

Foundation for Change 2008

A position statement.

C. Mark Taylor, Jane Tizard,
Nadeem Moghal, Moin Saleem, Sally Hulton,
Stephen Marks, and David Milford,

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Executive summary

The BAPN has completed an assessment of the changes needed for the next 5 years to promote and update patient care, and to enhance the skills and academic performance of the specialty. A strategy will be drawn up for each of the summary points outlined below. Each task will be allocated to the relevant executive structure of the BAPN that was revised in 2006-7, and overseen by the executive committee.

Priorities include:

1. Working with the Department of Health in England and the equivalents in Scotland, Wales and Northern Ireland, the Royal College of Paediatrics and Child Health (RCPCH) and the Renal Association (RA) for agreement on the national configuration of services for children and adolescents with kidney disease to ensure that there is equality of access.
2. Working with Commissioners at a national level to ensure that there is equality of care, that clinical networks are developed both nationally and regionally, and that the service is sustained.
3. Developing pathways for adolescent and transitional care
4. Developing national clinical audit appropriate for Paediatric Nephrology in partnership with the UK Renal Registry; ensuring effective electronic links capable of handling the necessary information.
5. Developing parent and patient access to clinical information via Renal Patient View.
6. Further defining the competencies and roles of the Paediatric Nephrology multidisciplinary workforce.
7. Developing a strategy for academic Paediatric Nephrology.
8. Developing a national portfolio of translational research through the Paediatric Nephrology Clinical Study Group.

Background

Changes taking place in the National Health Service (NHS) will have a radical and lasting impact on Paediatric Nephrology as a specialty and the provision of services for children with kidney disease. The BAPN is engaged in the decision forming process in the current round of reforms at various levels within the Department of Health (DH) and influential professional bodies such as the RA and RCPCH. The BAPN has well developed views about service structure and function, specialty training and education, research and development, and the interface with other health care professionals. At the heart of this is the need to secure and advance the well-being of patients with kidney disease and their families.

This document draws on the collaborative, integrated and forward-looking views of its members, and incorporates invited comments from patients and families. It summarises these views and builds on the 2003 document “*Review of Multi-Professional Paediatric Nephrology Services in the UK - towards standards and equity of care*”. It indicates the desired direction for the next 5 years and has two functions. Firstly, it serves as an internal position statement on which the

BAPN will construct its strategy for this period. Secondly, it has an immediate external utility in underpinning the advice and responses that the BAPN gives to questions raised by the DH, Royal Colleges and other external bodies involved in the current round of organisational change.

Principles

The executive identified six principles on which BAPN opinion is formulated:

1. Equality of access to services, matching services to populations
2. Specific issues of healthcare delivery and infrastructure in relation to chronic care, dialysis, transplantation, acute renal failure, and rare diseases
3. Adolescents and the interface with adult services
4. Education and development of the workforce
5. Manpower, team structure and critical mass
6. Research, development and audit

1. Access to services

Children with kidney disease are treated at three levels of care determined by clinical complexity:

1. Locally by general practitioners,
2. By referral to general paediatricians (secondary level care in District General Hospitals),
3. By comprehensive, regional or national (tertiary) Paediatric Nephrology centres.

It is essential that these three levels operate holistically, and that there is a seamless journey for patients between them. Comprehensive (tertiary) paediatric renal units all provide outreach services to general paediatric departments in local hospitals within their region. This includes telephone advice available 24 hours a day operating at a consultant-to-consultant level, and renal outpatient clinics in general paediatric departments in local hospitals. The tertiary level centres are therefore critical in sustaining and developing secondary level care, local to the patient.

Comprehensive paediatric renal services, offering dialysis and transplantation developed during the 1980s with supra regional, and later regional funding. The centres therefore map to the regional boundaries of the time. The reorganisation of regions in 2002 to some extent alters the relationship between regional health authorities and the centres. However the present geographic distribution of these centres, based in large cities with good communications, means that most of the child population of the UK has relatively straightforward access. Special arrangements are required in remote areas.

Tertiary services provide specialist knowledge, specific diagnostic procedures such as renal biopsy, that are not available in secondary level paediatric care, and dialysis services. Most but not all centres also undertake kidney transplantation, although all offer follow-up after transplant surgery. Two London centres share the same transplant surgical team. Only one centre provides combined liver and kidney transplantation. It is clear from this that there is an emerging

interdependence between regional centres driven by issues such as transplantation or highly specialised clinical advice. Commissioning of the service therefore requires a national dimension in addition to a regional one.

This has an impact on how the services should be funded. The BAPN fully supports the principles of cost analysis and efficient use of national resources contained in Payment by Results (PbR). However, the BAPN has expressed concern that basing service provision entirely on PbR does not account for the fixed-cost infrastructure needed to maintain a comprehensive service, a view concordant with that of the National Audit Office. If based entirely on PbR, there is real concern that Trusts will be forced to make short-term economic decisions (e.g. not replace staff lost by natural wastage) to ensure costs are covered by income (activity). While efforts are being made to try and ensure that the tariffs accurately reflect the true cost of delivering complex, multidisciplinary care, PbR does not measure or pay for invisibles (supporting secondary care by email, telephone etc.), quality of care, multidisciplinary clinics or network and shared care relationships. These activities are essential for delivering the services. Infrastructure requirements are common across all units and a national view with regional input is needed to ensure that the quality and development of Paediatric Nephrology is sustained, and any unforeseen consequences of the PbR mechanism obviated.



Distribution of 13 Paediatric Nephrology Units in the UK providing dialysis +/- transplantation.

2. Special issues of healthcare delivery

Established Renal Failure is rare in children, the incidence and prevalence being 8 patients per million population (pmp) and 47.7 pmp respectively under the age of 15. Chronic care demands that integrated multi- professional teams deliver and co-ordinate care for a region. Such regions need to be large enough for staff to develop and maintain their skills, and to justify the service investment both in terms of manpower and of capital (equipment) infrastructure costs. Integration with secondary services is essential to provide care as close to home as possible and extend the expertise provided by the regional centre.

The elements that make up the multi-disciplinary team (MDT) are generic in terms of professional input, and extensively described in “Review of Multi-professional Paediatric Nephrology Services in the UK 2003”. They include:

- Medical –Consultants, Staff and Associate Specialist Grade, and doctors in training
- Renal nurse specialists
- Paediatric renal dietician
- Child Psychologist
- Play therapist
- Social worker
- Teachers
- Support workers (youth workers, counselors)
- Pharmacist

Some of the expertise of these professionals is sufficiently generic to be able to cross cover work in other specialties. However there is a specific core of expertise necessary for continuity of care. This is delivered particularly by the consultants, renal nurse specialists, paediatric renal dieticians and paediatric renal pharmacists.

For comprehensive care of the patient with renal disease it is necessary to have immediate access to some specialties and easy access to others on a less urgent basis. This includes diagnostic specialties such as radiology, genetics, renal pathology and immunology. Paediatric nephrology also has a specific need for input from the paediatric surgical specialties, particularly urology and specialised paediatric anaesthesia. Another area in which paediatric nephrology interacts with other specialties is within perinatal medicine. Advice and counseling for parents is sought when fetuses are identified with urinary tract malformations.

Similarly, other specialties have a requirement for access to Paediatric Nephrological expertise. The precise nature of this interdependency has been the subject of a review of “*Commissioning Safe and Sustainable Specialised Paediatric Services*”. This will lead to further discussions on the configuration of all specialised paediatric services in the UK.

Haemodialysis (HD) is a small but essential part of any comprehensive Paediatric Nephrology service. HD is capital and labour intensive and has a high variability in demand. The number and distribution of HD units needs to balance the ability to deliver care at a reasonable distance from the patient while enabling staff to maintain skills to deliver a safe service.

Transplantation is another area that demands the concentration of expertise and co-location not only with other paediatric specialties but also with adult transplant units. Combined liver- kidney transplantation requires further concentration of expertise and is currently delivered in one centre.

Acute renal failure may be secondary to multi-system failure. Joint working with Paediatric Intensive Care Units (PICUs) to manage these patients is essential to offer optimum care and therefore will also be integral to the configuration of services in the UK.

Not only are the kidney diseases of childhood often very rare, but they are also different from those that affect adults. A higher proportion of childhood kidney diseases are associated with inherited abnormalities, inborn errors of metabolism, and syndromes of abnormal development and function that affect systems other than the kidney alone. These diseases are complex, have an ethnicity bias, and are often poorly understood in scientific terms and difficult to manage. Patients with these disorders quite often require input from other medical subspecialties, for example genetics, metabolic medicine, and neuro-developmental medicine. This added complexity has to be addressed at the service level and has profound implications for funding the service and for the appropriate geographic distribution of paediatric renal units.

Patients and their families, who often feel isolated because of the rarity of significant kidney disease in children, need to be empowered to derive the greatest benefit from available health care. Renal Patient View (RPV) does this by providing information on the child's own medical condition and general education on many areas of nephrology. RPV is of particular importance to teenagers and young adults in the process of transition. It is currently only available to a minority of patients and it is essential that it becomes accessible to all.

3. Adolescents and the interface with adult services

Following publication of the Renal NSF, the DH in 2007 invited renal units at Great Ormond Street and Birmingham Children's Hospitals to establish multi-professional groups, including both paediatric and adult practitioners, to review transition and transfer of patients to adult renal units using the principle of Action Learning. The following key issues were identified.

Most adolescents, having attended a paediatric unit from an early age, are accustomed to being cared for by a small number of health professionals from a multi-disciplinary team. Parents who have hitherto supervised their care are expected to relinquish control to allow independence during adolescence. Adult renal units have limited psychosocial resources and expect self-reliance.

Normal adolescence is marked by risk-taking behaviour and in chronic disease this may be expressed as non-adherence, leading to high rates of renal allograft loss in teenagers.

Each regional paediatric unit transfers adolescents to approximately 10 adult renal units. As the number of transfers is small, an adult renal unit may only accept an adolescent every two or three years. Young renal patients are a minority group in an adult renal unit and have difficulty making

contact with other patients. However, larger adult renal units offer a greater choice of services, e.g. timing of haemodialysis sessions, which provide benefits for college and work timetables.

The following analysis of what constitutes good practice is fully endorsed by the BAPN.

An essential starting point is to recognize the distinction between the *process of transition* and the *event of transfer*. The process of transition for adolescent renal patients and their families should begin in school year 9 and continue after transfer. The event of transfer should not occur before the end of school year 11 and may need to be adjusted according to the developmental maturity of the adolescent.

Good practice includes considering the opinion of the adolescent patient when planning the timing of transfer to adult care. Independence should be promoted using independence training programmes and ‘parent-free’ consultation in paediatric outpatient clinics. Adolescent patients and their families should have incremental exposure to the adult unit by providing 1) transition clinics at the paediatric centre, 2) informal visits to see the adult unit, 3) transition clinics at an adult centre. Complex care meetings with the multi-professional teams from both adult and paediatric services, together with the patient and their family, can help the smooth transition of the most complicated patients.

Adult units should ensure that the first outpatient appointment after transfer provides at least 30 minutes with the consultant, and consideration should be given to grouping adolescents and young people in outpatient clinics to focus resources and develop expertise. A support worker, able to operate in both the paediatric and adult setting, is essential to provide continuity throughout transition and to undertake the necessary annual assessment of transition progress.

A proportion of adolescent kidney patients have rare diseases that would have been fatal until quite recently. For many of these, clinical management in adulthood is uncharted and the knowledge of paediatric nephrologists has not transferred into adult medicine along with the patient. There is a pressing need for coordinated disease-specific follow up of such patients into adult life. This needs leadership from both paediatric nephrologists and adult renal physicians, supported by research and audit. The UK Renal Registry will be an essential tool for the seamless follow-through of patients into adult services, but to achieve this it will need to adapt to the special requirements of this patient group.

A proportion of adolescent survivors of kidney disease have physical, intellectual or psychological co-morbidity for which there is little provision in adult renal units. Practical ways of maintaining this support beyond paediatric care need to be found.

At present the lack of transitional support services for adolescents threatens to undermine much of the investment in care that takes place in childhood. The BAPN, supported by the RA and the RCPCH, regards the need for transitional provision as a priority that will need new resources allocated on the grounds of quality improvement.

4. Education and development of the workforce

The responsibility for education and training of medical undergraduates is the General Medical Council, enacted through Universities, while that for postgraduates is the Postgraduate Medical Education and Training Board (PMETB) which is advised by Royal Colleges, in this case the RCPCH, and enacted by the newly formed regional postgraduate schools of paediatrics, incorporating the postgraduate deaneries as part of the executive of the DH.

The BAPN has no formal role in postgraduate training, but works symbiotically with the RCPCH Specialist Advisory Committee that is largely made up of BAPN members and includes trainee representation.

Paediatric Nephrology demands very high standards from its consultant workforce. This is achieved by national recruitment and selection for higher professional training in the specialty (National Training Grid). A revised Paediatric Nephrology curriculum was accepted by the RCPCH and PMETB in 2006 and an appropriate assessment strategy is under development. A formal exit examination is under consideration and may be required in future consultant revalidation. Modular training programmes will be developed for paediatricians planning to provide specialist paediatric nephrology at secondary care level as consultants in DGHs.

Training currently takes place in the larger tertiary centres that offer 2 years of comprehensive experience including transplantation. Centres with a smaller caseload may offer 1 year of experience linked with larger UK or international centres to broaden the training experience. The BAPN supports the European training agreement that indicates the need for a minimum of 3 years of training in the specialty. UK trainees need to complete 2 years of clinical nephrology within a Grid post plus one additional year in a relevant activity, such as research, an allied sub-specialty or overseas experience.

The RCPCH is increasingly using competency as its framework for assessment. Paediatric Nephrology deals with rare disorders, and the BAPN through the CSAC has signalled the need for clinical experience to be safeguarded in training programmes. Experience is threatened further by European Working Time Directive 2009 and the increasing requirement for nephrology trainees to participate in the general paediatric out-of-hours service. The placement of trainees and duration of training therefore needs urgent review if competence leading to expertise is to be upheld. The BAPN favours rotation between centres and overseas placements to widen experience. The BAPN also sees advantages in paediatricians having exposure to adult renal medicine, a particular requirement for the development of transitional care of adolescents.

Tertiary nephrologists have traditionally held responsibilities for both teaching and research. The teaching and research environment has changed, as has the engagement of clinicians in NHS management. Paediatric nephrologists may therefore have a major commitment to teaching, research or management outside their service work, much of which presently goes unrecognised and un-resourced. There is a trend for Trusts to undervalue the importance of the 2.5 Supporting Programmed Activities (SPA) in England. This allocation of working time is essential for maintaining and developing up-to-date knowledge and skills, and participating in the national agenda of the specialty and the NHS as a whole.

Paediatric Nephrology has a strong academic tradition. Academic training in all branches of paediatrics is in crisis and only 5 tertiary nephrology centres have academic posts, three being personal chairs awarded to NHS consultants towards the end of their careers. Career structure is poorly developed and there has been a loss of senior academics in the specialty capable of supervising trainees. Academic trainees are therefore heavily dependent on research supervision from outside the specialty. The BAPN believes it is essential to reverse this trend and develop a coherent plan for academic Paediatric Nephrology in the UK.

5. Manpower, team structure and critical mass

This section mainly addresses comprehensive renal services. Much of the leadership, if not the day-to-day activity, of the whole service for children with kidney diseases comes from a regional level. The manpower and team structure has to address a modern agenda of bringing services as close as possible to families, offering choices where they exist. There is a much greater need for agreed care pathways and patient information, all of which has impact on tertiary unit manpower. In order to strengthen the professional relationship between nephrologists and general paediatricians, for example with shared local renal paediatric clinics, there is a need for manpower development both medical and in the multidisciplinary support services. PbR-determined income streams and the delay in getting an agreed national IT structure for the NHS impedes this integration.

In response to these issues the BAPN has increased its internal collaboration to develop care pathways and guidelines at a national level. It also has an agenda for matching these to patient information. This is a sizable task but will maximise the efficient use of manpower. No longer will each centre re-invent pathways in isolation. It will lead to a truly national service, based on national standards, providing the same high quality irrespective of a child's location.

In December 2007 the BAPN reviewed various options for providing safe and appropriate medical supervision of regional services, cognisant of the landscape outlined above. There was unanimous agreement that the appropriate model requires consultant Paediatric Nephrologists to be available for their service on a rota system to provide expertise 24 hours a day, every day. The EWTD has an impact on the number of consultants needed to deliver this care for two reasons. Firstly, its effect on training grades has dramatically reduced contact time within the specialty placing further clinical duties on consultants. Secondly it has a direct impact on consultant's working time. For full-time consultants delivering 7.5 PA DCC per week it has been calculated that it will require 6 WTE for most renal units. This number excludes academic staff. The calculation also applies whether or not a tertiary centre undertakes transplant surgery. It is also independent of any new ability of nursing staff to takeover tasks previously done by doctors.

The structure of the multidisciplinary team necessary to care for children with complex renal disease is well described in "*Review of Multi-Professional Paediatric Nephrology Services in the UK 2003*". However, an additional component of an adolescent support worker per region is now recognized as being necessary to take forward the agenda of adolescent transition.

6. Research, development and audit

Paediatric Nephrology is a relatively young sub-specialty that needs to advance care and knowledge for many complex disorders. It is clear from the history of the specialty that a research-orientated approach has guided clinical care (for example the International Study of Kidney Disease in Childhood that set standards for the investigation and treatment of children with glomerular diseases in the 1970s). However, the last decade has seen a worrying reduction in clinical research activity in this specialty, particularly in the UK. Research and development is a core activity, and without it the discipline cannot be sustained.

A requirement for comprehensive multi-centre research stems from the rarity of the disorders that fall within the therapeutic remit of paediatric nephrologists. The BAPN demands that the tertiary unit workforce is restructured to allow multi-centre clinical research conduct at the highest standard. This requires the appointment of research leads with dedicated sessions in each tertiary centre and the development of academic departments of nephrology in the larger centres. Trusts need to understand that this is essential now to safeguard the speciality in the future. Developing and delivering innovative therapies is predicated on research

In order to re-establish a strong position in clinical research, the BAPN has reorganised its structure from 2008. Firstly, it will use the facilities of the Medicines for Children Research Network (MCRN), with nephrology being a Clinical Study Group (CSG) supported by MCRN. All tertiary renal units will be represented through the CSG. Secondly, the BAPN has furthered its links with adult renal research in the UK and is represented on the newly formed UK Kidney Research Consortium, led by the Academic Vice President of the RA. In addition, it seeks a revitalised participation in the UK Renal Registry, not just for collection of data on patients followed into adulthood with End Stage Renal Failure, but for new initiatives for registries for rare diseases and epidemiology. Together these initiatives fit well within the new climate for translational research spelt out in the DH document “*Best Research for Best Health*”

It is also essential to further our research links with Europe and North America, to broaden the capacity for multi-centre research and to link to international registries which complement the work being done in the UK. There are a number of important developments for example in international biobanks, in which the UK centres should participate in order both to contribute to the critical mass of data and have access to bioinformatics data when required, for specific studies.

Research Career Structure and Training

Paediatric Nephrology by its specialist and technical nature attracts high calibre trainees, some of whom are capable of becoming academic leaders given the right research environment. Exposure to research is an integral component of training, but not all trainees have ready access to it. More opportunities, greater nurture and higher expectations are needed. Research exposure during training can take the form of any of the activities outlined above. For some it will lead to full-time out of programme research and completion of a higher degree. This requires competitive applications for research training funding by individuals and departments. It also requires a career structure for successful candidates. In the field of translational research this will only become a

reality once the research initiative outlined here has been shown to be successful, and NHS trusts or universities buy into it.
