

REPORT OF THE HEALTH CARE STRATEGY UNIT
REVIEW OF RENAL SERVICES

November 1994

INTRODUCTION

1.1. This review was commissioned from the Health Care Strategy Unit by HSSG and the (then) NHS Management Executive in July 1993. It was established following the publication of epidemiological evidence by the Renal Association which suggested that the level of need for renal replacement therapy (RRT) in England as a whole is likely to be about 80 new cases per million population per year (pmp) in people under 80.

1.2. The review team was chaired by Professor Netar Mallick, consultant nephrologist at the Manchester Royal Infirmary and the Chief Medical Officer's consultant advisor, and included representatives from the Renal Association, the nursing profession, Regional Health Authorities, various branches of the NHS Executive and professional medical groups within the Department of Health. The full membership and terms of reference are at Annex 1.

1.3. The review took account of work being carried out following the Tomlinson report to review renal services in London, in particular the Report of the Specialty Review team, also chaired by Professor Mallick. It was not asked to consider paediatric renal services, but received evidence from and communicated with paediatric clinicians. The review addresses services in England.

1.4. The review concentrates on the purchasing and provision of renal replacement therapy (RRT) as treatment for end stage renal failure (ESRF). In broad terms this covers haemodialysis, continuous ambulatory peritoneal dialysis (CAPD) and transplantation. However, most contracts for renal services also include services for acute and pre-end stage chronic renal failure, which will generally be delivered in the same renal unit as services for end stage renal failure.

1.5. The review team developed a programme of work which addressed the issues in a number of ways. The work undertaken included:

- Comments from a range of organisations and individuals.
- A survey of all providers of renal services in England, which effectively provided a 'census' of all facilities and staff providing for patients with end stage renal failure, as well as a picture of patients currently on the programme, and annual acceptance rates for new patients. It is important to bear in mind that the data collected for the review refers to 1991-92; the last complete year for which figures were available. The take on rates and patient stock figures noted below and in Part II may therefore have changed in the last two years.
- A questionnaire to all Regional and District Health Authorities, on purchasing renal services.
- The commissioning of work analysing the cost of renal services to purchasers. This was discussed with a specially convened group of providers.

- Development of purchaser guidance, in consultation with a specially convened group of purchasers.
- Visits to all NHS Regions in England to explain the purpose of the Review and to discuss local issues. These meetings were well attended by both purchasers and providers. All had seen drafts of the purchaser guidance, and were invited to comment.

1.6. The HCSU is grateful to the review team members for their hard work in taking forward the review, and would like to express its thanks to all those who gave their time to meet them or sent their written comments, and who expressed themselves freely and helpfully.

1.7. There are three main parts to the review:

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| Part I: | The report itself, including the conclusions and recommendations of the review; |
| Part II: | The detailed evidence that led to the review's findings; this includes the results of a detailed survey of all renal providers, which builds upon the epidemiological evidence published by the Renal Association and detailed information about the current cost of the service; |
| Part III: | Draft purchaser guidance, prepared by the (then) Purchasing Unit of the NHS Executive as part of the review (to be promulgated early-1995); this includes some information on modelling End Stage Renal Failure patient numbers and a template for costing renal services. |

PART I: FINDINGS AND RECOMMENDATIONS

Introduction

2.1. This report reviews the current provision of renal services in England, and considers what needs to be done by purchasers in order to assess need properly and to develop their purchasing skills; the position of community and primary care services in relation to renal services; and transplantation, staffing and cost issues.

2.2. The recommendations in the report are directed at the NHS Executive, with a view to improving the work of purchasers, as they must take the lead in assessing population need and planning to meet that need. The report does not recommend any single preferred level of provision across the country; that is for purchasers to decide in discussion with providers and clinicians. However, it is accepted that the market in renal services needs to be 'managed', ie. that at a level above that of the individual purchaser there needs to be a coherent framework for the purchasing and delivery of renal services, with adequate monitoring of progress towards locally-defined goals and agreed quality standards.

Background

2.3. Over the last ten years renal services, and especially renal replacement therapy, have made remarkable progress in their ability to treat patients. Acceptance rates have trebled over the last decade, and patients are now being successfully treated who would have died five years ago. In the past treatment for end stage renal failure was rationed, and only younger, fitter patients ever received dialysis or transplantation. This is no longer the case. These are achievements of which everyone involved with the renal services should be proud. The task now is to ensure that the benefits of these developments continue, and it is hoped that this review will help the service to cope with ever-increasing demands.

2.4. Renal Replacement Therapy has been shown to be an extremely effective treatment, providing many years of active life for those who receive it. Evidence on outcomes is good^{1,2}, but varies with age and co-morbidity; there are some geographical variations, but the figures for the whole of Europe stand up well in these comparisons.

¹ *Report on Management of Renal Failure in Europe, XXIII, 1992 in NEPHROLOGY DIALYSIS TRANSPLANTATION* (Official Publication of the European Dialysis and Transplant Association). Oxford (in press)

² **EA FRIEDMAN** (ed) *Death on Haemodialysis: Preventable or inevitable?* DEVELOPMENTS IN NEPHROLOGY VOL 35 (Cluwer Academic Publishers 1994) (in press)

Renal Association Report

2.5. In November 1991 the Renal Association published a Report³ which, after considering the available epidemiological evidence, concluded that *"There is a need to continue the expansion and development of renal services in the UK to provide for the treatment of patients with renal disease, the true incidence of which has now been established. This expansion has important work force and planning implications."*

2.6. The Renal Association undertook peer-reviewed epidemiological studies which showed that there is likely to be a need to provide RRT for 75-80 new adult Caucasian (white) patients per million population each year up to the age of 80, and that this need was not being met. However, the rate of incidence of ESRF is dependent on other factors such as age, ethnicity and co-morbidity, and in many sectors of the population is likely to be higher than 80 per million per year. The acceptance rate for new patients in the UK in 1991 was 60.7 patients per million population, suggesting that the need was not being met in full. The prevalence of renal replacement therapy - ie. the number of patients receiving RRT ('patient stock') - will continue to rise until a 'steady state' is reached, in which the number of deaths of those under treatment equals the entry rate. This stock will be expanded further if the acceptance rate of new patients were to reach and remain at the levels which meet population need.

2.7. Although the Renal Association's findings were significant, they give only a notional figure for the average level of need across England, and do not take account of the excess risk in ethnic minority groups (around 6% of the population), which could raise the level of need for the UK as a whole by around 5-10%. In any individual purchasing authority the figure of 80pmp is a guideline only; each purchaser must assess its own needs, and the figures will be increased locally if there is a higher than average population of elderly people or of Black or Asian people (see paragraph 2.12).

Current levels of purchasing

2.8. To test the current level of service across the country, a survey of all providers was commissioned from Dr Paul Roderick of the Wessex Institute of Public Health. The detailed findings and analysis of this work are at Part II of this report. The survey provides a comprehensive database of renal services in England, and more work should be commissioned to analyse the data further, in particular to investigate how age, ethnicity and proximity to and supply of services affects the rate of acceptance onto the renal replacement programme. Furthermore, as the work represents a substantial and probably unique set of data on the prevalence of RRT, the NHS Executive should consider ways in which the material could be published, suitably anonymised. The last section of Part I (paragraphs 2.124-2.131) discusses what further work might be commissioned to develop the work begun for this review.

³ *Provision of Services for Adult Patients with Renal Disease in the United Kingdom* THE RENAL ASSOCIATION (1991)

2.9. The survey shows that acceptance rates onto RRT programmes vary enormously between districts, from a lowest figure of 19pmp to a highest figure of 128pmp, with a median of 60pmp. These wide variations inevitably lead to concerns about the level of service which is being purchased at the lower end of the range. From an analysis of the data on age and ethnicity (see paragraph 2.12 below), these alone do not account for the wide disparity between different and even neighbouring purchasing authorities. It is likely that, in those districts where acceptance rates are extremely low, there are patients below the age of 65 who are not receiving treatment for ESRF.

2.10. More analysis is needed to determine the extent to which proximity to a renal unit leads to higher take-up of RRT; anecdotally this seems to be the case, and the raw data suggest that acceptance rates are higher in large centres of population. However, it is also true that there are generally larger concentrations of at-risk populations in these areas, and this too may be a major determining factor in raising acceptance rates.

2.11. The obvious conclusion is that some purchasing authorities are purchasing lower levels of service than others, where demographic factors suggest that their need is not so dissimilar. If this is the case, then it seems that access to RRT is determined by place of residence, not clinical need, and patients who could benefit from RRT are not receiving treatment. The review has not attempted to recommend rigidly the appropriate level of service to be purchased by each authority, but has concluded that purchasers must take immediate action to determine the level of need locally. The action that needs to be taken to help in this process is discussed later (see paragraphs 2.29 - 2.35). Some purchasers, in discussion with the review group, agreed that they were wary of carrying out a comprehensive assessment of need because they feared it would fuel demand for which they would have difficulties in purchasing services, not least because of the extra demands it would place on already committed budgets. However, it is clear that rational decisions cannot be made without first properly assessing needs.

2.12. Ethnicity and age are considered to be the key socio-demographic determinants of ESRF. There is cogent evidence that the incidence of ESRF increases significantly with age. Whilst not achieving yet the levels attained in other major European countries, the trend in the UK has been for older patients to be accepted, resulting in the rising age-profile of new patients in recent years. Evidence from the United States suggests that the relative risk of ESRF in the Black population (predominantly of African origin) is two to four times higher than for whites⁴. Data collected during the Review of Renal Specialist Services in London suggest that there is a similar increased risk of renal failure in the ethnic populations (Asian and Afro-Caribbean) in the Thames Regions compared with whites⁵. Data collected for this review (see Part II) show the overall incidence of renal failure amongst the Black and Asian populations to be 2.8 times higher than that for the white population. People from the Indian subcontinent have a higher prevalence of non-insulin dependent diabetes, and there is a higher prevalence of severe hypertension in the

⁴ *US Renal Disease Survey Annual Report 1993* DEPARTMENT OF HEALTH EDUCATION AND WELFARE, WASHINGTON DC (1993)

⁵ *Report of the Review of London Renal Services* HMSO (1993)

Black population; both are important causes of ESRF. This partly explains the higher acceptance rate of Asians on to RRT programmes. Not only does the incidence of ESRF rise with age, but this increase is steepest in the Black and Asian populations. This factor, taken with the younger age distribution of these populations, suggests that there is likely to be a marked increase in population need in areas with large Black and Asian populations. Further work is needed on the epidemiology of renal disease in these population groups.

Patient Stock

2.13. The stock of dialysis patients by region shows broad variation. However, the figures, which range from 86pmp to 284pmp, are affected by cross-boundary flow of patients. Total stock will continue to rise over the next decade, as those new patients who have been accepted on to the RRT programme continue to receive dialysis or transplantation, while new patients continue to join the programme.

2.14. An increase in total stock is inevitable, and purchasers will need to plan to increase provision to meet that increased need. If acceptance rates increase over the next few years, the total stock will increase faster, and will take longer to reach the plateau where the number of patients being accepted on to the programme is equal to the number dying each year. This has important implications for purchasers, not least in terms of their spending on RRT, and these are considered later (see paragraph 2.30).

2.15. Work carried out for this review has estimated the likely increase in patient stock until 'steady state' is reached. This work shows that nationally there is likely to be an 80% increase in the numbers of patients receiving RRT over the next decade, at an average growth of around 7% per year.

Service Provision

2.16. The survey of providers provides information on current levels of service provision. The major conclusion is that levels of service provision vary widely across the country. This is important in indicating areas in which purchasers should give particular priority to assessing need and increasing acceptance onto the RRT programme if the need is confirmed.

2.17. The ratio of beds and dialysis stations to population is a crude but robust indicator of availability of renal services. Availability of beds by (pre-April 1994) region ranged from 5 per million to 30 per million, and haemodialysis stations from 5 to 29 per million. Clearly crude rates of beds to population will not take into account other factors such as level of need and cross-boundary flows of patients, but if there is particularly low provision in a more remote region where cross-boundary flow is likely to be small, there might be difficulties for purchasers in providing for the needs of their population.

2.18. There are areas in most regions where there seems to be substantial under-provision; there are towns of substantial size where there are no services within

reasonable travelling distance. This is often a result of historical pattern of service provision, and is not simply a matter of ease and equity of access for patients. There is evidence of a link between a low level of provision of services and a low level of acceptance onto renal replacement therapy programmes. This suggests that lack of provision might lead to unmet need.

2.19. Historical factors and geography are the most important determinant of service patterns locally, and any 'ideal' model of service is unlikely to be applicable in every area. Historically, renal services in the UK have developed around a small number of units, mainly in the larger cities or associated with university teaching hospitals. Some of these are now reaching the limit of their physical capacity. The further development of these services will require careful planning with particular emphasis on capital development. It is for local purchasers to agree with providers the most appropriate pattern of service, based on the assessed needs of their population. An important factor will be the increasing age of new patients accepted onto the RRT programme, for whom travel to receive treatment must be minimised. This will undoubtedly influence any new developments of renal services.

2.20. The pattern of service provision should be related to the size of population required to support a comprehensive and effective service, given the likely demand for service per unit of population. The service configuration should take account of geography, demography and the need for cost-effective aggregation of the service. These requirements can lead to several patterns of service, with some having advantages in specific circumstances. It seems inevitable, however, that there will be aggregation of specialist centres, because this makes the most cost-effective use of staff and facilities.

2.21. The appropriate population base for a comprehensive programme of renal care appears to be between 2.5 and 3 million people. Considerations leading to this view include:

- This population will require 130 to 150 transplants annually, if sufficient organs are available to prevent waiting lists increasing even further. At present only around three-fifths of this supply exists, so the service in such a unit will perform 80-100 transplants per year. This is an appropriate number of procedures for a renal transplant unit having regard to the provision of cost-effective staffing and infrastructure and training needs in this specialty.
- This size of population is sufficient to require a comprehensive nephrology centre, with its associated academic and research interests.

2.22. Setting geographical factors aside, a typical renal service for such a population of around 3 million might comprise:

- A nephrology/transplant centre providing full services for the assessment and management of patients with the full range of renal diseases, usually with a number of satellite dialysis units and with facilities for transplantation. As is desirable, the academic, nephrology and transplantation services will normally be

linked together. It seems likely that there will be around 20 such centres in the United Kingdom.

- Nephrology units each serving a population of 1-1.5 million in densely populated areas (but less where the population is less dense). These would provide for the management of RRT for (on average) 80-100 new patients annually, but not including transplantation. They would be linked to a nephrology/transplant centre, especially for renal transplantation and for training. The senior medical staff concerned may be either whole time nephrologists or general physicians with an interest in nephrology. Such a unit may be located in a DGH or a teaching hospital.
- Satellite Units and perhaps Minimal Care Units support these services and offer a cost-effective way of bringing services closer to the patient

2.23. Actual patterns of provision are likely to differ from this idealised picture. Thus, all services in Carlisle except transplantation are provided from a small unit because the only alternative would be for patients to travel long distances to Newcastle or Preston. In other places - usually major conurbations - the distribution of units results mainly from historical factors. In London the problems have already been addressed by the Specialty Review carried out for the London Implementation Group.

2.24. Satellite Units, which are best sited at DGHs, provide maintenance haemodialysis services for patients who need nursing supervision without immediately available medical back-up, together with CAPD outpatient supervision. These units need to be sufficiently large to make the most efficient use of staff and facilities. The Renal Association estimated the optimum size to be of 6-12 stations, running two or three shifts per day for six days per week⁶. On these figures, each unit would provide somewhere between 72 and 216 sessions per week, ie. services for between 24 and 72 patients (allowing three sessions per week per patient). This gives sufficient flexibility for satellite units to be established successfully in locations of greatly differing populations. As part of shared care, local general practitioners may play a variable role according to their wishes in running these units, together with local community dialysis nurses, and other staff such as clinical assistants.

2.25. Minimal Care Units provide haemodialysis services for patients who are sufficiently fit and capable to set up machines and dialyse without the supervision of nursing staff. As such patients are uncommon, managers of services should ensure before establishing a Minimal Care Unit that it will be an effective use of resources. Some satellite units might incorporate a minimal care shift.

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Provision of Services for Adult Patients with Renal Disease in the United Kingdom THE RENAL ASSOCIATION (1991)

Type of Treatment

2.26. The survey looked at the type of treatment which patients were receiving in each unit. Again, there was a very wide range of responses. The percentage of dialysis patients on CAPD ranged from 7% to 76%; the percentage of dialysis patients receiving hospital haemodialysis ranged from 6% to 93%; and the percentage of dialysis patients receiving home haemodialysis ranged from 0% to 23%. Home haemodialysis is becoming increasingly rare, and very few new patients receive this type of treatment. Clearly the decision as to the most appropriate mode of treatment remains one for the clinician in consultation with the patient, but it is important that purchasers are aware of the benefits and drawbacks, and clinical- and cost-effectiveness of each type of treatment, and develop quality measures which can be used in the contracting process.

2.27. In some cases, it appears that cost constraints are affecting the type of treatment purchased. The material at Section D of Part II shows that the cost per patient per annum is lower for patients appropriately placed on CAPD than for hospital haemodialysis. However, this in itself is insufficient reason for placing a patient on CAPD rather than another form of dialysis. The most important factor must be the appropriateness of the particular form of treatment bearing in mind the patient's clinical need and home circumstances. Hospital haemodialysis is necessarily more costly in terms of staff time and because patients often have concurrent medical or social problems which preclude them from receiving CAPD. Patients on satellite or home haemodialysis have a lower cost profile, reflecting their relative independence. Finally, inappropriate placement on a particular type of treatment is likely, in the long-term, to lead to higher costs as the patient will need further treatment as a result.

2.28. For most patients transplantation is the optimum form of treatment, and in many units transplant patients constitute about half the patient stock. There are difficulties in harvesting sufficient organs for transplantation. The need to address this is discussed later (see paragraphs 2.111 - 2.117).

Improving Purchasing

Current Position

2.29. The wide variation in acceptance rates across the country suggests that some purchasers have not assessed adequately the needs of their population. In discussion, many purchasers accepted that this was the case, and suggested that guidance and information would be welcome.

2.30. There is in many districts an apparent lack of understanding by purchasers of the range of issues associated with ESRF, and many purchasers have not yet addressed the problems they are likely to face. Most importantly, many purchasers have not yet understood the argument that, as long as new patients are being taken on to the programme faster than patients already receiving renal replacement therapy are dying, there will be a general increase in the total stock of patients receiving treatment until a 'steady state' is reached, whether or not the acceptance rate is increased. Some purchasing authorities have understood this, and have developed sophisticated needs assessment procedures to anticipate future demand. Others need help to develop their needs assessment and planning skills.

Purchaser Guidance

2.31. Purchasers across the country have expressed almost unanimously a need for help in developing purchasing, and in particular for the centre to take a lead, by issuing purchaser guidance to enable them to develop their knowledge and skills in this area, and to help purchasers address some of the issues raised in this report.

2.32. The review commissioned the Purchasing Unit of the NHS Executive to draft purchaser guidance. This has been developed in consultation with purchasers and, as well as information on the factors which purchasers need to consider when contracting for renal services, it includes newly-developed tools to assist purchasers including a costing template to facilitate the contracting process. The draft purchaser guidance forms Part III of this report, and should be issued to purchasers as soon as possible.

Recommendation 1: The NHS Executive should arrange for the purchaser guidance at Part III to be published and disseminated to purchasers as soon as possible.

Needs Assessment

2.33. The first step for purchasers must be to undertake a proper assessment of the needs of their population for RRT. For the most part, comprehensive health needs assessment has not been carried out and it is noticeable that, where this has been done, acceptance onto the renal replacement programme has risen, and an increase in service has been planned to take account of the increased patient stock. Purchasers must therefore carry out a thorough and comprehensive assessment of the needs of their population. The first task must be to ensure that those responsible for needs assessment within the purchasing authority are fully aware of the nature of and incidence and prevalence of renal disease in general terms. There are varying levels of awareness of the issues around the country and it is clear that, where purchasers are ignorant of the epidemiology of renal disease, needs assessment is poor.

2.34. Purchasers, and particularly professionals working in public health, must use the available information. The NHS Executive has recently commissioned a series of reports on epidemiologically-based needs assessments⁷, one of which addresses renal services. This sets out a broad approach to needs assessment, and provides a good historical overview. However, the information collected for this review, and particularly that at Part II, develops the knowledge base even further, and to a large extent supersedes the information in that document.

2.35. Purchasers should continue to use the information in "Health Care Needs Assessment" - which has been sent to all Directors of Public Health and Chief Executives of Regional and District Health Authorities and of Family Health Services Authorities - to inform their needs assessment procedures. In order that purchasers have access to the most up-to-date available information, the NHS Executive should ensure that the information in 'Health Care Needs Assessment' is updated and revised in line with the findings of this review in particular the information at Part II - and re-issue the report on renal services as soon as possible. The information required by purchasers from providers is discussed at paragraphs 2.109 - 2.110.

Recommendation 2: The NHS Executive should revise the renal services report in 'Health Care Needs Assessment' to take account of new information collected for this review.

Consortia and Lead Purchasing arrangements

2.36. Until recently, purchasing for renal services has commonly been carried out at regional level. With the changing role of regions, this function is being passed back to districts. However, as individual districts have assumed responsibility for purchasing renal services, some have found they lack the knowledge, experience and expertise to carry on at the same level as previously. In many instances this is being addressed by the formation of consortia or the adoption of lead purchasing arrangements. Even in some of the areas where there has never been regional purchasing, individual purchasing authorities had not developed the necessary skills. This particularly seems to be the case where providers had traditionally taken the lead in planning services.

2.37. As ESRF is a relatively uncommon condition, affecting few people in an average district, districts will inevitably find it useful to form larger groupings in order to be able to plan effectively for the service. Many purchasers have realised this, and are moving towards purchasing for larger populations. Similarly, providers have expressed concerns that purchasers who act individually often lack the appropriate knowledge of renal services, a problem which would be overcome if a lead purchaser were to take responsibility for a group of DHAs. There is no single optimum model for these developments; local factors such as access and proximity to providers, relationships with purchasers and local demographic

⁷ STEPHENS A, RAFTERY J (eds.) *Health Care Needs Assessment - The epidemiologically based needs assessment reviews* OXFORD (1993)

patterns will mean that purchasers will develop the arrangement which most suits their local circumstances. However, a purchaser which does not move towards some form of joint purchasing arrangement is likely to perform less well, and the NHS Executive should consider what help and guidance it needs to give purchasers in these positions.

Recommendation 3: The NHS Executive should consider what advice and guidance it can give purchasers in order to encourage and assist them to develop consortia or lead purchasing arrangements for renal services.

Advice for Purchasers

2.38. Few purchasers have adequate knowledge of renal replacement therapy. In particular, inadequate knowledge of the need for different types of treatment means that the issue of the most appropriate pattern of service locally is not thought through and addressed. The information provided by the NHS Executive to assist needs assessment and purchaser guidance at Part III will be helpful. However, there is also a need for a source of advice specific to individual purchasers, which can provide help and assistance on particular problems.

2.39. Purchasers described the difficulties they have experienced in obtaining truly independent advice on renal services: on what services they should purchase; the effectiveness of particular modalities of treatment; clinical outcomes; and other issues of a clinical rather than an epidemiological nature. Purchasers cannot be expected to have the same level of knowledge as highly trained specialist clinicians, and it is not surprising if they sometimes feel that the advice they have been given is not completely disinterested. This may be the case particularly where a purchaser is faced with several providers competing for contracts.

2.40. Similarly, providers have expressed to us the need for an independent source of advice, especially on epidemiological issues. The expertise is available in the UK to provide this advice and to act as independent arbitrators where disagreements arise. The Renal Association, the Royal Colleges and various Institutes of Public Health all have a great deal of experience in these areas. Such advice need not be difficult or expensive to provide, and it is likely to be simply a matter of co-ordinating current sources of expertise and advising purchasers and providers whom they could contact when in need of advice and information.

Recommendation 4: The NHS Executive should explore the means by which advice is obtained, and consider whether mechanisms need to be put in place to make expertise more widely available to purchasers and providers.

Service Quality

2.41. Renal services are an important and evolving field in which continued improvements in terms of clinical outcomes should be achievable. Dialogue between purchasers and clinicians is essential for this, and if that dialogue is to be meaningful and productive purchasers will need to improve their knowledge base. To a large extent purchasers lack authoritative information about appropriate measures of effectiveness and outcomes. The level of knowledge and information will improve if purchasers have access to independent advice and comprehensive purchaser guidance and, most importantly, if formal relationships are developed with providers. However, there is also an argument for a lead from the centre.

2.42. The Renal Association, together with the Royal College of Physicians (RCP), is due to publish shortly guidance on quality in renal services⁸, which will address issues of standards in all forms of treatment for ESRF. Although essentially aimed at clinicians, the document could form a useful tool to help purchasers, in discussion with clinicians, to develop quality measures in the contracting process. Purchasers also need to have access to measures of effectiveness of the various forms of treatment. Although these will for the most part be developed in discussion with local providers, there is a clear role for the centre in helping with this process, by providing information and guidance. The NHS Executive should therefore consider what guidance it should produce. In terms of quality standards, the Renal Association/RCP publication will provide a useful framework, and consideration needs to be given to developing this into some form of guidance for purchasers. An *Effectiveness of Health Care Bulletin* might be a useful vehicle for guidance on clinical effectiveness, and the NHS Executive should consider whether to commission work in this area.

Recommendation 5: The NHS Executive should consider what guidance it might issue to assist purchasers and providers in developing quality standards on the contracting process.

Treatment protocols

2.43. Purchasers are responsible for establishing local priorities in the light of other competing demands and on the basis of thorough needs assessment. The assessed needs of the local renal population should be taken into account by purchasers in preparing purchasing strategies and establishing priorities. On the basis of these priorities, purchasers will need to make informed choices about the types of treatment available, taking account of clinical effectiveness so as to ensure patients are treated appropriately. Cost-effective treatment can best be achieved in consultation with provider clinicians on the basis of agreed protocols or treatment guidelines.

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Now published: RENAL ASSOCIATION/ROYAL COLLEGE OF PHYSICIANS OF LONDON
Treatment of Adult Patients with Renal Failure: Recommended Standards and Audit Measures (April 1995)
LONDON/RCP

2.44. Since renal disease may arise as the consequence of otherwise fatal disease, or may occur in association with other serious diseases, it follows that not all patients with ESRF will benefit from RRT. If it is thought possible that renal replacement therapy might be beneficial, all such patients should be referred to a nephrologist for assessment. Many patients are referred at the point at which dialysis is needed urgently to maintain life; a time at which a considered view of the desirability of long-term renal replacement therapy is not possible. Such patients can be considered broadly as *acute uraemic emergencies*. Renal units must have the facilities for the prompt management of such patients.

2.45. Although, theoretically, purchasers are free to decide the level at which they will fund treatment for ESRF and so could refuse treatment to someone who would benefit from it, it is difficult to imagine a situation in which this would occur. No patients for whom RRT is appropriate should be denied it, and clinicians are unlikely to agree to a course of action which would result in the avoidable death of a patient from ESRF.

2.46. The decision to undertake regular RRT is a clinical one, which should be made by the doctor in close consultation with the patient. Essentially no other person is involved, although naturally both doctor and patient will wish to consult colleagues in medical and other disciplines and the patient's family.

2.47. Before the decision to proceed to regular renal replacement therapy is taken, both doctor and patient must agree that the treatment will provide for a sufficient time a quality of life that the patient can accept as worthwhile. It takes time to reach such a conclusion, and patients should be assessed well before renal replacement therapy becomes necessary so that these matters can be considered fully in advance of the need for such treatment. As already mentioned, one of the most important factors influencing the decision is the presence of co-morbid conditions, and the likelihood that the combination of renal failure and another serious condition would have a disproportionate effect on either the likely success of treatment or the patient's subsequent quality of life.

2.48. It may take up to three months for a patient presenting as an acute uraemic emergency to be fully assessed in terms of physical and mental status and social conditions, and for it to be reasonably clear that return of renal function will not occur. In elderly patients this may take longer.

2.49. Once the decision to begin long-term renal replacement therapy has been taken, it should be deemed retrospectively to have commenced with the first emergency dialysis. As a rule, patients accepted for regular renal replacement therapy will return to as independent a home life as was available to them before the therapy was needed, and it is unusual for renal replacement therapy to be instituted unless survival with such independence is likely to continue for at least two years. However, there will be exceptions to this, and the opinion of both doctors and patients should be respected.

2.50. Just as the decision to commence renal replacement therapy is one for both patient and doctor, so is the decision that therapy should cease. The clinical and social condition of any patient may change with time, sometimes unexpectedly, and the value of renal replacement therapy may be influenced by such change. Continuing assessment of the value of treatment is necessary in this as in any other branch of medicine, and it must be recognised that there will be times when it is in the patient's interest that treatment should be discontinued. It is essential that wide consultation should precede such a decision, but it remains essentially one for the patient and doctor alone.

2.51. It is important that all these factors are considered when purchasing renal services, and protocols should be developed by provider clinicians and purchasers which establish local guidelines for commencing treatment for ESRF. This aspect of contracting is at present relatively underdeveloped, and the NHS Executive could take steps to develop guidance for establishing such protocols. These protocols should be broadly-based, so as not to restrict the advancement of research and service development.

Recommendation 6: The NHS Executive should develop guidance for purchasers to assist them in establishing treatment protocols for acceptance onto the renal replacement programme.

Contracting for renal services

2.52. Our investigations (Part II(D)) show that purchasers across the country use a range of contract types when purchasing renal services, from simple block to more sophisticated contracts. There are some areas where renal services are contracted for using ECRs or case-by-case contracts. These are generally only appropriate when purchasing very low volumes of services. Contracts should be developed to be sophisticated enough to address issues of quality and clinical standards, and should be subject to regular monitoring.

2.53. The advice issued by the NHS Executive on contracting, especially EL(93)60 (Medical Advice to Purchasers) and EL(93)98 (Contracting for Specialised Services) is relevant to the purchasing of renal services, and it is important that purchasers use these to inform their contracting. The draft purchaser guidance at Part III addresses these issues. Contracts should address the need for good practice in infection control. A number of infections can be transmitted by blood, for example the hepatitis and HIV viruses. Routine discipline in the renal unit is designed to prevent transmission of such infections from patient to patient, and we are aware that the Department of Health is currently looking at the existing guidance on hospital infection control, with a view to revising and reissuing it. However, all patients should be assessed, and it may be necessary to allocate separate beds or dialysis machines for infected patients. This should be reflected in contracts for renal services.

2.54. Where purchasers do use ECRs for renal services, they should ensure that arrangements are in place which will ensure that authorisation procedures do not delay the immediate treatment of patients, for example when an acute uraemic emergency occurs or when donated organs become available for transplantation.

2.55. Transplantation takes place only infrequently, and small changes in the numbers of organs available will generally have a disproportionate effect on the performance of the contract. For this reason, contracts will ideally be for a total RRT service, including transplantation, and allow sufficient flexibility for movement of funds in-year between dialysis and transplantation. Some authorities are setting targets for transplantations in their contracts with providers. This is unrealistic. Appropriate transplantation requires attention to tissue matching and to patient fitness at the time of transplantation. This cannot be achieved within any constrained timetable. At the other extreme, in theory at least, too rigid a contract may lead to fewer transplants than would otherwise be possible, if the number of available organs exceeds the number of transplants contracted for. Targets for numbers of transplants performed should not be set at DHA level as allocation of kidneys on a geographical basis is inequitable and ineffective.

Recommendation 7: Transplantation services should be planned at a level higher than the individual DHA; and contracts should not place any constraints on kidney transplantation. Transplantation should always be given immediate priority when a kidney becomes available.

Planning Services

2.56. Renal services provide considerable scope for developing long-term planning of services because the patient numbers are reasonably predictable (given proper needs assessment), and individual patients generally remain on the programme for many years. They often develop an intense loyalty to their renal unit and become anxious at the prospect of changing to another unit. Any changes in purchasing which require such moves must be carried out at a pace designed to minimise disruption for patients.

2.57. Purchasers have a central role in ensuring that renal services are properly planned to take account of likely future demand. Purchasers are increasingly becoming the drivers of development within the NHS, and this trend can be expected to increase as purchasing and contracting skills are developed, and knowledge of outcomes and clinical effectiveness increasingly influences the contracting process.

2.58. Providers need an element of certainty in terms of what services they will need to provide over at least the medium term. There is a need, especially in a relatively stable specialty such as renal services, to move away from the annual contracting cycle which is a feature of the 'open' market towards longer and more forward-looking contracts. If providers could be certain of the levels of services required by purchasers over, for example, the next five years a great deal of instability would be removed from the market, and they would be able to plan jointly with purchasers their workforce, plant and infrastructure requirements over a reasonable length of time.

2.59. The NHS Executive should explore with purchasers and providers the possibility of developing longer term contracts for renal services. These should build on initiatives already being developed around the country, such as those which have introduced five year rolling contracts.

Recommendation 8: The NHS Executive should encourage purchasers and providers to develop longer term contracts for renal services.

Contact between purchasers and providers

2.60. In many districts there is very little contact between purchasers and local providers. Where contact does take place, it often fails to involve senior clinicians responsible for the day-to-day planning of services. Where meetings do involve clinicians, the level of understanding of renal services among purchasers is well developed, and relationships with clinicians are generally good.

2.61. It would be helpful if purchasers and providers (managers and clinicians) were to establish fora where renal services are discussed. This would serve as an important arena for the exchange of information, for contract monitoring and for planning the development of the service. Purchasers and providers would discuss and agree the appropriate levels of services, and agree what action should be taken to ensure that the needs of the local population are met.

Recommendation 9: The NHS Executive should encourage the development of local fora where purchasers and providers can discuss and plan future services.

The role of the centre

2.62. The recent changes in the regional structure of the NHS have removed what has been until now an important focus for the planning of specialist services. Although that function will not be carried out by the enlarged regions or the regional offices of the Executive, there is a continuing role for the centre in establishing the basis for the planning of services as this function is increasingly devolved to individual Trusts and purchasers.

2.63. The complexity of the service, the size of the population base which is necessary for an effective service and the geographical focus of renal services argues for the operation of a 'managed' rather than a purely open market. It is the task of purchasers to find ways to act in consortia in order to 'manage' the renal services market. The NHS Executive has an important function, not only in monitoring the operation of the market and the performance of purchasers, but also in providing guidance to purchasers and providers to assist in the development of renal services to meet future need in a planned and controlled manner.

Recommendation 10: The NHS Executive should monitor the development locally of needs assessment by purchasers, and the subsequent planning and development of renal services, in order to ensure that services are provided in a way which best meets the needs of local people.

Medical Staffing

General Issues

2.64. At present there are 129 consultants (79 WTE) in England, including those with an interest in nephrology providing RRT for a population of around 48 million in England. Each WTE consultant carries a workload of about 250 patients on renal replacement therapy, together with the essential work in nephrology, acute renal failure and the management of renal impairment before the end stage. The service has traditionally been sustained in part by senior registrars in the later stages of their training, or by using associate specialist, staff grade or clinical assistant posts.

2.65. The purchaser guidance at Part III describes the importance of optimum skill mix including the role of the renal nurse and of health care assistants. In order to utilise medical staff time efficiently the renal team will need to continue to develop innovative staffing patterns, which address the need to maximise the efficient use of non-medical and non-clinical staff. Such developments will be locally driven. While there are no rigid models of staffing and skill mix, consideration of appropriate consultant workload, on-call responsibilities and the requirement for training tend towards a broadly appropriate pattern of staffing. This is developed in paragraphs 2.67 - 2.72, and in the draft purchaser guidance at Part III. Purchasers should be involved in the development process through their role in planning and contracting for services.

2.66. Medical staffing is affected by the *New Deal* and by *Hospital Doctors: Training for the Future* (see purchaser guidance). The complex nature of renal medicine precludes cross-cover by doctors without experience in nephrology and this limits the potential for extending cross-cover. The implications of this are explored in the purchaser guidance.

Requirements

2.67. The number of patients receiving treatment for ESRF is growing, and is likely to continue to grow for the next 10 years. Nationally, it is likely that a 'plateau' will be reached in around 10 years, by which time patient numbers are expected to have increased by around 80% (see paragraph 2.15).

2.68. Increased numbers of patients receiving RRT will inevitably lead to an increased need for medical and non-medical staff. The numbers of WTE nephrologists in England rose from 68 to 79 between 1984 and 1993, during which period the total numbers of patients receiving RRT increased by an estimated factor of three or four. It is reasonable therefore to assume that nephrologists are now working at or near capacity, and there will be little possibility of absorbing the new workload into current staffing numbers.

2.69. Thus the anticipated increase in workload can be expected to require a corresponding increase in consultant numbers. If patient stock increases by the projected 80%, consultant numbers might need to increase by a similar proportion. If acceptance rates increase, and those new patients taken on to the programme are, as expected, for the most part aged over 65, and therefore likely to be less suitable to receive CAPD or a

transplanted organ, the workload for medical staff will increase disproportionately to numbers. Finally, implementation of *Hospital Doctors: Training for the Future* is likely to increase the need for consultants. There is therefore a clear need for renal services to plan for substantial increases in medical staffing over the next decade.

2.70. Current professional (Renal Association) guidelines indicate that a WTE consultant is required for each of the following:

- The workload produced by approximately 300,000 people, equivalent to an average of around 25 new renal replacement therapy patients annually. This equates to 200-250 RRT patients and associated non-RRT workload. Presently stock levels are approximately 400pmp - around half the expected stock at steady state - and, since consultants are working to capacity (see paragraph 2.68), the increased stock necessitates an appropriate increase in medical staff over time.
- The workload generated in a transplantation unit carrying out 100 transplants annually.
- The work produced by the outreach service base, research, teaching and continued education commitments of a service for 1.5 million people.

This would suggest 13 - 13.5 WTE consultant nephrologists per 3 million population.

Note: The clinical service offered collectively by two academic physicians equates to one WTE consultant nephrologist.

2.71. Thus it seems likely that, depending on a number of variables, including geography, population characteristics and current patterns of service, it will be necessary to have in place somewhere between 12 and 14 WTE consultant nephrologists (including academic nephrologists and general physicians with an interest in nephrology) per 3 million population in England. This estimate is linked to a presumed move to 80pmp and the build up of patient stock over time, and the implementation of *Hospital Doctors: Training for the Future*. This would represent a substantial increase on the present figures (an average of 5 WTE per 3 million population), and will need to be addressed as early as possible. Nationally it would mean that somewhere between 180 and 220 WTE consultants are likely to be needed in England once the plateau is reached.

2.72. Figures derived as above are necessarily approximate and assessment of need and judgements on priorities by purchasers will determine the actual figure. Nevertheless, it seems clear that the number of places in higher specialist training must provide for a substantial increase in consultant nephrologists. The roughly 70 UK/EC such places under current training arrangements in England are therefore unlikely to be reduced significantly, though precise numbers will need more detailed consideration than can be presented here.

Recommendation 11: The NHS Executive, in planning the numbers in higher specialist training, should take account of the likely future expansion in renal services.

Staff Duties

2.73. Staffing patterns must represent a balanced team for the work of the service and provide staff sufficiently experienced for safety net cover. These will vary, depending on the size and type of unit. Most transplantation/nephrology centres are also academic centres. Typically they run a much more intensive training programme, undertake basic scientific and clinical research and do a higher proportion of complex and difficult clinical cases; this requires a particular staffing mix. Following transplantation, care is usually provided jointly by the medical and surgical teams.

2.74. On-call arrangements depend on the staffing mix. Thus in a nephrology/transplant centre SHOs would be first on call with intermediate grade staff and consultants sharing second on call. In a nephrology unit first on call would comprise SHOs plus one intermediate grade staff with cover by the remaining intermediate grade staff plus consultants.

2.75. For the most part renal services in nephrology units are provided by two renal physicians but implementation of *Hospital Doctors: Training for the Future* is likely to mean an increase to 3. Purchasers and provider units must bear this in mind when planning future provision of services.

Staffing costs

2.76. The costs to the service of increasing clinical staffing to cope with the increased numbers of patients and the changes to medical workforce structures must be addressed by both purchasers and providers. Although many providers are aware of the changes needed, purchasers are to a large extent unaware of the consequences of this for them, in terms of funding an increased service. This issue needs to be addressed in the planning of future provision, and is covered in more detail in the later section on service costs (see paragraphs 2.118 - 2.123).

Nursing and other Non-Medical Staff

2.77. Purchasers need to bear in mind that any planned increase in medical staff will inevitably lead to an increase in numbers of non-medical staff, in order to support the work of the consultant and his or her medical team.

2.78. Although in the management of renal disease there is a continuing requirement for skilled non-medical, hospital-based staff, emphasis on outpatient care and care at home for patients on renal replacement therapy also promotes quality care and family support, and can prevent hospital admission. Increasingly, patients receive expert advice near to or in the home from a renal nurse specialist who has a close professional relationship with patients and their families. Investment in staff training needs to be carefully considered so as to make full use of this approach.

2.79. The skills of nursing staff are utilised to various degrees in renal units and in the community. Data collected for this review (at Part II) demonstrate a wide variation in workforce numbers and skill mix. Workforce and skill mix issues are crucial to quality of service, and must be considered by purchasers and providers in negotiating contracts and in planning future developments of renal services. Where, for example, there are at present few community-based staff or there is little outreach work it is likely that haemodialysis will be for the most part hospital-based, irrespective of the wishes and needs of patients. This has important implications for the quality of life of patients receiving RRT and for the cost effectiveness of the service delivered. The evidence at Part II shows that the level of and workloads of community nursing staff vary enormously between providers; the workload index (average number of patients per nurse) ranges from 7 to 190. This does not take into account the differing practices in each renal unit, but it is likely that these variations reflect the differing balance between community-based and unit-based work. It is for providers to identify and provide appropriate staffing to meet the quality standards contracted for and agreed with the purchasers.

2.80. Without the appropriate levels and mix of staff it is unlikely that a unit can provide the optimum service for patients. It is therefore important that, in ensuring that contracts for renal services include appropriate measures of quality, purchasers discuss workforce issues with providers and ensure that contracts include standards for levels and mixes of nursing and other non-medical staff. The purchaser guidance at Part III includes information which should assist purchasers in this, and includes details of the roles of non-nursing staff.

Appropriate skill mix

2.81. Purchasers of renal services should contract for high quality care and providers have to consider the appropriate skill mix of staff to meet quality standards. This mix will vary, depending upon the forms of renal replacement therapy being offered and the needs of patients and their families.

2.82. A senior nurse with clinical and managerial expertise will be a key participant in negotiating the contract and in providing the service agreed. This expert nurse leader is needed to head a team of nursing staff providing quality care, giving consideration to skill mix, grade mix, rotation, minimal shift overlap, cost-effective treatment patterns, training for dialysis staff and nursing research. In large nephrology/transplant centres or nephrology units a clinical nurse specialist would support the expert nurse leader.

2.83. The "Scope of Professional Practice" published by the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC)⁹ provides a clear framework for the development of nursing practice, promoting greater flexibility and reflecting the dynamic nature of nursing practice. The framework also reflects the personal responsibility and accountability of the individual practitioner to protect and

⁹ *The Scope of Professional Practice* UNITED KINGDOM CENTRAL COUNCIL FOR NURSING, MIDWIFERY AND HEALTH VISITING (1992)

improve standards of care. Some clinical experts in renal nursing are extending their competencies and developing additional specialised knowledge and skills which the framework of the UKCC guidance encourages. This enables such a nurse to function as a practitioner with authority to use these extra skills as the first line health care professional for some patients. Within a multi-professional team roles and responsibilities can be reviewed and reallocated. This expert nurse is often the patient's first point of contact and works within a hospital setting but more frequently in the community, thereby providing continuity and a quality of care relevant and responsive to the needs of individual patients and their families.

2.84. Typical examples of this specialist renal nursing practice include:

- Nurse led clinics
- Home consultation and treatment management
- Patient assessment and diagnosis, eg peritonitis
- Treatment and care planning and implementation
- Drug maintenance
- Monitoring and evaluation of care interventions
- Counselling and support for patients and carers
- Direct access to hospital admission in an emergency.

Training

2.85. Existing arrangements for education and training of NHS staff are designed to carry forward Government policy that training should be provider-led and that it is for providers, in consultation with professional advisors, to determine the workforce requirements and staff training needs. Providers have the purchasing power to influence the shape and content of training to match identified requirement. Some provider units commission their own ENB or other courses, which include renal nursing, from a College of Health directly. Health Care Assistants must also train and update their skills. Professional advisers have a key part to play in monitoring the quality and delivery of training.

2.86. Changing patterns of service provision require a flexible and innovative approach to training. Providers need to assess their workforce needs for retraining in the light of service development. Professional development for qualified renal nurses is an essential element of their career structure. All nephrology/transplant centres should provide clinical placements for post-registration training, for example in diabetic care or in primary healthcare. This training fosters innovation and advancements based on sound research evidence.

2.87. The 1993 publication of the "Report of the Task Force on the Strategy for Research in Nursing, Midwifery and Health Visiting" referred to the involvement of the nursing professions in a variety of problems impinging on all care groups and all settings. Problems which can affect quality of life often influence the length of health care episodes and may have a substantial impact on the effectiveness and cost of treatment. Nursing practice must be research-based to validate good quality care and facilitate innovative

practice. It is essential to include opportunities for nursing research in the provision of renal services. Nephrology/Transplant centres should provide opportunities for nurses to have appropriate training for research.

2.88. Nurses have an important role to play in the field of patient education, which can prevent or delay the onset of complications. Good practice helps maintain good quality of life - for example, preventing peritonitis helps to maintain the integrity of the peritoneum. Good dietary discipline may delay the need for renal replacement therapy. Education and support prepare families for coping with chronic sickness and provide an enhanced quality of life.

Recommendation 12: The NHS Executive should continue to encourage purchasers to involve relevant clinical staff in addressing overall quality standards in contracts.

Non-nursing workforce

2.89. Other essential team members include dietitians, social workers, technicians, counsellors, business manager and transplant co-ordinators. The promotion of locally-provided services to suit the needs of patients and families will require greater emphasis, as will teamwork between healthcare professionals in both the hospital and the community settings. As with the nursing workforce, non-nursing staff must be considered by purchasers and providers in negotiating contracts and in planning future developments of renal services. The draft purchaser guidance at Part III includes information at Annex 2 which will assist purchasers in these negotiations.

The Role of Primary and Community Health Care

2.90. GPs and professionals providing health care in the community have an important role in providing an effective service for ESRF. Most GPs will see very few patients requiring treatment for ESRF. A large GP practice with a list of 10,000 patients is unlikely to see more than 1 or 2 new patients requiring RRT each year, although practices with large numbers of elderly patients or patients from ethnic minority populations are likely to have more such patients.

2.91. However, as patients are taken on to the RRT programme, the total number of patients receiving treatment will, although remaining small, continue to rise. The total numbers, even in areas of high incidence because of ethnic mix or other local factors, is unlikely to exceed 1000 per million population. This would result in perhaps at most 10 patients receiving treatment for ESRF in a practice of 10,000 patients.

2.92. However, perhaps 20 or 30 patients will have some degree of renal failure in a practice of this size, and it is likely that around 70% of these will be aged 60 or over. These patients are crucial, since the majority have not been identified as renal patients, and measures to slow the progress of their disease or to address co-morbid conditions are available. Other patients in at-risk groups need screening at regular intervals to detect the onset of renal failure at the earliest possible moment.

2.93. Only around 5% of patients receiving RRT are inpatients - the remainder live in their own homes and receive outpatient or home dialysis treatment. This suggests that primary and community health care should play a major role in the management of end stage renal failure. For the most part, and with few exceptions, this does not appear to be happening.

2.94. As patients already receiving RRT age and the stock of patients receiving RRT increases, it is already evident that the majority of patients undergoing treatment will be elderly, may have other illnesses and may already have or will develop problems with daily living. Other specialists, particularly specialists in old age medicine, will need to play a greater part in the management of ESRF in the community.

2.95. Not all GPs are fully informed about kidney disease and ESRF, and this can result in inadequate identification and referral of patients, thereby contributing to low acceptance rates locally and nationally. Renal medicine is not always included in the core of an undergraduate curriculum and plays only a small part in postgraduate education through postgraduate medical centres. The Renal Association is actively looking at this, and has taken the issue up with the GMC. The undergraduate curriculum should include elements which will improve knowledge of renal disease and the benefits of early detection of renal failure.

Recommendation 13: The place of RRT and the importance of understanding, detecting and preventing ESRF should be included in the curriculum for undergraduate and postgraduate teaching.

Prevention and early detection of ESRF

2.96. Opportunities for preventive management of renal disease are limited. However, improved awareness among GPs of renal disease will inevitably lead to better and earlier identification of ESRF and improved prospects for good outcomes for patients. At the moment GPs are not always particularly well-equipped to detect or manage patients with ESRF. This is not surprising given the comparative infrequency of such cases. There are however several steps which purchasers can take to improve this situation.

2.97. Improved detection and management of hypertension by GPs and community health professionals will limit further damage to an already impaired kidney - hypertension is very common in renal patients - and it will prevent renal damage in patients with severe hypertension. Earlier and better management of diabetes can be expected to reduce significantly the burden of diabetic renal failure; there is evidence that better control of insulin-dependent diabetes mellitus reduces the incidence of nephropathy, although no firm evidence is yet available to show that the same is true for non insulin-dependent diabetes mellitus. Early detection and management of all renal impairment are essential: complications can be managed better and reversible features identified. Recent

observations suggest that the late referral of patients results in prolonged morbidity and probably in increased mortality during the treatment of ESRF^{10,11}.

2.98. Purchasers should ensure that services purchased include measures for the early detection and appropriate referral of patients with conditions such as severe hypertension and diabetes, especially in the black and Asian populations known to be at risk. The incidence of ESRF rises by up to tenfold in the elderly. Purchasers can and should identify such at risk groups in their contracts for services for the elderly or community health services.

2.99. GPs are increasingly involved in health promotion, and there are measures which can be taken within primary care to improve the early detection of ESRF. Knowledge of those groups likely to be at risk will mean that GPs and community health staff can 'target' patients for testing. For example blood pressure measurement and dipstick testing of urine for blood and protein assists in the early identification of patients with renal or urinary tract disease which might progress to ESRF. Purchasers should encourage GPs and community health services to develop better means of targeting and testing patients thought to be at risk of renal disease. In their checks of the over-75s, GPs should be alert to the implications of a positive dipstick test. More important would be to test any adult patient in an at-risk group for whom early diagnosis could lead to much earlier detection and treatment of conditions which could lead to serious renal problems in later life and to be alert to the implications of a positive dipstick test. This might be taken forward by the Health Technology Assessment Screening Panel, and the NHS Executive should consider whether to ask the Panel to look at the issue.

Recommendation 14: The NHS Executive should consider commissioning work to review the evidence so as to identify the most cost-effective ways of identifying patients with renal disease which might progress to ESRF, including the evidence for screening for renal impairment.

"Health Literacy" and information for GPs

2.100. In addition, as part of "health literacy" programmes, purchasers should target at risk groups such as diabetics, the elderly and ethnic minorities. This will mean that purchasers will need to develop appropriate literature and other means of communicating health information, and to ensure that they are made accessible to groups whose first language is not English.

2.101. The steps described above should be part of a general process of raising awareness of renal disease among non-renal clinicians including General Practitioners, specialists in the care of the elderly and community health workers. This should be a

¹⁰ EADINGTON DW, CRAIG KJ, WINNEY RJ. Co-morbidity and biological indices modulate the impact and the rate of referral and survival on RRT *Nephrology Dialysis Transplantation* 1994; Vol 9: 960

¹¹ RADCLIFFE PJ, PHILLIPS RE, OLIVER DO. The late referral for maintenance dialysis *Br Med J* 1984; 288: 441-4432

joint exercise involving purchasers, the FHSA and provider clinicians. One possible approach could be through the joint-funding of a renal services adviser, similar to a pharmaceutical adviser or diabetic adviser or, more appropriately given the relatively low level of need, increasing the skills and knowledge of medical advisers to encompass renal services. Although this is included in the draft purchaser guidance at part III, the NHS Executive should consider whether further guidance might be needed in this area.

Recommendation 15: In order to improve the early detection and treatment of ESRF, the NHS Executive should consider what guidance it should provide to enable Purchasing Authorities and FHSAs to develop knowledge and understanding of renal services and related conditions among GPs, community health workers and specialists in other fields; and how the current role of the medical adviser could be expanded to provide advice on renal services.

"Shared Care."

2.102. Most of the medicines taken by patients in renal failure can be prescribed by their GPs helped by a 24-hour telephone information service that advises on dose modification. There is increasingly a view that erythropoietin is best prescribed by the renal unit allowing for continuity of clinical practice and cost-effectiveness. Although some GPs have until now assumed responsibility for prescribing CAPD fluid on an FP10, this practice is to be discontinued. Separate guidance will be issued to clarify the new arrangements.¹²

2.103. GPs, primary care teams and community staff have key roles in preventing renal disease, in identifying incipient renal disease and ensuring early referral, and in recognizing and addressing unmet need. The new joint DHA/FHSA commissioning agencies once established, subject to the necessary legislative framework, will be in a better position to take an integrated approach to purchasing renal services for patients who are already on RRT and for prevention of renal disease which should be given a high priority. Improved detection and management of hypertension and insulin-dependent diabetes mellitus by GPs and community health professionals will limit further damage to an already impaired kidney.

Recommendation 16: The NHS Executive should consider what steps it might take to encourage the development of shared care between renal specialists and GPs.

¹² EL(95)5, "Purchasing high-tech health care for patients at home", issued in January 1995.

The role of other professionals

Specialists in the care of the elderly

2.104. Although renal failure occurs predominantly in the elderly, physicians specialising in the care of the elderly have been little involved in the detection or management of renal disease. Their participation is needed, especially at community level, because of the many problems that ESRF patients face, either coincidentally or as a result of their renal failure. Provider units need to establish liaison with their colleagues specialising in the care of the elderly to assist in the detection of renal failure, discharge from hospital and ongoing care in the community.

Social workers

2.105. The need for social workers to be involved in dealing with the problems of patients living in the community was recognised by renal physicians and nurses many years ago, but changes in the structure of social work have made it more difficult to concentrate expertise or act in a co-ordinated and effective manner in this area.

2.106. The review has taken evidence from the Renal Special Interest Group of the British Association of Social Workers (BASW), and it is clear that there are a number of problems in the provision of social work services to renal patients. One of the major issues is that, where a social worker is attached to a renal unit, the local authority responsible for providing the service will invariably refuse to fund services for patients from outside the local authority area. In major renal centres, where patients may be drawn from a wide area, this results in some patients receiving no social work support at all. A further problem drawn to the attention of the review group was that, in a number of cases, local authorities have refused to employ a social worker who would be attached to a renal unit, even when that post would be wholly funded by another organisation (eg. the British Kidney Patient Association). The reason given in one such case was that the social services departments resources are "concentrated on statutory and child protection duties".

2.107. A number of posts already exist where social workers are attached to a renal unit. These posts are mainly charitably-funded or receive only "pump-priming" funding from statutory sources. Thus, unintentionally, this service is less well provided than formerly at a time when the mix of patients in the community requires more, rather than less, support. The evidence submitted to the review by the BASW Renal Special Interest Group suggests that the difficulties stem from the changes in 1974 when local authorities became responsible for the provision of social work to health authorities. The problems created by social workers having no jurisdiction over patients from outside their area would be overcome if they were to be employed by units. This has potential drawbacks in that social workers need to maintain links with their profession, and would in some cases require a difficult shift away from current practice. However, this solution

appears to have been successful in a number of units, where the cost of social work is included in the contract with the purchasing health authority. These costs are in any event not great, and can be recovered by the DHA from the home local authority. The advantage of this system is that the unit-based social worker can work closely with both the medical and nursing team in the unit and the social work team from the home local authority.

2.108. Clearly these issues need to be addressed: all patients should receive the services they need. The Department of Health should consider how the provision of social work services to renal patients could be improved; similarly, the NHS Executive should consider ways in which purchasers and providers could be more flexible on the employment and funding of social work services.

Recommendation 17: The Department of Health and the NHS Executive should consider how the provision of social work services to renal patients might be improved.

Information requirements

2.109. There is an urgent need for adequate collection of data to inform purchasers and to ensure that information about effectiveness of treatment can be collected and collated centrally. A national renal registry is being developed, supported by the Department of Health, and this should develop an appropriate template for the collection of data. Purchasers will need to ensure that providers are linked with this, and that national and international data are available. This could provide both population-based information on acceptance and stock rates for purchasers and data on outcomes of treatment adjusted for case mix and process measures for clinical audit. Such data sets will be developed by the Renal Registry, and the Renal Association/Royal College of Physicians standards document (see paragraph 2.42) will provide a suitable framework for developing process and outcome measures.

2.110. Purchasers need to understand the service which they are purchasing on behalf of their populations and build measures of quality into the contracting arrangements. In order to do so they need to be provided with information in an accessible form about standards, outcomes and effectiveness to monitor the service. Providers need to ensure that their information systems are able to provide comprehensive data for purchasers and, for their part, purchasers should recognise that they will need to fund these through contracts. In order to inform their needs assessment and to plan for future need, purchasers will need as a minimum from provider units serving their population data on acceptances and stock by age, sex, ethnicity and modality of treatment, ideally over a 3 - 5 year period. When quality standards have been agreed and made routinely available, information relevant to them should be collected and made available by individual unit.

Transplantation

2.111. While not formally included in the review's terms of reference, transplantation is in most cases the optimum mode of treatment. Thus the review took advice from the British Transplantation Society and its Transplantation Training Advisory Committee.

2.112. Data collected for this review (Part II(A)) shows that, of the 30 units carrying out renal transplants in England, 24 are based in teaching hospitals (83 %, roughly equal to the average figure in Europe). The number of transplants carried out annually ranges from 8 to 121. Paragraph 2.114 notes the issues that those units at the lower end of the range will need to face in the future, and it is questionable whether a unit carrying out very small numbers of transplants each year will remain viable over the long term.

2.113. The purchaser guidance at Part III points out that the balance of opinion favours a combined nephrology and transplantation service. With the current system of recording consultant activity it is not possible to record the workload of nephrologists and transplant surgeons separately. It should be possible to find a way of doing this. That would help purchasers to judge the assignment of costs and to confirm that patients are receiving an optimal service.

2.114. Ideally a transplantation unit would serve around 2.5 - 3 million people. Not all units are of this size, but in many cases the issues are being addressed. While small transplant units are generally undesirable and the establishment of new ones should be considered only with great care, there are occasional smaller units which have achieved acceptable results through the dedication and hard work of a small number of individuals, who work under conditions which should not be perpetuated indefinitely. As long as these units continue to offer a high standard of care they should not be closed precipitately, but it is unlikely that they can remain viable, given the requirements for defined consultant workloads, restricted availability of junior doctors in training, the dangers of cross-cover by non-specialist staff and the increasingly sophisticated infrastructure a transplant unit requires. It is most important that patients have the best available treatment and this should not be compromised in order, for example, to reduce travelling times.

2.115. The major problem facing renal transplantation services, not just in the UK but worldwide, is the lack of suitable donors. Advances in medicine in the last twenty years have led to more and more patients becoming suitable for transplantation, but at the same time in the UK the original "pool" from which potential donors came has altered - due mainly to a remarkable decrease in the number of deaths from intra-cranial haemorrhage. Clearly the number of suitable donors is limited. However, evidence suggests that up to 30% of potentially suitable organs may be lost due to the unwillingness of relatives to give consent.^{13,14}

¹³ GORE MS, HINDS CJ, RUTHERFORD AJ. Organ Donation from Intensive Care Units in England *Br Med J* 1989; 299: 1193-7

¹⁴ GORE MS, TAYLOR RMR, WALLWORK J. Availability of transplantable organs from brainstem death donors in intensive care units. *Br Med J* 1991; 302: 1053-5

2.116. Purchasers have a crucial role to play in supporting the efforts made by clinicians and Transplant Co-ordinators to ensure that as many organs as possible can be harvested and transplanted. Some regions have much better retrieval rates than others, and purchasers in the less successful regions will no doubt wish to look at the methods employed by those which are more successful. In North-Western Region a pilot programme of training under the European Donor Hospital Education Programme (EDHEP) is currently being provided to help staff learn the most effective ways of approaching relatives so as to maximise organ retrieval. If the programme proves successful it should be considered for wider implementation. The report by the King's Fund Institute, *A Question of Give and Take*¹⁵, published earlier this year discusses a number of measures that might lead to increased donation, although it should be noted the report does not recommend all these methods. Some of them, like xenografting (the use of animal organs), raise complex ethical issues. In any case xenografting has not yet been developed. But other methods, like the Spanish Transplant Co-ordinator scheme are worth further examination¹⁶.

Recommendation 18: The NHS Executive should consider what steps it might take to increase the amount of kidneys available for transplantation, for example by investigating whether the pilot scheme in North West Region could be extended; and looking at the lessons which might be learned from the Spanish Transplant Co-ordinator scheme.

2.117. Purchasers should ensure that contractual arrangements for renal services include policies for promoting organ donation and for the equitable and effective allocation of kidneys. This should include participation in the National Kidney Sharing Scheme. The transplant co-ordinator's role is essential in facilitating the retrieval of all organs and in providing professional and public education to encourage donation. Adequate staffing and funding should be available to fulfil these functions. Evidence presented to the review suggests that the costs of transplant co-ordinators is often borne solely by the renal unit. However, all those transplant services which make use of the co-ordinator (eg. heart and lung, liver, corneal) should contribute to the cost of running the service. The relationship between renal units, and the transplant centres (eg. heart, liver) will need to be taken into account. Purchasers should ensure that their local acute units have policies which facilitate appropriate organ retrieval, particularly where there are neurosurgery units.

¹⁵ NEW W, SOLOMON M, DINGWALL R, McHALE J *A Question of Give and Take - Improving the Supply of Donated Organs for Transplantation* KINGS FUND INSTITUTE (1994)

¹⁶ *Report on Management of Renal Failure in Europe, XXIII, 1992* in NEPHROLOGY DIALYSIS TRANSPLANTATION (Official Publication of the European Dialysis and Transplant Association), Oxford (in press)

Costs

2.118. Information on the present costs of renal services in England is limited. The survey of purchasers carried out for the review (see Part II) demonstrated the lack of knowledge of costs on the part of purchasers. It is difficult to see how purchasers can plan service developments without this basic information.

2.119. Two pieces of work were commissioned for the review from Graham Shipp of RMS Ltd. The first was a detailed study of unit costs in a single renal unit. The costs derived from this were tested against a number of other units, and were found to be representative of costs across the whole service. The results of this work, along with a study of the likely increase in costs given the growth in patient stock which is likely to occur over the next few years, are at Part II. The second piece of work was the development of a costing template for use by purchasers and providers. This is included with the draft purchaser guidance at Part III, and aims to provide a tool which can be used to determine much more precisely the current cost of the service, and thereby to plan more effectively any development of services. The template has been discussed with and piloted by a number of provider units.

2.120. The review has not attempted to develop precise estimates of future costs of providing renal services. However, calculations based on the data collected for the review suggest that, over the next decade, the costs nationally are likely to increase by as much as 100%. The assumptions on which this broad estimate is based are as follows:

- the number of patients receiving RRT will rise by around 80% nationally over the next 10 years, when a plateau will be reached;
- there will be few developments in clinical practice over the period in question which will radically affect the way patients can be treated, and the cost of treatment is unlikely to fall further by competitive reductions in unit costs of methods already being employed;
- new patients taken on to the programme will be on average older than current patients. Because of the increased incidence of co-morbid conditions in the elderly, these new patients are less likely to be suitable for transplantation than younger patients. Thus the treatment for new patients being accepted for RRT will have a higher unit cost than treatment for patients already on the programme;

2.121. From the data collected for this review, it is possible to estimate the current cost of renal services at approximately £300 million per year. It is clear from the survey of purchasers in Part II that purchasers may at present have little idea of true present or likely future cost of the service - since the costs of the service are complex, purchasers need detailed information: the costing template at annex 4 of the draft purchaser guidance (Part III) should assist in the collection of this data. An initial estimate of costs when the 'plateau' of patient stock is reached indicates that renal services are likely to account for between £450 and £550 million of NHS expenditure in 10 years time, depending on whether take-on rates increase and the type of treatment

2.122. The review has collected a great deal of detailed information on costs and levels of provision. However, more work is required in order to produce accurate estimates of costs.

2.123. It should be possible to produce robust estimates of costs both nationally and, with suitable adjustments, locally. The NHS Executive might find it helpful to commission work to build on the start made by this review, in order to produce estimates of costs which will assist in planning future provision nationally and locally.

Recommendation 19: The NHS Executive should develop accurate estimates of the costs of providing renal services in the future by building on the work carried out for the review.

Further work

2.124. This review has collected a unique set of data encompassing all aspects of the provision of renal replacement therapy in England. The data is at Part II of this report. The data set comprises a description of the facilities and staffing in all renal units; individual data on all patients accepted and receiving treatment; costing data of the components of a renal services; and a model with which to estimate future demand. The analyses of these data have been limited by the time available. There is scope for further analysis in a number of areas which would enhance understanding of the current and likely future need for RRT. Specific areas where further analysis could be undertaken follow.

2.125. Patient Stock Data: The database has individual data on all patients on RRT in England. This database could be analysed for population-based acceptance rates by age, sex, ethnicity, primary disease, and geographical area (DHA and Region).

2.126. Paediatric Data: Staffing and facilities data are available for all paediatric renal units and data on acceptances and stock under age 16 wherever they are treated. The review did not address paediatric renal services, but this data should be analysed (possibly in collaboration with the British Association of Paediatric Nephrologists) to show acceptance rates by sex, ethnicity and geographical area.

2.127. Ethnicity and Need for ESRF: Acceptance rates of non-white ethnic groups are increasing. Further work is needed to standardise these rates by age and sex, to analyse them by underlying disease, and to standardise DHA and regional rates to take account of ethnicity. At present the non-white population is younger than the white population, and projection of the impact of their ageing on the need and demand for RRT should be undertaken.

2.128. Geographical variation in acceptance rates: There is a marked interdistrict variation in crude acceptance rates. These need to be standardised by age and sex. Variation is likely to be determined by local supply (main units, dialysis stations and satellite units), access to services and by population need (eg., the size of the non-white population). It is important to explore further the relative determinants of acceptance at

small area level by appropriate statistical modelling. The effect of deprivation has never been investigated to date, and these data provide the opportunity to do so.

2.129. Modelling future need: The predictions of patient numbers developed for the review are robust for steady state projection given a variety of input data. They are not designed to assess year-on-year build up to steady state. To allow analysis of the dynamics of the change in stock that is likely to occur in England as a whole and in areas with different starting stocks and population need the present model would need further development. It should be borne in mind that detailed year-on-year modelling is subject to distortion since there are invariably shifts in treatment protocols which, unaccounted for, result in continued divergence of reality from the model. Furthermore, the precision of year-on-year data is best for large populations; for smaller populations (for example at average DHA levels) precise numbers are difficult to assess. We note that development of this model could have benefits for other specialities, allowing much more accurate estimate of future demand and resource needed than has hitherto been possible.

2.130. Current and future resource use: The indicative costs of all current patterns of service for RRT could be determined by applying the costings data derived for the review to the information on DHA and renal unit patient stock. Future resource needs could be modelled by linking this to the model developed by Dr Ivor Wood (see paragraph 2.129), with costings by modality of treatment.

2.131. While much of this work is of academic value, it will add to the body of knowledge of renal services, and will be invaluable to purchasers assessing need and planning future development of renal services. The Department of Health should consider funding further work on this or enabling the data to be used for further analysis in an academic setting, and the results made more widely available.

Recommendation 20: The Department of Health should consider how the data collected for the review can be further analysed, and the work used by purchasers and providers in assessing need and planning services.

ANNEX 1: MEMBERSHIP AND TERMS OF REFERENCE

Membership

Chairman

Professor Netar Mallick, Department of Renal Medicine, Manchester Royal Infirmary

Members (External)

Professor Stewart Cameron, Guy's-St Thomas's Hospitals
Mr Chris Spry, Regional Director, South Thames RHA
Mrs Linda Whitworth, Nurse Manager, Manchester Royal Infirmary.
Professor David Kerr, North Thames RHA

Members (Department of Health)

Mr Richard Murray (Economics and Operational Research Division)
Mrs Patricia Edwards (Nursing Division)
Dr Norman Halliday (Health Care (Medical) Division) (Until January 1994)
Dr Norman Melia (Health Care (Medical) Division) (From January 1994)
Mr Paul Pudlo (NHS Executive Acute Services Policy Unit) (Until April 1994)
Mrs Janet Walden (NHS Executive Acute Services Policy Unit) (From April 1994)
Ms Claire Phillips (NHS Executive Acute Services Policy Unit) (From June 1994)
Mr Edward Colgan (NHS Executive Purchasing Unit)
Dr Hugh Tolland (NHS Executive Medical Education, Training and Staffing Division)
Miss Jenny Harper (Health Care Strategy Unit) (Until October 1993)
Mr Mark Davies (Health Care Strategy Unit) (From October 1993)
Mr Shaun Gallagher (Health Care Strategy Unit) (Until December 1993)

Terms of Reference

"To look at the provision of renal services in the light of the recent report by the Renal Association which concluded that there was under-provision nationally, in absolute terms and with geographical imbalances; that there was a shortage of trained staff; and that there were increasing demands as a result of demographic trends. To consider the Renal Association report and to determine in light of this what improvements in renal services nationally might be achieved."