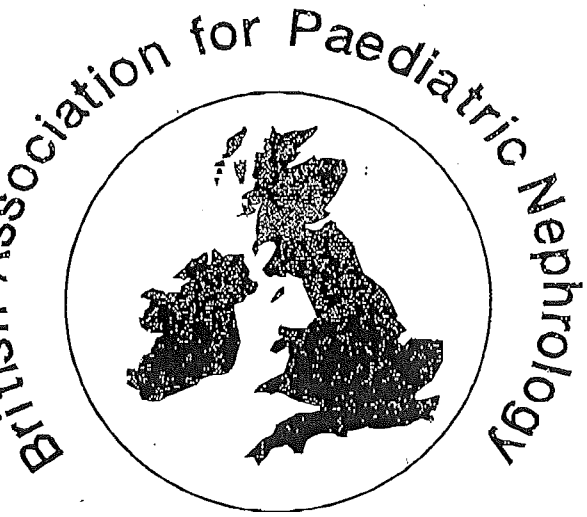

THE PROVISION OF SERVICES IN THE UNITED KINGDOM FOR CHILDREN AND ADOLESCENTS WITH RENAL DISEASE

Report of a Working Party of the British Association for Paediatric Nephrology March 1995

Endorsed by the Royal College of Physicians of London, the British Paediatric Association and the Renal Association

PREFACE

In July 1993 the British Association for Paediatric Nephrology published its report *Paediatric Nephrology in the Nineties*. This traced the evolution of the specialty from its modest beginnings in the sixties, outlined its philosophy and highlighted the fundamental clinical differences from adult nephrology which make the provision of separate services for children mandatory.

However, because the report lacked some of the basic factual information to support its manpower recommendations, it was resolved to establish a Working Party with the object of assembling this information. This necessitated the circulation of carefully designed questionnaires and the analysis of responses, and I am grateful to members of the Working Party for their important contributions, as well as to the many BAPN colleagues who took the trouble to respond, recognizing the possible implications of the findings. Additionally, Dr JE Deal provided information on admission and anaesthetic practices in renal biopsy (Appendix 5), and Mrs M McDermott, RSCN, supplied urodynamics attendance figures (Appendix 6). The illustrations were prepared by the Medical Illustration Departments of the Birmingham Children's and Maternity Hospitals and the Nottingham City Hospital. The manuscript was kindly typed by Miss AJ Jackson. I would also like to thank Dr Kate Verrier Jones for help with proof reading.

The Clinical Standards Advisory Group has recommended the development of supradistrict arrangements for the purchase of specialist services and has emphasized the need for professionally agreed national guidelines for both purchasers and providers. It is hoped that this report, which should be read in conjunction with *Paediatric Nephrology in the Nineties*, will fulfil this need. The report is endorsed by the Royal College of Physicians of London, the British Paediatric Association and the Renal Association. Once again it is my pleasure to acknowledge the generous support of the Foundation for Nephrology.

RHR White, Chairman

March, 1995

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1. SUMMARY OF RECOMMENDATIONS

- Children with renal disease are first and foremost children. Any unit offering care for children and young people with renal disease would be expected to implement in full the Department of Health Guidelines *Welfare of Children and Young People in Hospital.*

- A high quality paediatric renal service must be family-orientated and delivered by a multidisciplinary team which includes specialist nurse, psychiatrist/psychologist, dietitian, social worker, school teacher and play worker, in addition to medical and surgical staff.

- Three areas of service which we have defined as **specific** (end stage renal failure, acute renal failure and renal biopsy) are highly specialized and dependent on costly equipment and supporting services. These services should only be delivered from major paediatric renal centres, each equipped with comprehensive facilities and suitably trained, experienced staff.

- In order to accumulate and maintain expertise, minimum workloads in these specific areas of service are required. A population base of 3 million is the minimum to sustain a comprehensive paediatric renal service, although exceptions are necessary on geographical grounds in Wales and Northern Ireland. Ideally each comprehensive unit should serve a population of at least 4 million. In London the maintenance of two units serving larger populations provides an academic base for teaching and research, of national importance.

- The present number of comprehensive paediatric renal centres (Appendix 1) should not be exceeded, since this would dilute experience, and thereby risk deterioration in the quality of service.

- However, to afford maximum convenience to patients in regions with small populations, there is a need for additional units, based on teaching hospitals, to provide general paediatric renal services. There are currently four such units, and we recommend the establishment of two more (Appendix 8). They should operate in collaboration with an adjacent comprehensive unit.

- Paediatric nephrology forms part of a spectrum of highly interdependent paediatric specialties. While, ideally, proximity to the adult renal unit can facilitate continuity of ongoing care for older adolescents, we consider the provision of a paediatric renal service from the same site as the other paediatric specialties to be of overriding importance.

- With few exceptions, the transplant and paediatric renal services in the UK are located on different sites, but we strongly urge the development of arrangements for children to be transplanted within the familiar surroundings of the paediatric renal unit, to facilitate continuity of care by the same multidisciplinary team.

- Firm links with district paediatricians are desirable, and we recommend the adoption and expansion of shared care clinics, which are both beneficial to patients and of educational value.

- The progressive increase in workload represented in Appendix 3 poses a threat to teaching, continuing medical education and research, as well as the quality of service delivered. Comprehensive units serving 3-5 million total population need four consultant paediatric nephrologists, and larger units proportionately more. We therefore recommend the establishment of a further 20 consultants at these units (Appendix 1), and at least two more in the two proposed new regional centres (Appendix 8), in the short to medium term.

- In order to train the future consultants to fill these posts, there is an urgent need to increase the number of higher specialist training posts in NHS and academic units to 12, subject to review once the increased consultant establishment has been implemented.

- Paediatric renal units are more heavily dependent on trained nurses than adult units, and goals for adequate staffing need to be developed. Nurses working in paediatric renal units should hold the RSCN or Child Branch Project 2000 diploma. Additionally the majority should hold a renal qualification. There is a serious deficiency of training courses in specialized paediatric renal nursing and appropriate courses need establishing as a matter of urgency.

3. INTRODUCTION

Background

3.1 In November 1991 the Renal Association published its report *Provision of Services for Adult Patients with Renal Disease in the United Kingdom* [1]. The remit of its Working Party specifically excluded the needs of children.

3.2 End stage renal failure management in children is a high-cost, low-volume activity and, as such, requires continuing planning on a national basis to ensure that sufficient facilities of good quality are maintained and further developed as economically as possible. This is reflected in the previous supraregional status of the specialty. Two reports of the British Association for Paediatric Nephrology (BAPN) in 1974 [2] and 1979 [3] laid out a strategy for the provision of renal services for children, taking into account the minimum size of centre necessary to maintain expertise as well as geographical constraints. Thirteen paediatric nephrology units [1] were originally designated as centres which fulfilled the requirements*, although subsequently the Edinburgh unit ceased to provide a comprehensive service for children of all ages and now collaborates with Glasgow in the management of small children with end stage renal failure [4] (Appendix 1). These reports gained general support and have been the basis for planning, but were confined to the provision of services for children with chronic renal failure. They did not consider acute renal failure and other aspects of paediatric nephrology, many of which have important preventive functions.

3.3 The burdens of renal failure on the child and family have been well documented [5-7] and these have implications for the long term success of treatment [8,9]. It is essential that adequate psychosocial support is provided to mitigate the difficulties associated with effective treatment and ensure the best quality of life.

3.4 The assessment of outcomes in children with renal diseases presents difficulties. Because both acute and chronic renal failure in children are rare, the experience of a single purchaser will be very limited. Moreover, although conditions such as urinary tract infection and some forms of glomerulonephritis are much commoner, outcomes may be delayed for many years, as has been demonstrated in reflux nephropathy ("chronic pyelonephritis") [10,11], recurrent haematuria [12], IgA nephropathy [13], Henoch Schönlein nephritis [14] and hereditary nephritis [15]. It is therefore essential that outcomes are defined as accurately as possible and are audited, to ensure that appropriate changes in the provision of care are made in order to maintain a service of quality.

* The Hospital for Sick Children, Great Ormond Street and the Royal Free Hospital, London, are integrated functionally and, for the purpose of this report, are considered as a single unit.

2. MEMBERSHIP OF THE WORKING PARTY

Professor RHR White (Chairman) Emeritus Professor of Paediatric Nephrology, The Children's Hospital, Birmingham	President, British Association for Paediatric Nephrology, 1991 - 1994
Dr RJ Postlethwaite (Secretary) Consultant Paediatric Nephrologist, Royal Manchester Children's Hospital	Honorary Secretary, British Association for Paediatric Nephrology
Dr P Sweny Consultant Nephrologist, The Royal Free Hospital, London	Committee on Renal Disease, Royal College of Physicians, London
Dr RWA Jones Consultant Paediatrician, Freedom Fields Hospital, Plymouth	British Paediatric Association
Mr JD Atwell Consultant Paediatric Surgeon, Southampton General Hospital	British Association of Paediatric Surgeons
Mr JAC Buckels Consultant Transplant Surgeon, Queen Elizabeth Hospital, Birmingham	British Transplantation Society
Dr SPA Rigden Consultant Paediatric Nephrologist, Guy's Hospital, London	British Association for Paediatric Nephrology
Dr AR Watson Consultant Paediatric Nephrologist, The City Hospital, Nottingham	British Association for Paediatric Nephrology
Dr ME McGraw Consultant Paediatric Nephrologist, Southmead Hospital, Bristol	British Association for Paediatric Nephrology
Miss N Hicklin, RSCN Sister-in-charge, Paediatric Renal Unit, Guy's Hospital, London	Royal College of Nursing
Dr NP Halliday Senior Medical Officer, Department of Health, London	Observer for the Department of Health

4. REMIT OF THE WORKING PARTY

4.1 The BAPN report *Paediatric Nephrology in the Nineties* [4], made broad recommendations regarding the further development of services. However, the report acknowledged the lack of up-to-date information on referral patterns, workloads and treatment trends, and one of the principal tasks of the Working Party was to obtain this information through a series of national questionnaire surveys undertaken by its members, the results of which are summarized in the Appendices. The Working Party met on five occasions between September 1992 and January 1994.

4.2 The purpose of this report is:

- to examine current practices in the care of infants, children and adolescents with renal disease, to observe trends and to predict future developments;
- to appraise the adequacy of staff, accommodation and equipment required to provide the current and predicted future services, and to make recommendations regarding resources and manpower and their efficient use;
- to provide data for the assessment and monitoring of the quality of the service delivered; and
- to assist purchasers and providers in decisions concerning the provision of renal services for infants, children and adolescents.

5. DEFINITIONS

5.1 **Neonates:** These are defined as being less than one month old.

5.2 **Infants and Children:** For the purpose of this document the term children covers infants and children unless a different meaning is specified. Children are defined as being between one month old and fifteenth birthday. This accords with the definition used by the European Dialysis and Transplant Association [16] in data analysis. The Working Party recommends that all children with renal disease should be investigated and treated by paediatricians, paediatric nephrologists, paediatric urologists and paediatric surgeons. Many older children with chronic renal failure will have delayed puberty and in such circumstances it is appropriate that they should also be managed within paediatric units.

5.3 **Adolescents:** We define adolescents as persons between the ages of 15 and 18 years. Flexibility is required, to take account of personal choice and varying rates of development. Completion of secondary education and/or completion of puberty and growth are logical times for transfer to ongoing adult care, where needed. Because of the delay in physical and emotional maturation that often characterizes chronic renal failure, many patients in this age range will remain appropriately under the care of paediatricians. Occasionally this process of maturation will be so delayed that patients should remain in the paediatric unit beyond the age of 18 years. The emotional and physical maturity of the patient must be the criterion for deciding on the appropriate placement rather than the chronological age.

6. SCOPE OF THE SERVICE

6.1 Taking into account the reasonable expectations of general paediatricians (Appendix 2), we have identified the following areas of activity in which there are significant workloads for paediatric nephrologists:

- Pre-end stage renal failure - for patients with significantly reduced renal function who have not yet started replacement therapy (Appendix 3).
- End stage renal failure - for patients undergoing dialysis or transplantation (Appendix 3).
- Acute renal failure (Appendix 4).
- Renal biopsy service (Appendix 5).
- Pre-biopsy assessment of glomerulonephritis, haematuria and proteinuria (Appendix 2).
- Urinary tract infection and associated conditions (Appendix 2).
- Neuropathic bladder and other conditions requiring urodynamic investigation (Appendix 6).
- Prenatal diagnosis (Appendix 7).
- Hypertension (Appendix 2).
- Renal tubular disorders (Appendix 2).
- Metabolic renal stone disease (Appendix 2).

6.2 The Working Party identified three of the above services as highly complex and of low volume, namely those for end stage renal failure, acute renal failure and renal biopsy. These we have designated **specific paediatric renal services**. They require a defined minimum population base in order to generate sufficient experience to maintain skills. Furthermore, as the staff and equipment necessary to support these services are expensive, concentration in a limited number of comprehensive centres is cost-effective. For the purposes of this document the other services identified above are designated **general paediatric renal services**.

7. STRATEGY FOR THE ORGANIZATION OF SERVICES

Basic considerations

7.1 Services for children with renal diseases must be:

- provided by specialists who can maintain and develop their expertise, which necessitates a minimum caseload and hence population base; and
- convenient for patients and their families.

These two principles are not invariably compatible and some compromises are necessary.

7.2 The organization of facilities for children with conditions requiring specific paediatric renal services (as defined above) needs to take into account the comparative rarity and complexity of the problems and the high cost of their provision, and thus the need for long-term planning.

7.3 The provision of both general and specific paediatric renal services requires links with other specialties, the following in particular:

- **Other paediatric specialists** who provide support for paediatric nephrologists and also receive a service from them in areas such as intensive care, cardiology, oncology, etc;
- **Paediatric surgeon or urologist** for the management of surgical disorders which threaten renal function, and the provision of vascular and peritoneal access surgery. (In some centres this access surgery service is provided by the transplant surgeon);
- **Fetal medicine service** including obstetrician, radiologist, ultrasonographer, urologist, neonatologist and geneticist, for the management of fetal uropathy;
- **Adult renal service** for the transfer of adolescents needing ongoing care;
- **Renal transplantation service** which in almost all regions is adult-orientated and located on a different site from the paediatric renal unit and/or other paediatric specialties, necessitating the paediatric nephrology service having links with at least one other hospital.

7.4 Additionally, facilities for postgraduate teaching are essential (Appendix 2) and an environment which encourages research is highly desirable.

7.5 Because of the importance of collaborating with a variety of other specialists in such areas as prenatal diagnosis, complicated urinary tract infection, neurogenic bladder, etc, it is essential that units providing either comprehensive or general renal services establish regular conferences with these specialists, to ensure the best quality service and the most efficient use of resources. The service should, wherever possible, be delivered from a single site. Working on split sites increases the difficulty of communication, is wasteful of medical and sometimes nursing time and requires duplication of facilities. Moreover, it seriously impedes postgraduate teaching and research.

Minimum workloads

7.6 In order to accumulate and maintain the level of expertise demanded of a high-quality service, the following **minimum** workloads in specific renal services are necessary:

- End stage renal failure - 5 new patients per year;
- Acute renal failure - 20 patients per year;
- Renal biopsy (including transplant biopsy) - 25 biopsies per year.

7.7 It is stressed these are minimum figures and under ideal circumstances the workload will be 30-60% greater. The workload generated by adolescents is additional.

Population bases

7.8 The NHS Executive, in its recently issued guidelines on contracting for specialized services [17], has emphasized the importance of "....taking into account the optimum population size, not only for the stability of contracted referrals but also to give sufficient `critical mass' for clinical effectiveness". To sustain the specific paediatric renal service workloads represented in Appendices 3-5, and the minimum workloads that we have defined, a total population base of at least 3 million is required. Strict adherence to this figure would, however, impose unjustifiable travelling distances in less densely populated areas, and exceptions clearly have to be made for Wales and Northern Ireland.

7.9 The population density of most major conurbations allows for units serving 4-5 million total population (Appendix 1), which is much closer to the ideal. The concentration of population in Greater London permits the maintenance of two larger units. Such units offer opportunities for research and development which are of benefit not only to the local population but to the nation as a whole. In line with our previous advice to the London Implementation Group on children's and renal services, we view the ideal arrangement for London as two or at most three paediatric renal units. The development of two or three academic units in the provinces based on existing comprehensive paediatric renal units, to complement the two London centres, should be encouraged additionally.

7.10 These considerations had previously led to the development of 13 designated units in the United Kingdom [2,3], subsequently reduced to 12 by combining Edinburgh with Glasgow functionally [4]. Ways now need to be explored of making these arrangements consistent with the responsibility of each district health authority to purchase or provide the care required for its residents. Children with any illness requiring specific renal services (as defined in paragraph 6.2) should whenever possible be referred to one of the comprehensive units. There is evidence that families are prepared to travel considerable distances in pursuit of high-quality care for their children, although ways of lessening the financial burdens imposed still need to be addressed. We emphasize that an increase in the number of comprehensive units beyond the 12 currently established would lead to dilution of expertise, with the consequent risk of deterioration in the quality of service.

7.11 General paediatric renal services (as defined in paragraph 6.2) are required much more frequently and often have an important preventive dimension. Clearly not all patients with these conditions need to be referred to the comprehensive units, although such units will have an important role in setting standards of care, offering advice and reviewing patients with complicated illnesses.

7.12 Accordingly the Working Party proposes two levels of paediatric renal services, as follows:

- The 12 existing comprehensive paediatric renal units [4] should be maintained. They provide the full range of services defined above as both specific and general. They should also maintain staffing levels and facilities for research and the training of future paediatric nephrologists.

- A few teaching hospitals serving smaller populations cannot accumulate sufficient workloads to justify providing specific paediatric renal services, but it is nevertheless important that such centres develop general paediatric renal services. They should develop links with geographically related comprehensive units to provide the three specific services for their patients. Such units already exist in Edinburgh, Sheffield and Leicester (Appendix 8). Similar arrangements are currently being developed in Southampton and we believe that there is a case for further centres, in Oxford and Cambridge (Appendix 8).

7.13 In our view the management of acute renal failure necessitates the availability of all modes of dialysis, together with the skills of a multidisciplinary team, including specially trained nurses. Certain difficulties may arise, however, and further clarification is needed:

- Where renal failure is likely to be the result of primary renal disease the patient requires the level of expertise only available in comprehensive units. Because such instances are uncommon, diagnostic and therapeutic techniques of high quality can only be developed if these patients are collected in a small number of units. They should therefore be referred to a comprehensive paediatric renal unit in anticipation of the need for dialysis, despite the disadvantages of travel. **Postponing referral to a comprehensive unit until problems with dialysis support arise is not good practice.**

- The situation is more complex when acute renal failure arises secondarily to some other condition (Appendix 4). Often the condition of the patient and the treatment of the primary problem make transfer difficult and, in these circumstances, short term acute renal failure management may have to be undertaken in the local paediatric intensive care unit.

Renal transplantation

7.14 Unfortunately, the majority of renal transplant units in the United Kingdom are located on different sites from their associated comprehensive paediatric renal units. Transplantation is a particularly difficult time for the child and family and it is essential that they have available all the support that can be offered from the multidisciplinary team in a comprehensive paediatric renal unit. We strongly urge the development of arrangements for children to be transplanted within the familiar environment of a comprehensive paediatric renal unit, to facilitate continuity of care by the multidisciplinary team. This necessitates both the willingness of transplant surgeons to operate in a different hospital, with initially unfamiliar supporting staff, and their acceptance by the staff of the host hospital. Such arrangements demand flexible attitudes and a commitment to placing the needs of the child first and foremost, and have already been achieved in some centres. It is essential that this co-operation between transplant surgeons and paediatric nephrologists is maintained and developed so that, whilst the transplants are performed in a paediatric environment, the team has access to all the experience gained from transplanting adult patients, which can then be applied to the children.

7.15 The problems of post-transplant management in children are predominantly those of acute renal failure and those requiring intensive care, problems which the paediatric unit commonly encounter. The paediatric renal unit is not working in isolation but can call on the expertise of the adult transplant team, not merely for surgical input but also for essential advice regarding immunosuppressive therapy and the diagnosis and management of rejection.

Minimal Care and Satellite Haemodialysis

7.16 There is no demand for such units to be developed specifically for paediatric patients. The few patients considered suitable for such units would be adolescents and could be either transferred to their local adult unit or managed in the satellite dialysis or minimal care unit under the joint supervision of the local adult nephrologist and paediatrician, with regular clinical review by the paediatric nephrologist.

Shared Care Clinics (Appendix 9)

7.17 Both comprehensive and general paediatric renal units should be encouraged to establish and extend the scope of shared care clinics. Members of the Working Party who have experienced contributing to shared care clinics were in no doubt about their benefits. Apart from the obvious advantage of convenience, patients and their families are afforded the opportunity of meeting the paediatric nephrologist in a familiar environment. The discussion of individual patients in a clinical setting is a far more effective means of communication than correspondence, and the clinics have undoubted educational value for the general paediatricians and their junior staff. Moreover, misunderstandings about the respective roles of the referring paediatrician and the nephrologist in the care of individual patients are avoided by mutual discussion.

8 REQUIREMENTS OF SERVICE

8.1 Children with renal disease are first and foremost children. The BAPN would expect that any renal unit caring for children and young people with renal diseases should fully implement the Department of Health Guidelines *The Welfare of Children and Young People in Hospital (1991)* [18]. The basic requirements of a comprehensive paediatric renal service are considered under the following headings:

- Diagnostic facilities
- Treatment services
- Accommodation
- Staffing - see Chapter 9

8.2 **Diagnostic facilities.** The following are required:

- Renal biopsy service provided by paediatric nephrologists and supported by histopathologists familiar with renal disease in children
- Conventional radiology and ultrasonography
- Nuclear imaging
- Arteriography
- Urodynamics
- Specialist biochemistry, microbiology and haematology

8.3 **Treatment services.** The services required are listed below:

- Peritoneal dialysis and haemodialysis for acute renal failure
- Continuous arteriovenous and venovenous haemofiltration
- Plasmapheresis
- Continuous ambulatory peritoneal dialysis (CAPD), continuous cycling peritoneal dialysis (CCPD) and haemodialysis for end-stage renal failure
- Vascular and peritoneal access surgery
- Renal transplantation

Accommodation

8.4 **Inpatient beds.** In most of the comprehensive units the number of beds required is insufficient to make the provision of a whole ward exclusively for renal services economically viable. When planning which services might share the area it is important to consider the nature of the patient mix from the point of view of both infectivity and the patients' psychosocial needs. Combined nephrourology wards, which have been developed in some regions, have particular attractions as children frequently require attention by both urologists and nephrologists, and continuity of nursing care can be achieved. No good estimates of bed numbers are available and they will vary from unit to unit. For example, older established units will have greater requirements for long-term dialysis as a consequence of accumulating patients in whom previous transplants have failed.

8.5 **Day case area.** Many investigations (renal biopsy, renal function assessment, urodynamics, imaging, etc) can be performed on a day case basis. These facilities can be sited in either the acute nephrology ward or a designated day case unit for various children's services.

8.6 **Urodynamics.** The success of urodynamic investigation in children depends on the paediatric nephrological or urological input and the skill and expertise of the paediatric nursing staff (Appendix 6). The basic accommodation required comprises:

- Laboratory equipped for invasive urodynamic investigations, ideally including videofluoroscopy and ambulatory urodynamics
- Cubicle for measuring urine flow rates
- Consulting/counselling room
- Patient waiting area, with kitchenette
- Toilet and sluice
- Staff office
- Storage space.

8.7 **Dialysis stations.** Children must receive haemodialysis separately from adults, under the care of paediatric renal nurses and paediatric nephrologists. The precise arrangements will depend on the number of children requiring haemodialysis, and the geographical relationships between the adult unit and the paediatric renal services.

8.8 **Isolation dialysis facilities.** Established practice in paediatric renal units aims to prevent the spread of viral and other infections to and from parents and staff. However, the risks are such that isolation of certain patients is advisable. This applies particularly to patients identified as carrying the Hepatitis B virus or HIV and also to those with methicillin-resistant staphylococci. As these are uncommon problems in current practice, the needs of patients will have to be addressed on an individual basis. In older children the use of adult isolation facilities might be appropriate; otherwise isolation dialysis facilities would have to be established on the dialysis unit or elsewhere in the hospital. Appropriate and regular viral testing of patients and staff, and the teaching and monitoring of safe practices remain essential in renal units. All staff working in dialysis units and acute nephrology wards should be encouraged to take advantage of Hepatitis B immunisation, which should be readily available, and the cost met by the employing authority.

8.9 **Outpatient Clinics.** Both general nephrology clinics and specialized clinics for pre-end stage and end stage renal failure and post-transplant patients are required. Many other professionals (nurses, social workers, dietitians etc) will have a role in these clinics and need accommodation. Some patients, for example those immediately after a transplant, require frequent follow-up; ideally the provision of a daily access clinic best meets the needs of these patients. Such a clinic, if not held in the main paediatric outpatient department, will require the provision of a suitable consulting room with weighing facilities and might appropriately be provided on the paediatric dialysis unit.

8.10 **Parents' Accommodation.** Children in hospital, especially the very young, are vulnerable to parental separation, while at the same time caring parents are naturally anxious about their children, faced with serious illness and perhaps major surgery. It is therefore imperative that paediatric renal units provide parents' accommodation of a welcoming nature, even if modest in style.

9 STAFFING

Consultant Medical Staff

9.1 None of the consultant paediatric nephrologists in the UK has an adequate safety net. While there is usually adequate middle grade general paediatric cover, specialized middle grade cover is unusual, and probably unattainable. Although the number of patients with specific renal problems might seem low, each demands a large amount of attention from medical staff. Furthermore, there is a considerable workload generated by patients with general paediatric renal problems, often requiring intensive treatment. In view of the very specialised and often technical demands of acute renal failure management, cross-cover is not appropriate for paediatric nephrology. This, together with the on-call commitment in the absence of an adequate safety net, and the time spent in travelling to and conducting shared care clinics, means that all consultant paediatric nephrologists are overloaded. The BAPN has already expressed concern at the inability of paediatric nephrologists to fulfil their teaching obligations and devote even a minimum of time to research on account of clinical pressures [4]. A Joint Declaration by the Royal Medical Colleges and their Faculties in 1993 recommended that every consultant should undertake 50 sessions per year of continuing medical education [19]. As with teaching and research, clinical workload is again one of a number of barriers to continuing medical education. Moreover, implementation of the Calman report's recommendations on training [20] will necessitate increased endeavour by teachers in view of the shortened training period.

9.2 Much of the clinical and laboratory research carried out in paediatric nephrology departments has led to the simplification and diminished costs of investigations, the replacement of inpatient management by day case attendance, and improved therapeutic outcomes for many patients. Observations at European and international paediatric nephrology conferences suggest that there has recently been a general decline in the pre-eminence of British contributions to knowledge, and the Working Party members believe that protection of research time in consultant contracts is essential.

9.3 These factors have led the Working Party to recommend that a minimum of four consultants, each devoting not less than eight notional half days per week to nephrology, should be available in every comprehensive centre providing a service for a population of 3-5 million. This level of staffing would afford a 1:4 on-call rota as has been recommended for adult nephrologists [1] and for general paediatricians with unselective emergency admissions [21]. Exceptions should clearly be made in the case of Wales and Northern Ireland, in view of the small populations served by the units in Cardiff and Belfast. While the workloads in these two small regions would not justify the appointment of four consultants, a skilled on-call service must nevertheless be provided with a rota not more arduous than 1:3. We therefore suggest three consultants for each of these units, of whom one might be a general paediatrician with a special interest in Nephrology. Units serving populations of 5-7.5 million would require five consultants and those serving more than 7.5 million six consultants. These numbers assume that all consultants have not less than eight notional half days devoted to paediatric nephrology; any reduction in this commitment would increase the number of consultants required. Current staffing levels are well below this optimum (Appendix 1), and a further 20 appointments should be made in the short to medium term.

9.4 Teaching hospitals which provide only general paediatric renal services will on occasion have to initiate acute renal failure management. This requires continuity of care, and arrangements need to be developed for an appropriately trained paediatrician to be available at all times. An ideal formula would comprise one whole-time paediatric nephrologist and two paediatricians with a special interest in nephrology, which would permit a 1:3 on-call rota. However, this ideal might not be attainable, at least in the short term, and a compromise, possibly entailing a 1:2 on-call rota for nephrology (but not general paediatrics), and occasional consultation with an adult nephrologist, might have to be entertained temporarily.

9.5 In drawing up contracts for paediatric nephrologists the following areas need to be considered:

- Patient care - inpatients in the renal ward and consultations on other wards
- Dialysis unit
- Transplant unit
- Outpatients
- Shared care clinics
- Renal biopsy
- Other investigations/interventions
- Multidisciplinary conferences
  - with radiologists for regular review of radiographs and other imaging
  - with pathologists for renal biopsy review
  - with other healthcare professionals for end stage renal failure patients
  - with obstetricians, radiologists, paediatric surgeons, neonatologists and geneticists for management of fetal uropathy
- Correspondence with general practitioners and other colleagues
- Administration of ward, dialysis unit and outpatients
- Management of renal services
- Audit
- Teaching of undergraduates, postgraduates, nurses and others
- Continuing medical education
- Research

Junior medical staff

9.6 **Higher specialist trainees.** With implementation of the Calman Report [19], the current senior registrar and registrar grades will merge to afford continuity of training. The training of a consultant paediatric nephrologist capable of delivering a high quality, family orientated service requires in-depth training in general paediatrics as well as nephrology, and details of the scope and timetabling of training in paediatric nephrology are in the process of being finalized. In order to train a sufficient number of future consultants to fill the 20 proposed new appointments (Appendix 1), the number of higher specialist training posts urgently needs to be expanded to a minimum of 12. This would allow expansion to the proposed new consultant establishment over a period of 5-10 years. Additionally, doctors in training for general paediatrics and other specialties should ideally acquire experience in paediatric nephrology; additional posts will need to be created to meet these training requirements.

9.7 **Senior House Officers.** Experience in paediatric nephrology at this level will generally be related to general professional training and rotations should be organised to take account of this. **It must be emphasised that in paediatrics there are no appointments below SHO level.** Emergency cover for the nephrology service in most units will consist of a higher specialist trainee in general paediatrics, and an SHO. Experience in paediatric nephrology at this level will be variable, and usually minimal or lacking. Consultants should operate a rota to provide 1:4 or 1:3 cover (depending on the unit's population base), frequently but not exclusively offering advice and hands-on help for resident doctors with no experience of nephrology.

9.8 **Permanent non-consultant staff.** Specialist hospital practitioners or staff grades have been employed successfully in some units. Such staff, by providing continuity of care, are a valuable asset to a service for patients with chronic illnesses such as renal failure, and might also find a role in other non-acute areas such as urodynamics.

Nursing staff

9.9 The Department of Health in its guidance documents *Welfare for Children and Young People in Hospital (1991)* [18] and the similar guidance for Northern Ireland, Wales and Scotland state the need for paediatric wards to have a minimum of two nurses per shift who possess the RSCN certificate or Project 2000 Child Branch Diploma. The Audit Commission in its report *Children First - A study of hospital services (1993)* [22] stressed the need for sick children to be cared for by paediatric nurses and highlighted the failure of governmental guidance to be implemented. Following the publication of the Allitt inquiry, the Chief Executive of the NHS Executive (Executive letter EL(94) 16) reminded regional general managers of the importance of employing sufficient numbers of nurses with statutory paediatric nursing qualifications.

9.10 Ideally at least two-thirds of the nurses employed in a paediatric renal unit should have completed an ENB renal course and obtained the renal qualification. At least one of these, referred to as paediatric renal nurses, must be available on each unit at all times, preferably on site, but failing that, on-call. The staffing complement must take into account the need for prolonged practical training of new recruits, even after completing the renal course.

9.11 Nationally there is serious difficulty in providing ENB renal course experience for paediatric nurses, and funding for attendance at these courses is an additional problem. At present the Hospital for Sick Children, Great Ormond Street, London, is the only unit with a purely paediatric renal course, and even this is under review at the present time. It is essential that adequate paediatric renal training courses are established.

Nurse Staffing Levels

9.12 **Haemodialysis service.** For acute renal failure a 1:1 staff:patient ratio is required. The requirements for end stage renal failure vary with age: 5 years and under, 1:1; more than 5 years, 1:2.

9.13 **Ward staffing.** A 1:3 staff:patient ratio with an additional nurse-in-charge is desirable, a ratio of 1:4 being the minimum acceptable for safety. Transplant recipients require 1:1 nursing for 48 hours postoperatively and up to 72 hours in children less than five years old. Thus ward staffing levels should take account of transplant activity within the unit.

9.14 **Community Liaison.** To ensure continuity of care, the child's named nurse in hospital should link directly with the named nurse in the community. Depending on the child's nursing needs and local services, a ward-based nurse may provide an outreach service or, alternatively, one of the paediatric community nurses in a local team may spend time in the hospital ward becoming familiar with the child's treatment. Most units have established at least one community liaison nursing sister to address the technical and other problems which are not infrequently associated with home peritoneal dialysis, and to reinforce information and advice given in hospital. It is particularly important that children with chronic renal disease are not deprived of the health care surveillance and health promotion services available to all children in the community, and appropriate links must be maintained with the primary health care team, including the school nurse.

9.15 **Peritoneal dialysis for end stage renal failure.** There should be at least one nurse available for CAPD training, outpatient review and continuing care. Cover must be provided in the absence of the CAPD nurse.

9.16 **Transplantation and chronic renal failure services.** Each of these services should have a designated specialist nurse to provide continuing care and outpatient cover.

9.17 Nephrology outpatients. This is a neglected area, few units providing specialist nursing. It is recommended that one specialist renal nurse should be available in each outpatient clinic. This should be in addition to the nursing staff normally needed to run an outpatient clinic.

9.18 Other areas. Urodynamics is another neglected area in most centres, there being little communication with the paediatric renal units. The importance of empathy with young patients being investigated cannot be overemphasised (Appendix 6). Similar nursing support is required for patients undergoing renal biopsy and for day case attenders. Some units include day cases in the ward bed establishment, while others have separate day case areas.

9.19 Organisation of nursing services. Each unit is geographically disposed and managed differently, and it is not the intent of this report to demand that every unit must have individual nurses for every one of the areas detailed. It is acknowledged that an individual nurse may have more than one role. However, we emphasise that every child should have a nurse available to fulfil each of these roles. Some units provide a named nurse who follows an individual child through all modes of treatment or areas of care. This can work but might be difficult to achieve in large units. Other units employ a specialised nurse in each area, as patient numbers are large enough to support this, eg. a transplant sister who is only involved in outpatient care. In smaller units this would not be feasible.

Dietitians

9.20 Dietary input is even more specialised in paediatric than in adult nephrology and intensive work is often required with patients and families. In addition to the routine dietary modifications required for such conditions as the nephrotic syndrome and chronic renal failure, many infants with advanced chronic renal failure are found to benefit from intensive nutritional support [23]. Liaison with schools is also time-consuming yet essential. Data available from the Children's Hospital, Birmingham, showed a 40% increase in activity between 1988 and 1993, and the existing single-handed renal dietitian is now able to offer only a basic service. An increase by 0.5 whole time equivalents (WTE) would facilitate the introduction of parent training, home visits, more regular monitoring of children's diets and the development of recipe ideas for children. Estimates of dietetic time required need further study but we suggest an approximate formula of 1 WTE for 3 million total population served. This requirement may need adjustment in the light of experience.

Psychiatrists and Psychologists

9.21 The development of a family-orientated service with adequate psychosocial support is an essential element of renal failure services for children. This meets not only the needs of patients and their families but also important areas of staff support which require attention. Individual units adopt different strategies for meeting these demands, some preferring to use psychology services, others child psychiatry and some a mixture of both. The provision of this service should be appropriate to local facilities and adequately resourced.

Social workers

9.22 In addition to advising parents on the DSS and other benefits available, and liaising with charitable bodies, social workers frequently undertake the additional role of counselling parents in matters such as long-term treatment options and prognosis, and provide essential psychosocial support. Thus familiarity with patients and the nature of their illness, through outpatient and ward round attendance, is mandatory. All comprehensive units will require at least one social worker dedicated to the children's renal services. While there are no reliable estimates for the social work requirement of children with renal disorders, evidence of workloads obtained from social workers currently in post suggests that 1 WTE is required for every 3 million total population served.

Play workers and Play therapists

9.23 Play is an essential part of the care of children with chronic renal disease, in inpatients, those on maintenance dialysis and outpatients. The terminology used is variable but the functions range from activities with preschool children akin to the activities undertaken in playgroups and nurseries (which we refer to as play work) to a much more developed therapeutic role in which play is used to explore children's psychological functioning (play therapy). Play work and play therapy are not necessarily the same activities, nor are necessarily undertaken by the same professionals. Both these functions need to be provided and to be integrated within the overall psychosocial support offered on the unit.

School Teachers

9.24 The role of teachers within the paediatric nephrology service is very wide, ranging from providing continuity of education for children in hospital to liaising with schools with regard to patients with chronic disease, and organising courses and employment advice appropriate to older patients with renal failure. In negotiation with the local educational authorities adequate resources need to be available to undertake these specialised tasks.

Other Staff

9.25 **Pharmacists with renal and paediatric experience.** Numerous complex questions with regard to medication arise in renal failure. These range from the simple issue of making sure that parents and families are adequately educated about the administration of their medication and its likely side effects, to communicating with primary care doctors concerning the prescription of certain medications, and advising on drug prescribing in renal failure. The availability of a specialised pharmacist to join ward rounds and outpatient clinics, to help in these tasks, is very important.

9.26 **Technicians.** The technical requirements for paediatric dialysis are different from those for adult dialysis, and support from technicians aware of these specialist requirements is essential. Cover must be provided for a 6-day week as well as out-of-hours emergencies. It may be uneconomical for the average sized paediatric dialysis unit to employ a whole-time technician and few paediatric units will be able to provide continuity of care outside hours. Therefore, arrangements generally need to be made with the associated adult renal unit.

9.27 **Business manager.** This is the person responsible for budget and stock control and the development of contracts. This role may be combined with that of a dialysis administrator and other administrative functions within the unit.

9.28 **Secretaries.** One whole-time secretary should be provided per consultant. Additional secretarial resources will be required to cover administrative and audit functions. Each renal unit needs staff competent and available to use information technology. Depending on local arrangements, this might be an additional function undertaken by the secretaries, and adequate resources will be necessary.

9.29 **Transplant Coordinator.** Special transplant coordinators for paediatric services are not required but adequate support from the regional transplant coordinator is necessary and this person must be conversant with the special problems of transplantation in childhood.

10 QUALITY ASSESSMENT

10.1 It is essential that providers and purchasers establish mechanisms to ensure that the principles set out in this document are put into practice both nationally and regionally. Service audits that should be initiated and maintained include:

- New patients and stock of patients on end stage renal failure management - regional and national.
- Workload data for specific renal services to maintain comprehensive unit status.
- Data on children receiving specialist renal services outside comprehensive renal units.
- Confidential enquiry into any child dying from acute or chronic renal failure, to identify preventable factors.
- Development of protocols and management guidelines on shared care problems eg. nephrotic syndrome, urinary tract infection, recurrent haematuria, for further audit.
- Establishment of new consultant posts. An average 7% increase in consultant numbers per year is needed to achieve the desired consultant expansion over a 10 year period, and greater than this if the expansion is to be achieved sooner.

11. CONCLUSIONS

11.1 This report is the product of wide consultation and discussion, based on a series of fact-finding exercises undertaken by members of the Working Party, which have demonstrated a substantial increase in the clinical workload of paediatric nephrologists during the past five years. This has been exacerbated by a diminishing amount of junior medical staff cover and by increased responsibility for management and audit. The BAPN has already expressed concern about the inability of its consultant members to fulfil their teaching obligations, and about the threat to research [4], yet implementation of the Calman Report [20] will necessitate increased endeavour by consultants, while the imposition of obligatory continuing medical education [19], although highly desirable, will further increase the demands on their time.

11.2 Because it is a high-cost, low-volume service, paediatric nephrology needs a degree of protection in the market place. The placing of contracts by the former Regional Health Authorities until recently ensured the viability of the twelve comprehensive paediatric renal centres, and we are conscious of the danger that the removal of such control could lead to managers buying renal services for children from their local district hospital adult units more cheaply, but of inferior quality [4], and this must be vigorously opposed.

11.3 The NHS Executive's guidelines [17] advise that the purchasing of specialist services should be supradistrict, and that purchasers "must ensure that professional standards and quality of specialist services are addressed through their purchasing arrangements". The guidelines also warn that purchasers "should not purchase from alternative providers or a generalist without appropriate specialist and clinical advice ...". This goes a long way towards alleviating our apprehensions.

11.4 The present report sets out standards that we believe should be maintained by providers and demanded by purchasers of services for children and adolescents with renal disease. To meet these standards, a substantial increase in consultant and trainee manpower will be needed in the short to medium term, if the quality of service is not to deteriorate. In responding to a previous BAPN report [3], Dr (later Sir) Gerard Vaughan, then Minister for Health, concluded his letter of 30 October 1981 to the late Dr M H Winterborn, a former Honorary Secretary:

> "I am hopeful that, despite the current difficult economic situation, we shall be able to maintain our position as one of the leading countries in the treatment of children with chronic renal failure."

This remains one of our aspirations, to the benefit of our patients and their families.

12. APPENDICES

Appendix 1. Regional populations, location of comprehensive paediatric renal units and consultant manpower in the United Kingdom, October, 1994.

Former Health Region	Population (million)[1]	Location of designated Paediatric Unit providing service	Population base of Unit	Consultants In post 10/94	Consultants Additional required
Northern	3.08	Royal Victoria Infirmary, Newcastle	3.08	2	2
Yorkshire	3.67	St James Hospital, Leeds	3.67	3[2]	1
Trent[3]	4.71	City Hospital, Nottingham	4.79	2	2
NW Thames	3.57	HSC, Great Ormond Street, and the Royal Free Hospital	11.65	5[2]	1
NE Thames	3.77				
SE Thames	3.70	Guy's Hospital, London	9.13	4[2]	2
SW Thames	3.02				
Wessex[3]	2.98				
Bath & Swindon	*.65*	*Southmead Hospital, Bristol*			
Remainder	*2.33*	*Guy's Hospital, London*			
Oxford[3]	2.55				
Northampton - part	*.16*	*Children's Hospital, Birmingham*			
Remainder	*2.39*	*N Thames Units*			
East Anglia[3]	2.08				
north - part	*.08*	*City Hospital, Nottingham*			
south - part	*.08*	*Guy's Hospital, London*			
remainder	*1.92*	*North Thames Units*			
South Western	3.28	Southmead Hospital, Bristol	3.93	3	1
West Midlands	5.25	Children's Hospital, Birmingham	5.49	3	2
Mersey	2.41	Alder Hey Hospital, Liverpool	3.06	2	2
North Western	4.00	Royal Manchester Children's Hosp	4.00	3	1
Wales	2.89				
Clwyd & Gwynedd	*.65*	*Alder Hey Hospital, Liverpool*			
Radnor & Montgomery	*.08*	*Children's Hospital, Birmingham*			
Remainder	*2.16*	Cardiff Royal Infirmary	2.16	2	1
Scotland[3]	5.11	Royal Hospital for Sick Children, Glasgow	5.11	2	3
Northern Ireland	1.59	Belfast City Hospital	1.59	1	2
TOTAL	57.66	----	57.66	32	20

[1] Source: OPCS—revised final rebased mid-1991 resident population. *Figures in italics are estimates.*
[2] Includes academic appointments (Leeds 1; GOS & Guy's 2 each) with minimal clinical commitments.
[3] See also Appendix 8.

Appendix 2. General paediatricians' referral intentions and service expectations.

In September 1991 a BAPN national survey was carried out to ascertain the referral intentions of general paediatricians regarding children with renal disease. Questionnaires were sent to 184 district paediatric departments, and responses were received from 129 (70%). The main findings are summarised in Table 2.1.

Table 2.1. Percentage of general paediatricians who would usually or always refer the listed conditions.

Condition	%	Condition	%
Nephrotic syndrome:		Urinary tract infection:	
steroid-responsive	29	in infancy	16
frequently relapsing	82	recurrent, normal imaging	19
steroid-resistant	94	recurrent, abnormal imaging	56
Glomerulonephritis:		Acute renal failure:	
poststreptococcal, uncomplicated	14	neonatal	77
" complicated or persistent	85	haemolytic-uraemic syndrome	93
other aetiology	89	all patients	86
Henoch-Schönlein nephritis:		Chronic renal failure:	
with isolated haematuria	20	GFR > 50 ml/min/1.73m^2	87
with proteinuria or hypertension	80	GFR < 50 ml/min/1.73m^2	95
Persistent haematuria:		Neuropathic bladder (excluding "difficult" wetter)	56
microscopic	77		
macroscopic	84		
Persistent proteinuria:		Fetal uropathy:	
moderate	26	cystic	75
heavy	79	obstructive	55
Hypertension:		Renal metabolic and tubular disorders	81
uninvestigated	53		
basic tests completed	87		

About 15% of general paediatricians would still refer children with isolated haematuria to urologists, despite the fact that surgical causes are rare at this age if an ultrasound scan and plain abdominal radiograph are normal [24]. The intended referral rates for urinary tract infection in infants, and in older children with abnormal imaging, are surprisingly low, and a matter for concern. In view of the potential dangers of functional obstruction arising from neuropathic bladder, and the excellent results of clean intermittent bladder catheterization (Appendix 6), the percentage of paediatricians intending to refer this condition is unacceptably low. A high proportion of paediatricians propose the referral of obstructive fetal uropathy to a urologist, but the view of the Working Party is that fetal uropathy cases should generally be reviewed at regular multidisciplinary clinical meetings (Appendix 7).

In the same questionnaire, general paediatricians were asked what services they expected from their regional paediatric renal unit. A whole-time, consultant-led service was expected by 92% of paediatricians, while 71% would like 24-hour telephone availability. Facilities for renal biopsy, nuclear imaging, invasive radiology and urodynamics were considered essential by 92%, and a radiological opinion service by 84%. From 73% to 97% expected the various modes of dialysis to be available, although only 56% considered children less than 10Kg suitable for transplantation. A travelling distance for patients of 25-50 miles was regarded as acceptable by 60% of paediatricians, but 50-100 miles by only 25%. More than 80% of general paediatricians would like to have visiting lecturers and written clinical management guidelines, and 69% regular seminars at the regional centre.

Appendix 3. Chronic renal failure

End stage renal failure

A national survey of end stage renal failure was conducted by questionnaire circulated to all thirteen comprehensive paediatric renal units, requesting information pertaining to 1992. Responses were received from every unit and, from the extensive data obtained, those relating to workloads and trends have been abstracted. They are presented as Tables 3.1 - 3.3.

Table 3.1. Patient gains and losses by Region, 1992.

Region	Patients starting RRT*		Transfers	Deaths	Balance
	No	No pmp/year			
Northern	4	1.3	3	0	+1
Yorkshire	12	3.3	0	1	+11
Trent	9	1.9	3	0	+6
North Thames		3.0			
GOS	13		2	1	+10
RFH	22		11	1	+10
South Thames	10	1.1	12	2	-4
South Western	8	2.0	2	1	+5
West Midlands	12	2.2	12	2	-2
Mersey	3	1.0	3	0	0
North Western	7	1.8	8	0	-1
Wales	4	1.9	0	0	+4
Scotland	6	1.2	1	0	+5
Northern Ireland	4	2.5	3	1	0
TOTALS	**114**	**2.0**	**60**	**9**	**+45**

* RRT=Renal replacement therapy; pmp=per million total population.

Of the 114 total patients, 8 (7.0%) were 15-17 years old. The 106 aged less than 15 years were derived from a child population of 11.05 million, giving an acceptance rate of 9.7 per million child population (pmcp). This compares favourably with that of other European countries [25], although these EDTA data unfortunately suffer from under-reporting. The acceptance rates were 6.64 pmcp in 1984, and 7.4 pmcp in 1986, indicating a 5-6% average annual rate of rise.

In Table 3.2 the patient numbers for the whole of the UK are broken down according to the modetreatment. The numbers of patients less than 15 years old are compared with those for 1986, and demonstrate an increase in workload.

Table 3.2. Patient stock by treatment modality and age at 31.12.92 and comparison of totals with those at 31.12.86.

Age (years)	Total		On haemodialysis	On peritoneal dialysis		Transplanted
	No	%		CAPD	IPD/CCPD	
0-1.99	16	*2.8*	2	6	7	1
2.0-4.99	55	*9.7*	5	4	17	29
5.0-9.99	150	*26.3*	11	15	21	103
10.0-14.99	208	*36.5*	20	23	15	150
15.0+	141	*24.7*	18	11	1	111
TOTALS						
All ages	570	*100.0*	56	59	61	394
<15yrs:						
1992	429		38	108		283
1986*	263		35	57		171
%change	*+63*		*+9*	*+89*		*+65*

* Data from the Royal Free Hospital were not available.

Of the 56 patients receiving haemodialysis, only two older children were on home treatment. There were more than twice as many patients on peritoneal dialysis as on haemodialysis. Although there has been a substantial increase since 1986 in the total workload involving children less than 15 years old, the percentage of patients transplanted has remained static at 66%. It should be noted that a quarter of all patients were aged 15 years or more, reflecting the problems of growth and physical development which characterize chronic renal failure (CRF) originating in childhood. This figure needs to be taken into account in planning the need for adolescent accommodation. Likewise, the 12.5% who were under 5 years old are relevant to the greater nursing demands of young children.

Renal transplant activity in the UK is presented according to Region in Table 3.3.

Only 7.8% of grafts were live related. Fifteen (14.7%) of the 102 transplants were performed in children less than 5 years old, and 15 (14.7%) in adolescents. It is noteworthy that the number of patients remaining on the transplant waiting list far outweighs the number transplanted in 1992, although this situation compares favourably with the rest of Europe [25].

Table 3.3. Renal transplant activity by Region, 1992.

Region	Cadaveric grafts		Live related grafts		Total	Waiting list
	first	subsequent	first	subsequent		
Northern	3	2	1	0	6	10
Yorkshire	7	1	0	0	8	23
Trent	6	1	2	0	9	7
North Thames						
Great Ormond St	5	0	2	0	7	10
Royal Free	12	2	2	1	17	13
South Thames	11	2	0	0	13	14
South Western	5	1	0	0	6	8
West Midlands	15	2	0	0	17	20
Mersey	1	0	0	0	1	8
North Western	4	0	0	0	4	14
Wales	4	0	0	0	4	6
Scotland	3	1	0	0	4	8
Northern Ireland	5	1	0	0	6	8
TOTALS	81	13	7	1	102	149

Pre-end stage chronic renal failure

Data on the prevalence of chronic renal failure by age were obtained from 9 comprehensive paediatric renal units. The other four centres were unable to provide data. The prevalence rates are calculated from the populations served by those 9 units (Appendix 1), and are shown in Table 3.4. Pre-end stage CRF was defined as a glomerular filtration rate <50ml/min/1.73m^2 at Great Ormond Street, but as <25-30 ml/min/1.73m^2 by the remaining units.

Table 3.4. Prevalence of CRF per million child population, by age, on 31.12.92.

Age (years)	0-1	2-4	5-9	10-14	Total <15	15+
No of patients	69	81	146	109	405	41
No pmcp	52.8		57.4	48.2	53.0	-

The prevalence of 53.0 pmcp for children less than 15 years old is much higher than the previously published estimates of 18.5 pmcp in Switzerland (1976) and 26.1 pmcp in Sweden (1978-85). If all units had used the higher GFR definition of CRF, the prevalence would have been even greater.

Data for acceptance rates during 1992, and balance at the year end, were available from 11 units, although they were incomplete in 3 units, as shown in Table 3.5.

Table 3.5. New patient acceptance rates per million total population in 1992, with balance and total number of patients attending at 31.12.92.

Provider unit's location	Acceptances			Losses		Balance at 31.12.92	Attending 31.12.92
	No	No pmp	to RRT*	deaths	transfers		
Newcastle	3	0.97	2	1	3	-3	29
Leeds	—	—	11	0	0	—	—
Nottingham	11	2.30	9	0	0	+2	33
Great Ormand St	87	7.47	14	0	21	+52	169
Royal Free Hosp	11	0.94	20	0	0	-9	9
Guy's Hospital	26	2.85	7	0	3	+16	76
Bristol	9	2.29	6	0	1	+2	32
Birmingham	—	—	13	0	—	—	52
Liverpool	6	1.96	3	1	3	-1	24
Cardiff	6	2.78	4	0	0	+2	22
Belfast	5	3.14	4	1	0	0	—
All units	164		93	3	31	+61	446
With complete data	159	4.04					

*RRT = renal replacement therapy. — = data not available.

The high acceptance rate at Great Ormond Street is partly due to the wider definition of CRF employed. If the other units had used the same definition, the overall rate would have been higher. Thus, the national acceptance rate of 4.04 pmp per year is not unrealistic, and may be an underestimate. This would represent at least 240 new patients per annum for the whole of the UK.

Appendix 4. Acute renal failure.

Figures have been obtained from eight comprehensive paediatric renal units, in Newcastle, Leeds, London (Great Ormond Street, Royal Free and Guy's), Bristol, Birmingham and Glasgow. All except the Royal Free Hospital are associated with busy cardiac surgical units. Birmingham also has a supraregional liver unit. The data are presented in Table 4.1.

Table 4.1. Patients admitted during 1992, according to diagnostic category, domiciliary origin, age and mode of dialysis.

	Total	%		Total	%
Total	315	*100*	Age on admission:		
			total	270	*100*
			< 1 year	*103*	*38.5*
Primary renal:			*1-5 years*	*104*	*38.5*
haemolytic-			*> 5 years*	*63*	*23*
uraemic syndrome	*110*	*35*			
other	*62*	*20*			
			Dialysis not required	41/215	*19*
Postoperative:			Dialysis mode*:		
cardiac	111	*35*	Total episodes	331	*100*
other surgical	6	*2*	*standard PD*	*169*	
			CAPD	*1*	
Trauma	26	*8*	*cross-flow PD*	*12*	
			CCPD	*13*	
Domiciliary origin:			All peritoneal dialysis	216	*65*
total	233	*100*	*haemodialysis*	*43*	
local/metropolitan	*60*	*26*	*CAVH +CVVH*	*41*	
regional	*102*	*44*	*plasmapheresis*	*31*	
extraregional	*71*	*30*	All vascular dialysis	115	*35*

*Some patients had more than one mode of dialysis.

The patients were derived from a population base of 42.2 million, yielding an incidence of 7.5 pmp per year. Haemolytic-uraemic syndrome was the cause in 68% of patients with primary renal disease. The cardiac surgical workloads accounted for the majority of neonates and infants requiring dialysis, and reflect the activity of most designated paediatric renal units. Of those requiring dialysis, various modes of peritoneal dialysis accounted for 65% of treatments, and haemodialysis, haemofiltration and plasmapheresis 35%.

Appendix 5. Renal biopsy service.

A renal biopsy service comprises the preliminary assessment of need and selection of patients; the procedure itself and aftercare; the interpretation of specimens; and the counselling of parents. A good quality service therefore requires skill and experience on the part of both paediatric nephrologist and pathologist.

National statistics

Questionnaires were completed in July 1993 by 13 comprehensive paediatric renal units, in addition to 2 university paediatric departments with and 4 without paediatric renal services, relating to the years 1987-91 . Three comprehensive units performed >50 biopsies per annum, 3 units 25-50 and 7 units <25. One of the 2 university departments with renal services did <25 and one referred patients elsewhere. Of the 4 other university centres, one referred patients to their designated paediatric renal unit, but in 2 centres biopsies were done by adult nephrologists, and in one by a radiologist. Where exact figures were supplied, the smaller paediatric renal units in which new consultant appointments had recently been made showed an upward trend in the annual biopsy rate. Transplant biopsies have only recently become routine in most units, and the numbers are rising sharply. Surprisingly, only 2 units admitted patients as day cases, although 90% of biopsies in children were performed under local analgesia.

All but one of the 14 units undertaking biopsies employed routine immunofluorescence and electron microscopy. Specimens were reported by a paediatric pathologist in 8 units and by an adult renal pathologist in 9; only 7 paediatric nephrologists also examined the sections, although regular clinicopathological review meetings were held in 13 units.

Birmingham survey

During the years 1988-92, 274 native renal biopsies were performed at the Children's Hospital, Birmingham — an average of 55 per annum. The clinical indications for biopsy were broadly categorised as:

- persistent or complicated glomerulonephritis 30%
- isolated haematuria 30%
- nephrotic syndrome 20%
  - *steroid-resistant* *17.5%*
  - *frequently relapsing* *2.5%*
- non-postural proteinuria & miscellaneous 10%

The patients were derived from a base population of 5.5 million, 5% being extraregional referrals. It can therefore be estimated that the national requirement is about 575 per annum, or 10 per million total population. The figure obtained in the national survey is somewhat less than this, and probably reflects a less aggressive approach to the investigation of recurrent haematuria; however, the Birmingham policy has yielded a high proportion of abnormality amongst this group [24]. An annual requirement of approximately 150 transplant biopsies is the best available estimate, but this may be too low and will need to be kept under review.

Recommendations

A minimum rate of 20-25 biopsies per annum is considered desirable for paediatric nephrologists and pathologists to maintain their expertise. As it is unlikely that there will ever be monospecialist paediatric renal pathologists in the UK, we consider it desirable that at least one member of the paediatric nephrology team has knowledge of renal pathology in children, particularly that affecting the glomerulus, so that informed clinicopathological conferences can be incorporated into the weekly routine [24]. This experience should ideally be gained during training.

The practice of adult nephrologists performing biopsies on children less than 15 years old should be discontinued; they cannot gain sufficient experience, and there are now adequate numbers of paediatric nephrologists trained in the procedure to provide the service. If, in an individual centre, it has been mutually agreed that a paediatric radiologist should perform the biopsies, this may be an acceptable arrangement; however, it must be appreciated that decisions regarding the adequacy of specimens, the selection of tissue for special processing, and the postoperative care of patients are the responsibility of the paediatric nephrologist, who must always be present during the procedure. The implications for training of future paediatric nephrologists must also be taken into account.

Children have been biopsied as day cases at the Birmingham Children's Hospital for more than six years, without serious complications. This policy is not only cost-effective, but is also much appreciated by patients and parents; we believe that it should be more widely applied.

Appendix 6. Urodynamics service.

It is regrettable that a substantial number of young adults presenting with end stage renal failure caused by congenital or acquired neuropathic bladder have had little or no nephrological care during childhood (J S Cameron, personal communication). Eighty-nine percent of general paediatricians have indicated that they would like to have a regional urodynamics service available (Appendix 2).

National statistics

In July 1993, a questionnaire was sent to 13 comprehensive and 3 other teaching hospital paediatric renal units, and all were returned. Access to a urodynamics service is available in 15 centres, provided wholly in the hospital delivering the paediatric renal service in 12 instances, partly in two, and elsewhere in the remaining centre.

Twelve centres provide non-invasive flow rate measurements, 13 video cystometro-urethrography, and 14 conventional cystometry and a catheter service for children not undergoing urodynamic investigation. Only 2 centres are currently equipped to undertake ambulatory cystometry. Although catheterization is performed by paediatric nurses in 12 centres, in 7 some children are catheterized by paediatric medical or surgical staff, in 4 by non-paediatric medical or surgical staff, and in one by urodynamics technicians. A continence advisory service is provided from 12 centres.

The service is directed by a paediatric nephrologist in 2 centres and jointly with a paediatric urologist in a third. In 9 other centres the principal director is a paediatric surgeon or urologist, but part of the service in 2 of these centres is provided by adult urologists. In 3 centres the service is directed entirely by adult urologists (one of whom has a special interest in childhood neuropathic bladder, however), and in one by a radiologist. Of the 12 centres where the urodynamics service is not directed by a paediatric nephrologist, there is a paediatric nephrological input in only 7.

Birmingham survey

National data on diagnostic categories are not available, but it is reasonable to assume that the figures shown in Table 6.1, which were obtained from the Urodynamics Department at the Birmingham Children's Hospital, are representative. The difficult wetter often receives treatment which lacks a scientific basis; it accounted for 24% of the Birmingham workload.

Table 6.1. The number of attendances in the Urodynamics Department at the Children's Hospital, Birmingham, during the period 1.11.91 - 30.10.92.

Diagnostic category	No	Subtotal	Domiciliary origin		
			Sth B'ham	Region	Other
Spina bifida	71				
Other neuropathic	8				
Obstructed/dilated tract	7				
Stress incontinence	3				
All organic		89 (76%)	14	68	7
Difficult wetter		28 (24%)	9	19	0
TOTALS		117 (100%)	23	87	7

The success of invasive and even non-invasive urodynamics in children is highly dependent on developing a good rapport through a patient, persuasive approach, and the service is best delivered by specially trained paediatric nurses. They are more likely to be available in departments run by paediatric medical or surgical consultants than by adult urologists. Whether the service is directed by a paediatric nephrologist, surgeon or urologist is not critical, but a nephrological input is essential, since most of the organic causes listed in the table carry a risk of functional or true obstruction, threatening renal function.

Appendix 7. Prenatal diagnosis.

The more frequent use and better resolution of antenatal ultrasound has resulted in the increased detection of urinary tract abnormalities ("fetal uropathy"). In the mid-1980s, most abnormalities were found coincidentally on scans undertaken for obstetric reasons during the last trimester of pregnancy [26]. However, in recent years, detailed scans have been performed at 18-20 weeks and also, in some units, routinely in late pregnancy. Not surprisingly, the rate of detection of fetal uropathy is increasing.

The reported incidence of fetal uropathy varies widely. In Nottingham it is currently 0.22% of livebirths; in Birmingham it is 0.46% amongst more than 10,000 pregnancies screened [27]. These may be underestimates; a prospective survey conducted on a stable population in Stoke-on-Trent [28] yielded an overall incidence of 0.76%.

The major causes of fetal uropathy [26, 27] are:

- Pelviureteric junction obstruction
- Multicystic dysplasia
- Vesicoureteric reflux
- Vesicoureteric junction obstruction
- Posterior urethral valves

Antenatal intervention in utero has a very limited role [29, 30]. However, the early recognition of obstructive uropathy and vesicoureteric reflux permits immediate postnatal intervention, with the potential for prevention or at least limitation of serious renal damage. The management of such problems depends on local arrangements, but it is widely recommended that pregnant women with fetal uropathy should be referred to a regional centre for joint consultation between the paediatric nephrologist, paediatric surgeon/urologist, radiologist, neonatologist, obstetrician and clinical geneticist, in order to plan investigation and follow-up, and the counselling of parents [26, 29, 30]. In Nottingham it is also the practice to involve the paediatric nephrologists in the antenatal counselling of parents; the Working Party commends this.

Postnatally infants should ideally be investigated according to a defined protocol. In Nottingham this is coordinated by a day case nurse, based on the paediatric renal unit. It is essential that these infants are followed up indefinitely, since the natural history of many conditions, such as incomplete pelviureteric junction obstruction, have not yet been defined. The overall management of fetal uropathy generates a significant workload for paediatric nephrologists.

Appendix 8. General paediatric renal services at teaching hospitals.

Edinburgh

In Edinburgh a service based at the Royal Hospital for Sick Children continues to be provided for a total population of approximately one million by a general paediatrician with a long-standing special interest. In addition to providing general paediatric renal services, children with acute and end stage renal failure are managed with the support of specialist nurses, adult nephrologists and transplant surgeons. However, transplants on smaller children are now carried out at the comprehensive unit situated in Glasgow, some 44 miles away.

Although this service is delivered from within a paediatric environment, the arrangements nevertheless fail to meet the criteria laid down in this document for the provision of a comprehensive service, in terms of the available population base, with its implications for minimum workloads, and the consultant staffing level. The long-term future of the service thus remains a matter for concern, and we reiterate our previously published recommendation [4] that there is a strong case for closer collaboration with Glasgow in the provision of special paediatric renal services.

Sheffield and Leicester

During 1993, two consultant paediatricians each with a special interest in nephrology were appointed to provide general paediatric renal services at Sheffield Children's Hospital and at Leicester Royal Infirmary. For many years there has also been a general paediatrician with a special interest at Derby Children's Hospital. Special renal services continue to be provided by the comprehensive unit at Nottingham City Hospital, and the arrangements are reported to be working well.

Southampton

A case has been successfully made for the provision of general paediatric renal services for children living in all the Wessex districts except Swindon and Bath, whose patients have traditionally been referred to Bristol. The effective total population base is 2.33 million (Appendix 1), which is too small to support the establishment of a fully comprehensive service, and it is proposed to continue collaborating with Guy's Hospital, London, and Bristol, as appropriate, in the management of end stage renal failure.

We strongly support this development, subject to the progressive development of an appropriate staffing structure, as described in this report. Initially, a whole-time consultant paediatric nephrologist was appointed in November 1994. We note with satisfaction that the service is to be based entirely at the Southampton University Hospital, which has the advantage of being the geographical hub of the region. This arrangement will provide essential links with other acute paediatric specialties, notably paediatric urology and infant cardiac surgery.

Oxford

The Oxford region has a total population of 2.55 million, of whom approximately 2.39 are served by the North Thames units, and the remainder by the Children's Hospital, Birmingham (Appendix 1). In geographical terms there is a large gap between London and Birmingham, which involves patients in long journeys to reach these comprehensive units. While the population base is insufficient to justify the establishment of a comprehensive service, we believe that there is a substantial case for the provision of general paediatric renal services, based at the John Radcliffe Hospital, Oxford. Such a development could also support the paediatric cardiac surgery service in Oxford.

Cambridge

Similar arguments apply to the East Anglia region, which has a total population of 2.08 million. The majority of children with renal disorders are referred to the North Thames units, although some go to Guy's Hospital and others to Nottingham City Hospital (Appendix 1). The provision of general paediatric renal services at Addenbrooke's Hospital, Cambridge, would lessen the travelling time and expenses of patients in this largely rural region, and at the same time would be able to support the major liver transplantation activities.

The implementation of these last two proposals would lead to a slight reduction in routine work in the London units but would not affect their specific paediatric renal service workloads.

Appendix 9. Shared care clinics.

Six-monthly shared care clinics were established in four outlying health districts in the West Midlands Region in the early seventies, and were subsequently extended to two further districts. In the North Western Region clinics are conducted in all districts, including those adjacent to the paediatric renal unit at the Royal Manchester Children's Hospital. However, in the national survey of general paediatricians carried out during 1992 (Appendix 2), only 40.4% of respondents stated that they already participated in shared care clinics, while another 34.2% expressed a wish for such clinics.

A survey of shared care clinics was undertaken in the Southwest Region. Clinics were held three or four times a year in 8 districts 40-160 miles from Bristol. A detailed analysis of figures from Plymouth showed an increase from 6 patients per clinic in 1986 to a plateau of 11-12 patients since 1990.

The principal reasons for referral were:

- vesicoureteric reflux with or without nephropathy
- nephrotic syndrome
- complicated or persistent glomerulonephritis
- chronic renal failure

Shared care paediatric urology clinics also take place in the South Western Region, and help to limit the nephrological caseload. In the West Midlands Region shared care surgical clinics were introduced relatively recently, and previously 10-15% of referrals to the nephrology clinics were primarily urological.

No firm recommendations can be made regarding the frequency of individual clinics, and the arrangements must be mutually agreed by those jointly concerned in their running. The principal limitation is consultant time. Specialist consultations in shared care clinics require an average of 20 minutes, so that more than 10 patients cannot comfortably be accommodated in a single session.

If the benefits of shared care clinics were to be extended to all districts in each region, quarterly clinics in a large region with, say, 20 districts would necessitate a minimum of 80 sessions per annum, to which should be added the time required for travelling, following up investigation results, preparing reports, arranging transfers, etc. This would generate a minimum of 120 sessions per annum — ie three sessions per week, allowing for annual and study leave.

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