

Commissioning Safe and Sustainable Specialised Paediatric Services

A Framework of Critical Inter-Dependencies

- Allergy • Blood and marrow transplantation
- Burns • CAMHS • Cardiology • Cardiothoracic surgery • Cleft lip and palate • Clinical Haematology
- Complex child & adolescent gynaecology • Cystic fibrosis • Dermatology • Endocrinology • ENT (Airway)
- Ear nose and throat surgery • Gastroenterology
- Haemophilia • Hepatology • HIV/AIDS treatment and care • Immunological disorder • Infectious disease
- Major trauma • Malignant haematology • Medical genetics • Metabolic medicine • Morbid obesity
- Neonatal intensive care • Neonatology • Nephrology
- Neurology • Neurosurgery • Non-malignant haematology • Nutritional support • Oncology
- Ophthalmology • Oral & maxillofacial surgery
- Orthopaedics and spinal surgery • Paediatric critical care • Pathology • Plastic surgery • Renal replacement therapy • Respiratory medicine • Rheumatology
- Specialised paediatric anaesthesia • Specialist paediatric surgery • Urology

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Professor Mike Richards – National Clinical Director for Cancer

“This framework is a unique piece of work with clinical credibility and I commend it to commissioners. At a time of ever-increasing clinical specialisation, it gives due focus to the inter-dependencies between our specialties. It therefore enables us to focus on patients and not just their condition. It also recognises the importance of safety and sustainability, and demonstrates that we cannot continue with ‘more of the same’ if we are to achieve our world-class ambitions.”

Professor Roger Boyle – National Clinical Director for Heart Disease and Stroke

“This framework is impressive and long overdue. Using it alongside the accompanying computer model, commissioners will be able to test the case for fewer, larger, centres for the most complex interventions, with local provision of as much care as can safely be provided there. In my own area of interest, the framework shows that complex cardiac surgery and paediatric intensive care (PIC) share an inter-dependency. Commissioners will find this tool supportive in developing service models that balance the needs of children with complex congenital cardiac conditions with children who have less specialised needs, but who nevertheless need access to PIC.”

Dr Donal O’Donoghue – National Clinical Director for Kidney Care

“Complex medical diseases such as advanced kidney disease in children don’t occur in isolation. This thoughtful document will help commissioners improve outcomes by aligning the inter-dependent aspects of specialised services, without compromising access or neglecting the social and developmental needs of young people living with such conditions.”

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1 Foreword by Dr Sheila Shribman, National Clinical Director for Children, Families and Maternity

I have sponsored and been involved in the development of this work since it started, and I am very pleased with the results. It is a clinically driven piece of work, which I consider sits well with Professor the Lord Darzi's work on the *NHS Next Stage Review*¹. It is therefore a timely and very helpful piece of support for commissioners as they work to ensure that the specialised children's services that their population use are safe, of high quality and sustainable for the future.

The number of children with specialised conditions is relatively small, and services are increasingly sub-specialising. These factors will inevitably mean fewer, bigger centres. At the same time, we want to minimise the disruption to the lives of these children and young people, and their families, and to provide them with services as close to home as possible where appropriate. In addition, we are clear that planning the provision of specialised services must address other competing pressures – maximising efficiency in one service can compromise provision of key services for other children, and specialised commissioners must optimise outcomes and balance access.

So, rather than focus one service in a very small number of units that could result in, for example, fewer intensive care units being viable, we must look at both single specialised services and the needs of the greater number of children with less specialised, but nevertheless urgent, requirements. This is complicated, difficult work and this report, along with the accompanying modelling tool, will provide significant help to commissioners.

I would like to offer my thanks to all who have worked on this project: to the Clinical Advisory Group members who have been exemplary in their open-minded approach to the clinical issues; to the Steering Group who have offered robust challenges and support; to the Royal Colleges who have supported it and who will be vital in ensuring its implementation; to those others who responded to the consultation with their support and suggestions for improvement; and to the core team who have made sure that the project has progressed to its conclusion. In particular, I would like to offer my sincere thanks to Dr Edward Baker, who has chaired the project.

The outcome of this work should focus minds on the future direction for these essential services, to ensure that we commission for world-class provision. Children and their families deserve nothing less.



2 Introduction by Dr Edward Baker, Project Chair

The needs of children and young people with complicated physical health conditions and diseases are very special, and they demand our best endeavours in delivering high-quality care and treatment.

The range of specialised services that has evolved to meet these needs is extensive and, generally, they have a good reputation. However, the Kennedy Report into paediatric cardiac surgery at Bristol Royal Infirmary alerted us to some major concerns, and six years later its recommendations have not yet been fully implemented.

Kennedy included recommendations on the accreditation of clinical specialists, but there are additional workforce challenges beyond this. We need to plan better for the future availability of our clinical specialists and to improve on-call arrangements. The use of clinical networks is emerging as a way of addressing these and other issues, but brings with it the need to work and use services differently.

Services are beginning to change but one of the critical factors is the complexity of many children's conditions. Children often require access to a number of different specialised paediatric services at the same time, and these services need to be considered as a whole, not individually. Historically, specialised paediatric services have developed in different ways across the country and have not been planned in a co-ordinated manner. It is no longer possible to safely sustain this diverse and sometimes fragmented pattern of service provision. Standing still is therefore not an option, but in moving forward, how can we promote safe and sustainable services for the future?

Our response has been to develop an inter-dependencies framework for specialised paediatric services. This framework establishes for the first time, a clear, clinically agreed statement of the relationships between services – and how these relationships will need to be taken into account when commissioning services or considering changes that directly involve or impact upon them.

These are challenging issues and need a considered approach. We believe that this inter-dependencies framework provides such an approach and will be crucial in establishing confidence in the whole system of care. Our report and the framework that it sets out will be of particular interest to specialised commissioning groups in the first instance, but it is accessible to all who share our interest in specialised paediatric services.

Let me thank the Department of Health for funding this work and all those at SymmetricSD, the consultancy that has supported it and developed the approach. I also thank all the members of our Clinical Advisory Group, Modelling Group and Steering Group for their hard work, and the Royal Colleges and other individuals who have provided invaluable comments as the work has progressed.

We have tried not to produce just another report, and sincerely hope that it will be used actively to make a difference. We commend it to you.

Ted Baker

3 Background

Specialised paediatric services are complex and mutually dependent. Some of our most vulnerable children depend on them. However, there is an emerging view among clinicians, commissioners and parents that the current trajectory for these services is neither safe nor sustainable^{2 3 4}.

This report sets out the initial results of a project that has been addressing these concerns. We identify the key specialised services (Section 4) and the pressures on them to change (Section 5). We then define the relationships between services and how these will govern any process of change – which services need to have others immediately available in order to function safely and which, while having a relationship, require less urgent contact. We set this out in a specialised service inter-dependency framework (Section 6). Initial work on a related computer model is described (Section 7) followed by our conclusions and recommendations (Section 8).

We established a Steering Group to oversee the programme of work, supported by a Clinical Advisory Group and a Modelling Group; details of the role and function of the groups, and their membership, are attached (Appendix 1).

In progressing this work we have been conscious of the following:

- We have sought to do more than produce a list of recommendations, but we are not prescriptive about specific changes to services or service configuration locally. The project aims to facilitate change by supporting and informing local planning of services.

- We are not the first to embark on this journey. In addition to earlier work on service dependencies undertaken by the Royal College of Paediatrics and Child Health, the project has acknowledged links to work by the National Institute for Health and Clinical Excellence (NICE) on children's cancers⁵; work emerging on paediatric congenital cardiac services; local development work being undertaken by specialised commissioning groups; the extensive work on specialised paediatric services in Scotland⁶ and Wales⁷; and work in Sweden on paediatric cardiac surgery⁸.
- The work was essentially about defining clinical relationships and was driven by clinicians. We are conscious though that the local application of the framework will require a process of engagement with service users, parents or representatives. In addition, any significant service change will be subject to a local equalities impact assessment. We are aware of a shortage of equalities research relating to specialised paediatric services and commissioners may wish to establish more detailed analysis of hospital inpatient datasets jointly, to support the process.

Our work is aimed predominantly at commissioners of specialised services but it has important messages for everyone involved. For children and their parents, it is about recognising that sometimes accessing the best possible care may mean using services in specialised centres, and sometimes it may not. For clinical specialists, it is about recognising the need to use wider clinical networks to deliver care. For local children's services, it is about ensuring that the appropriate level of support is provided to the child and family.

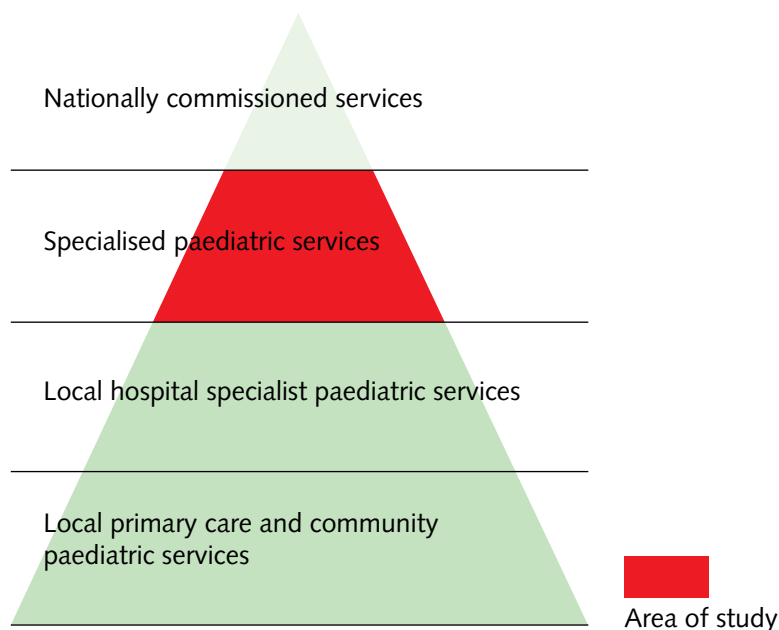
4 Specialised Paediatric Services

In the UK, all paediatric services are regarded as specialist. Within paediatrics, some services are regarded as specialised (sometimes referred to as 'tertiary') and have been included in the *Specialised Services National Definitions Set*⁹; a list is attached (Appendix 2). We also noted from this work that an absolute listing of 'specialised' services in this context may not be possible and that some broader principles should apply, including:

- **diagnosis** – some conditions are so serious or rare that all treatment relating to the condition will be considered specialised;
- **severity** – severe or intractable cases of otherwise general conditions will often require specialist expertise;
- **other underlying conditions** – a relatively straightforward procedure may become specialised when the patient has other serious underlying problems;
- **complications** – some procedures are not effective when first performed and may require a specialist to repeat the operation to correct the problems that have occurred; and
- **age** – simple procedures such as surgical interventions become specialised when the patient is very young, and specialised support services such as anaesthetics are required.

We were also aware that there are a number of services commissioned on a national basis. Their configuration had already been subject to careful consideration and so we did not feel able to add anything further through our work. Nevertheless, we recognised that when using the outcomes of our project locally, commissioning groups would need to take nationally commissioned services into account.

In addition, we were aware of the relationships between specialised services and the broader range of children's services delivered through local hospitals and community services. In summary, we represented our area of study as follows:



The final list of 23 services that we chose to work with is attached (Appendix 3). We were concerned to focus on those services that were:

- more likely to have critical inter-dependencies; and
- most likely to drive the process of service configuration.

In each case, we had considered only the specialised or tertiary children's elements of those services, not the generic children's or adult services. For example, specialised paediatric surgery covers the description in the Specialised Services National Definitions Set and does not include surgical work outside that definition. In addition, we acknowledge that there is a broad range of specialist hospital paediatric services. Occasionally, each of these will have clinical inter-dependencies with the services that are the focus of this report. There are important service links between them, and our recommendations address this.

The 23 services we have focused on are not a definitive list of specialised paediatric services – commissioners need to consider the full list of nationally defined services (in Appendix 2) and inter-dependencies between them for example, paediatric rheumatology, when planning services.

5 Pressures on Specialised Paediatric Services to Change

Some of the pressures facing services and challenging their ability to stand still are as follows:

- a. Over six years after the publication of the Kennedy Report¹⁰ into the care of children receiving complex heart surgery at Bristol Royal Infirmary, its recommendations have still to be fully implemented at a local level. The recommendations extended to all children's services and, in particular, the need to undertake an adequate volume of work to promote safe practice remains a key concern. The report identified the need for strategic guidance on "the optimal integration of all the relevant services so that they are organised around the needs of children and their families, rather than around the needs of providers".
- b. There are growing concerns about aspects of the medical workforce:
 - i. *Shortages of paediatric specialists* – there are significant workforce shortages in most paediatric specialties and a number of smaller specialised services are often provided single-handedly by a consultant. This is not satisfactory. It makes sense to develop expert teams that can provide a high-quality, safe and sustainable service together with an outreach programme. This will mean fewer in-patient units for many specialties and a requirement to develop and strengthen clinical networks.
 - ii. *Working time directive (WTD)* – providing the required rota for WTD 2009 will require larger units so that doctors in training are exposed to a sufficient caseload of patients to develop their expertise.
 - iii. *Age profile of senior consultants in paediatric specialties* – given changes in medical training, the workforce of tomorrow will not be as broadly experienced. This must be taken into account when considering succession planning; a low-volume caseload that has been delivered by a single practitioner of many years' experience will not be sustainable with a younger, less experienced consultant who will require a significantly larger caseload to develop the specialised expertise required.
- c. There are a number of related changes that will impact on the configuration of services:
 - i. Delivering services closer to home is now part of a national programme of change. In part, this will mean more active discussion between tertiary centres and local services about care pathways, the process of referral and the return to local care.
 - ii. Specific work in children's services that may lead to reconfiguration (for example NICE guidelines on children's and young people's cancers, or work on paediatric congenital cardiac services) will need to take account of the full impact of change across the range of specialised children's services. For example, as cardiac services account for 30% of paediatric intensive care unit (PICU) admissions, if the services are reconfigured how could the PICU remain able to manage its remaining work, such as acute respiratory illness, which also accounts for 25–30% of admissions?
 - iii. Plans for service reconfiguration may not take account of links between adult and specialised children's services and the inter-dependencies between different children's services.

iv. There is growing awareness of the need for age-appropriate care for children and young people and for effective transition of care for adolescents into adult services. To ensure sustainability, only a small number of 'adolescent' units may be feasible.

d. Other pressures include the following:

- i. One of the critical factors in paediatrics is that often the child's condition is particularly complex and in many instances individual patients will have complicated pathologies. The need is for rapid assessment and treatment, with onward referral to specialised services when necessary. An example of a pathway demonstrating this need is the recently developed work on paediatric audiology, which has emerged from the application of the national maximum 18-week standard for elective services¹¹.
- ii. The introduction of national tariffs for specialised services as part of the 'payment by results' process may limit the number of tertiary centres wanting to offer specialised services, due to financial viability.
- iii. The need to ensure that local emergency services for children are configured to provide effective and safe standards of care¹².
- iv. There is a range of workforce issues affecting other members of the multi-disciplinary team, in particular links to the availability of specialist nurses and advanced nurse practitioners.

Addressing these issues will need services to develop and strengthen clinical networks, and there will need to be wider discussion about

which aspects of the care pathway can be managed outside specialised centres^{13 14}.

The project recognised these pressures and the fact that, in trying to address them, local communities sometimes seemed unable to make progress due to the complexity of the relationships between specialised paediatric services. Our work has attempted to address this key issue and the results are described in the next section.

6 Service Inter-Dependency Framework

As suggested, the need to clarify the nature and implications of the relationships between specialised paediatric services has formed the core of this project. While other related work had been undertaken, we were not aware of a clinically agreed statement that could form the basis of a shared understanding about these relationships and inform discussions across the NHS about paediatric configuration issues. We suggest that the absence of such a statement so far has led to system-wide inertia in the commissioning and planning of service change. We also believe that for the future, with the additional pressures on services to change (as set out above), there are significant risks to safety and sustainability without an agreed set of clinical reference points. Whether to inform the process of service configuration or to enable the development of networks, the key issues are which services need to be together, and under what circumstances; and which services do not need to be together.

The work was led by the project's Clinical Advisory Group. Having agreed the listing of 23 services to include (see Section 4 and Appendix 3), the group used a simple 23 by 23 matrix and specified the nature of the relationships between services using a colour-coding system, as follows:

Red	Absolute dependency, requiring co-location
Amber	Relationship under some circumstances, requiring varying levels of access and contact between specialists, but not necessarily co-location
Green	Indirect or no relationship

Co-location in this context was defined as meaning either:

- location on the same hospital site; or
- location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site. These would be reinforced through formal links such as:
 - consultant job plans; and
 - consultant on-call rotas.

Relationships coded Amber were further differentiated using a scoring system of 1 to 3 to denote access to and type of medical care required, as follows:

1	<ul style="list-style-type: none"> ● Planned intervention ● Timescale – as required
2	<ul style="list-style-type: none"> ● Visit by consultant specialist, or transfer of care ● Timescale – next working day
3	<ul style="list-style-type: none"> ● An integrated clinical service ● Visit by consultant paediatric specialist, or transfer of care ● Timescale – available within four hours

In this context:

- An 'integrated clinical service' would be demonstrated by reference to consultant job plans and on-call arrangements, and agreed clinical guidelines and pathways of care.
- 'Transfer of care' would be direct to the optimum site of treatment, avoiding a sequence of successive referrals. In addition, effective transfer requires the presence of an appropriate transport support system to and from the specialist service. The group recognised that, depending on the specific location, there may be additional work necessary

- **Service 17**, Endocrinology, has no co-location requirements with other services.
- **Service 21**, Specialised Paediatric Surgery, needs to be co-located with Paediatric Critical Care and Specialised Paediatric Anaesthesia, but has close relationships with another eight services.

This simple but powerful representation helps to clarify which services have dependent relationships and which have no direct relationship, and both will be of use to those involved in either the commissioning or delivery of specialised services safely. It also helps to clarify the justification for increasingly delivering other services – especially the Amber relationships – through clinical networks.

a. Red Relationships

The key area for the project was that of Red relationships between services – that is those, in our terms, that require co-location. Examples of the type of clinical conditions involved are shown below:

EXAMPLES
<p><i>Oncology requires co-location with Paediatric Critical Care for:</i></p> <ul style="list-style-type: none"> ● acute septic shock and multi-organ failure in patients with neutropenia on chemotherapy.
<p><i>Nephrology requires co-location with Paediatric Critical Care for:</i></p> <ul style="list-style-type: none"> ● multi-system disease associated with acute renal failure.
<p><i>Cardiothoracic Surgery requires co-location with Cardiology for:</i></p> <ul style="list-style-type: none"> ● joint management of children before and after cardiac surgery.

In our matrix, to ensure that the relevant range of conditions is supported, services may have a Red relationship with multiple other services. We were aware that this in turn could generate a cumulative effect, such as:

- Major Trauma (including Maxillofacial and Plastic Surgery) in the matrix above requires co-location with Neurosurgery; ENT (Airway); Specialised Paediatric Surgery; Paediatric Critical Care and Specialised Paediatric Anaesthesia. Neurosurgery though, also requires co-location with Neurology. What emerges is the following group of services that require co-location, using Major Trauma as the starting point:
 - Major Trauma (including Maxillofacial and Plastic Surgery)
 - Neurology
 - Neurosurgery
 - ENT (Airway)
 - Specialised Paediatric Surgery
 - Paediatric Critical Care
 - Specialised Paediatric Anaesthesia.
- Blood and Marrow Transplantation (BMT) requires co-location with Clinical Haematology, Immunological Disorder and Paediatric Critical Care. Working through the relationships in the same way indicates the following overall list of services that require co-location, with BMT as the starting point:
 - Blood and Marrow Transplantation
 - Clinical Haematology
 - Immunological Disorder
 - ENT (Airway)
 - Specialised Paediatric Surgery
 - Paediatric Critical Care
 - Specialised Paediatric Anaesthesia.

b. Amber Relationships

Amber 3 and 3* relationships will be achieved by co-location, and this should generally be the expectation as there are important clinical linkages between services. However, unlike Red relationships, there is some flexibility in terms of service location. Examples of the type of clinical conditions involved in Amber 3 relationships are shown below:

EXAMPLES
<p><i>Oncology has an Amber 3 relationship with Neurology for:</i></p> <ul style="list-style-type: none"> the management of chemotherapy-induced encephalopathy.
<p><i>Nephrology has an Amber 3* relationship with Urology for:</i></p> <ul style="list-style-type: none"> chronic renal failure including neuropathic bladder, requiring bladder drainage procedure and urological review.
<p><i>Cardiology has an Amber 3* relationship with Cardiothoracic Surgery for:</i></p> <ul style="list-style-type: none"> supporting the provision of complex interventional catheter procedures.

Decisions about the distribution of services will need to be sensitive to the links set out in this report, in particular those shown as Amber 3 and Amber 3*. As suggested above, in the majority of instances Amber 3 and Amber 3* relationships will be best served by co-location. In particular, Amber 3* relationships are between related medical and surgical specialities (Respiratory Medicine/ Specialised Surgery, Neurology/Neurosurgery, Oncology/Neurosurgery, Cardiology/Cardiac Surgery, Nephrology/Urology). If an Amber 3* relationship is not co-located, the medical specialty would not be able to provide a full specialist service and a very close clinical network with the relevant surgical specialty would be essential. For example, an Oncology service without co-location of Neurosurgery would not be able to provide a Neuro-Oncology service, and would need a network relationship with a neurosurgical centre.

We will be pursuing this further within the modelling work but in the interim would draw the attention of commissioning groups and trusts to the significance of the Amber 3 relationships.

c. Essential Supporting Services

The report discussed in detail the essential role of some of the supporting clinical services. The key points that emerged were as follows:

- Any given specialised paediatric centre will require a critical mass of specialist paediatric services to ensure comprehensive and sustainable supporting services.
- The emotional and psychological wellbeing of children and young people is a critical part of the care pathway. In addition, children and young people may of course exhibit emotional and psychological symptoms at the same time as physical symptoms. This will require continuing good access to child and adolescent mental health services (CAMHS).
- Specialised paediatric services need access to a range of specialist services, such as: Specialist Paediatric Radiology; Paediatric Pathology and Laboratory services; Nutrition services; Rehabilitation services (which will include community-based provision); Pain services; Palliative Care; and expert child protection support.
- Specialist Paediatric Echocardiography is required by many other specialised services. This does not necessarily require the presence of a full-time Cardiology service located on site but does require appropriate access to an expert echocardiography opinion. The service may be provided by a dedicated technician or a non-cardiac sub-specialist, provided that expert cardiological review is readily available. Services that require access to echocardiography on a 24-hour basis, from our list, are as follows:

- i. Blood and Marrow Transplantation
- ii. Metabolic Medicine
- iii. Oncology (including Haemato-oncology)
- iv. Neurology
- v. Major Trauma (including Maxillofacial and Plastic Surgery)
- vi. Spinal Surgery
- vii. Nephrology
- viii. ENT (Airway)
- ix. Neonatology
- x. Paediatric Critical Care.

7 Modelling Specialised Paediatrics Services

The focus of the service inter-dependency framework has been about supporting safe practice; the focus of the modelling element of our project is about service sustainability.

Following initial preparatory work at the NHS South West, work is now progressing to look at the provision nationally. The model, once complete, will combine the use of the inter-dependency framework with data on the specialised services, including sustainable on-call rotas and the volumes of workload required to support accreditation.

While the model will not make specific recommendations in terms of locations, it will be used to inform discussions relating to the optimum number of specialist paediatric centres required nationally. This work will be made available separately and is expected to be available during the Autumn of 2008.

8 Conclusions and Recommendations

The aim of this project has been to support the commissioning of safe and sustainable specialised paediatric services.

We suggest that our project has resulted in some important and innovative work at a time when there are growing concerns about specialised paediatric services, but also when there are huge opportunities.

As a result of our work, our conclusions are as follows:

- Specialised paediatric services are facing a number of pressures to change, and standing still is not a safe or sustainable option.
- Delivering this change will in part only be possible by recognising and working with the complexity of the relationships between services and a recognition that change in one service will have consequential effects for others. Optimal results can only really be achieved by considering the wider impact of change.
- Service inter-dependency works in two directions: between specialised services themselves and also with less specialised services. Dependency needs to be addressed in both directions, but the focus of our work has been on the relationships between specialised services.
- These dependencies have been recognised in the past but the complexity, or rather lack of agreement about that complexity, may have prevented development in services.
- We have developed, for the first time, a clinically agreed framework of those dependencies, and this can now guide the commissioning and provision of specialised paediatric services for the future.
- Given the pressures on specialised paediatric services, the wider development and introduction of formal networks of care will be crucial.

- Agreed pathways of care for specialised paediatric services, delivered within clinical networks, should enable a child to be treated close to home provided that services can safely be delivered there, and be required to travel only for those elements that are essential.

Our recommendations are as follows:

- a. We recommend that local services and commissioning groups use the inter-dependency framework for specialised paediatric services as the basis of a planned approach to the distribution and configuration of services that reflects clinically agreed dependencies.
- b. We recommend that the list of core services identified from our work be considered as the minimum grouping of services required in any defined specialised paediatric service centre.
- c. Commissioners need to commission the full range of specialised services for children (Appendix 2) and recognise the inter-dependencies between them.
- d. To support the safe and effective delivery of accessible services for children with specialist needs, informal clinical networks will need to be replaced with formal managed networks. These will need to agree:
 - i evidence-based care pathways supporting local protocols;
 - ii integrated clinical information systems and clinical audit;
 - iii service delivery by appropriately accredited practitioners and skilled multi-disciplinary teams;
 - iv where and when care is to be delivered (in the right place, at the right time); and
 - v a common clinical governance structure with an improvement process to identify and rectify weak points on the pathway or within the network, so that the best clinical outcomes are achieved.

- e. We recognise that effective networks involve clinicians working across individual primary care trust and hospital trust boundaries. These arrangements should be made explicit, and enabled further through discussions between service providers and relevant service commissioners.
- f. Centres providing specialised paediatric services must have a sufficient volume of specialised paediatric care to ensure that they can provide sustainable and comprehensive support services.
- g. Reconfiguration of specialised paediatric services should take into account the needs of children of all ages, including teenagers and the need for a managed transition to adult services.
- h. While links to adult specialised services are important, the inter-dependencies between specialised children's services should take precedence.
- i. Specialised commissioning groups need to work collaboratively in order to deliver this agenda consistently across the country.
- j. We recognise that, depending on the specific location, there may be additional work necessary to ensure that transport support is available covering the range of dependencies, not just for critical care.

We will add further conclusions and recommendations in the light of outcomes from our work on national modelling.

Appendix 1 Project Structure and Membership

a. Structure

The project began in September 2007. It has worked with the following structure:

- **Steering Group** – membership was drawn from: specialised paediatric services (the members of the Clinical Advisory Group (CAG) below were also members of the Steering Group); the Royal Colleges – Paediatrics and Child Health, Physicians, Surgeons, Anaesthetists and Nursing; the Association of Chief Children’s Nurses; the National Specialised Commissioning Group and the Specialised Commissioning Group Directors network; and the Department of Health. Its key responsibilities were to:

- oversee the project and offer a wider perspective on its work;
- review, and amend as necessary, the work of the CAG (see below);
- endorse a set of recommendations on the future commissioning of specialised paediatric services;
- engage with key external bodies;
- ensure robust and deliverable recommendations; and
- support national implementation.

- **Clinical Advisory Group** – membership comprised primarily clinicians from the larger-scale specialised services. The group’s key tasks were to:

- provide expert paediatric advice for the project;
- agree the service inter-dependencies and broader factors affecting the distribution and configuration of specialised paediatric services; and
- input to the Modelling Group and project report.

- **Modelling Group** – the initial focus involved a range of commissioner and provider colleagues from the NHS South West. The group’s key tasks were to:

- develop and pilot a computer-based model to support the commissioning of specialised paediatric services;
- integrate within the model the results of the work of the CAG; and
- advise on lessons learned to facilitate subsequent NHS roll-out.

Subsequently, the focus has moved to developing a broader-based model with the potential for national application. The key task in the next phase will be to assess the number of specialist paediatric centres required nationally (without reference to location) based on:

- the inter-dependencies set out in the project’s matrix, with particular reference to the Red and Amber 3 relationships;
- available data on the minimum clinical caseloads required to ensure safe practice; and
- available data on optimal on-call rotas.

b. Membership

The membership of the project's Steering Group was as follows:

Name	Post	Organisation
Dr Frances Ackland*	Consultant Paediatrician	Northampton General Hospital NHS Trust
Steve Arnold*	Management Consultant	SymmetricSD
Dr Edward Baker (Chair)*	Consultant Paediatric Cardiologist	Guy's and St Thomas' NHS Foundation Trust and King's College
Prof Alan Craft*	Professor of Child Health	Sir James Spence Institute, Royal Victoria Infirmary, Newcastle
Mr David Drake	Paediatric Surgeon, Great Ormond Street Hospital	British Association of Paediatric Surgeons
Rachel Ferris	Deputy Director, Specialised Commissioning Group NHS South West	SCG Directors Network
Dr Rowan Hillson	Consultant Physician, Hillingdon Hospitals NHS Trust	Royal College of Physicians
Mr David Hunt	Consultant Orthopaedic Surgeon, Imperial College Healthcare NHS Trust	Royal College of Surgeons
Dr Simon Lenton	Vice-President	Royal College of Paediatrics and Child Health
Dr Ian Lewis*	Consultant Paediatric and Adolescent Oncologist	Leeds Teaching Hospitals Trust
Dr Timothy Martland*	Consultant Paediatric Neurologist	Central Manchester and Manchester Children's Hospitals NHS Trust
Sue McLellen	Director, Specialised Commissioning Group, NHS London	SCG Directors Network
Marcia Mercer	Acting Chief Nurse, Royal Liverpool Children's Hospital NHS Trust	Association of Chief Children's Nurses
Dr Kevin Morris*	Consultant Paediatric Intensivist	Birmingham Children's Hospital NHS Foundation Trust

Adrian Pollitt	Director, National Specialised Commissioning Group	NHS London
Pam Scoular*	Partnerships for Children, Families and Maternity	Department of Health
Dr Sheila Shribman	National Clinical Director for Children	Department of Health
Fiona Smith	Adviser in Children's and Young People's Nursing	Royal College of Nursing
Julia Stallibrass	Deputy Director, National Specialised Commissioning Group	NHS London
Dr Jane Tizard*	Consultant Paediatric Nephrologist	Bristol Royal Hospital for Children, United Bristol Healthcare NHS Trust
Mr Rick Turnock*	Consultant Paediatric Surgeon	Royal Liverpool Hospital NHS Trust
Dr Isabeau Walker	Consultant Anaesthetist, Great Ormond Street Hospital	Royal College of Anaesthetists
Dr Ted Wozniak*	Medical Adviser in Paediatrics and Child Health	Department of Health

*Also a member of the Clinical Advisory Group.

The core membership of the project's Modelling Group in the NHS South West was as follows:

Steve Arnold	Management Consultant	SymmetricSD
Rachel Ferris	Deputy Director, Specialised Commissioning Group	NHS South West
Douglas McKelvie	Management Consultant	SymmetricSD
Dr Jane Tizard	Consultant Paediatric Nephrologist	Bristol Royal Hospital for Children, United Bristol Healthcare NHS Trust

We are grateful to all the other colleagues from NHS South West who gave their time to the initial modelling work.

Appendix 2 Summary of Nationally Defined Specialised Services for Children

The following table sets out both the range of specialised services for children and the services in the 'all ages' categories that children will use:

Definition no. 23: Specialised services for children
<p>Section A</p> <ol style="list-style-type: none"> 1. Cardiology and cardiothoracic surgery 2. Nephrology, including renal replacement therapy 3. Gastroenterology/hepatology (National Commissioning Group commissioned)/ nutritional support 4. Respiratory
<p>Section B</p> <ol style="list-style-type: none"> 1. Oncology and malignant haematology 2. Non-malignant haematology 3. Neonatal intensive care 4. Paediatric intensive care 5. Immunological disorder/infectious disease/allergy 6. Paediatric pathology
<p>Section C</p> <ol style="list-style-type: none"> 1. Paediatric neurosciences 2. Metabolic disorders 3. Paediatric endocrinology and diabetes 4. Rheumatology 5. Specialised child and adolescent mental health services 6. Specialised dermatology
<p>Section D</p> <ol style="list-style-type: none"> 1. Paediatric surgery 2. Paediatric orthopaedic surgery 3. Paediatric ophthalmology 4. Paediatric ear, nose and throat surgery 5. Paediatric oral and maxillofacial surgery 6. Paediatric plastic surgery 7. Paediatric urology 8. Complex child/adolescent gynaecology, congenital anomalies and intersex 9. Paediatric anaesthesia
Definition no. 2: Specialised services for blood and marrow transplantation (all ages)
Definition no. 3: Specialised services for haemophilia and other related bleeding disorders (all ages)
Definition no. 5: The assessment and provision of equipment for people with complex physical disability (all ages)
Definition no. 9: Specialised burn care services (all ages)
Definition no. 10: Cystic fibrosis services (all ages)

Definition no. 14: HIV/AIDS treatment and care (all ages)
Definition no. 15: Cleft lip and palate services (all ages)
Definition no. 16: Specialised immunology services (all ages)
Definition no. 17: Specialised allergy services (all ages)
Definition no. 20: Medical genetic services (all ages)
Definition no. 25: Specialised pathology services (all ages)
Definition no. 32: Specialised ear surgery (all ages)
Definition no. 35: Morbid obesity services (all ages)

Source:

Department of Health, *Specialised Services National Definitions Set (Second Edition)*;
Specialised Services for Children – Definition No 23, March 2003

Work is underway to update these definitions and a revised set will be available in late 2008.

Appendix 3 Specialised Paediatric Services Included in the Inter-Dependency Matrix

The agreed list of services that became the focus of the project is listed below. In each case we are considering **only the specialised children's elements of services**, not the generic children's or adult service.

1	Blood and Marrow Transplantation
2	Clinical Haematology (Non-malignant)
3	Immunological Disorder
4	Metabolic Medicine
5	Oncology (inc Haemato-oncology)
6	Burns
7	Infectious Diseases
8	Respiratory Medicine
9	Cardiology
10	Cardiothoracic Surgery
11	Neurology
12	Neurosurgery
13	Major Trauma (inc Maxillofacial and Plastic Surgery)
14	Spec Orthopaedics and Spinal Surgery
15	Nephrology
16	Urology
17	Endocrinology
18	Gastroenterology
19	ENT (Airway)
20	Neonatology
21	Specialist Paediatric Surgery
22	Paediatric Critical Care
23	Specialist Paediatric Anaesthesia

Appendix 4 Service Inter-Dependency Matrix

The matrix below sets out the results of the work on inter-dependencies (described more fully in Section 6 of the main report):

Specialised Paediatric Service	A BMT	B Clinical haemo	C Immun	D Met Med	E Onc	F Burns	G Infect Dis	H Resp Med
1 Blood and Marrow Transplant					3		2	3
2 Clinical Haematology (Non-malignant)			1					
3 Immunological Disorder	2	1					3	2
4 Metabolic Medicine		2						1
5 Oncology (inc Haemato-oncology)	1						1	3
6 Burns								
7 Infectious Diseases			2					1
8 Respiratory Medicine			1				2	
9 Cardiology								1
10 Cardiothoracic Surgery		1						2
11 Neurology		1	1	2			1	2
12 Neurosurgery					3			
13 Major Trauma (inc Maxfax and Plastics)		1						
14 Spec Ortho and Spinal Surgery					1			2
15 Nephrology		2	2	1	1		1	2
16 Urology					2			
17 Endocrinology								
18 Gastroenterology			2	1			2	
19 ENT (Airway)								3
20 Neonatology								
21 Specialised Paediatric Surgery		3			1			3
22 Paediatric Critical Care		3	1	2			1	3
23 Specialised Paediatric Anaesthesia		1						1

I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W
Cardio	Card Surg	Neuro	Neuro Surg	Major Trauma	Spec Ortho & Spinal	Neph	Uro	Endo	Gastro	ENT Airway	Neonato	Spec Paed Surg	Paed Crit Care	Spec Paed Anaesth
1		1				3			2			3		1
1													2	1
						1			3			1	1	1
2		2				1								1
1	1	3	3*	1	1	3	2	1	2	1				
		1		3		1								
1		1							1				2	1
3		1						1	3	3		3*	3	1
	3*	1										1		1
		2				1				2	1	3		
1			3*		1	1		1	1	2		1		1
				3*	2	1	1	2		2	1	2		
2	2	1			1	1	2							
1		2	1				1					1	3*	
3		2			2		3*	2	2	2	3			
						3*		2				3		1
			1										1	1
												3	1	1
2	2	1		1								2		
2												3		1
1	1	2	3	1	3		3	3	3	1	3			
3		2	3	2		2	1		1					
1								1		1	1	1		

Appendix 5 Summary of Cumulative 'Red' Dependencies

The matrix below sets out the results of the work on inter-dependencies (described more fully in Section 6 of the main report):

Specialised Paediatric Service	A BMT	B Clinical haemo	C Immun	D Met Med	E Onc	F Burns	G Infect Dis	H Resp Med
1 Blood and Marrow Transplant								
2 Clinical Haematology (Non-malignant)								
3 Immunological Disorder								
4 Metabolic Medicine								
5 Oncology (inc Haemato-oncology)								
6 Burns								
7 Infectious Diseases								
8 Respiratory Medicine								
9 Cardiology								
10 Cardiothoracic Surgery								
11 Neurology								
12 Neurosurgery								
13 Major Trauma (inc Maxfax and Plastics)								
14 Spec Ortho and Spinal Surgery								
15 Nephrology								
16 Urology								
17 Endocrinology								
18 Gastroenterology								
19 ENT (Airway)								
20 Neonatology								
21 Specialised Paediatric Surgery								
22 Paediatric Critical Care								
23 Specialised Paediatric Anaesthesia								

I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W
Cardio	Card Surg	Neuro	Neuro Surg	Major Trauma	Spec Ortho & Spinal	Neph	Uro	Endo	Gastro	ENT Airway	Neonato	Spec Paed Surg	Paed Crit Care	Spec Paed Anaesth
										Red		Red	Red	Red
										Red		Red	Red	Red
										Red		Red	Red	Red
										Red		Red	Red	Red
										Red		Red	Red	Red
Black										Red		Red	Red	Red
Red	Black									Red		Red	Red	Red
		Black								Red		Red	Red	Red
		Red	Black							Red		Red	Red	Red
		Red	Red	Black						Red		Red	Red	Red
					Black					Red		Red	Red	Red
						Black				Red		Red	Red	Red
							Black			Red		Red	Red	Red
								Black		Red		Red	Red	Red
									Black			Red	Red	Red
										Black		Red	Red	Red
											Black	Red	Red	Red
										Red		Red	Black	Red
										Red		Red	Red	Black

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Notes

Notes

Extracts of quotes from National Clinical Directors:

“Complex medical diseases such as advanced kidney disease in children don't occur in isolation...”

Dr Donal O'Donoghue – National Clinical Director for Kidney Care

“This framework is a unique piece of work with clinical credibility and I commend it to commissioners...”

Professor Mike Richards – National Clinical Director for Cancer

“Using it alongside the accompanying computer model, commissioners will be able to test the case for fewer, larger, centres for the most complex interventions, with local provision of as much care as can safely be provided there.”

Professor Roger Boyle – National Clinical Director for Heart Disease and

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