodialysis	1895	1541	2330	1894
Peritoneal dialysis	215	175	250	203
Ward based (Renal & Transplant)	1529	1243	1834	1491
Healthcare Assistants				
Haemodialysis	712	570	876	701
Peritoneal dialysis	44	35	51	41
Ward based (Renal & Transplant)	621	497	746	597

5.1.2 The multi-professional renal team provides renal replacement therapy (RRT) options for patients with chronic renal disease. Although renal disease has many manifestations and is associated with a range of comorbidities many renal healthcare professionals practice mainly in renal replacement therapy. The work force recommendations have therefore been factored for the number of patients requiring renal replacement therapy wherever possible rather than the total population served or other measures of need. For certain professional groups e.g. transplant surgeons and coordinators the number of practitioners pmp remains a better currency and for others e.g. clinical technologists, requirements are factored for the number of haemodialysis patients. For nurses, healthcare assistants and dietitians it has been possible to provide recommendations based on requirements for each modality. The recommended ratio of practitioners to patients receiving renal replacement therapy is shown in Table 5.1.2.

TABLE 5.1.2
CURRENT AND RECOMMENDED SPECIALIST RENAL STAFF TO PATIENT ON RRT RATIOS

PROFESSIONAL GROUP	CURRENT WORKFORCE RATIOS	RECOMMENDED WORKFORCE RATIOS
Renal Physicians	1 physician per 131 RRT patients (1 wte in nephrology per 185 RRT patients)	1 physician per 75 RRT patients (1 wte in nephrology per 100 RRT patients)
Transplant Surgeons	1.35 surgeons pmp (0.85 wte pmp)	2 surgeons pmp (1.2-1.5 wte pmp)
Dialysis Access Surgery	1 consultant vascular access session per 120 haemodialysis patients[35]	1 dialysis access session per 120 patients on dialysis. This equates to 1 wte surgeon per 350 cases per year
Donor Transplant Co-ordinators	1 wte pmp	1 wte pmp and 1 wte per 20 live donor transplants
Histocompatibility and Immunogenetics Scientists	1 wte consultant clinical scientist per 4231 RRT pts and 1 wte healthcare scientist per 260 pts on RRT	1 wte consultant clinical scientist/medical consultant per 1200 RRT pts and 1 wte healthcare scientist per 135 RRT
Renal Nurses and Health Care Assistants • **Haemodialysis** * **Skill Mix**	1 wte per 5.1 Haemodialysis pts 2.7 nurses : 1 HCA	1 wte per 4.5 Haemodialysis pts 1.5 nurses: 1 HCA
• **Peritoneal Dialysis** * **Skill Mix**	1 wte per 24 community dialysis pts 2.5 nurses: 1 HCA	1 wte per 20 community dialysis pts 5 nurses: 1 HCA
• **Renal Wards (includes transplant wards)** * **Skill Mix**	1.2 wte per bed. 2.5 nurses: 1 HCA	1.4 wte per bed 2.5 nurses: 1 HCA
Dietitians	1 wte per 260 RRT patients	1 wte per 135 Haemodialysis patients* 1 wte per 270 Peritoneal Dialysis patients 1 wte per 180 low clearance patients 1 wte per 540 transplant patients
Social Workers	1 wte per 693 RRT pts	1 wte per 140 RRT patients
Clinical Psychologists	1 wte per 15233 RRT patients	1 wte per 1000 RRT patients
Clinical Technologists	1 wte per 59 haemodialysis patients	1 wte per 50 Maintenance Haemodialysis plus 1 wte per 20 Home haemodialysis
Pharmacists	1 wte per 1120 RRT patients	1 wte per 250 RRT patients plus 1 wte per 60 transplants per annum
Managers/ Administrators	1wte per 382 dialysis pts	1 wte per 150 dialysis patients

*Inpatient dietetic care requires additional support as quantified in table 3.9.5

5.1.3 This Work Force Plan is based on patient centred care, integrated multi-professional working and the current best practice. The recommendations for each professional group have been reviewed together to ensure consistency. Where possible the impacts of developments in practice and technological advances have been considered. Three scenarios of future dialysis and transplant patient numbers have been modelled using different assumptions with regard to the starting stock, acceptance rate, transplant supply and survival on haemodialysis (Tables 5.1.3 (a) and (b)).

Table 5.1.3 (a) and (b)
Total numbers of patients on RRT in 2001 and projected mean numbers in 2006 and 2010 in England and the United Kingdom

(a)	England						
	2001 Actual	2006 Estimated			2010 Estimated		
		Low	Med	High	Low	Med	High
Total Dialysis	15,801	18,335	20,448	24,749	19,114	24,393	30,520
Peritoneal Dialysis	5,034	4,876	5,604	6,365	4,783	6,468	7,550
Haemodialysis	10,767	13,460	14,844	18,384	14,331	17,925	22,970
Transplantation	15,400	19,240	18,398	18,882	23,042	21,762	20,100
Total RRT Numbers	**31,201**	**37,575**	**38,846**	**43,631**	**42,156**	**46,155**	**50,620**

(b)	United Kingdom						
	2001 Actual	2006 Estimated			2010 Estimated		
		Low	Med	High	Low	Med	High
Total Dialysis	19,082	21,491	23,968	29,010	22,550	28,778	36,007
Peritoneal Dialysis	5,846	5,715	6,569	7,461	5,643	7,631	8,907
Haemodialysis	13,236	15,777	17,399	21,549	16,907	21,148	27,100
Transplantation	19,000	22,552	21,565	22,133	27,185	25,674	23,714
Total RRT Numbers	**38,082**	**44,044**	**45,533**	**51,142**	**49,735**	**54,453**	**59,721**

Explanation of scenarios used to estimate RRT population

Data used for scenarios				
Scenario	**Starting Stock**	**Acceptance rate**	**Transplant Supply**	**HD Survival**
Low	Renal Association Estimate[29]	Current Scottish	UK T target increase (11%)	Current
Medium	Renal Association Estimate[29]	Current Welsh	Pragmatic increase (9%)	Current
High	1998 Renal Survey[8]	Current Welsh + 10% increase in diabetes	No increase	Increased to IDOPPS

Demand for renal replacement therapy (RRT) will continue rise beyond 2010 for the following reasons:

- Demographic change with an ageing population, which is particularly marked in ethnic minority populations;
- Type 2 diabetes epidemic leading to increased ESRD rates despite the implementation of treatments to reduce the progression rates of diabetic ESRD[42];
- Increased referral of patients to meet population true need;

- In all countries a steady state has not been reached at which input (acceptances per year and transfers in) is equal to the annual death rate and transfers out. Previous modelling suggested that this would not occur for over 20 years;
- Improvements in the management of patients on RRT by implementation of national guidelines may improve survival and hence increase the stock of patients, though accepting sicker patients onto RRT might counterbalance this.

5.1.4 The higher projection of total patients on RRT has been used to forecast the workforce requirements to take account of changing patterns of work, increasing complexity and, in the belief that European standards of care can be achieved and will improve patient survival. However, no attempt has been made to factor for any changes in the character or proportion of non renal replacement therapy work undertaken by the specialist renal staff. The workforce requirements are shown as whole time equivalents, based on patient numbers and recommended workforce ratios, and as total number of practitioners based on the current average proportion of time each group of practitioners provides in renal healthcare. It is also assumed that the European Working Time Directive will be adhered to and for certain professional groups, e.g. transplant surgeons, the rota requirements to fulfil this is a major driver for workforce expansion. The other key assumptions for each professional group are shown in Table (currently called 5.1.4)

TABLE 5.1.4
KEY ASSUMPTIONS MADE IN CALCULATING THE RENAL WORKFORCE REQUIREMENTS TO 2010 BY PROFESSIONAL GROUP

Renal Physicians
- The proportion practicing general internal medicine remains unchanged (56%).
- Each renal physician/renal and general physician will provide an average 0.71 wte in nephrology.
- Recommendations are based on "Physicians Working for Patients"[36] and assume a similar model of service.

Transplant Surgeons
- A minimum of 5 surgeons to provide a compliant rota
- Transplant surgeons will provide access surgery in transplanting centres and some other renal centres.
- Transplant surgeons provide both the adult and paediatric transplant service.

Dialysis Access Surgery
- Formal arrangements for the timely provision of dialysis access will be implemented.
- Adequate diagnostic and interventional radiological support will be available.
- Dialysis access activity is unlikely to be the major component of an individual surgeon's job plan.

Donor Transplant coordinators
- The recommendations are based on the UK Transplant Plan and the UK Transplant Task Group recommendations.
- A minimum of 4 donor transplant coordinators is required to provide a compliant rota.
- The donor transplant coordinator requirements for non heart beating donor programmes may need additional staff.

Histocompatibility and Immunogenetics Scientists
- The recommendations are based on the UK Transplant Plan and assume an increase in live donation.
- A minimum of 4 healthcare scientists is required to provide a compliant rota.
- The service standards are based upon the recommendations of the British Transplant Society and Renal Association.

Renal Nurses and Healthcare Assistants

Haemodialysis

- The staff to patient ratio during dialysis should be between 1:3 and 1:4 (assume 1:3.5) this equates to 1 wte per 4.5 patients.
- The skill mix should be between 70% nurses, 30% healthcare assistants to 50:50 (assume 60% nurses).
- Each renal nurse and renal healthcare assistant will provide an average 0.8 wte in line with current NHS practice (applies to haemodialysis, peritoneal dialysis and ward staffing)[164].

Renal Nurses and Healthcare Assistants

Peritoneal dialysis

- Community dialysis nurses will provide training and ongoing support for peritoneal dialysis patients.
- The skill mix will remain greater than 80% nurses, less than 20% healthcare assistants.
- The community dialysis teams will provide ongoing support for home haemodialysis patients (assume 5% by 2010).

Renal Nurses and Healthcare Assistants

Ward based

- The total number of renal beds required in 2001 is based upon the Royal College of Physicians' recommendations for renal beds (37 pmp) and the Renal Association recommendation for transplant beds (4 pmp).
- These bed requirements have been increased in line with the increase in RRT patients to 59 renal beds pmp and 7 transplant beds pmp by 2010.
- Additional beds and theatre capacity will be required to both live donor transplantation and kidney-pancreas transplantation.

Dietitians

- The requirements have been calculated from the time required to manage patients on different modalities and the inpatient bed requirements shown above.
- A chronic kidney disease rate of 160 pmp requiring specialist renal dietetic support is assumed.
- The recommendations are based on "Setting Standards and Achieving Optimum Nutritional Status for Adult Renal Patients over 18 Years Old"[95].

Social Workers

- Renal social workers are part of the hospital social work team and funded by health commissioning.
- The requirements assume adequate counselling and psychological support for renal patients.
- On average, each wte social worker would manage 30 active cases at any one time.

Clinical Psychologists

- The psychological service involves training, development and support of other direct care staff.
- The requirement assumes adequate counselling and social work support for renal patients.
- Future recommendations should be based upon a more detailed analysis of the psychological needs of renal patients and their carers.

Pharmacists

- The service model assumes provision of a comprehensive medicines management service to the standards developed by the UK Renal Pharmacy Group.
- Pharmacist prescribing, either as independent or dependent prescribers, will impact on future renal pharmacist requirements.
- Economies of scale occur in units of greater than 800 RRT patients where the requirement is 3 wte in non-transplanting centres and 4 wte in transplanting centres.

Clinical Technologists

- Home haemodialysis will increase to 5% of all haemodialysis.
- A minimum of 3 clinical technologists is required to provide a compliant rota.

Managers/Administrators

- The recommendations allow for renal unit manager assistants with holiday dialysis arrangements.
- Renal unit managers should be considered as core members of the renal multi professional team.

5.1.5 Professional regulation and aspects of both education and training are considered across the United Kingdom as a whole but Healthcare delivery is managed by each country individually. The work force requirements are therefore shown for both the England and United Kingdom for in Tables 5.1.5a and 5.1.5b.

Table 5.1.5 (a)
Workforce requirement for England

	England							
	2001 Establishment		2001 Required		2006 Projected		2010 Projected	
	Total	Renal wte	Total	Renal wte	Total	Renal wte	Total	Renal wte
Renal Physicians	226	161	429	305	600	426	696	494
Renal Transplant Surgeons	68	42	105	75	105	75	105	75
Renal Transplant Donor Coordinator	67	50	68	50	112	83	112	83
Histocompatilibity Scientists								
Consultant Scientist	12	8	39	26	54	36	63	42
Healthcare Scientist	180	111	370	231	517	323	598	374
Renal Dietitians	142	118	382	318	530	442	618	515
Renal Social Workers	56	43	297	229	406	312	470	362
Renal Clinical Psychologists	6	2	93	31	132	44	153	51
Renal Clinical Technologists	173	173	221	221	395	395	493	493
Renal Pharmacists	66	28	294	125	411	175	475	202
Renal Admin & Managers	55	43	134	105	211	165	260	203
Renal Nurses								
Haemodialysis	1895	1541	1731	1407	2862	2327	3578	2909
Peritoneal dialysis	215	175	267	217	371	302	444	361
Ward Based (Renal & Transplant)	1529	1243	2507	2038	3485	2833	4034	3280
Renal Healthcare Workers								
Haemodialysis	712	570	1173	938	1943	1554	2425	1940
Peritoneal dialysis	44	35	56	45	78	62	93	74
Ward Based (Renal & Transplant)	621	497	1040	832	1446	1157	1675	1340

Table 5.1.5 (b)
Workforce requirement for the United Kingdom

	United Kingdom							
	2001 Establishment		2001 Required		2006 Projected		2010 Projected	
	Total	Renal wte	Total	Renal wte	Total	Renal wte	Total	Renal wte
Renal Physicians	290	206	512	364	688	488	803	570
Renal Transplant Surgeons	81	51	130	89	130	89	130	89
Renal Transplant Donor Coordinator	87	59	87	59	144	98	144	98
Histocompatilibity Scientists								
Consultant Scientist	14	9	48	32	64	43	75	50
Healthcare Scientist	252	151	468	282	629	379	734	442
Renal Dietitians	180	147	464	380	636	521	738	605
Renal Social Workers	73	55	356	272	475	365	555	427
Renal Clinical Psychologists	7	3	106	38	143	51	168	60
Renal Clinical Technologists	225	225	272	272	463	463	583	583
Renal Pharmacists	97	34	425	152	574	205	669	239
Renal Admin & Managers	65	50	165	127	51	193	312	240
Renal Nurses								
Haemodialysis	2330	1894	2127	1729	3357	2729	4223	3443
Peritoneal dialysis	250	203	312	254	435	354	524	426
Ward Based (Renal & Transplant)	1834	1491	2958	2405	4112	3343	4760	3870
Renal Healthcare Workers								
Haemodialysis	876	701	1441	1153	2275	1820	2860	2288
Peritoneal dialysis	51	41	65	52	91	73	109	87
Ward Based (Renal & Transplant)	746	597	1228	982	1706	1365	1978	1582

5.1.6 This Work Force planning exercise has identified a number of gaps in our knowledge about the working practice in Renal Health Care, the demography of the work force and the proportion of working time spent on renal replacement therapy. We recommend that a more detailed census of the renal workforce is undertaken regularly to inform the Work Force Planning Cycle.

5.1.7 The early detection of renal disease and the implementation of strategies to retard progression are vital to achieving a "preventative dividend". This requires a co-ordinated approach across the patient pathway by primary and secondary care professionals. Renal disease is common, particularly in the elderly, and new models of care are being developed to manage this case load[165]. The wider health care and work force implications for both primary care and specialist renal health care professionals are likely to be profound. These will need to be considered in the future Work Force Planning Cycles.

5.1.8 The roles of information technology specialists in delivering new models of care and in performance management has not been addressed in this report. We recommend that the NHS information authority consider these workforce requirements in developing the IT strategy to underpin the implementation of the Renal National Service Framework.

5.1.9 This report does not provide detailed workforce recommendations for non-renal specialist healthcare staff such as histopathology, interventional radiology and virology, nor has it been possible to accurately identify the occupational therapy, physiotherapy and rehabilitation workforce requirements to support renal patients. It is expected that comprehensive renal patient pathway work and modelling will enable a more complete renal workforce plan including primary, secondary and tertiary healthcare workers to be developed. The Skills for Health project will work on developing a competency framework to support this.

5.1.10 The report also highlights the need to more accurately identify and define the skills and competences required to manage patients with renal disease at the various points along the patient pathway. It is anticipated that the Skills For Health Project[166] will define these competences and assist in the development of robust methodologies to evaluate new ways of working and the impact of advances in information technology.

5.1.11 For Renal Physicians the age and gender of the current work force and those in training is known from the Royal College of Physicians Census[77] and the Speciality Training Committee records[167]. To achieve the requirement for 803 Renal Physicians in the UK by 2010 will require 591 appointments to new and replacement posts assuming the current 3% per annum retirement rate. At present there are 188 specialist Registrars in renal medicine. A gap analysis indicates a current need for 330 national training numbers (NTNs), assuming a 5-year training period, in order to deliver the consultant requirements for 2010. If the training period remains at the current 6.5 years the NTN requirements increase to 429 posts.
For most of the other professional groups the age and career intentions of the Renal Work Force are not known.

5.1.12 In England the Renal Workforce Group of the Long Term Conditions Care Group Workforce Team (LTCCGWT)[50] will be supporting the Renal NSF. All the data accumulated and assumptions made in the compilation of this report by the national renal workforce planning group, has been made available to the LTCCGWT.

5.1.13 Local Work Force Plans should in addition take account of the clinical, cultural and social complexity of their client group. The configuration of renal services, demography, geopolitical factors, maturity of the Renal Unit and local strengths all need to be considered in regional and individual Unit Planning.

5.1.14 We recommend that a national recruitment and retention plan for Renal Healthcare Practitioners is developed in collaboration with the Workforce Development Confederations as part of the Renal NSF implementation strategy.

5.1.15 We believe that adoption of this plan will enable efficiency gains and effective use of resources that will result in considerable improvement in the quality of life and survival of patients with renal disease.

5.2 Paediatric Renal Services Workforce Requirements

5.2.1 The BAPN audit[132], detailed in section 4, identified the current shortfall in specialist paediatric renal staff. The key assumptions for each professional group can also be found in section 4. Table 5.2.1 summarises the future specialist paediatric renal workforce requirements.

Table 5.2.1
Summary of Paediatric Renal Workforce requirements for the United Kingdom (in wtes)

	Current workforce	Projected requirements
Paediatric Nephrologists	37.8	72
Dieticians	10.9	25.1
Pharmacists	4.5	31.4
Social workers	10.4	25.1
Psychologists	6.1	12.5
Play Specialists	NK	31.4

SECTION SIX

REFERENCES

References

1 The Kidney Alliance, End Stage Renal Failure – A Framework for Planning and Service Delivery, January 2001

2 The National Plan for the NHS; A Plan for Investment, A Plan for Reform, (HMSO) July 2000

3 Provision of Services for Adult Patients with Renal Disease in the United Kingdom, Royal College of Physicians of London and the Renal Association, London 1991

4 The Provision of Services in the United Kingdom for Children and Adolescents with Renal Disease: British Association for Paediatric Nephrology, 1995

5 Report of the Working Party to Review Organ Transplantation: The Royal College of Surgeons of England, 1999

6 Report of the Healthcare Strategy Unit. Review of Renal Services, HMSO 1994

7 Department of Health, Review of Renal Services in England 1993-4. London: NHS Executive, 1996

8 Roderick P, Ferris G, Feest T. The Provision of Renal Replacement Therapy for Adults in England and Wales: recent trends and future directions. QJM 1998, 91(8):581-7

9 The Renal Association. Treatment of adult patients with renal failure. Recommended standards and audit measures (2nd edition). Renal Association and Royal College of Physicians. London, 1997

10 British Transplant Society, Towards Standards for Organ and Tissue Transplantation in the United Kingdom. 1998

11 Ansell D, Feest T, 2nd Annual Report of the UK Renal Registry, 1999

12 United Kingdom Transplant Service Special Authority. Renal Transplant Audit, 1996-8. Bristol: UKT, 2000

13 Skill Mix and the Hospital Doctor, New Roles for the Healthcare Workforce Report from the Royal College of Physicians of London, 2001

14 A Health Service of all the talents: Developing the NHS Workforce. NHS Executive, April 2000.

15 Department of Health. Working Together: Securing a Quality Workforce for the NHS, (HSC 1998/162,220998),1998

16 Department of Health. Improving Working Lives, (HSC 1999/218,240999), 1999

17 Department of Health. Renal National Service Framework discussion document. http://www.doh.gov.uk/nsf/renal.htm

18 Greater Manchester Renal Project, Plan for District Nephrology and Local Dialysis Services 2000-2004, Manchester 2000

19 Securing Our Future Health: Taking a long-term view – The Wanless Review, April 2002

20 Department of Health. Integrated Workforce Planning across all Healthcare Related Disciplines. Workforce Development Confederations, 2001

21 Quinton W, Dillard H, Scribner D. Cannulation of blood vessels for prolonged haemodialysis. Trans Am Soc Artif Intern Organs 1960;8:963.

22 The European Dialysis and Transplant Association. Combined report on regular dialysis and transplantation in Europe, VIII, 1977

23 Baillod R, Comty C, Hahi M. Overnight haemodialysis in the home. Proc Eur Dial Transplant Assoc 1966;2:99-104.

24 Beardsworth S, Goldsmith H. Continuous amulatory peritoneal dialysis (CAPD) on Merseyside – cost/cost effectiveness. Health Trends 1982;14:89-92

25 The European Dialysis and Transplant Association. Combined report on regular dialysis and transplantation in Europe, XVI, 1985

26 Bradley B, Selwood N. The natural history of transplantable kidneys. Health Trends 1983; 15:25-27

27 Feest TG, Mistry CD, Grimes DS, Mallick NP. Incidence of advanced chronic renal failure and the need for end stage renal replacement treatment. BMJ 1990;301:897-900

28 Department of Health. Report of the Health Care Strategy Unit Review of Renal Services. Part II: Evidence for the review, 1994.

29 Report of the Service Provision and Delivery Sub-committee. Renal Association Spring Meeting, York 2002.

30 Ansell D, Feest T.eds. UK Renal Registry Report 2001. Bristol: UK Renal Registry 2001

31 National Institute for Clinical Excellence. Guidance on home compared with hospital haemodialysis for patients with end-stage renal failure. London: National Institute for Clinical Excellence 2002

32 National Definitions Set. Specialised.services.defins@doh.gsi.gov.uk

33 NHS Executive. Commissioning in the New NHS. Commissioning Services 1999-2000. London: Department of Health 1998

34 Department of Health. Commissioning Arrangements in the New NHS. Review into Commissioning Specialised Services. 2002

35 Renal Services for Dialysis: Commissioner and Provider Perspective. National Kidney Research Fund 2002

36 Consultant Physicians Working for Patients, Royal College of Physicians, 2nd Edition. London, 2001

37 Ansell D, Feest T, 3rd annual report of the UK Renal Registry. Bristol: UK Renal Registry, 2000

38 Data on 2001 activity supplied by UK Transplant in personal communication

39 European Renal Association – European Dialysis and Transplantation Association. ERA-EDTA Registry Annual Report 2000. 2002. Amsterdam, ERA-EDTA.

40 Roderick P, Raleigh, V, Hallam L et al. The need and demand for renal replacement therapy in ethnic minorities in England. Journal of Epidemiology in Community Health 1996; No.50: 334-339.

41 Roderick P, Clements S, Diamond I et al. Estimating demand for renal replacement therapy in Greater London: the impact of demographic trends in ethnic minority populations. Health Trends, 1998; No.30: 46-50.

42 Newman A, Ryan R, Khunti K, et al. Prevalence of diagnosed diabetes mellitus in general practice in England and Wales 1994 to 1998. Health Statistics Quarterly 2002

43 Davies R, Roderick P. Predicting the future demand for renal replacement therapy in England using simulation modelling. Nephrol Dial and Transplant. 1997; 12(12) 2512-2516.

44 UK Transplant. 2001. Transplant. More Transplants - New lives: Business case to the Department of Health, England and the Health Departments in Scotland, Wales and Northern Ireland. Bristol: UK, 2001.

45 Pisoni RL, Young EW, Greenwood RN, Hecking E, Goodkin DA, Eolfe Ram Held PJ. Comparison of vascular access use in the UK and Europe: The Dialysis Outcomes and Practice Patterns Study (DOPPS). American Society of Nephrology, Toronto, 2000

46 Khan, I, Catto G, Edward N, Macleod A, Chronic renal failure: factors influencing nephrology referral. QJM, 1994; 87(9): 559-64.

47 Culleton, B. Prevalence and correlates of elevated serum creatinine levels: the Framingham Heart Study. Arch Intern Med, 1999; 159(15): 1785-90.

48 John R, Young A, Stevens P, Webb M. Abstract Title: The prevalence of unreferred chronic renal failure in East Kent. Abstracts of the Renal Association Spring Meeting, 9-10 April 2002, York St Johns College, York, UK. Published in KI, full paper in preparation

49 Kissmeyer L, Kong C, Cohen J et al. Community nephrology: audit of screening for renal insufficiency in a high-risk population. Nephrol Dial Transplant 1999; 14:2150-215

50 The Long-Term Conditions Care Group Workforce Team (LTC CGWT) Terms of Ref www.doh.gov.uk/cgwt , 2002

51 Registered Homes Act, 1984

52 The Care Standards Act, 2000

53 Department of Health NHS Executive. Information for health - An information strategy for the modern NHS 1998 – 2005, a national strategy for local implementation. London, 1998

54 http://www.nhsia.nhs.uk/ppt/iaconf_2001/1-2bMargaret_Haines.ppt

55 Systematic review of cost effectiveness studies of telemedicine interventions. Whitten P, Mair F, Haycox A et al. BMJ 2002;324:1424-7.

56 The Expert Patient: A New Approach to Chronic Disease Management for the 21st century, DOH, 2001

57 Department of Health: "Working Together – Learning Together". November 2001

58 Brock M Uncertainty, information needs and coping effectiveness of renal families. ANNA Journal, 1990; 17:3, 242-245

59 Larkin J, Factors influencing one's ability to adapt to chronic illness. Nursing Clinics of North America, 1987; 22:3, 535-542

60 Feldman D Chronic disability illness: a holistic view Journal Chronic Disease 1974;27:16-27

61 Winder E. Stress among staff in the renal unit. MTP Press, 1983; 215-218

62 Pritchard C. The challenges of care for the long-term dialysis patient. British Journal of Renal Medicine, Autumn 2000

63 Styles B. Viol Bodies, Health Service Journal, 1994; 104: 5388, 30-32

64 Dasgupta I. Management of hypertension in patients developing end-stage renal failure. QJM, 1999. 92(9): 519-25.

65 Ratcliffe P, Phillips R, Oliver D. Late referral for maintenance dialysis. Brit Med J 1984; 288(6415): 441-3

66 Eadington D. Delayed referral for dialysis. Nephrol Dial Transplant 1996; 11(11): 2124-6.

67 Chesser A, Baker L. Temporary vascular access for first dialysis is common, undesirable and usually avoidable. Clin Nephrol 1999; 51(4): 228-32.

68 Metcalfe W. Can we improve early mortality in patients receiving renal replacement therapy? Kidney Int, 2000. 57(6): p. 2539-45.

69 Dhingra R. Type of vascular access and mortality in U.S. hemodialysis patients. Kidney Int, 2001. 60(4): 1443-51.

70 Roderick P., et al., Late Referral for dialysis: improving the management of chronic renal disease. QJM, 2002. 95(6): p.363-70.

71 National Institute of Clinical Excellence, Guidance on Type II Diabetes, 2002

72 Morbidity and mortality of renal dialysis: an NIH consensus conference statement. Consensus Development Conference Panel. Ann Intern Med, 1994. 121(1): p.62-70.

73 Churchill D.N., et al., Clinical practice guidelines for initiation of dialysis. Canadian Society of Nephrology. J Am Soc Nephrol, 1999. 10 Suppl 13: p.S289-91.

74 Ramsay L, Williams B, Johnston D. Guidelines for management of hypertension: Report of the Third Working Party of the British Hypertension Society. J Human Hypertens 1999; 13: 630-5

75 National Kidney Foundation, K/DOQI Clinical Practice Guidelines for Chronic Kidney Disease, 2002

76 Cockcroft, D, Gault M. Prediction of creatinine clearance from serum creatinine. Nephron, 1976. 16(1): 31-41

77 Census of Consultant Physicians in the UK, 2001. Medical Workforce Unit, Royal College of Physicians of London on behalf of The Federation of Royal Colleges of the United Kingdom

78 Kumwenda, M, NCCGs in Nephrology, Poster presentation at The British Renal Society Conference, Manchester, 2002

79 The tenure track clinician scientist: a new career pathway to promote recruitment into clinical academic medicine (the Savill Report). Academy of Medical Sciences, 2000 (available http://www.admedsci.ac.uk/Clinic.pdf)

80 Drey N. The epidemiology of diagnosed chronic renal failure in Southampton in South West Hampshire Health Authority. PhD Thesis. Southampton: University of Southampton 2000

81 National Criteria for Consultant Appointments in Renal Transplant Surgery. The Royal College of Surgeons of England, London, January 1998

82 Chalmers, N. The role of Vascular Radiology in haemodialysis access. Sem Dial, 2002 15 (4): 259-268

83 The Review of the United Kingdom Transplant Support Service Authority (UKTSSA) 1998/9. London: Department of Health, 2000

84 Transplant Co-ordinators Structure Grading Report – NHSP February 2002

85 Report of Recommendations from Task Group 4 of the Transplant Co-ordinators Advisory Group for the Educational Strategy of the Donor Transplant Co-ordinators. UK Transplant, January 2002

86 Report of Recommendations from Task Group 4 of the Transplant Co-ordinators Advisory Group for the Educational Strategy of the Donor Liaison Sister/Charge Nurse. UK Transplant December 2001

87 Report of recommendations from Task Group 2 of the Transplant Co-ordinators Advisory Group. UK Transplant July 2001

88 Report of recommendations from Task Group 1 of the Transplant Co-ordinators Advisory Group – UK Transplant June 2001

89 Department of Health. Making the Change – Strategy for the Professions in Healthcare Science, 2001

90 European Federation of Immunogenetics, Standards of Histocompatibility Testing; 4th version, 2000.

91 Department of Health, Healthcare Science – Agenda for Change, 2000

92 Renal Society of Australasia. Competency standards for the Australian Advanced practice nephrology nurse, Sydney, 1999

93 Department Of Health Nurse, Midwife and Health Visitor consultants: Establishing posts and making appointments. Health Service circular 1999/217 September 1999

94 Manley K. Organisational Culture and Consultant Nurse Outcomes: Part 1 Organisational Culture, Nursing Standard, 14 (36) 34-38, 2000

95 Renal Nutrition Group. Setting Standards and Achieving Optimal Nutritional Status for Adult renal patients over 18 years old, 1998

96 The British Dietetic Association. National Professional Standards for Dietitians Practicing In Healthcare, 1997

97 The British Dietetic Association. PD Briefing Paper No 8, The Extended Role of the Dietitian, 1999

98 Report of the Crown Committee. Review of Prescribing and Administration of Medicines, Department Of Health, 1999

99 Department of Health. Review Body for Nursing Staff, Midwives, Health Visitors and Professions Allied to Medicine, September 2001.

100 Department of Health. Meeting the Challenge: A Strategy for the Allied Health Professions, November 2000

101 The British Dietetic Association. Professional Development Committee Briefing Paper No 10, Dietetic Assistants, 1999

102 The Role of Healthcare Professionals within critical care services. AHP and HCS working Group Paper, NHS Modernisation Agency, Jun 2002

103 The BASW Renal Social Work Job Description, BASW Renal Special Interest Group, 2000

104 The Social Services Inspectorate Report, 'McLennon Report' HMSO, 1998

105 The Provision of Renal Social Work in the UK – 2000, BASW Renal Special Interest Group, 2000

106 Fitzgibbon G, Savory S. The role of clinical psychologists in renal services to working age and older adults, available on www.britishrenal.org, 2001

107 Paxton R, D'Netto C. Guidance in Clinical Psychology workforce planning. DCP Information leaflet No.6 BPS Leicester, 2001

108 Paxton R, D'Netto C. British Psychology Society purchasing recommendation, British Psychology Society, 2001

109 Cystic Fibrosis Trust. Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK, 2001

110 BRI Inquiry Secretariat (1999) Bristol Inquiry Paper on Support and Counselling for Parents of Children in Acute Healthcare Setting, in annex to BRI Inquiry, Final Report, DOH 2001.

111 Ethical Framework for Good Practice in Counselling and Psychotherapy. British Association for Counselling and Psychotherapy (BACP) April 2002. www.bacp.co.uk

112 Department of Health NHS Executive. Controls Assurance Standard – Medical Devices, Department Of Health, 2000

113 James R. Report and Recommendations for Future Renal Technical Services, Association of Renal Technicians, 2001

114 Department of Health. Modernising Regulation – The New Health Professions Council, A Consultation Document. Department of Health, 2000

115 Chisolm M, Vollenweider L, Mulloy LL et al. Cost-benefit analysis of a clinical pharmacist-managed medication assistance programme in a renal transplant clinic. Clin. Transplantation 2000; 14: 304-7

116 Harchowal J. Drug-related problems on a renal unit. British Journal of renal medicine 1997; 22-24

117 Chisolm M, Vollenweider L, Mulloy L et al. Direct patient care services provided by a pharmacist on a multidisciplinary renal transplant team. Am J Health-Syst Pharm 2000; 57: 1994-6

118 Joy MS, Neyhart CD, Dooley MA. A multidisciplinary renal clinic for corticosteroid-induced bone disease. Pharmacotherapy 2000; 20(2): 206-16

119 A Spoonful of Sugar – Medicines management in NHS Hospitals. Audit Commission, December 2001.

120 Greater Manchester Renal Project: Meeting the Challenge: A Strategy for Renal Recruitment & Retention, October 2001

121 UKRPG Survey of Current Establishment of Renal Pharmacists, April 2001 (access at www.britishrenal.org)

122 UKRPG Standards of Pharmaceutical Care for Renal Patients (access at www.britishrenal.org)

123 Tawney K, Tawney P, Hladik G et al. The life readiness programme: a physical rehabilitation program for patients on haemodialysis. Am J Kidney Dis. 2000;36:581-91

124 Smye S, Lindley E, Will E. Simulating the effect of exercise on urea clearance in haemodialysis. J Am Soc Nephrol. 1998;9:128-32.

125 The NHS and Community Care Act, 1990

126 NHS Responsibilities for Meeting Continuing Health Care Needs, HMSO; WHC (95)7, 1995

127 Report of the Working Group on Terminal Care (Wilkes Report), 1980

128 'Changing Gear' Guidelines for Managing the Last Days of Life in Adults. The Research Evidence Working Party on Clinical Guidelines in Palliative Care. National Council for Hospice and Specialist Palliative Care Services, 1997

129 Action for Sick Children (1996) Health Services for Children and Young People - A Guide for Commissioners and Providers, Action for Sick Children, London

130 Framework for Assessment of Children in Need and their Families. Department of Health, 1999

131 Access to Education for Children and Young People with Medical Needs. Department for Education and Skills, 2001

132 Review of Paediatric Renal Units on behalf of the British Association for Paediatric Nephrology (in press) BAPN Audit

133 Kari JA, Gonzalez C, Lederman SE, Shaw V, Rees L. Outcome and growth of infants with severe chronic renal failure. Kidney Int.2000; 57 : 1681-1687

134 Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. Pediatr Nephrol (2000) 14: 469-472

135 Stapleton FB, Andreoli S, Ettenger R, Kamil E, Sedman A, Chesney R Future workforce needs for pediatric nephrology: an analysis of the nephrology workforce and training requirements by the Workforce Committee of the American Society of Pediatric Nephrology. J Am Soc Nephrol 1997;8(5 Suppl 9):S5-8

136 Deleau J, Andre J-L, Briancon S, Musse J-P Chronic renal failure in children: an epidemiological survey in Lorraine(France) 1975-1990Pediatr Nephrology 1994 Aug 8(4):472-6

137 Ehrich JHH, Elgendi AA Pediatric nephrology around the world:Europe In: Pediatric Nephrology 5th edition Eds Avner ED, Harmon W, Niaudet P(In press)

138 Workplans for paediatric nephrologists. British Association for Paediatric Nephrology, 2000.

139 Postlethwaite RJ, Johnson RJ, Armstrong S et al . The outcome of paediatric cadaveric renal transplant in the UK and Eire. Paediatric Transplantation 2002: 6: 367-377

140 RCN Paediatric Renal Nursing document

141 Clothier report

142 Growth failure in children with renal diseases. J Pediatr. 1996: 129 : S1-S3 supplement

143 Coleman JE. The kidney in : Shaw V, Lawson M (eds). Clinical Paediatric Dietetics. Blackwell Scientific Publications, Oxford 1994 : pp 125-142

144 Guidelines for Nutrition in Chronic renal failure: Paediatric Guidelines. American Journal of Kidney Diseases, Vol.35, No 6, Suppl 2 (June) 2000 pp S105-S136

145 Norman LJ, Coleman JE, MacDonald, Tansett and Watson AR. Nutrition and growth in relation to severity renal disease in children. Paed. Neph. 2000 15: 259-265

146 Watson AR, Coleman JE and Taylor EA. Gastrostomy buttons for feeding children on continuous cycling peritoneal dialysis. Advances in Peritoneal Dialysis, 1992, 8: 391-395

147 Harvey E, Secker D, Braj B, Picone G, Williamson Balfe J. The team approach to the management of children on clinical peritoneal dialysis. Advances in Renal Replacement Therapy, 1996, 3(1), 3-13

148 Framework for Assessment of Children in Need and their families. Department of Health 1999

149 Division of Clinical Psychology (2001). The Core Purposes and Philosophy of the Profession. Leicester: British Psychological Society

150 National Occupational Standards for Applied Psychologists. Consultation documents on: www.bps.org.uk/docdownload/docdownload2.cfm?category_id=23

151 Guidance on Clinical Psychology Workforce Planning. Leicester: British Psychological Society. Division of Clinical Psychology, 2001.

152 Guidelines for Clinical Psychology Services. Leicester: British Psychological Society Division of Clinical Psychology, 1998

153 Guidelines for Continuing Professional Development. Leicester: British Psychological Society. Division of Clinical Psychology, 1998

154 See the National Association of Hospital Specialists web site. www.nahps.org.uk

155 Hawkey CJ, Hodgson S. Effect of reactive pharmacy intervention on quality of hospital prescribing. BMJ 1990;300:986-90

156 Cole P, Emmanuel S. Drug Consultation: its significance to the discharged patient and its relevance as a role for the pharmacist. Am J Hosp Pharm 1971; 256:65-7

157 Discharging patients from hospital. Health Service Circular (1998). London: DoH 1998

158 Duggan C, Feldman R. Reducing adverse prescribing discrepancies following discharge. Int J Pharm Pract 1998;6:77-82

159 The Royal Pharmaceutical Society of Great Britain. From compliance to concordance; towards shared goals in medicine taking. London:The Society;1997

160 David J Armour et al. The Economics of a Pharmacy-Based Central Intravenous Additive Service for Paediatric Patients. Pharmacoeconomics 1996;10 (4):386-394

161 M. Phillips. Multiple use of injections. Regional Circulation. Jan 2001

162 Ham C, Merry P, editors. NHS Handbook, 9th Edition. National Association of Health Authorities and Trusts. Tunbridge Wells Kent: JHM Publishing, 1993

163 Allwood MC. Practical guides: Central Intravenous Additives Services. J Clin Pharm Ther 1994;19:137-45

164 NHS Hospital and Community Health Services Non-Medical Workforce Census, England, as at 30 September 2001. Crown copyright 2002, Statistics (Workforce) Branch, Department of Health, February 2002

165 Personal Communication, C Tomson. Chair of the Joint Working Party of the RCP, RA, RCGP 2002. Royal College of Physicians, Renal Association and Royal College of General Practitioners Joint Working Party, 2002

166 Department of Health, Long Term Conditions Care Group Workforce Team, Skills for Health Project, 2002

167 D Adu. Personal communication 2002

168 The Renal Association. Treatment of adults and children with renal failure. Standards and audit measures (3rd edition). Renal Association and Royal College of Physicians. London, 2002.

APPENDIX 1 – ACRONYMS

AAL	Anytime, Anywhere Learning Programme
ACE	Angiotensin converting enzyme
AHP	Allied Health Professionals
APD	Automated peritoneal dialysis
ARF	Acute Renal Failure
ARI	Association of Renal Industries
ARM	Association of Renal Managers
ART	Association of Renal Technologists
AVF	Arteriovenous fistula
BAPN	British Association of Paediatric Nephrologists
BASW	British Association of Social Workers
BDA/RNG	British Dietetic Association/Renal Nutrition Group
BRS	British Renal Society
BSHI	British Society for Histocompatibility and Immunogenetics
BTS	British Transplant Society
CAPD	Continuous Ambulatory Peritoneal Dialysis
CGWT	Care Group Workforce Team
CHD	Coronary Heart Disease
CKD	Chronic Kidney Disease
CPD	Continuing Professional Development
DGH	District General Hospital
DOH	Department of Health
EDTNA/ERCA	European Dialysis & Transplant Nurses Association/European Renal Care Association
ERA/EDTA	European Renal Association/European Dialysis Transplant Association
ESRD	End Stage Renal Disease
GFR	Glomerular Filtration Rate
HA	Health Authority
HCA	Health Care Assistant
HD	Haemodialysis
HDU	High Dependency Unit
HEIs	Higher Education Institutions
HImP	Health Improvement Programme
H&I	Histocompatibility & Immunogenetic
IDOPPS	International Dialysis Outcomes and Practice Patterns Study
IT	Information Technology
ITU	Intensive Therapy Unit
KPAs	Kidney Patient Associations
LA	Local Authority

APPENDIX 1 – ACRONYMS contd

LTC CGWT	Long-term Conditions Care Group Workforce Team
MRC	Medical Research Council
MHD	Maintenance Haemodialysis
MTO	Medical Technical Officer
NHS	National Health Service
NKF	National Kidney Federation
NKRF	National Kidney Research Fund
NCSC	National Care Standards Commission
NCCGs	Non Consultant Clinical Grade Practitioners
NTN	National Training Numbers
NICE	National Institute for Clinical Excellence
NKF	National Kidney Federation
NSF	National Service Framework
PCG	Primary Care Group
PCT	Primary Care Trust
PD	Peritoneal Dialysis
PFI	Private Finance Initiative
PICUs	Paediatric Intensive Care Units
PMP	Per Million Population
PMCP	Per Million Child Population
PMPPA	Per Million Population Per Annum (year)
RA	Renal Association
RCN/NNF	Royal College of Nurses/Nephrology Nurses' Forum
RPG	Renal Pharmacy Group
RRT	Renal Replacement Therapy
RSCG	Regional Specialised Commissioning Group
S DGH N	Society for District General Hospital Nephrologists
SLA	Service Level Agreement
SpR	Specialist Registrar
StHA	Strategic Health Authority
UK	United Kingdom of Great Britain and Northern Ireland
UKT	United Kingdom Transplant
UKTCA	UK Transplant Co-ordinators Association
UKTSSA	UK Transplant Support Service Authority (now UKT)
WDCs	Workforce Development Confederations
WTE	Whole Time Equivalent

APPENDIX 2 – GLOSSARY of TERMS

By permission of The Renal Association[168]

Access A method of gaining entry to the bloodstream to allow haemodialysis or to the peritoneum for peritoneal dialysis. Access methods used for haemodialysis include a catheter, fistula or graft; a catheter is inserted as peritoneal dialysis access.

Acute renal failure (ARF)
The rapid loss of kidney function over a few hours or days.

Albumin A type of protein that occurs in the blood.

Alphacalcidol A form of vitamin D used to treat renal bone disease.

Anaemia A deficiency of red blood cells which can lead to a lack of oxygen, causing tiredness, shortage of breath and pallor. One of the functions of the kidneys is to produce a hormone epoetin, which helps make blood cells. In kidney failure, epoetin is not made and anaemia results.

Angiotensin converting enzyme inhibitors
Drugs which lower blood pressure, improve heart function and have been shown to delay the progression of renal failure.

Anthropometry The measuring of the human body or part of the human body.

Antibiotic A chemical substance produced by a micro-organism which has the capacity, in dilute solutions, to inhibit the growth of or to kill other micro-organisms. Antibiotics are used in the treatment of infectious diseases.

Arteriogram A type of X-ray that uses a special contrast medium to show the blood vessels. The contrast medium is put into the blood vessels via a tube that is inserted into the groin and passed up to the kidneys.

Artificial kidney Another name for the dialyser or filtering unit used in haemodialysis.

Atheroma (also called Artherosclerosis)
Deposits of cholesterol and other fats that cause furring and narrowing of the arteries (also called atherosclerosis).

Automated peritoneal dialysis (APD)
A form of peritoneal dialysis that requires a machine to control the movement of fluid into and out of the peritoneal cavity. APD is carried out at home each night whilst the patient sleeps.

Azathioprine An immuno-suppressant drug used to prevent the rejection of a transplanted kidney.

Beta-blockers Drugs that slow down the heart rate and lower blood pressure. Examples are atenolol, metoprolol and propranolol.

Bicarbonate An alkaline substance that is normally present in the blood. A low blood level of bicarbonate shows there is too much acid in the blood.

Biopsy A test involving the removal of a small piece of an organ or other body tissue and its examination under a microscope.

Bladder The organ in which urine is stored before being passed from the body.

Blood cells The microscopically tiny units that form the solid part of the blood. There are three main types: red blood cells, white blood cells and platelets (which are cell fragments).

Blood group An inherited characteristic of red blood cells. The common classification is based on whether or not a person has A and/or B antigens on their cells. Each person belongs to one of four blood groups. A, B, AB and O.

Blood pressure The pressure that the blood exerts against the walls of the arteries as it flows through them. Blood pressure measurement consist of two numbers. The first shows the systolic blood pressure, the second, the diastolic blood pressure. The kidneys help to control blood pressure and in kidney failure, the blood pressure tends to be high.

Brain death A term indicating that the brain has permanently stopped working, and that further life is possible only on a life-support machine. A person must be diagnosed as brain dead before their organs can be removed for a cadaveric transplant.

Cadaveric transplant
A transplant kidney removed from someone who has died.

Calcium A chemical element obtained through the diet. It is essential for the maintenance of healthy teeth and bone, and is essential for many metabolic processes such as nerve function, muscle contraction and blood clotting.

Catheter A hollow tube used to transport fluids to and from the body.

Cholesterol A lipid (sterol) that is a major contributor to atheroma.

Chronic renal failure (CRF)
The slow and progressive deterioration of kidney function. Initially there may be little to see or find, and this means that many patients present for medical help very late in their disease, or even in the terminal stages.

Clearance The rate at which toxic waste products are removed from the body. Excreting these products is one of the main functions of the kidneys. In kidney failure clearance by the kidneys is inadequate and toxins build up in the blood.

Cochrane Review A Cochrane Review is a systematic, up-to-date summary of reliable evidence of the benefits and risks of healthcare. Cochrane Reviews are intended to help people make practical decisions. For a review to be called a 'Cochrane Review' it must be in the Parent Database maintained by the Cochrane Collaboration.

Continuous ambulatory peritoneal dialysis (CAPD)
A form of treatment for kidney failure in which fluid is instilled into the patient's peritoneum through a catheter and drained out some hours later. Normally about four such exchanges are performed at regular intervals throughout the day.

Creatinine A natural waste product of muscle metabolism which is normally excreted by the kidney. When renal function is reduced the level of creatinine in the blood (plasma creatinine) rises and the amount cleared from the kidneys (creatinine clearance) falls..

Creatinine clearance
A calculation to assess the kidneys' ability to remove creatinine from the blood. It is a more accurate guide to how well the kidneys are working than plasma creatinine. Peritoneal creatinine clearance is used as a measure of how well peritoneal dialysis is removing toxins.

Cross-match The final blood test before a transplant operation is performed. It checks whether the patient has any antibodies to the donor tissue that might damage the transplanted kidney. The operation can proceed only if the cross-match is negative (ie no such antibodies are found).

Cyclosporin An immunosuppressant drug used to prevent the rejection of a transplant kidney.

Cytomegalovirus (CMV)
A virus that normally causes only a mild 'flu-like' illness. In people with a kidney transplant (and in other people whose immune system is suppressed), CMV can cause a more serious illness, affecting the lungs, liver and blood.

Diabetes Mellitus A condition in which the blood glucose (sugar) level is higher than normal. It takes two forms: insulin dependent diabetes usually developing in young people and non insulin dependent diabetes seen in these who are elderly or overweight. Both can result in renal failure.

Dialyser A filtering unit attached to a dialysis machine. It provides the dialysis membrane for patient on haemodialysis. The dialyser removes body wastes and excess water from the blood thus mimicking some of the functions of a normal kidney.

Dialysis An artificial process by which the toxic waste products of food and excess water are removed from the body while retaining essential substances. Dialysis performs some of the work normally performed by healthy kidneys. It is derived from a Greek word meaning 'to separate'.

Dialysate/Dialysis fluid
A sterile fluid used to remove toxic waste products and water from the body during dialysis.

Dialysis machine The machine which pumps the patient's blood through the dialyser, and monitors the dialysis process as it takes place. The dialyser or artificial kidney is attached to it.

Dialysis membrane
In haemodialysis a thin layer of cellulose or synthetic fibre with many tiny holes in it, through which the process of dialysis takes place. In peritoneal dialysis, the patient's peritoneum provides the dialysis membrane. In each case, the membrane keeps the dialysis fluid separate from the blood (essential because dialysis fluid is toxic if it flows directly into the blood). The tiny holes in the membrane make it semi-permeable, allowing water and toxic waste substances to pass through and be removed.

Diastolic blood pressure
A blood pressure reading taken when the heart is relaxed. It is taken after the systolic blood pressure and is the second figure in a blood pressure measurement.

Diffusion A process by which substances pass from a stronger to a weaker solution. Diffusion is one of the key processes in dialysis (the other is ultrafiltration). During dialysis, body wastes such as creatinine pass from the blood into the dialysis fluid. At the same time, useful substances such as calcium pass from the dialysis fluid into the blood.

Donor A person who donates (gives) an organ to another person (the recipient).

Donor kidney A kidney that has been donated.

Electrocardiogram (ECG)
A test that shows the electrical activity within the heart.

Echocardiogram (ECHO)
An ultrasound scan showing the structure and function of the heart.

End-stage renal disease (ESRD)
End stage renal disease is reached when chronic renal failure cannot be controlled by conservative management and when the patient requires either dialysis or a kidney transplant in order to maintain life.

End-stage renal failure (ESRF)
An alternative name for end-stage renal disease.

Erythropoietin (Epoetin, epo)
A hormone, made by the kidneys, which stimulates the bone marrow to produce red blood cells.

Exchange In peritoneal dialysis this term means the process of draining fluid out of the peritoneal cavity and instilling fresh dialysate into the peritoneal cavity.

Exit site The point where a catheter comes out through the skin. Exit site infections can occur in haemodialysis patients when a catheter is used for access or in those undergoing peritoneal dialysis.

Fistula A connection between an artery and vein, usually at the wrist or elbow, created surgically to give access to the circulation for haemodialysis. The increased blood flow causes the vein to enlarge, making it suitable for haemodialysis needles.

FK506 Another name for tacrolimus. An immunosuppressant drug used to prevent and treat rejection of a transplanted kidney.

Fluid overload A condition in which the body contains too much water. It is caused by drinking too much fluid, or not losing enough. Fluid overload occurs in kidney failure because one of the main functions of the kidneys is to remove excess water. Fluid overload is often associated with high blood pressure. Excess fluid first gathers around the ankles (ankle oedema) and may later settle in the lungs resulting in breathlessness (pulmonary oedema).

Glomerulus One of the tiny filtering units inside the kidney.

Glomerulonephritis (GN)
Inflammation of the glomeruli, which is one of the causes of kidney failure.

Glucose A type of sugar. There is normally a small amount glucose in the blood. This amount is not usually increased in people with kidney failure unless they also have diabetes mellitus. Glucose is the main solute in peritoneal dialysis fluid, drawing excess water into the dialysis fluid from the blood by osmosis.

Graft A type of access to the bloodstream for haemodialysis. The graft is a small plastic tube that connects an artery to a vein and is inserted surgically. Haemodialysis needles can then be inserted into the graft. The term graft can also be used for a transplanted kidney.

Haemodialysis (HD)
A form of treatment in which the blood is purified outside the body, by passing it through a filter called the dialyser or artificial kidney. The filter is connected to a machine which pumps the blood through the filter and controls the entire process. For patients with end stage renal disease each dialysis session normally lasts from three to five hours, and sessions are usually needed three times a week.

Haemodialysis catheter
A plastic tube used to gain access to the bloodstream for haemodialysis.

Haemodialysis unit
The part of a hospital where patients go for haemodialysis.

Haemoglobin (Hb) A substance in red blood cells that carries oxygen around the body. Blood levels of haemoglobin are measured to look for anaemia. A low Hb value indicates anaemia.

Heart-beating donor
A term used to describe a donor whose heart is still beating after brain death has occurred. Most, but not all, cadaveric transplants come from heart-beating donors.

Hepatitis An infection of the liver, usually caused by a virus. Two main types, called hepatitis B and hepatitis C, can be passed on by blood contact. This means that dialysis patients, especially those on haemodialysis, have an increased risk of getting these infections. Care is taken to reduce this risk, and regular virus checks are made on all kidney patients.

Home haemodialysis
Treatment on a dialysis machine installed in a patient's own home.

Hormones Substances that act as chemical messengers in the body. They are produced in parts of the body called endocrine glands.

Hyperkalaemia An abnormally high level of potassium in the blood.

Hyperparathyroidism
A disorder in which the parathyroid glands make too much parathyroid hormone.

Immune system The body's natural defence system. It includes organs such as the spleen and lymph nodes and specialist white blood cells called lymphocytes. The immune system protects the body from infections, foreign bodies and cancer. To prevent rejection of a transplant kidney, it is necessary for patients to take immuno-suppressant drugs.

Immunosuppressant drugs
A group of drugs used to dampen down the immune system to prevent or treat rejection of a transplant kidney. Commonly used examples are cyclosporin, azathioprine and prednisolone. Tacrolimus (FK506), mycophenolate mofetil and rapamycin are newer examples.

Kidneys The two bean-shaped body organs located at the back of the body, below the ribs. The kidneys remove toxic waste products of protein breakdown and remove excess water from the body. They also help to control blood pressure, manufacture of red blood cells and keep the bones strong and healthy.

Kidney biopsy Removal of a small piece of kidney through a hollow needle for examination under a microscope. It is required to diagnose some causes of kidney failure; biopsies of transplanted kidneys may also be required.

Kidney donor A person who gives a kidney for transplantation.

Kidney failure A condition in which the kidneys are less able than normal to perform their functions of removing toxic wastes, removing excess water, helping to control blood pressure, control red blood cell manufacture and keep the bones strong and healthy. Kidney failure can be acute or chronic. Advanced chronic kidney failure is called end-stage renal disease (ESRD).

Kidney machine Another name for a dialysis machine.

Kidney transplant A name both for the transplant operation during which a new kidney is given to a recipient or for the new kidney itself.

Kt/V A measure of dialysis adequacy.

Lipids Another name for fats. People with kidney failure tend to have raised lipid levels in the blood.

Living related transplant (LRT)
A transplant kidney donated (given) by a living relative of the recipient. A well-matched living related transplant is likely to function for longer than either a living unrelated transplant or a cadaveric transplant.

Living unrelated transplant
A kidney transplant from a living person who is biologically unrelated to the recipient (such as a husband or wife).

Lymphocytes Specialist white blood cells that form part of the immune system.

Malnutrition Loss of body weight, usually due to insufficient intake of foods especially foods providing protein and energy.

Membrane The material used as a filtering agent in haemodialysers. Many are formed from a cellulose base, others from synthetic materials. The peritoneum is a natural membrane used as the dialysis membrane in peritoneal dialysis.

Methylprednisolone
A drug used to prevent or treat the rejection of a transplant kidney.

Molecule The smallest unit that a substance can be divided into without causing a change in the chemical nature of the substance.

Nephr- Prefix meaning 'relating to the kidneys'.

Nephrectomy An operation to remove a kidney from the body. A bilateral nephrectomy is an operation to remove both kidneys.

Nephritis A general term for inflammation of the kidneys. Also used as an abbreviation for glomerulonephritis (GN). A kidney biopsy is needed to diagnose nephritis.

Nephrology The study of the kidneys in health and disease.

Nephrologist A doctor who cares for patients with kidney disease.

OKT3 Abbreviation for Orthoclone K T-cell receptor 3 antibody, treatment for the rejection of a transplant.

Organ A part of the body that consists of different types of tissue and that performs a particular function. Examples include kidney, heart and brain.

Osmosis The process by which water moves from a weaker to a stronger solution through tiny holes in a semi-permeable membrane. In peritoneal dialysis, it is osmosis that causes excess water to pass from the blood into the dialysis fluid.

Parathyroidectomy
An operation to remove the parathyroid glands.

Parathyroid hormone (PTH)
A hormone produced by the parathyroid glands, which helps control blood levels of calcium. When the level of calcium in the blood is low, PTH increases it by causing calcium loss from the bones into the blood.

Peritoneal cavity The area between the two layers of the peritoneum (or peritoneal membrane) inside the abdomen. The peritoneal cavity contains the abdominal organs, including the stomach, liver and bowels. It normally contains only about 100 ml of liquid, but expands easily to provide a reservoir for the dialysis fluid in peritoneal dialysis.

Peritoneal dialysis (PD)
A treatment of renal failure in which blood purification takes place, using the patient's own peritoneum as the membrane. Bags of dialysis fluid, containing glucose (sugar) and various other substances, are drained in and out of the peritoneal cavity via a PD catheter.

Peritoneal dialysis (PD) catheter
A plastic tube through which dialysis fluid for peritoneal dialysis is drained into, and removed from, the peritoneal cavity. The catheter is about 30 cm (12 in) long and is as wide as a pencil. A small operation is needed to insert the catheter into the abdomen.

Peritoneal equilibration test (PET)
A measurement of the rate at which toxins pass out of the blood into the dialysis fluid during peritoneal dialysis. Patients are described as 'high transporters' (if the toxins move quickly) and 'low transporters' (if the toxins move more slowly). The test is used to assess a patient's suitability for different types of PD.

Peritoneum (peritoneal membrane)
A natural membrane that lines the inside of the wall of the abdomen and that covers all the abdominal organs (the stomach, bowels, liver, etc). The peritoneum provides the dialysis membrane for peritoneal dialysis. It has a large surface area, contains many tiny holes and has a good blood supply.

Peritonitis Inflammation of the peritoneum which can occur in patients on peritoneal dialysis. It is caused by infecting organisms, usually bacteria and can normally be successfully treated with antibiotics.

Phosphate A mineral that helps calcium to strengthen the bones. Phosphate is obtained from foods such as diary products, nuts and meat. The kidneys normally help to control the amount of phosphate in the blood. In kidney failure, phosphate tends to build up in the blood.

Phosphate binders Medication (eg calcium carbonate) that helps prevent a build-up of phosphate in the body. Phosphate binders combine with phosphate in food and the phosphate passes out of the body with the binder.

Potassium A mineral that is normally present in blood and is removed by the kidney. High values can occur in renal failure which can be dangerous, causing the heart to stop. People with renal failure often need to restrict the amount of potassium in their diet.

Prednisolone A drug used to prevent the rejection of a transplant kidney.

Radio-isotope scan A method of obtaining pictures of the body's interior, also called a radionuclide scan. A small amount of a mildly radioactive substance is either swallowed or injected into the bloodstream. The substance gathers in certain parts of the body, which then show up on pictures taken by a special machine.

Radionuclide scan Another name for a radio-isotope scan.

Randomised Controlled Trial (RCT) (synonym: Randomised Clinical Trial)
An experiment in which investigators randomly allocate eligible people into (eg treatment and control) groups to receive or not to receive one or more interventions that are being compared. The results are assessed by comparing outcomes in the treatment and control groups.

Recipient In the context of transplantation, a person who receives an organ from another person (the donor).

Red blood cells Cells in the blood which carry oxygen from the lungs around the body.

Rejection The process by which a patient's immune system recognises a transplant kidney (or other transplanted organ) as not its 'own' and then tries to destroy it and remove it from the body. Rejection can be acute or chronic.

Renal Adjective meaning relating to the kidneys.

Renal bone disease
A complication of kidney failure, in which bone abnormalities develop because of low blood levels of calcium and vitamin D and high levels of phosphate. Without treatment, renal bone disease can result in bone pain and fractures.

Renovascular disease

Narrowing of the renal arteries caused by deposite of atheroma ('reno-' means relating to the kidney, and '-vascular' means relating to the blood vessels). Renovascular disease is a common cause of kidney failure in older patients.

Satellite haemodialysis unit

A place where some patients go for haemodialysis away from the main hospital renal unit. They are more suitable for patients whose medical condition is stable, and patients there may do some of the haemodialysis preparation themselves. Such units tend to be more easily accessible to patients than most units in main hospital buildings.

Semi-permeable An adjective, often used to describe a dialysis membrane, indicating that it will allow some but not all substances to pass through it. Substances made of smaller molecules will pass through the holes in the membrane, whereas substances made of larger molecules will not.

Sphygmomanometer

The instrument used to measure blood pressure.

Staphylococcus One of a group of bacteria responsible for various infections. It is a common cause of peritonitis in patients on peritoneal dialysis and of catheter infections in haemodialysis patients.

Systolic blood pressure

A blood pressure reading taken when the heart squeezes as it beats. The systolic blood pressure is measured before the diastolic blood pressure and is the first figure in a blood pressure measurement.

Tacrolimus An immunosuppressant drug used to prevent and treat transplant rejection, also known as FK506.

Tissue type A set of inherited characteristics on the surface of cells. Each person's tissue type has six components (three from each parent). Although there are only three main sorts of tissue type characteristic (called A, B and DR), each of these exist in several forms. Given the large number of possibilities, it is unusual for there to be an exact tissue type match between a transplant kidney and its recipient. In general, the more characteristics that match, the more likely is a transplant to succeed.

Tissue typing A blood test that identifies a person's tissue type.

Toxins Poisons. One of the main functions of the kidneys is to remove toxins from the blood.

Transplant A term used to mean either a transplanted kidney (or other transplant organ) or a transplant operation.

Transplantation The replacement of an organ in the body by another person's organ. Many different organs can now by successfully transplanted, including the kidneys, liver, bowel, heart, lungs, pancreas, skin and bones.

Transplant operation

The surgical operation by which a patient is given a donated organ. A transplanted kidney is placed lower in the abdomen than the patient's own kidneys, which are usually left in place.

Transplant waiting list
A list of patients awaiting transplantation, held locally or nationally. The national list is coordinated nationally by UKTSSA, whose computer compares patients' details (including blood group and tissue type) with those of cadaveric organs that become available.

Tunnel infection Complication of peritoneal dialysis. It occurs when an infection spreads from the exit site into the 'tunnel' (ie the route of the PD catheter through the abdominal wall).

Ultrafiltration The removal of excess water from the body. Ultrafiltration is one of the two main functions of the kidneys. In kidney failure, problems with ultrafiltration result in fluid overload. Dialysis provides an alternative means of ultrafiltration.

Ultrasound scan A method of obtaining pictures of internal organs, such as the kidneys, or of an unborn baby, using sound waves. A device that sends out sound waves is held against the body. The sound waves produce echoes, which the scanner detects and builds up into pictures.

Urea A waste product of protein breakdown normally removed by the kidney. When the kidney fails it accumulates in the bloodstream.

Ureters The tubes that take urine from the kidneys to the bladder.

Urethra The tube that takes urine from the bladder to the body surface.

Urinary catheter A plastic tube inserted into the bladder for the removal of urine.

Urine The liquid produced by the kidneys, consisting of the toxic waste products of food and the excess water from the blood.

Virus A type of organism (much smaller than a bacterium) responsible for a range of mild and serious illnesses.

Vitamin D A chemical that helps the body to absorb calcium from the diet. Blood levels of one form of vitamin D (calcitriol) are usually low in people with kidney failure.

NOTES

AFFILIATED ASSOCIATIONS

Association of Renal Industries • Email: ARI@mandmconsultants.co.uk
Association of Renal Managers • www.armmanagers.org
Association of Renal Technologists • www.artery.org.uk
British Association for Paediatric Nephrology • www.bapn.uwcm.ac.uk
British Association of Social Workers / Renal Special Interest Group • www.basw.co.uk
British Dietetic Association / Renal Nutrition Group • www.bda.uk.com
British Paediatric Renal Symposium • www.britishrenal.org
British Transplant Society • www.bts.org.uk
EDTNA/ERCA • www.edtna-erca.org
National Kidney Federation • www.kidney.org.uk
RCN Nephrology Nursing Forum • www.rcn.org.uk
Renal Association • www.renal.org
Renal Pharmacy Group • www.renalpharmacy.org.uk
Society for DGH Nephrologists • Email: Paul.Stevens@ekh-tr.sthames.nhs.uk
UK Transplant Co-ordinators Association • www.uktca.co.uk

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