

# Improving the standard of care of children with kidney disease through paediatric nephrology networks

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**Kidney Care**



**RCPCH**

Royal College of  
**Paediatrics and Child Health**

*Leading the way in Children's Health*

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Report of a working party of  
Royal College of Paediatrics and  
Child Health

British Association for Paediatric Nephrology

NHS Kidney Care

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## Executive summary

There are 13 tertiary centres for paediatric nephrology in the UK of which 10 provide renal transplantation services. The geographical area covered, the populations served and the number of hospitals from which the tertiary centre receives referrals varies and thus the model of services is necessarily different for each region. The care of children with renal disease is not confined to the tertiary centre and many children live long distances from their tertiary centre and have care delivered by local services. Currently provision of care is not always joined-up across traditional organisational boundaries. Although robust evidence is scarce, this fragmentation can result in a lack of quality in both equity of and access to care.

The focus of this document has been the patient; exploring how structured, formalised networks of care provision can provide a co-ordinated, high quality pathway of care, providing as much treatment as possible close to home whilst ensuring the best possible outcome for the child. The aim has been to provide guidance for those commissioning, providing and using paediatric nephrology networks.

This has been achieved by studying the current provision of care, researching examples of good practice both within paediatric nephrology and in other specialties, and drawing upon the expertise of the many organisations represented in the Working Group, including input from patient and carer representatives. The result is a set of principles and standards against which those commissioning, providing and using the services may evaluate their own services.

This work is closely aligned to 'Bringing Networks to life' a Royal College of Paediatrics and Child Health publication setting out the vision and strategy for high quality paediatric care within networks, and with which there are many principles in common. Standards have been taken from a wide range of national documents and are referenced.

Healthcare is forever being delivered in a changing political and social climate. Within this it is important that there is a planned approach and continuing drive to raise the quality of care for each individual patient. In his review of children's services in 2010 Professor Sir Ian Kennedy wrote *"In successful networks of care built around specialist children's hospitals, children will receive the best possible quality of care as close to where they live as possible. Without successful networks, children might receive inappropriate or poorer-quality treatment locally, or else may be required to travel long distances, receiving treatment in specialist centres that could just as easily take place in their local hospital."* Kidney disease in children is fortunately rare, but the consequences on individual families with children with kidney problems can be devastating. With appropriate co-ordinated networks of care these families, wherever they live, can be supported to manage the conditions to achieve the best quality of life.

This report has been developed by a working group of experts convened by the British Association for Paediatric Nephrology (BAPN) and the Royal College of Paediatrics and Child Health (RCPCH), which included representation from patients and carers. Details of the contributors are appended to this document.

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# Recommendations

## A. Principles for commissioning for paediatric networks

1. There are agreed commissioned pathways of care that reflect the principle of providing as much care and treatment as close as possible to the child's home, whilst ensuring the best possible outcome for the child (3.1.1)
2. Outreach clinics are conducted jointly throughout the network by the local consultant paediatrician and the tertiary specialist, with input from the multidisciplinary team (3.1.3)
3. A successful network is highly reliant on collaboration. There is adequate tertiary and local multi-professional team support with close liaison between all members of the multi-professional teams at the tertiary centre and local centres, with agreed shared care protocols of care and robust systems of communication and information sharing (3.1.4)
4. All networks have a nominated network lead who is responsible for ensuring that referral criteria and standards are agreed and that all the necessary protocols to support delivery of care are in place (3.1.5)
5. The population base for a network takes into consideration not only the critical mass for clinical effectiveness but also acceptable travelling times for those requiring frequent care at the tertiary centre (3.2.1)
6. If there are aspects of highly specialised care that cannot be provided by a network, linkage is established with a neighbouring network to enable such care to take place (3.2.2)
7. All networks have an effective patient transfer system both for emergencies and for routine aspects of patient care (3.3.2)
8. Patients and carers are involved at all stages in the development and evaluation of nephrology networks (3.5.1)
9. All children and young people with specialist conditions have access to information that enables them with their carers to make informed decisions and encourages partnership in decision making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life (3.5.2)
10. Commissioning arrangements ensure that entire paediatric nephrological pathways are commissioned. Pathways conform to the critical inter-dependencies framework having sufficient volume to be safe and configured in such a way that sustainability and cost effectiveness is assured. (4.1)
11. All members of the multi-disciplinary teams providing care for children in the network are appropriately trained to do so and have access to continuing professional development (5.1.1)
12. The network has a remit to provide training for all those within the network to gain and maintain clinical competences. Resources to deliver this are commissioned and protected (5.1.2).

13. Training and workforce planning for those becoming the local clinical lead within a network is identified and commissioned both through local commissioning arrangements and at a national level through training and workforce planning strategies (6.3.1)

## **B. Network provider standards: paediatric nephrology specific**

14. All Trusts providing children's services have a nominated consultant paediatrician who is the local clinical lead for paediatric nephrology services in that centre (3.1.2)
15. A paediatric transplant unit offers the full range of deceased and live donor transplants, including ABO incompatible transplantation, to all appropriate patients. There is a full multi-professional team with appropriate support services and robust transition processes in place. Each unit has at least two surgeons who have expertise particularly in the younger child (3.2.3)
16. Specialised nephrology advice on all aspects of medical and nursing care, and adequate capacity for transfer to the tertiary centre, is available 24/7 to support the network. Access to dieticians should be available daily. Medical discussion takes place at consultant to consultant level (3.3.1)
17. Larger centres which have other specialist children's services have a local paediatrician trained to support those services as well as to provide the local nephrology service, that is a paediatrician with a special interest in paediatric nephrology (6.2.1)
18. Each network has a named renal nurse responsible for managing training, on going development and communication (6.4.1)
19. Each of the specialists in the multi-professional team at the specialist centres liaises with their counterparts in the local areas to ensure continuity of provision of care along the entire patient pathway (6. 6.2)
20. Staffing levels of all paediatric nephrology units in the UK meet the recommendations of the Review of Multi-professional Paediatric Nephrology Services in the UK (2003) (6.6.1)

## **C. Network commissioner standards: paediatric nephrology specific**

21. The critical inter-dependencies of the different specialised children's services are recognised. Paediatric nephrology is co-located on the same site as specialised surgery, paediatric critical care and specialised anaesthetic services (3.4.1).
22. Paediatric nephrology and paediatric urology networks are where possible co-located with jointly agreed referral and management protocols (3.4.2)

23. Paediatric nephrology networks are co-located with relevant adult services such as transplantation, dialysis access surgery and interventional radiology and include preparation for transition and transfer to adult services (3.4.3).
24. Those commissioning and providing the paediatric radiology services consider the paediatric nephrology service need for procedures such as biopsies, nephrostomies, and insertion of both vascular and ureteric stents (3.4.4).
25. There is a renal IT system or equivalent that is capable of transferring appropriate data, wherever collected in the network, to the UK Renal Registry. That system is available in all centres to support day to day multidisciplinary clinical care including access to results for patients and families (3.6.1).
26. Paediatric nephrology networks are expected to participate in high quality research and audit and participate in the setup and sustainment of Disease Working Groups for optimal management of paediatric renal diseases (3.7.1)
27. Children with rare kidney disease requiring complex treatment are managed largely by the tertiary centre. Those with moderately rare kidney disease with a few requiring complex treatment may be managed almost entirely in secondary care using shared care protocols, with advice from the tertiary team and occasional care at the tertiary unit. Those with common conditions not requiring complex treatment may be managed entirely in secondary care with no referral to tertiary care (5.2.1)
28. Nephrology networks meet the quality requirements of the National Service Framework for Renal Services (5.3.1).
29. Paediatric nephrology networks meet the British Association for Paediatric Nephrology quality standards for the management of chronic kidney disease, Acute Kidney Injury, nephrotic syndrome, Henoch Schonlein nephritis, antenatally detected urinary tract disorders and hypertension (5.3.2a-e)
30. Paediatric nephrology networks follow NICE guidelines, with agreed local amendments as appropriate, for the diagnosis management and treatment of children with urinary tract infections. (5.3.3)



# **1. The case for change**

There are 13 tertiary centres for paediatric nephrology in the UK of which 10 provide renal transplantation services. The size of the regions, the populations served and the number of hospitals from which the tertiary centre receives referrals varies and thus the model of services is necessarily different for each region. The care of children with renal disease is not confined to the tertiary centre and many children live long distances from their tertiary centre and have care delivered by local services. Currently there is often fragmentation of, and a lack of expertise in, providing care which compromises patient safety and provision of a high quality service.

A working group was convened to address how establishing paediatric nephrology networks could address these issues. This document provides guidance for those commissioning, providing and using those networks.

## 2. What is a network?

A provider network has been defined as “linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner, unconstrained by existing professional and organisational boundaries to ensure equitable provision of high quality, clinically effective services.”<sup>1-3</sup>

Networks are increasingly seen as structures which will help NHS Trusts providing children’s services to rise to the challenges of high quality healthcare delivery in a resource limited system.<sup>4</sup> Furthermore in the complex world of public service commissioning, delivery and regulation, it is increasingly recognised that more formal network arrangements are required. These need explicit relationships and accountability rooted in governance structures in order to reduce risk and achieve safer services with better outcomes, particularly when working across resource limited multi-agency environments.

Reviews of other specialties have also endorsed the development of networks. A review of Paediatric Children’s Cardiology services<sup>5</sup> suggested that there should be “*clinical networks, with the tertiary centre taking the lead role, collaborating with other centres to establish the most logical and convenient network of outreach clinics, and helping with training and support to local paediatricians, so that they can play their full part in the care of patients.*” Service specification standards looking at children’s heart surgery centres<sup>6</sup> also focus on the network approach setting the standard “that there should be agreed pathways of care with local services that reflect the principle that as much care and treatment should be as close as possible to the child’s home, whilst ensuring the best possible outcome for the child”

Recommendations have also been made that the most effective way to provide children’s general paediatric surgical services<sup>7</sup> is through managed clinical networks of care which the Royal College of Surgeons defines as “*an interconnected system of service providers which allows collaborative working and the development of standards of care and routes of communication.*” They emphasise that networks are vital in underpinning the delivery of safe systems locally by defining where services will be provided, supporting a whole team approach and optimising multi-directional flow of services within the network.

Progress with the development of networks varies across the United Kingdom. In Scotland the concept of Managed Clinical Networks was first established in 1998 and set out a number of core principles for these networks<sup>1</sup>. It was recognised that the strength of these networks lay in the promotion of consistency and quality of service even though the structures may vary to suit local circumstances. In Wales the Welsh Assembly Government established a project in 2008<sup>2</sup> to take forward delivery of specialised healthcare services for children and young people through effective managed clinical network models. This established service specific standards.

In his review of children’s services in 2010<sup>8</sup> Professor Sir Ian Kennedy wrote “*In successful networks of care built around specialist children’s hospitals, children will receive the best possible quality of care as close to where they live as possible. Without successful networks, children might receive inappropriate or poorer-quality treatment locally, or else may be required to travel long distances, receiving treatment in specialist centres that could just as easily take place in their local hospital.*” The purpose of this document is to provide a basis for service commissioners and providers to plan and deliver effective services.

### 3. Current Structures for delivery of care

Current structures are based on the relationships between tertiary centres and other NHS trusts providing children's services within a geographically defined area. A British Association for Paediatric Nephrology (BAPN) survey undertaken in 2009 of tertiary centres and general paediatricians identified that the 13 tertiary centres currently receive patients from over 200 paediatric departments. Each centre will relate to between 7-20 hospitals.

Outreach clinics conducted jointly by the tertiary specialist and the local paediatrician have been recommended<sup>5</sup> for paediatric cardiology services in a way that not only provides expert care nearer to home but also provides a key educational value. Patients seen jointly allows two way exchange of clinical information and mutual learning leading to a rise in the quality of care, meeting one of the Scottish Executive Core principles for Networks<sup>1</sup> that the educational and training principles for networks should be used to the full.

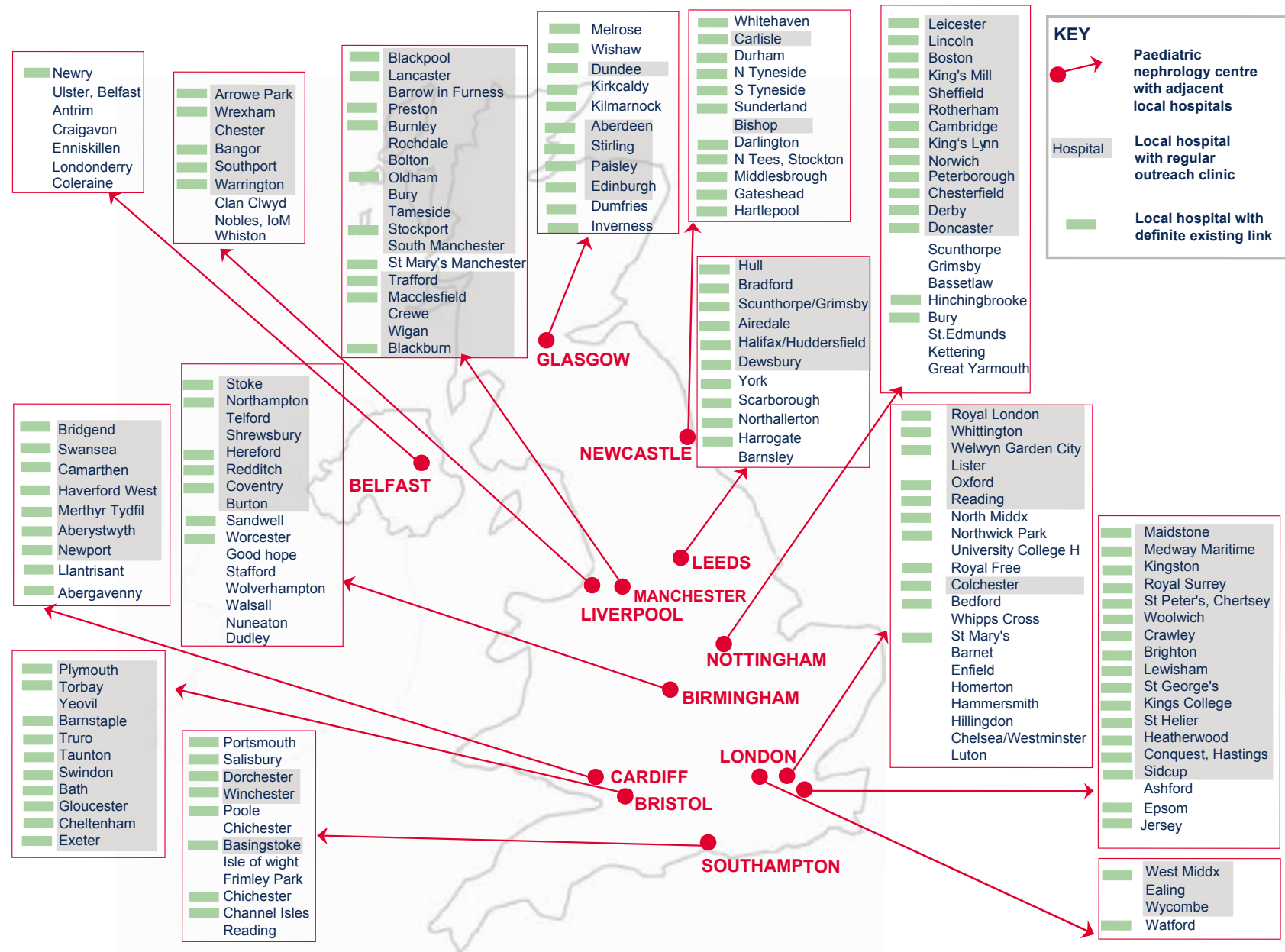
Many tertiary paediatric nephrology centres do have a system of outreach clinics but the quality of service and the degree of involvement of local paediatricians and allied healthcare professional varies greatly. It was reported that outreach clinics are undertaken in approximately 83% of the Trusts providing children's services. Some tertiary centres hold clinics in all hospitals in their locality, while others don't hold clinics in any of their hospitals.

Approximately 60% of centres have identified a clinical lead for paediatric nephrology and 22%, although having no clinical lead, do have outreach clinics. However approximately 18% of centres have no formal links with their tertiary centre having neither a local lead nor any outreach service. This is illustrated in figure 1.

To support the principle of care as close to home as possible the Specialised Services National Definition set<sup>9</sup> has recommended that each local hospital within the clinical network should have at least one general paediatrician with a special interest in nephrology who takes a lead for the service locally and participates in the joint clinics.

Figure 1 Current relationships of those delivering paediatric nephrology care

PAEDIATRIC NEPHROLOGY NETWORKS (2009)



Improving the care of children with kidney disease

## 3.1 Overall structure

Individual kidney diseases are rare so there will be insufficient experience for all those providing care for children to gain and maintain expertise. Whilst much of the expertise will necessarily be concentrated in the tertiary hospital it is essential that structures are put in place to support care close to home whilst providing the highest overall standard of care for the child.

Specialised renal services<sup>9</sup> can be delivered in a number of ways:

- care within a specialist paediatric renal unit (both in-patient and out-patient)
- expert advice from a paediatric nephrologist to other paediatric specialists within a referral centre - e.g. paediatric intensive care, oncology, endocrinology, cardiology
- outreach clinics held with the general paediatrician in the local hospital
- expert advice from other multidisciplinary nephrology team members to other healthcare staff working in peripheral hospitals or within the community.
- expert advice from other multidisciplinary team members to other healthcare providers
- multi-disciplinary team visits to the patient's home and school to provide training and support to the child, family and other carers

### 3.1.1 Recommendation

There are agreed commissioned pathways of care that reflect the principle of providing as much care and treatment as close as possible to the child's home, whilst ensuring the best possible outcome for the child

The geography and local resources need to be taken into consideration when deciding upon the structures to deliver these services. A few Trusts providing children's services may be in the same city as, or a very short journey away from, the tertiary centre, and so the most appropriate use of resources may be for all nephrology care to be delivered from the tertiary centre. However children with renal disease often present to their local hospital with non-renal conditions and advice may be needed on how to manage their care. It is therefore important that all Trusts providing children's services should have defined links to the tertiary centre for support and advice and that a nominated consultant paediatrician provides a lead for that link.

### 3.1.2 Recommendation

All Trusts providing children's services should have a nominated consultant paediatrician who is the local clinical lead for paediatric nephrology services in that centre

To avoid fragmentation and to promote integration of care the nominated clinical lead should jointly conduct the outreach clinics with the tertiary nephrologist. This model of joint working in a clinic setting is a visible and tangible structure that shows to the patient and family that there is a good collaborative relationship between colleagues, which in turn builds trust for the family and results in higher patient and family satisfaction. The frequency of these clinics will depend on the clinical demand, which will be dependent not

just on numbers of patients but also other important factors such as case mix and social deprivation. If a Trust is in the same city or a short travelling time from the tertiary centre and has a low clinical demand, patients may be seen exclusively at the tertiary centre for their paediatric nephrology care. However in these circumstances there remains a need for close, collaborative working relationships between teams at both centres as there may be other aspects of the child's care that are undertaken by the local hospital.

### **3.1.3 Recommendation**

Outreach clinics are conducted jointly throughout the network by the local consultant paediatrician and the tertiary specialist, with input from the multidisciplinary team

It is also important to consider the skill set and roles of all members of the multi-professional team. As with medical staff the rarity of renal disease in children means that other professionals in local hospitals are likely to have limited or no expertise in caring for the specialised needs of children with renal problems. It is therefore important for all members of the local team to be provided with support so that as much care as possible can be delivered locally. To facilitate this, as with medical staff liaison, it would be helpful to have an identified paediatric nurse in each local centre to liaise with the paediatric renal nurses in the tertiary centre. Children's community nurses play a crucial role in supporting services and yet provision of children's community nurses is inconsistent and often difficult to identify. It would be helpful to have a directory of children's community nurses available in each area with indications of their roles and responsibilities to facilitate referral to the most appropriate individuals. The development of shared protocols will enable local community nurses to provide aspects of care such as dressing, flushing and administration of medications through vascular lines even though the specialised dialysis support will need to be provided by the nephrology nurses from the tertiary centre.

Many children with renal disease require complex dietary advice and/or specialist renal feeds but secondary care paediatric dieticians are unlikely to have the required experience or knowledge to give this advice, or construct complex feed recipes. Close liaison between the paediatric renal dietician at the tertiary centre and the local dietician will facilitate local delivery of care. Adequate staffing and training is necessary and will be further discussed.

With all these arrangements there must be robust systems of communication and information sharing.

An implementation plan for national delivery of paediatric nephro-urology services in Scotland<sup>10</sup> recognised that whilst networks are capable of delivering high quality tertiary care supporting local clinical management where appropriate, there is a risk that due to lack of local multidisciplinary team workforce those patients with more complex problems will be increasingly reliant on their health care needs being delivered only in the tertiary centres with the result that local hospital and community teams will become increasingly de-skilled. Therefore support and development of the local teams is essential to ensure provision of high quality appropriate care

### **3.1.4 Recommendation**

A successful network is highly reliant on collaboration. There is adequate tertiary and local multi-professional team support with close liaison between all members of the multi-professional teams at the tertiary centre and local centres, with agreed shared care protocols of care and robust systems of communication and information sharing.

Within a defined structure for delivery of services appropriate for the local circumstances, there needs to be clarity about its management arrangements. Clinical governance may be defined as a systematic approach to maintaining and improving the quality of patient care within a health system. It embodies three key attributes: recognisably high standards of care, transparent responsibility and accountability for those standards, and a constant dynamic of improvement. All those participating in the networks should adhere to the principles of clinical governance, agree on the standards to be met and have protocols that define clear lines of responsibility and accountability. Essential to this is that all those delivering these services should have the skills and resources to do so.

The Scottish Executive<sup>11</sup> has recommended that this is addressed through having a nominated network lead from the tertiary centre to manage the service and to be responsible for ensuring that referral criteria and quality standards are agreed and that all the necessary protocols to support delivery of care are in place. The network lead must have authority and be accountable and appropriately resourced.

### **3.1.5 Recommendation**

All networks have a nominated network lead who is responsible for ensuring that referral criteria and standards are agreed and that all the necessary protocols to support delivery of care are in place

## **3.2 Population bases**

Guidelines on the provision of specialised services emphasize the importance of taking into account the optimum population not only for the stability of contracted referrals but also to give sufficient critical mass for clinical effectiveness. This has to be balanced against patients having unjustifiable travelling time in less densely populated areas. Appendix 1 which gives the prevalence of some of the renal conditions illustrates the challenge this provides for the provision of renal services. As with other paediatric specialties, although individual renal diseases are rare, collectively there is a significant cohort who may present to the average paediatric department. If the experience were to be shared amongst all the paediatricians in that department then it is unlikely that they could all gain and maintain the necessary expertise. The identification of a nominated paediatrician who is the clinical lead for nephrology will allow that development and maintenance of expertise to manage these patients.

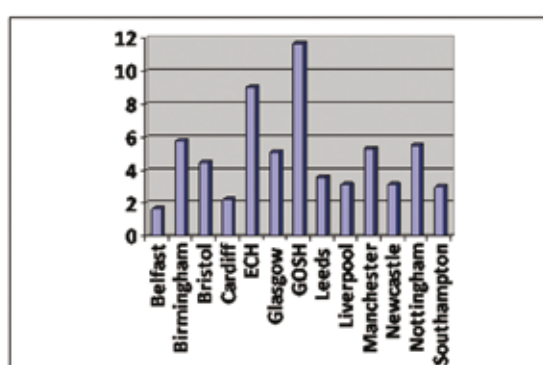


A report published in 1995<sup>12</sup> suggested that the minimum population base for a tertiary unit is 3 million with a population of 4-5 million being closer to the ideal. This consideration led to the current designation of 13 tertiary units.

The current populations served by the tertiary units is illustrated in Figure 2. The total population is greater than that of the UK as there are some areas that refer to more than one unit.

The provision of dialysis requires specialist nursing staff and is one of the key drivers for the centralisation of tertiary paediatric renal services. Families with children living a long way from the tertiary centre usually opt for peritoneal dialysis but this is not always technically possible. In view of the expertise required for dialysing often very small children dialysis in an adult unit is not possible.

**Figure 2 Total population in millions served by current tertiary units**



Therefore all populations require outpatient paediatric haemodialysis facilities within a reasonable distance from the patients' homes. In practice in some geographically larger regions, for example South West England, patients travel 350 miles round trip 2-3 times per week for haemodialysis. This is not ideal but provision of additional units would reduce the critical mass and thus threaten the maintenance of clinical competence and risk safe delivery of care.

### 3.2.1 Recommendation

The population base for a network takes into consideration not only the critical mass for clinical effectiveness but also acceptable travelling times for those requiring frequent care at the tertiary centre

Three of the smaller units (Liverpool, Southampton, Cardiff) whose populations are insufficient to support a transplant service do not provide transplantation but link to another tertiary unit for transplantation. This requires detailed transplant pathway planning to ensure that there are no aspects of care that are unnecessarily duplicated or omitted.

There may be other aspects of highly specialised care that cannot be provided by all of the networks. Consideration may need to be given in some circumstances that whilst the network may provide all specialised renal services there may be some supra-specialised care that is provided by only some of the networks and that strong linkages between those networks would need to be established to enable such care to take place.



### 3.2.2 Recommendation

If there are aspects of highly specialised care that cannot be provided by a network, linkage is established with a neighbouring network to enable such care to take place

Recommendations for the provision of renal transplant services, of which paediatric transplantation is a part, are summarised in a recent document produced by the British Transplantation Society<sup>13</sup>. This does not deal with paediatric transplantation specifically, but much of it is of direct relevance. A paediatric transplant unit should offer the full range of deceased and live donor transplants, including ABO incompatible transplantation, to all appropriate patients. There should be a full multi-professional team with appropriate support services and robust transition processes in place. There is no published data on what volume of transplants performed by a unit is required to maintain expertise amongst the entire professional team although numbers of at least 12-15 per year would be expected. It is important to ensure outcomes in terms of surgical morbidity and 1 and 5 year graft survival are consistent with national data.

Likewise there is no published data on the number of transplants that a single surgeon is required to do to maintain competence. However current accepted practice is that UK units should be performing at least 50 transplants per year to give sufficient expertise across the surgical team. It is recognised that the surgical aspects of paediatric transplantation are different when transplanting to children under 5 years of age and each unit should have at least two surgeons who have expertise particularly in the younger child.

### 3.2.3 Recommendation

A paediatric transplant unit offers the full range of deceased and live donor transplants, including ABO incompatible transplantation, to all appropriate patients. There is a full multi-professional team with appropriate support services and robust transition processes in place. Each unit has at least two surgeons who have expertise particularly in the younger child.

## 3.3 Access to service

Access to all children's services should be equitable. This means access both to facilities and expertise which require services to be linked across geographical, political and NHS boundaries. One of the key considerations for paediatric nephrology services is availability of urgent care and advice, especially outside normal working hours. If a single lead paediatrician in each children's department is responsible for the local service, providing day to day advice to colleagues on the management of children with renal disease, arrangements must be in place to ensure this high quality care continues when that individual is not available. This is a strength of a network in that this advice can be obtained from the specialist centre. Agreed shared network protocols should be available for others to consult and 24/7 advice should be available through the tertiary centre.

### 3.3.1 Recommendation

Specialised nephrology advice on all aspects of medical and nursing care, and adequate capacity for transfer to the tertiary centre, is available 24/7 to support the network. Access to dieticians should be available daily. Medical discussion takes place at consultant to consultant level

Crucial to any network is an effective patient transfer system both for emergencies and routine aspects of patient care. It is unacceptable for patients to be unable to access services in the appropriate location because of the unavailability of suitable transport.

### 3.3.2 Recommendation

All networks have an effective patient transfer system both for emergencies and for routine aspects of patient care.

## 3.4 Inter-relationships with other services

The document “Commissioning Safe and Sustainable Specialised Paediatric Services”<sup>14</sup> recognised the critical inter-dependence of specialised children’s services and there is an emerging view among clinicians, commissioners and parents that the current trajectory for these services is neither safe nor sustainable. This work set out to define the relationships between services and how these will govern any process of change, i.e. which services need to have other services immediately available in order to function safely and which, whilst clinically related, require less urgent contact. It defined three categories;

- red where co-location on the same site was mandatory. For paediatric nephrology this was limited to specialised surgery, paediatric critical care and specialised anaesthetic services.
- amber where there is an identified relationship under some circumstances. For paediatric nephrology the most important was urology where it was recognised that if the services were not co-located, the medical specialty would not be able to provide a full specialised service.
- green where co-location was not necessary.(see figure 3)

### 3.4.1 Recommendation

The critical inter-dependencies of the different specialised children’s services are recognised. Paediatric nephrology is co-located on the same site as specialised surgery, paediatric critical care and specialised anaesthetic services.

Many children with severe renal disease have this as a result of complex urological problems and therefore the availability of joint care is extremely important. Most paediatric urology centres already have tertiary nephrology support and vice versa but those that do not should have particularly clear and supportive networks with the expectation that severe renal impairment may require transfer to a co-located centre. In addition many children with less complex problems may be managed by either urology or nephrology. It is therefore crucial that the two services work closely together establishing joint protocols for referral and management. Paediatric urology and paediatric nephrology share the need for some resources such as radiological imaging and urodynamic services and like paediatric nephrology, paediatric urology is also a high cost low volume specialty. For all these reasons co-location of paediatric nephrology and urology networks should be encouraged. There are more paediatric urology centres than paediatric nephrology centres and therefore inevitably this will not always be possible. However all those urology centres not co-located with a paediatric nephrology centre should be linked to a nearby paediatric nephrology centre.

### 3.4.2 Recommendation

Paediatric nephrology and paediatric urology networks are where possible co-located with jointly agreed referral and management protocols

“Commissioning Safe and Sustainable Specialised Paediatric services<sup>14</sup>” considered only linkages to specialised paediatric services and did not consider issues such as transplantation and dialysis access that is often provided by surgeons based in adult units. Adolescents and young people with renal disease are a vulnerable group of patients and closely co-ordinated work between paediatric and adult renal teams is essential. A joint report by the Renal Association and the BAPN<sup>15</sup> details a number of recommendations to ensure safe transition and transfer of young people to adult services. This report focused on young people with end stage renal disease and although the principles cover young people with a broad spectrum of complex renal disease there is no national model for transfer of care of those with general nephrology problems and rare diseases. There are many more adult renal units than paediatric renal units and therefore each paediatric nephrology network may relate to several adult nephrology networks. This complex inter-relationship needs to be taken into consideration when planning transition services and adequate support needs to be in place once the patient has been transferred. Currently NHS Kidney Care is currently undertaking a national project in which five pilot sites are looking at the support needed for adolescents and young adults with kidney disease, in order to identify good practice and key features that should be incorporated into future commissioning.

Figure 3 Service inter-dependency matrix of specialised children’s services

Specialised Paediatric Services  
Commissioning Safe and Sustainable Services

Specialised Paediatric Service	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U		W
	BMT	Haemo Clin	Immun	Met med	Onc	Burns	Infect dis	Resp med	Cardio	Card surg	Neuro	Neuro surg	Major Traum	Spec Ortho & Spinal	Neph	Uro	Endo	Gastro	ENT - Airway	Neonatology	Spec Paed surg	Paed critical care	Spec Paed anaesth
1 Blood and marrow transplantation					3		2	3	1		1				3			2			3		1
2 Haematology (non malignant)			1						1														1
3 Immunological disorder	2	1					3	2							1			3			1		1
4 Metabolic medicine		2						1	2		2				1								1
5 Oncology (inc Haemato-oncology)	1						1	3	1	1	3	3*	1	1	3	2	1	2	1				
6 Burns											1		3		1								
7 Infectious diseases			2					1	1		1							1					1
8 Respiratory medicine			1				2		3		1						1	3	3		3*		1
9 Cardiology								1		3*	1										1		1
10 Cardiothoracic surgery		1						2			2				1				2	1	3		
11 Neurology		1	1	2			1	2	1			3*		1	1		1	1	2		1		1
12 Neurosurgery					3								3*	2	1	1	2		2	1	2		
13 Major trauma (inc maxfax and plastics)		1							2	2	1			1	1	2							
14 Spec Ortho & Spinal surgery					1			2	1		2	1				1					1	3	
15 Nephrology		2	2	1	1		1	2	3		2			2		3*	2	2	2	3			
16 Urology					2										3*		2				3		1
17 Endocrinology											1												1
18 Gastroenterology			2	1			2														3		1
19 ENT (Airway)								3	2	2	1		1								2		
20 Neonatology									2												3		1
21 Specialised paediatric surgery		3			1			3	1	1	2	3	1	3		3	3	3	1	3			
22 Paediatric critical care		3	1	2			1	3	3		2	3	2		2	1		1					
23 Specialised paed anaesthesia		1						1	1								1		1	1	1		

### 3.4.3 Recommendation

Paediatric nephrology networks are co-located with relevant adult services such as transplantation, dialysis access surgery and interventional radiology and include preparation for transition and transfer to adult services

“Commissioning Safe and Sustainable Specialist Paediatric services” also did not consider radiology services.<sup>14</sup> On rare occasions children with complex kidney disease may require the services of other specialists for example interventional radiologists. The most appropriate delivery of these services will vary for each organisation depending on the volume of cases and availability of skills and facilities.<sup>16</sup> It is crucial that those commissioning and providing the paediatric radiology services at a regional level take into consideration the paediatric nephrology service need for procedures such as biopsies, nephrostomies, and insertion of both vascular and ureteric stents.

### 3.4.4 Recommendation

Those commissioning and providing the paediatric radiology services consider the paediatric nephrology service need for procedures such as biopsies, nephrostomies, and insertion of both vascular and ureteric stents

## 3.5 Patient and Carer involvement

Patients and carers should be involved at all stages in the development and evaluation of nephrology networks. Issues of concern may vary between networks for example transport may be of a greater issue in networks covering large geographical areas or in more rural areas. It is important in planning the networks to determine the key priorities of those using the service. Evaluation through consultation with patients and carers will allow audit of whether standards set have been met.

Whilst there are good examples of toolkits to allow commissioners and providers to evaluate quality criteria on generic standards for health services for young people, for example the “You’re Welcome”<sup>37</sup> quality criteria, there are currently few evaluation instruments that have been developed to look specifically at the care of children with kidney disease. The British Association for Paediatric Nephrology (BAPN) has developed a series of questionnaires to evaluate the experience of children and their families of the care of children on haemodialysis, peritoneal dialysis and with kidney transplants. These are available on the BAPN website.<sup>40</sup> Although these patient reported experience measures (PREMS) can provide a useful indication of patients’ and their carers’ perspectives on their care, by their nature these reflect experience of process rather than outcome.

The need for better measurement of health improvement and for information to come from patients themselves has led to an increased interest in patient reported outcome measures (PROMS). A number of research studies have used generic quality of life instruments looking at outcomes of children on renal replacement therapy but no

condition specific instruments, which generally perform better than generic instruments, have yet been developed for children with kidney disease. This is clearly an area for development in the future and instruments do need to be developed to measure patients' evaluation of their treatment outcomes.

### **3.5.1 Recommendation**

Patients and carers are involved at all stages in the development and evaluation of nephrology networks

Children with complex problems often necessarily require treatment across centres. This can be very confusing for families to understand who is responsible for which aspects of a child's care. The structure of the network must be clear to the patients and carers so that it is explicit how a child's care is to be delivered across the network. It should be clear which aspects of a child's care can be delivered locally and what criteria are used for referral to and from different parts of the network.

Access to information is important not only on the structure of the service delivering care but also at the level of the individual care plan for the child which is written and delivered in an age appropriate manner. Parents and carers should be encouraged to take an active part in that planning. Structures such as Renal PatientView (RPV), an electronic information system, which enables families to view the important aspects of a child's care such as results of blood tests and lists of medications, are very helpful in facilitating partnership in patient care. Recent modifications of RPV funded by NHS Kidney Care are being piloted which allow patients and carers to input home monitored information into this system such as weight and blood pressure; this will further encourage involvement by patients, parents and carers.

### **3.5.2 Recommendation**

All children and young people with specialist conditions have access to information that enables them with their carers to make informed decisions and encourages partnership in decision making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life<sup>17</sup>

## **3.6 Information technology**

Facilities to share clinical information are essential to the functioning of any network and for patient safety at all points along the care pathway. There are aspects of care of children with renal disease that make this particularly crucial.

Monitoring of children with renal disease is highly reliant on regular surveillance of biochemical parameters and key clinical information such as weight and blood pressure. It is essential that the results of the investigations and monitoring are readily available at all points of the network as clinical management plans often need to be made on the

basis of these. Sometimes these need to be made on an urgent (same day) basis so rapid transfer of information is important.

Prescribing in children with renal disease is particularly complex not only because of the wide range of medication used outside normal paediatric practice, but also because drug doses often have to be modified in renal disease. Therefore having a single centrally available electronic list of current medications is invaluable in preventing drug errors. Facilities for reciprocal sharing of clinical information, in particular laboratory data, medications and key clinical information, ideally electronically, are essential.

There is a mandatory requirement for all adult and tertiary paediatric renal units to submit electronic returns to the UK Renal Registry on all patients on renal replacement therapy. A renal IT system or equivalent that is capable of transferring the appropriate data is essential across the network. Access to the electronic renal record should be available in the local hospital setting so that data collected outside the tertiary centres can be included. This will facilitate monitoring of the outcomes of clinical care across the network and once established the system could be used to monitor and provide care for all children with kidney disease.

The provision of a renal IT system also allows patients and their families access to Renal PatientView. This enables patients and families electronic access to their blood test results, medication lists, clinical letters and information about renal conditions.

Many aspects of paediatric nephrology care, particularly those shared with urologists, rely upon radiological investigations. The introduction of electronic radiological systems in many areas allows a patient's radiological images to be viewed at all points of the network. This has transformed the quality of care.

### **3.6.1 Recommendation**

There is a renal IT system or equivalent that is capable of transferring appropriate data, wherever collected in the network, to the UK Renal Registry. That system is available in all centres to support day to day multidisciplinary clinical care including access to results for patients and families.

There is huge potential for telemedicine to enhance further patient care across networks. Consultations with families could occur using these facilities, reducing travelling times and costs and facilitating effective and efficient communication.

## **3.7 Research and audit**

Renal disease in children is rare and therefore meaningful research can only be carried out through co-operation in multi-centre trials. The National Institute for Health Research (NIHR) Medicines for Children Research Network (MCRN) has been created to improve the co-ordination, speed and quality of randomised controlled trials and other well designed studies of medicines for children and adolescents, including those for prevention, diagnosis and treatment. Within this, a paediatric nephrology clinical studies group has been created which plans and co-ordinates research for children with renal disease, not only on the use of medications, but also for a wide range of studies, recommending those to be adopted by MCRN. Studies adopted by MRCN are high quality studies and all those in paediatric nephrology networks should participate in those studies.

In addition the UK renal community caring for both adults and children with renal disease has published a strategy document<sup>18</sup> that brings together clinical care pathways, diagnostic services, research and audit. Central to each level of activity is the participation of patients and their families and the strategy maps onto the evolving national plan for rare diseases. If it is shown to be successful it will have generic utility beyond renal medicine. Implementation of the strategy will involve the development of Disease Specific Working Groups that will develop proposals for seamless integration of diagnostic and treatment services and patient information. These groups will undertake audit and research to improve the effectiveness of care pathways. A comprehensive UK Registry for rare kidney diseases (eponym Renal RaDaR) is being developed, with Medical Research Council and Kidney Research UK funding to support this work.

### **3.7.1 Recommendation**

Paediatric nephrology networks are expected to participate in high quality research and audit and participate in the setup and sustainment of Disease Working Groups for optimal management of paediatric renal diseases



## 4. Commissioning

Paediatric nephrology is a high cost, low volume specialty and is defined for England in Specialised Services National Definitions Set 23 section 19 Specialised Services for Children<sup>1</sup>. The document recognises the different ways in which paediatric nephrology services may be delivered and gives some guidance on conditions that need to be managed by a specialised paediatric nephrology centre and those that can be managed by a local hospital with shared care arrangements. It also details existing currencies, ICD diagnostic codes and OPCS intervention codes but acknowledges the limitations of these as they do not identify severity and hence are often of little use in identifying what is managed in a specialist paediatric nephrology centre and what is not. It also recognises those activities that are excluded from current Payment by Results tariffs and that therefore require locally negotiated tariffs. In the next year with the move towards new national commissioning arrangements in the NHS in England, the arrangements for the current definition sets will be reviewed.

As previously highlighted, “Commissioning Safe and Sustainable Specialised Paediatric Services”<sup>14</sup> sets out the relationships between the paediatric nephrology service and other paediatric services in terms of the proximity or essential co-location of specific services necessary to provide a safe service. These co-locations, and links to other services already mentioned such as adult renal and radiology services, need to be considered when commissioning paediatric nephrology networks.

Many nephrological conditions are managed by shared care arrangements between the specialist renal centre and the local hospital. Paediatric patients’ nephrological pathways can be complex. Mapping existing provision can inform the development of a strategic vision for future commissioning.

Commissioning is also occurring in an ever changing political environment. Within England the Health and Social Care Bill which builds on the White Paper ‘Equity and Excellence Liberating the NHS’<sup>19</sup> and associated documents set out a new vision of clinician led care, focusing on patient choice. Clinicians, led by GPs will commission the majority of healthcare for the local population, based on a market led system monitored through delivery of defined outcomes. The National Commissioning Board will be responsible for commissioning services within all the national definition sets. It is anticipated that commissioning of children’s specialist services such as paediatric nephrology services will be conducted by the national NHS Commissioning Board but the details of the arrangements have not yet been revealed. Commissioning whole pathways to improve patient experience will be challenging. The National Commissioning Board will work closely with clinical commissioning groups to commission a national pathway with defined shared care arrangements within the network. Collaborative processes between clinicians and commissioners are essential to meet the child’s best interests.

Different arrangements are in place in the devolved nations. Regardless of the political structure commissioning arrangements must ensure that pathways are safe and sustainable, having sufficient volume to be safe and configured in such a way that sustainability and cost effectiveness is assured.

## **4.1 Recommendation**

Commissioning arrangements ensure that entire paediatric nephrological pathways are commissioned. Pathways conform to the critical inter-dependencies framework having sufficient volume to be safe and configured in such a way that sustainability and cost effectiveness is assured.

## 5. Quality assurance standards

### 5.1 Clinical competences

It is essential that all those providing care for children with renal disease are appropriately trained. All those training to be a consultant paediatric nephrologist must successfully complete the Framework for Competences for Paediatric Nephrology<sup>20</sup> and be recognised on the specialist register as having that expertise. In 2009 the Royal College of Paediatrics and Child Health (RCPCH) introduced a special study module<sup>21</sup> in paediatric nephrology. Completion of this module would equip a general paediatrician to provide the nephrology lead within a secondary care setting. Meeting the shortfall of 40% of centres without a local lead by relying on trainees following these modules is likely to take some time. However this curriculum is also a resource for those currently providing services, and those newly taking up the lead for paediatric nephrology services, to review their skills and identify where further training and support may be required.

Although there is currently not a similar national training package for nurses a new foundation in paediatric nephrology course for nurses is to be launched shortly.

Play specialist support in the care of children with kidney disease is invaluable both in providing age appropriate preparation for treatment but also in providing support for practical procedures with, for example, distraction techniques for those with needle phobias. Training packages again would support local play specialists to become involved in this support.

Dieticians leading at the larger networked regions should be working at an Advanced Specialist level (Agenda For Change Band 7/8a) and possess a high level of service management and organisational skills. There is a strong need to develop dietetic education programmes for paediatric renal disease within the network. The only current recognised renal paediatric training comprises 3 lectures and 2 workshops within a module in the MSc in Paediatric Dietetics It is not mandatory for dieticians to attend these courses, though person specifications could be written with attendance at this module essential, rather than a desirable requisite for dieticians working at an advanced specialist grade. Many dieticians working outside a specialist centre will not have the advantage of working alongside dietetic colleagues with extensive experience and their posts may be banded at AFC band 6 only. Advanced specialist training may not be felt to be necessary by employers in secondary care. It is likely these dieticians will not have the knowledge, skills and expertise to share the care of children with more complex chronic kidney disease. The lead nephrology dietician in the network should therefore be adequately resourced to offer training to dieticians in their region and it should be recognised that outreach clinics in the locality, with the lead dietician in attendance, can provide a useful platform for training and checking clinical competencies. A formal competency checklist needs to be developed along with a way of reviewing that these skills are kept up to date.

### **5.1.1 Recommendation**

All members of the multi-disciplinary teams providing care for children in the network are appropriately trained to do so and have access to continuing professional development

The network itself can serve a training function; a major role for all clinicians working in the tertiary centre should be to provide education for those working in other parts of the network through personal contact, provision of written materials, and development of electronic learning tools.

### **5.1.2 Recommendation**

The network has a remit to provide training for all those within the network to gain and maintain clinical competences. Resources to deliver this are commissioned and protected.

## **5.2 Disease specific referral criteria**

Individual kidney diseases are rare but collectively there is a significant cohort of children with renal disease who do require expert care. There is a large variation in the incidence and prevalence in different kidney diseases as well as the level of expertise that is required to manage those conditions. It is therefore necessary to consider disease specific pathways of care and although all will adhere to the principle of care close to home, inevitably some conditions will require greater tertiary centre involvement than others.

One of the key elements of the Renal Rare Disease strategy<sup>18</sup> will be the development of disease specific care pathways. These will take into consideration the age of presentation, the nature and range of clinical manifestations, the diagnostic process, the logistics and constituents of treatment, co-morbidities, psychosocial issues and end of life care. They will also address the necessary balance between convenience of care closer to home and the need for highly specialised services that can only be provided in a few centres. Care pathways will be linked to specific, high quality information both for patients and clinicians.

It is beyond the scope of this document to define pathways of care for each and every clinical condition. However based on the incidence, prevalence and the complexity of management it is possible to group renal diseases into several categories as follows (and as outlined in the Specialised Services Definition Set.<sup>9</sup>)

Rare and requiring complex treatment: eg Chronic kidney disease, (CKD) stage 3-5 or CKD with declining function, Acute Kidney Injury with oligoanuria or severe metabolic disturbances. All children in this group are likely to be largely managed by the tertiary nephrology team.

Moderately rare with a few requiring complex treatment: this group consists of a wide range of renal conditions without renal failure such as the glomerulopathies (eg nephrotic

syndrome, Henoch Schonlein nephritis), tubulopathies and multi-system diseases with renal involvement and complex hypertension. This group would represent the largest group for whom care is shared between secondary and tertiary centres. Those with uncomplicated problems could be managed entirely in secondary care with the use of agreed shared protocols but those with more complex conditions are likely to require the advice of the tertiary team and occasional care at the tertiary unit.

Common, not requiring complex treatment: e.g. antenatal hydronephrosis and structural abnormalities of the renal tract. The majority of these patients will be suitable for management in secondary care with no referral to tertiary nephrology. A small proportion will also require input from paediatric urology services.

Very common, not requiring complex treatment e.g. urinary tract infection: Many of these children will be managed by primary care with agreed shared care protocols between primary and secondary care.

A table of the relative incidence and prevalence of these conditions is summarised in Appendix 1.

In addition antenatal counselling by a paediatric nephrologist needs to be available for those couples where it is anticipated the foetus may have significant renal impairment.

### **5.2.1 Recommendation**

Children with rare kidney disease requiring complex treatment are managed largely by the tertiary centre. Those with moderately rare kidney disease with a few requiring complex treatment may be managed almost entirely in secondary care using shared care protocols, with advice from the tertiary team and occasional care at the tertiary unit. Those with common conditions not requiring complex treatment may be managed entirely in secondary care with no referral to tertiary care.

Using these categories we have been able to derive suggested disease- specific quality standards for diagnosis, referral and management.

## **5.3 Disease specific quality standards**

Another of the core principles for managed networks<sup>1</sup> is to use a documented evidence base where available, and draw upon evidence arising through audit and research, to set standards. Unlike adult practice the evidence base for many aspects of paediatric nephrology is limited. The Renal Association has developed a series of clinical guidelines for adults, aspects of which are relevant for children.<sup>22</sup> The BAPN is currently developing a similar range of guidelines for children. The suggested standards in this document have been derived from these guidelines and from what other evidence is available.

## Chronic kidney disease

In addition to the standards of the National Service Framework for Children Young People and Maternity services (NSF)<sup>23</sup>, part 1 of the National Service Framework for Renal Services established five standards for dialysis and transplantation in people with established renal failure.<sup>17</sup>

The first of these concerns access to information that enables patients to make an informed choice about care and is applicable to all children with renal disease.

Standards 2-5 refer only to patients with chronic renal failure. Criteria for monitoring success with these standards have been published.<sup>24</sup>

Part 2 of the NSF<sup>25</sup> sets four quality requirements and identifies 23 markers of good practice that can support NHS organisations in the prevention of chronic kidney disease in people at risk. All the standards of this NSF should apply to paediatric nephrology networks.

### 5.3.1 Recommendation

Nephrology networks meet the quality requirements of the National Service Framework for Renal Services.

The National Institute for Health and Clinical Excellence (NICE)<sup>26</sup> has produced guidance on the management of chronic kidney disease but this refers only to adults. More recently it has consulted on quality standards for patients with chronic kidney disease and the BAPN has contributed to this suggesting some key quality standards for children with kidney disease (see table 1).

**Table 1 Quality standards for chronic kidney disease (CKD)**

<b>Quality Standard Diagnosis</b>	<b>Quality standard Referral</b>	<b>Quality Standard Assessment and Management</b>	<b>Quality indicators</b>
<p>All children with the following should be screened for CKD.</p> <ul style="list-style-type: none"> <li>·Antenatal diagnosis of renal disease/ known structural renal disease</li> <li>·Family history of renal disease</li> <li>·Multi-system disease</li> <li>·Hypertension (Blood pressure above 95th centile for age and sex on three separate measurements)</li> <li>·Proteinuria and/or haematuria</li> <li>·Recurrent urinary tract infections</li> </ul>	<p>All children with eGFR &lt;90 should be referred to SPIN/paediatric nephrologist</p>	<p>All children with CKD and declining function, or stable patients with CKD 3B or less should be reviewed at least annually by a paediatric nephrologist</p> <p>All children with CKD and hypertension should have their blood pressure maintained at the 50th centile for age</p> <p>All children with CKD and significant proteinuria (first voided urine Up/ Uc &gt; x3 upper limit of normal (ULN) or alb/creat &gt; x3 ULN) should have a trial of ace inhibitors (ACEi) or angiotension 2 receptor blockers (ARB) singly or in combination to reduce proteinuria</p> <p>All children with CKD 3 or higher should be reviewed at least annually by a renal dietician</p> <p>All children with CKD 3B or higher should be reviewed by, or have access to, a psychologist annually</p> <p>All children with CKD 3B or higher, and their parents, should have access to high quality education to enable understanding and informed choices about present and future treatment options</p> <p>Systems should be in place to ensure that the network audits Renal Association<sup>22</sup> guidelines and responds to results.</p>	<p>All children with risk factors for CKD should have</p> <ul style="list-style-type: none"> <li>·Proteinuria measured in the first urine sample of the day Blood pressure measurement</li> <li>·eGFR calculated using the formula height (cms)/plasma creatinine (umols/L) x 40, normal &gt;90 mls/min/1.73 m2</li> <li>·growth measured and plotted at least 6 monthly</li> </ul> <p>All children with CKD and significant proteinuria should have a trial of ACEi or ARB unless contraindicated eg hyperkalemia</p> <p>All children with CKD 3B or higher should be reviewed at least annually by a paediatric nephrologist and discussed with a renal dietician and a psychologist</p> <p>Evidence of education programme for families should be in place</p> <p>There should be evidence of annual audit against Renal Association guidelines, with response to and improvement of outcomes</p>

### 5.3.2a Recommendation

Paediatric nephrology networks meet the British Association for Paediatric Nephrology quality standards for the management of chronic kidney disease.

### Acute Kidney Injury

Acute Kidney Injury in children is uncommon and therefore secondary care paediatric units will have infrequent experience of managing children with Acute Kidney Injury. Whilst not all children will need to be managed in a tertiary centre all should be discussed with that centre. Protocols for the management of the complications of Acute Kidney Injury should help support local care when appropriate. The quality standards in table 2 should allow networks to evaluate their services.

**Table 2 Quality standards for the management of Acute Kidney Injury**

<b>Quality Standard Diagnosis</b>	<b>Quality Standard referral</b>	<b>Quality Standard assessment and management</b>	<b>Quality Indicator</b>
<p>Acutely ill children admitted to hospital should have urinalysis and their blood pressure measured; there should be consideration of renal function measurement<sup>27</sup> especially in children with moderate to severe dehydration</p> <p>All children with EColi 0157 infection or bloody diarrhoea should have a full blood count and renal function<sup>28</sup> on admission and their urine dip tested for blood and protein daily</p>	<p>All children with Acute Kidney Injury that persists for &gt;24 hours with deterioration in renal function should be discussed with a paediatric nephrologist</p>	<p>A local protocol should be in place for management of complications of Acute Kidney Injury e.g. hyperkalemia</p> <p>All patients should have their weight recorded on admission and daily thereafter</p>	<p>Blood pressure and urinalysis should be checked on admission in all acutely ill children</p> <p>All children with E Coli 0157 should have a full blood count and renal function measurement on admission</p> <p>All children with documented Acute Kidney Injury should have their weight recorded daily and blood pressure measured 4-6 hourly and their input and output accurately documented</p>

### 5.3.2b Recommendation

Paediatric nephrology networks meet the British Association for Paediatric Nephrology quality standards for the management of Acute Kidney Injury

### General nephrology

This group of conditions consists of a wide range of renal conditions including glomerulopathies, tubulopathies and children with multi-system disease. The two commonest conditions in this group are nephrotic syndrome and Henoch Schonlein Purpura. Standards against which networks can be evaluated have thus been limited to these two conditions.



**Table 3 Quality standards for nephrotic syndrome**

<b>Nephrotic syndrome</b>	<b>Quality Standard Diagnosis</b>	<b>Quality Standard Referral</b>	<b>Quality Standard Assessment and management</b>	<b>Quality Indicators</b>
Initial presentation	All children with oedema have their urine tested for proteinuria	All children with nephrotic syndrome should be referred to a paediatrician/ SPIN  The need for diuretics+/- albumin should always be discussed with SPIN/paediatric nephrologist	There should be a local protocol in place for management agreed by network which should be followed	All children should have documented •Pneumococcal immunisation/ immunity; assessment of intravascular volume status; renal function,haematocrit, protein creatinine ratio; •and should receive dietary advice about no added salt diet  All families should receive written information on nephrotic syndrome
Later management	Those with steroid dependence (SDNS) or resistance (SRNS) should be identified	Those with SDNS should be referred to SPIN/tertiary nephrologist Those with SRNS should be referred to tertiary nephrologist	There should be a local protocol in place for management based on national guidance <sup>29</sup> agreed by network which should be followed	Children with steroid sensitive nephrotic syndrome should have their urine tested for proteinuria daily at home  All families should have a management plan in case of relapse and details of who to contact should they have concerns

Table 4 Quality standards for Henoch Schonlein nephritis

Quality Standard Diagnosis	Quality Standard referral	Quality Standard assessment and management	Quality Indicator
<p>All children with acute painless macroscopic hematuria should have at least renal function, full blood count, blood pressure, renal ultrasound scan and ASOT +/- complement checked</p> <p>Children with symptoms suggestive of HSP (rash +/- arthritis, abdominal pain or hematuria) should be identified</p>	<p>Children with HSP should be referred to a paediatrician/SPIN</p> <p>Those with renal dysfunction should be referred to a paediatric nephrologist; those with proteinuria &gt;2+ or hypertension should be discussed with a SPIN/ paediatric nephrologist</p>	<p>There should be a local protocol in place for management of HSP agreed by network</p>	<p>All children admitted with acute nephritis should have their blood pressure measured 4 hourly and fluid balance monitored</p> <p>All children with HSP should have their blood pressure measured and the first morning urine tested after admission and regularly (at least weekly) for 6 weeks</p> <p>All families should receive written information about HSP</p>

### 5.3.2c Recommendation

Paediatric nephrology networks meet the British Association for Paediatric Nephrology quality standards for the management of nephrotic syndrome and Henoch Schonlein nephritis

### Antenatal hydronephrosis and structural abnormalities of the renal tract

With the increasing use of antenatal ultrasound many structural abnormalities of the renal tract are being detected before birth. Appropriate investigations must be planned and families should be counselled about both the investigations needed and the implications of the findings. There is a rapidly changing evidence base for the investigation and management of antenatally detected urinary tract disorders and it is important that all those involved keep up to date, apply that evidence and neither order unnecessary investigations or fail to investigate those who may have significant abnormalities.

**Table 5 Quality standards for antenatally-detected urinary tract disorders (ADUTD)**

<b>ADUTD</b>	<b>Quality Standard: Diagnosis</b>	<b>Quality Standard: Referral</b>	<b>Quality Standard: Assessment and management</b>	<b>Quality Indicators</b>
Pre and Perinatal management	Those with severe antenatal abnormalities detected early in pregnancy should have access to counselling on prognosis from those with the expertise to provide that counselling  Fetal diagnostic information to be available during delivery and after birth	For high-risk cases immediate referral to appropriate specialist (eg those with suspected obstruction to a paediatric urologist and those with renal impairment to paediatric nephrologist/ SPIN)	An agreed nephro-urology network protocol should be in place to define the initial referral pathways and investigations	Evidence of antenatal counselling being available to those with severe abnormalities detected early in pregnancy  Evidence of mechanisms to ensure transfer of antenatal diagnostic information to neonatal team  Evidence that the local protocol is being followed and that appropriate investigations are being undertaken in an efficient and timely manner
Further management	Those with significant urinary tract abnormalities to be identified	Babies should be referred to SPIN, paediatric nephrologist or paediatric urologist according to a protocol agreed by the local nephro- urology network	A local network protocol should be in place to define the algorithm for management, radiological investigation and referral to specialists	There should be evidence of regular audit of current practice with review of the protocol for management and investigation  There should be evidence that appropriate information is given to families on the investigations and their findings eg that antibiotics should be increased to therapy doses before MCUG

### 5.3.2d Recommendation

Paediatric nephrology networks meet the British Association for Paediatric Nephrology quality standards for the management of antenatally-detected urinary tract disorders

### Hypertension

Hypertension in children is most commonly secondary to renal disease and many children with chronic kidney diseases have high blood pressure. Therefore the investigation and management of children with high blood pressure is an essential competency for those managing children with kidney problems.

Table 6 Quality standards for the management of children with hypertension

Quality Standard Diagnosis	Quality Standard referral	Quality Standard Assessment and Management	Quality Indicators
All children should have BP measured on admission using an appropriate sized cuff	BP should be interpreted by referring to normal data <sup>31,32</sup> . All children with BP > 97 <sup>th</sup> centile should be referred to SPIN/ paediatric nephrologist. Children with BP >10% above 97 <sup>th</sup> centile should be referred to a paediatric nephrologist	All children with persistently elevated BP should have ECG/ echocardiogram, fundoscopy by ophthalmologist, first morning urine tested, USS, renal function measurement and consideration of ambulatory blood pressure monitoring. There should be a local protocol in place for referral to SPIN/ paediatric nephrologist	All children admitted have BP measurement.  All children with persistently elevated BP have ECG/ echocardiogram, fundoscopy by ophthalmologist, first morning urine tested, USS, renal function measurement

### 5.3.2e Recommendation

Paediatric nephrology networks meet the British Association for Paediatric Nephrology quality standards for the diagnosis and management of hypertension

### Urinary tract infection

The NICE guidelines on urinary tract infection<sup>30</sup> provide guidance on the diagnosis management and investigation of children with urinary tract infection. The majority of these will be managed in primary care. However those with recurrent infections and abnormal investigations should be referred to a paediatrician/SPIN.

### 5.3.3 Recommendation

Paediatric nephrology networks follow NICE guidelines, with agreed local amendments as appropriate, for the diagnosis, management and treatment of children with urinary tract infections.

## 6. Workforce Planning

In 2002 & 2003 a National Renal Workforce<sup>33,34</sup> group undertook a detailed analysis of the provision of staff for tertiary paediatric renal services. This identified a significant under-provision of medical paediatric renal staff and even greater inequality in access to other members of the multi-professional team. A balance must be made between aspiration and resource limitations when calculating workforce requirements. However paediatric nephrology services are highly specialised with a significant proportion of emergency care being required by both appropriately trained medical and nursing staff. Because of the very specialised and technical demands of renal failure management, cross-cover from other specialties is not appropriate. Therefore one of the key parameters in considering tertiary unit staffing is the need to provide continuous cover and yet work within the Working Time Regulations.

### 6.1 Tertiary paediatric nephrologists

A suggested target in a 1995 report<sup>12</sup> based on a minimum of 4 WTE consultants in every comprehensive centre providing a service to 3-5 million population was 59 WTE paediatric nephrologists across the 13 tertiary centres. This level of staffing would afford a minimum 1 in 4 rota as had been recommended for both adult nephrologists and general paediatricians with unselective emergency admissions at that time. Increased workloads due to an increase in the intensity of treatments, absolute numbers of patients being treated and absence of resident medical staff with any paediatric nephrology experience led to this estimate being revised upward to 72 WTE in 2002<sup>33</sup>. No unit has yet achieved these recommendations.

Recent RCPCH data<sup>32</sup> on the average number of general paediatricians in a district general hospital is between 9-11 WTE dependent on the size of the unit with an average of 8.5 consultants participating in the acute on call rota. Recall rates and out of hours care is not dissimilar for paediatric nephrologists and general paediatricians and thus it is likely that even the 2002 recommendations may be insufficient. 2009 data on consultant paediatric nephrology workforce compared with the 2002 recommendations is illustrated in table 7.

Table 7 2009 Paediatric nephrology consultant workforce

Unit	2002 NHS WTE	2002 academic WTE	2002 proposed NHS WTE	Current NHS WTE 2009	Current Academic WTE
Belfast	1.5	0.5	5.0	2.5	0.5
Bristol	3.6	0.4	5.0	4.3	1.3
Birmingham	2.8	0	6.0	4.2	0
Cardiff	1.6	0.4	5.0	3.8	0
ECH London	3.5	0.5	7.0	5.6	0
Glasgow	4.0	0	5.0	4.6	0
GOSH	3.8	2.0	7.0	6.0	3.0
Leeds	2.5	0.5	5.0	4.0	0
Liverpool	3.0	0	5.0	4.0	0
Manchester	4.0	0	6.0	5.5	0.5
Newcastle	3.5	0	5	3.5	0
Nottingham	2.0	0	6.0	4.6	0
Southampton	2.0	0	5.0	3.0	0
Total	37.8	4.3	72	55.6	5.3

Training for paediatric nephrology is via a national sub-specialist training scheme ('the Grid') organised by the RCPCH. Appointment is made in year 6 of an 8 year training programme. Each year the number of appointments made is calculated based upon the predicted manpower requirement. This is calculated from annual surveys undertaken by the BAPN on plans for consultant retirements and new appointments. Those exiting the scheme who have geographical constraints may choose not to take up a tertiary appointment but to take up an appointment as a general paediatrician with a lead responsibility for paediatric nephrology in a local centre (see below). This gives flexibility and reduces risk of doctors training and then being unable to find suitable jobs.

## 6.2 Paediatricians with a special interest in paediatric nephrology ('SPIN' doctors)

The BAPN nephrology networks survey confirmed the diversity of need for renal services in local paediatric centres (outside tertiary paediatric nephrology units) around the UK. This diversity is partly dependent on size of child population served, but also on the presence of other local specialist services such as intensive care, neonatal care and surgical services. Larger centres which have other specialist services will require a paediatrician with a special interest in paediatric nephrology (SPIN) to support those services as well as provide the local nephrology service.

### 6.2.1 Recommendation

Larger centres which have other specialist children's services have a local paediatrician trained to support those services as well as to provide the local nephrology service, that is a paediatrician with a special interest in paediatric nephrology

From the survey, at least 25 centres require the services of a paediatrician with special interest in paediatric nephrology (SPIN), and this need is likely to grow in the future, with greater sophistication in renal investigation and management, and the retirement of more senior general paediatricians with relevant experience.

An alternative would be a far greater role from visiting paediatric nephrologists which would not be practical under present arrangements.

As identified earlier a curriculum for specifically training these doctors has only recently been developed<sup>21</sup>. Appointment to these modules is at a local level, and based on the preferences of trainees wishing to pursue this route, and capacity within the local "middle-grade" workforce. Training and workforce planning for those becoming SPIN doctors needs to be more closely co-ordinated. The BAPN intends to monitor the numbers entering such schemes, but is limited by not having direct responsibility for these trainees unlike the tertiary trainees for whom there is direct contact and responsibility.

## 6.3 Link paediatricians ("local leads")

Smaller paediatric centres are likely to have fewer patients with specialised complex nephrological problems, but there will be significant numbers of patients with "general nephrology" conditions, such as those illustrated in this document in Quality Standards.

With 9-11 general paediatricians in general hospitals offering paediatrics, the burden of renal conditions falling on individual consultants is often very small. As recommended earlier there should be a "link paediatrician" in each hospital, acting as the "local lead" for nephrology. These paediatricians may not necessarily be clinically responsible for all local children with nephrological problems, but are, at the least, the common link with the regional paediatric nephrology centre, and will ensure that pathways of care for children meet the quality standards. In future many of these doctors may also have completed the SPIN curriculum.

There is currently a shortfall of about 40% of paediatric centres without a local lead for paediatric nephrology. This needs to be addressed both by commissioners ensuring that commissioning arrangements consider the delivery of care along the entire pathway and also by the ongoing training of consultants currently in post.

### **6.3.1 Recommendation**

Training and workforce planning for those becoming the local clinical lead within a network is identified and commissioned both through local commissioning arrangements and at a national level through training and workforce planning strategies.

## **6.4 Paediatric renal nurses**

The review of Multi-professional Paediatric Nephrology Services in the UK in 2003<sup>34</sup> gave comprehensive recommendations for the patient nursing staff ratios for children managed in tertiary centres as inpatients, on peritoneal dialysis and on haemodialysis. Although many units have still not achieved these and roles and responsibilities are changing, these recommendations are still felt to be valid.

It is acknowledged that there are varied configurations of in-patient services. However for the care of renal patients the recommendations are in line with the RCN document defining Staffing levels for Children and Young People Services<sup>36</sup>. This recommends that the nursing establishment in specialist areas should reflect the type and number of clinical interventions and the families' need for support. Some children should be classed as needing high dependency care, e.g. post transplantation. Other patients require a ratio of 1:3.

Nurses are increasingly taking on management roles with responsibilities in all clinical areas to increase flexibility. However there still need to be identified leads for specialised areas of work such as CKD 4 and 5, haemodialysis, peritoneal dialysis and transplantation. All nurses working in these areas have responsibility for preparing and training families for future treatments, liaising not only with other health professionals but also with social services and education in addition to providing direct nursing support. They also have a strong educational role in supporting local teams and development of protocols so that as much care as possible can be delivered locally. All these require leadership and each network should have a named lead nurse with responsibility for managing training, on going development and communication.

### **6.4.1 Recommendation**

Each network has a named renal nurse responsible for managing training, on going development and communication.



## 6.5 Dietiticians

Dietiticians leading on nephrology at the centres should be at least at an Advanced Specialist Paediatric grade (Band 7) and where there is more than one dietician in post in a specialist centre it is recommended that a management grade (Band 8a) is in post<sup>34</sup>

In the absence of new agreed workforce planning figures, the recommendations in figures in the 2003 report should be followed. These state that dietetics should be funded to 2.0 Whole Time Equivalents (WTE) for 3.5 million population if patient care is shared. The number of WTE should reflect the population within the network and the caseload mix (see recommendations in table below). There also need to be arrangements in place for dietetic cover on a daily basis and children with renal failure may need urgent manipulation of their diet if acutely ill. Whilst some areas have weekend and on call dietetic service in the specialist centre, others do not, which can result in suboptimal care. As outlined in recommendation 16(3.3.1) specialised nephrology advice on all aspects of clinical care including dietetics should be available at all times.

It is important to note that the Workforce Planning Recommendations made in 2003 are still not being met in the vast majority of centres and in some, the shortfall in dietetic workforce being provided is as much as 62% according to data collected by the Paediatric Renal Nutrition Interest Group (PRING) (see Table 8).

**Table 8 Current Dietetic Staffing Levels for Specialist Nephrology Centres (April 2009)**

Unit	Current Funded WTE	Staffing Grade	Previous staffing 2003	Recommendation 2003 ( Unit only-does not allow for shared care)
Belfast	0.7	B7	0.25	0.7
Birmingham	1	0.5 B7 0.5 B8a	0.8	2.2
Bristol	1	B7/B6	1	1.6
Cardiff	1	B7	0.4	1.0
Dublin Temple	1.3	1 Snr 0.3 BG		
Dublin Crumlin				
Edinburgh	0.35	B6	-	-
Glasgow	1.5	B6	0.4	2.0
Kirkcaldy	0.2			
Leeds	1	B7	0.6	1.4
Liverpool	1.2	B7	0.3	1.2
London GOS	3	1 B8a 2 B7	2	4.7
London Evelina	1	B7	0.6	3.6
Manchester	1.75	0.75 B8a 1.0 B7	1.55	2.2
Newcastle	1.1	0.6 B7 0.5 B6	0.5	1.2
Nottingham	1.5	0.7 B7 0.8 B6	2	2.2
Southampton	1	B7	0.5	1.1

The dietician leading the regional network needs to be adequately skilled and resourced not only to effectively manage and oversee the highly complex patient case load, but also to take on an organisational role within the network, aiding in the development of local services. This will include agreement of shared protocols, training and education of dieticians and other healthcare professionals working in peripheral clinics, and the production of shared patient information, leaflets, audit and continuing professional development (CPD) material.

## **6.6 Other allied health professionals**

The review of Multi-professional Paediatric Nephrology Services in the UK in 2003<sup>34</sup> also made recommendations for pharmacists, psychologists, social workers and play specialists. All these recommendations remain valid. Each of these specialists in the tertiary centres need to link to their counterparts in the local areas to ensure that there is continuity of provision of care along the entire patient pathway.

### **6.6.1 Recommendation**

Staffing levels of all paediatric nephrology units in the UK meet the recommendations of the Review of Multi-professional Paediatric Nephrology Services in the UK (2003)

### **6.6.2 Recommendation**

Each of the specialists in the multi-professional team at the specialist centres liaises with their counterparts in the local areas to ensure continuity of provision of care along the entire patient pathway

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# Appendix 1

## How common are kidney disorders?

Disease	Prevalence	Incidence	DGH (population 30k children 5000 deliveries)
Chronic kidney disease 5 (dialysis and transplant)	56 pmcp	2.4pmcp	Prevalence 1.7 Incidence 0.07pa
Chronic kidney disease 3-4	50pmcp	-	Prevalence 1.5
Acute Kidney Injury (Haemolytic uraemic syndrome)		0.7/100,000cp	Incidence 0.21pa
Henoch Schonlein nephritis		10-20/100,00cp	Incidence 3-6pa
Steroid sensitive nephrotic syndrome	16/100,000	2-4/100,000cp	Prevalence 4.8 Incidence 0.6 to1.2 pa
Antenatal Hydronephrosis		1 per 100 live birth	Prevalence 40 pa (10 vesico-ureteric reflux , 1 posterior urethral valves)
Urinary tract infection		7% girls and 2% of boys by age of 6 years	?80 pa

## Appendix 2

### Membership of the Working group

<b>Name</b>	<b>Representing</b>
Dr Mary McGraw	BAPN (president)
Dr Milos Ognjanovic	BAPN (chair clinical services)
Dr Peter Houtman	BAPN (SPIN) & CSAC
Dr Michelle James-Ellison	BAPN (SPIN) & Wales
Dr Craig Oxley	BAPN (SPIN) & Scotland
Dr Mary O'Connor	BAPN & N Ireland
Shahid Muhammad	BAPN Patient Representative
Mr Keith Rigg	British Transplant Society
Beverley Matthews	NHS Kidney Care
Dr Donal O'Donoghue	Department of Health
Sarah Trace	Paediatric Dieticians group (PRING)
Shelley Jepson	Paediatric renal nurses group
Tracey Daglar	Paediatric renal nurses group
Dr David Shortland	RCPCH (VP Health Services)
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Dr Lisa Kauffman	RCPCH (Paediatricians in medical management)
Dr Carol Ewing	RCPCH (Officer for Workforce)
Caroline Millar	RCPCH (Parent and Carers group)
Barbara Howe	Commissioner
Fiona Mackison	Commissioner
Gail Warnes	Commissioner
Nanette Grant	Commissioner
Selena Blake	Commissioner
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