

Children's and young people's project

London's specialised children's services: Guide for commissioners

March 2011



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Part one: A case for change



Introduction

In previous years, numerous reports have emphasised the need for significant and urgent changes in London's specialised or tertiary children's services. Despite the urgency of these recommendations, little change has taken place. This means that children with complex medical conditions and their families are not receiving the care that best meets their needs.

While London has stood still over the past decade or so, cities including Manchester, Glasgow, Dublin and Paris have taken forward major evidenced based improvements in their specialised children's services. Furthermore, London's arrangement of service provision compares poorly in contrast with a city such as Toronto, whose model of specialised children's care has been cited for some time as a key example of best practice internationally.

The purpose of this case for change is to present the evidence that identifies the key issues of concern regarding London's specialised children's services. This evidence is the foundation for the development of a proposed new model of care based on best practice.

London's tertiary paediatric services provide care for a uniquely large and diverse population of children. This presents the services with a significant challenge to provide high quality care in a complex environment. It also gives the services an exceptional opportunity to lead clinically and academically in the UK and internationally.

The case for change has been led by a dedicated expert panel of 16 clinical staff from a range of specialities and hospitals. The expert panel's role has been to represent the views and expertise of their peers who deliver these services across the capital.

The project board and expert panel agreed that the experiences of patients and their families must be a driving force for arriving at the best proposals. Given this, the case studies throughout this document are included to help illustrate that without change, patients in London will continue to go without the best-planned care.

Taking account of patients/families needs, the views of clinical staff, and the findings of previous reports, the following key issues are examined in this case for change:

- Fragmentation - there is no link between services and they remain fragmented, as well as fragile in some instances;
- Interdependencies - the critical clinical interdependencies between services are not adequately accounted for;
- Critical mass - there is concern about critical mass with some services not undertaking an adequate level of work to be considered safe practice;
- Workforce and training - there is a shortage in adequately trained specialist staff and overall the workforce is not organised effectively.



Reviewing London's Specialised Children's Services

The Children and Young People's Project established three project workstreams: Primary and community care; secondary care; and specialised children's care (tertiary paediatrics). The tertiary paediatrics workstream was established in November 2008, following the successful joint publication of the primary and community care, and secondary care workstreams: *Meeting the health needs of children and young people: Guide for commissioners*.¹ The guidance sets out a framework to enable significant changes to the way primary and secondary paediatric health services are currently provided.

The intention of the tertiary paediatrics workstream was to explore and address the diverse and fragmented specialised children's services. This document is presented to commissioners by London's paediatric clinical community to make both a compelling argument for service change, and to set out an ambitious way forward for specialised children's services in the capital.

The review of specialised children's services has been clinically led. A clinical lead, Professor Edward Baker, was appointed by Commissioning Support for London's Medical Director, along with a Senior Responsible Officer (SRO), Jane Schofield, Chief Executive of Greenwich PCT, who was also SRO for the wider Children and Young People's project.

Applications for involvement in the review were sought from London's paediatric community and 40 submissions were received. An expert reference group was formed from the successful applicants. The group consisted of 16 individuals from a range of professions and joint chairs were chosen from among its members. The group met at monthly intervals and were engaged with frequently in between times, both individually and as a group, to provide further evidence and clinical input to the development of the documents.

Two stakeholder events were held in 2009 with over 80 commissioners and health professionals to inform the case for change and model of care. A forum held on 5th May 2009 brought together 70 GPs, clinicians, nurses and other clinical staff involved in tertiary paediatric care to discuss the elements that should comprise a new model for delivering tertiary paediatric care in London. The feedback received from the event was collated into a summary paper, and informed the development of subsequent project documents, including the model of care. A second forum held on 2nd October 2009 with 70 delegates discussed and provided feedback on the draft model of care.

In seeking the views of children and young people about their experiences of health services, the Children's and Young People's Project sought their input through a number of avenues including a series of workshops and focus groups. The findings from these workshops have also fed into this document on specialised children's services.

Appendix 1 provides an overview of patient and clinical feedback into the project.

¹ Commissioning Support for London, *Meeting the health needs of children and young people: Guide for commissioners*, November 2009



1 Definitions

1.1 Services focussed on in this document

Children and young people

Children and young people are defined as those who have not yet reached their 18th birthday. In this document, we are abbreviating 'specialised services for children and young people' to 'specialised children's services'.

'Specialised' and 'tertiary' 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*².

However, an August 2008 report, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*³ produced by the Department of Health and endorsed by relevant medical Royal Colleges⁴, acknowledges that an absolute listing of specialised paediatric services is not possible as a paediatric service may become specialised due to the following:

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 specialised expertise;

Other underlying conditions – a relatively straightforward procedure may become specialised when the patient has other serious underlying problems;

Complications – arising from surgical procedures; 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.

This document focuses on a subset of services for children and young people with complex or rare conditions (referred to as specialised or tertiary). Analysis for this document has focused on the 23 specialities that *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*⁵ analysed in detail. These services were selected as key specialised services based on clinical consensus.

² Department of Health, *Specialised Services National Definitions Set (Second Edition); Specialised Services for Children – Definition No 23*, March 2003

³ Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008

⁴ The Royal College of Paediatrics and Child Health, The Royal College of Anaesthetists, Royal College of Physicians, The Royal College of Surgeons of England, Royal College of Nursing, and Association of Chief Children's Nurses.

⁵ Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008



Specialised services

Blood and marrow transplant	Burns
Cardiology	Cardiothoracic surgery
Clinical haematology (non-malignant)	Endocrinology
ENT (airway)	Gastroenterology
Immunological disorder	Infectious diseases
Major trauma (including maxfax and plastics)	Metabolic medicine
Neonatology	Nephrology
Neurology	Neurosurgery
Oncology (including haemato-oncology)	Paediatric critical care
Respiratory medicine	Specialised orthopaedic and spinal surgery
Specialised paediatric anaesthesia	Specialised paediatric surgery
Urology	

Whilst the focus has been on these 23 services, the recommendations and conclusions are for all specialised services for children and young people.

1.2 Population served and patient numbers

London's specialised children's services are an important national resource. They serve the capital's population of eight million and also receive patients from a much wider area. This wider population is not precisely defined, but our analysis indicates that it is up to a further nine million. The effective population served by London's specialised children's services therefore lies between 8 and 17 million.



Children and young people's specialised health services

As a world-class city, there is a significant expectation that London's specialised children's services offer the highest standards of care. The work performed in the capital is, on many counts, provided by both nationally and internationally recognised experts in the field. However, the lack of a planned system for coordinating the delivery of services in London means that these cannot achieve the standards of excellence in care exemplified by internationally recognised services in other cities.

The scattered spread of London's specialised children's services is the result of these developing historically at various hospital sites. This has taken place without a framework to consider the interdependency of these services or how they fit into an overarching system that can serve the entire London population rather than discreet sections. Poor planning pan-London also means that these services do not make effective use of a limited and highly skilled workforce. In most cases, these services do not make the best use of available resources.

Overall, the lack of planning and coordination of specialised children's services has led to service provision that may be excellent in some instances, but equally often provides children and young people with disorganised and fragmented care. This, and a lack of critical mass (a minimum number of procedures undertaken in a particular speciality that is necessary for a service to sustain consistently safe practice), places service quality and sustainability at risk.

Because most specialised children's services are highly dependent on each other, integrated commissioning needs to be at the centre of any service change. Planning each service in isolation does not take account of the interdependencies and often leads to unsustainable service models. The 'one service at a time' approach has failed in the past to bring about effective change and must be avoided in future.



2 Fragmented services

The issue that is most widely recognised as having a detrimental affect on London's specialised children's services is their 'fragmentation'. This refers to the existence of a range of services across various sites in an unplanned and uncoordinated manner. However, fragmentation exists both within *single* specialised services provided at several different hospitals, as well as between *different* specialised services that are provided at numerous hospitals, even though they have critical interdependencies.

The fragmentation of services is of major concern. Whilst services should be modelled around patient's needs first, multiple transfers across departments and sites continue to routinely take place.

- There are small pockets of service provision that are unlikely to be safe or sustainable.
- In most cases the interdependencies between services are not adequately planned / accounted for.
- The workforce coverage is currently stretched across too many sites.

Case study

Patient G is a 12-year-old boy with severe cerebral palsy. He underwent an operation for appendicitis in a local hospital before being transferred, post-operatively, to a high dependency unit at a specialist hospital as his health deteriorated. Patient G continued to get worse and was taken to theatre at the specialist hospital – where adhesions and multiple intra-abdominal abscesses were found and drained, and a colostomy fashioned. He remained very unwell after the operation and required ventilating. An intensive care transfer to another specialist hospital took place where he spent two nights. He was then transferred back to the first specialist hospital as there was no surgical staff availability at the second specialist hospital.

Collecting evidence on the fragmentation of services

In July 2009, a survey sent to the Chief Executives of 28 trusts requested that they identify which of the 23 specialised children's services they provide and indicate if any of these are outreach services, meaning that clinicians from another centre are providing the services on their site.



Figure 1⁶ illustrates the specialised children’s services that acute trusts reported they provided, with in-house services highlighted in blue and outreach services from another centre indicated in green.

Figure 1 – Specialised children’s services provided by 28 acute trusts in London

Trust	1 Blood and marrow transplant	2 Burns	3 Cardiology	4 Cardiothoracic surgery	5 Clinical haematology (non-malignant)	6 Endocrinology	7 ENT (airway)	8 Gastroenterology	9 Immunological disorder	10 Infectious diseases	11 Major trauma (including maxfax and plastics)	12 Metabolic medicine	13 Neonatology	14 Nephrology	15 Neurology	16 Neurosurgery	17 Oncology (including haemato-oncology)	18 Paediatric critical care	19 Respiratory medicine	20 Spec ortho and spinal surgery	21 Specialised paediatric anaesthesia	22 Specialised paediatric surgery	23 Urology
Barking, Havering and Redbridge University Hospitals																							
Barnet and Chase Farm																							
Barts and the London																							
Chelsea and Westminster																							
Ealing Hospital																							
Epsom & St. Helier University Hospitals																							
Great Ormond Street Hospital																							
Guy's and St Thomas'																							
Hillingdon																							
Homerton University Hospital																							
Imperial College Healthcare																							
King's College Hospital																							
Mayday Healthcare																							
Moorfields Eye Hospital																							
Newham University Hospital																							
North Middlesex																							
Royal Brompton and Harefields																							
Royal Free Hampstead																							
Royal Marsden																							
South London Healthcare																							
St George's Healthcare																							
The North West London Hospital																							
The Royal National Orthopaedic Hospital																							
University College London Hospital																							
University Hospital Lewisham																							
West Middlesex University Hospital																							
Whipps cross hospital																							
Whittington Hospital																							

■ In-house services
■ Outreach services from another centre

Source: Project survey of acute trusts, 2009

⁶ The accuracy of information received from the 28 acute hospitals and foundation trusts in response to the survey, can not be guaranteed as definitive. Figure one should therefore be viewed as an 'impression' of services delivered across hospitals, as in some specialties the actual number of providers delivering the service is questionable.



Of the 28 trusts surveyed:

- 17 indicated that they were providing tertiary services for children and young people.
- Nine hospitals indicated that they only provided tertiary paediatric services as an outreach service from another provider.
- Two hospitals did not provide any of the tertiary services identified in the survey.

Of the 17 providers that delivered in-house services, only five hospitals provided 15 or more of the 23 specialised children's services. It is clear from this snapshot of services across acute hospitals in London, that they are indeed fragmented, with few hospitals providing close to a full complement of specialised children's services and many others providing very few, in some cases only one service, in isolation.

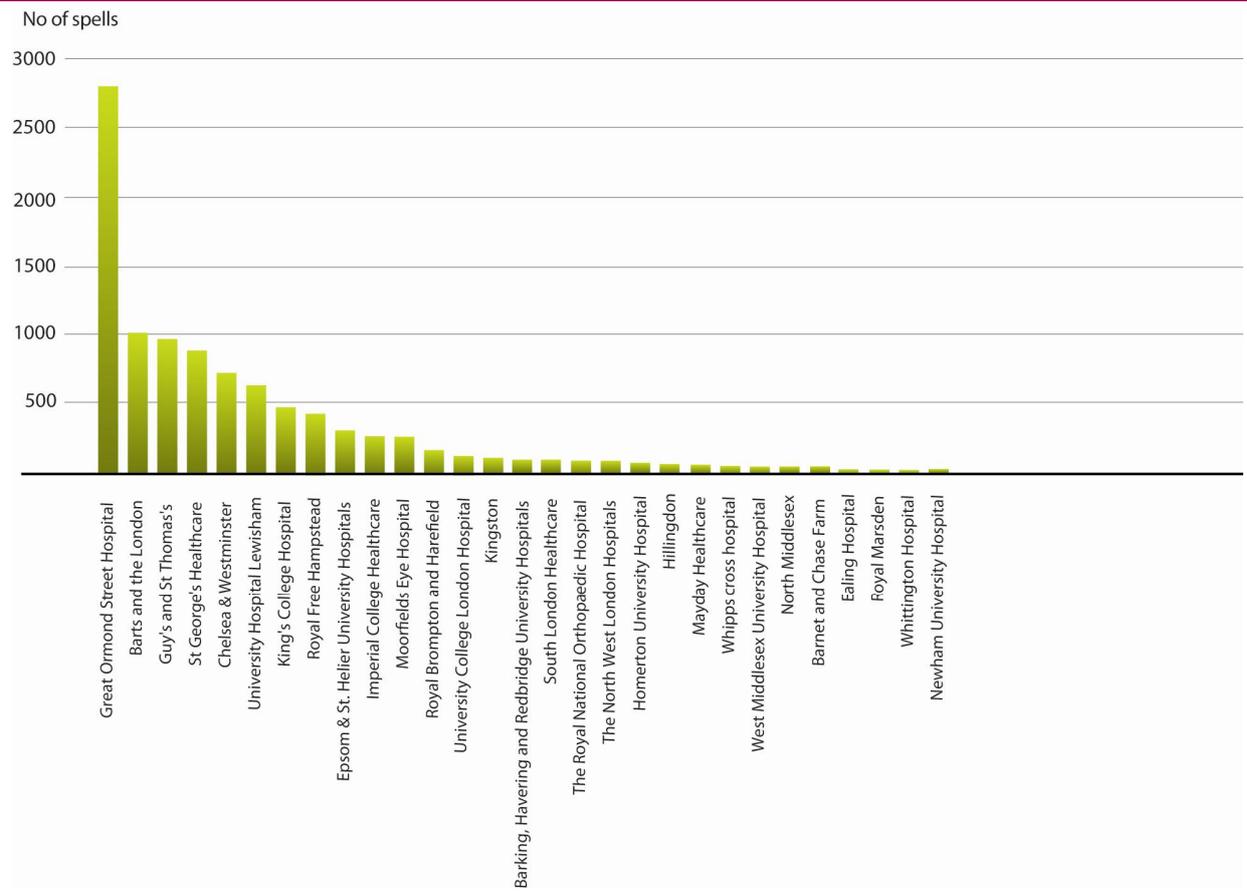
Further, when considering major specialities such as 'paediatric critical care', it is important to acknowledge that this may constitute a hospital delivering Paediatric Intensive Care Unit (PICU) or Paediatric High Dependency Unit (HDU). Clarity for this and other specialities is essential when considering the future modelling of service provision.

Taking account of the above points, the survey results indicate that services are spread across a vast range of providers, which is the major contributing factor to the fragmented service provision that currently exists.

Fragmentation in specialised children's service provision can be further demonstrated in individual specialities, by breaking down specialised activity by provider. Anaesthetics for under two year olds is regarded as a key specialised area. Figure 2 shows a distribution of anaesthetic activity for children under two years old in London trusts. As can be seen, it is estimated that trusts are undertaking between 14 and 2795 spells, which highlights the huge difference in provision across London.



Figure 2 – Anaesthesia for children under two years old treated in London Trusts



Source: HES Inpatients, 2007/08, spells

The following maps (Figures 3 and 4) concentrate on separate individual specialised children's services. Different colours represent various hospitals that provide that specialised service. The colour in each area shows the hospital that the majority of patients from that area attend for that specialised service.

When we map patients' destination for treatment by a service in this way, it is evident that some patients in certain areas will go to one hospital providing the service, whilst others from an adjacent area will go to another. This geographical analysis highlights the lack of effective planning.



Figure 3 – Paediatric orthopaedics provided across London

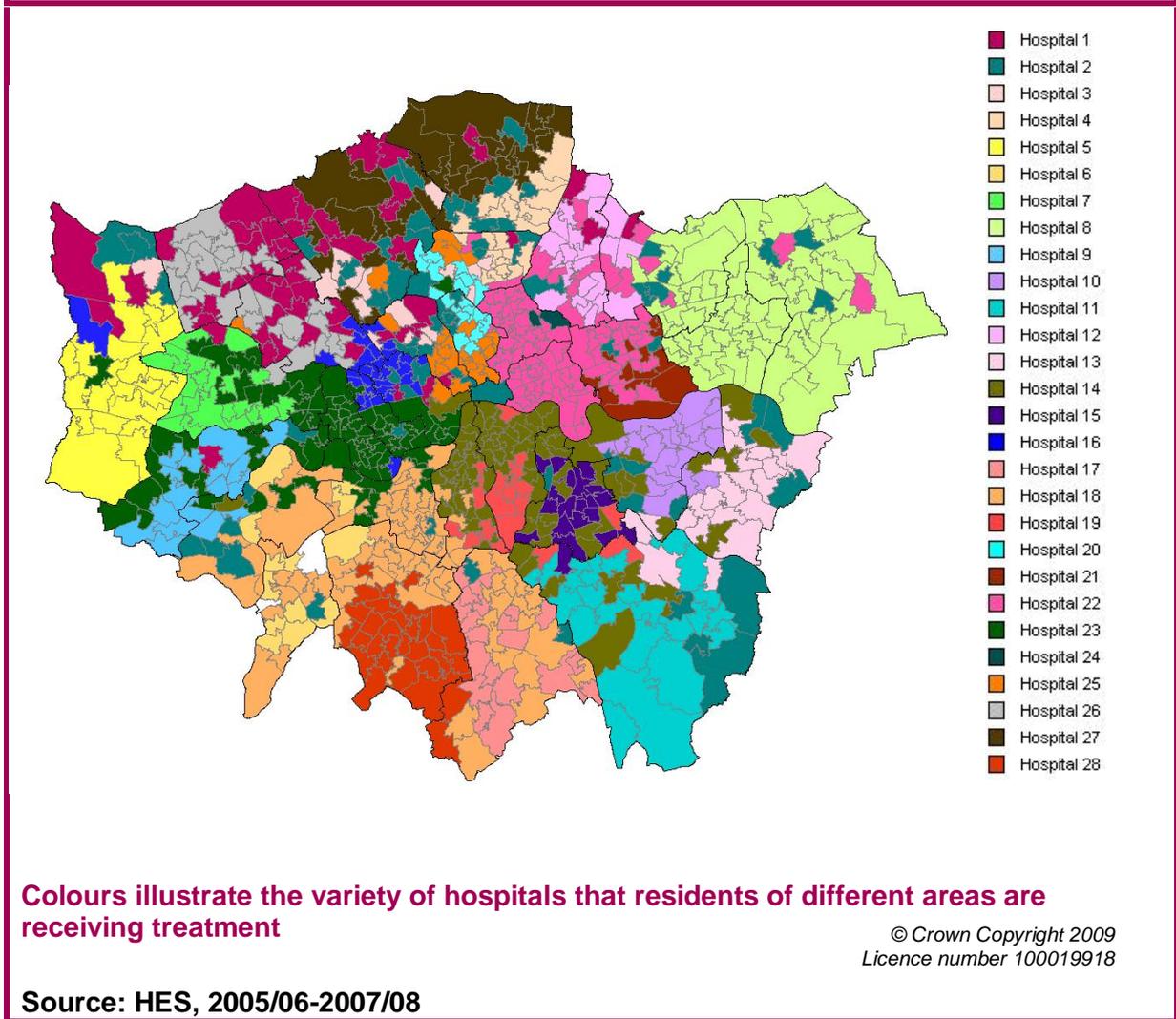


Figure 3 shows that patients across London are receiving treatment at a range of hospitals for orthopaedic care. It appears that there is little planning behind this as there are patchy areas where patients from the same borough are being treated at up to four different providers instead of being referred to a few specialist centres that could possibly cover the majority of work for London.

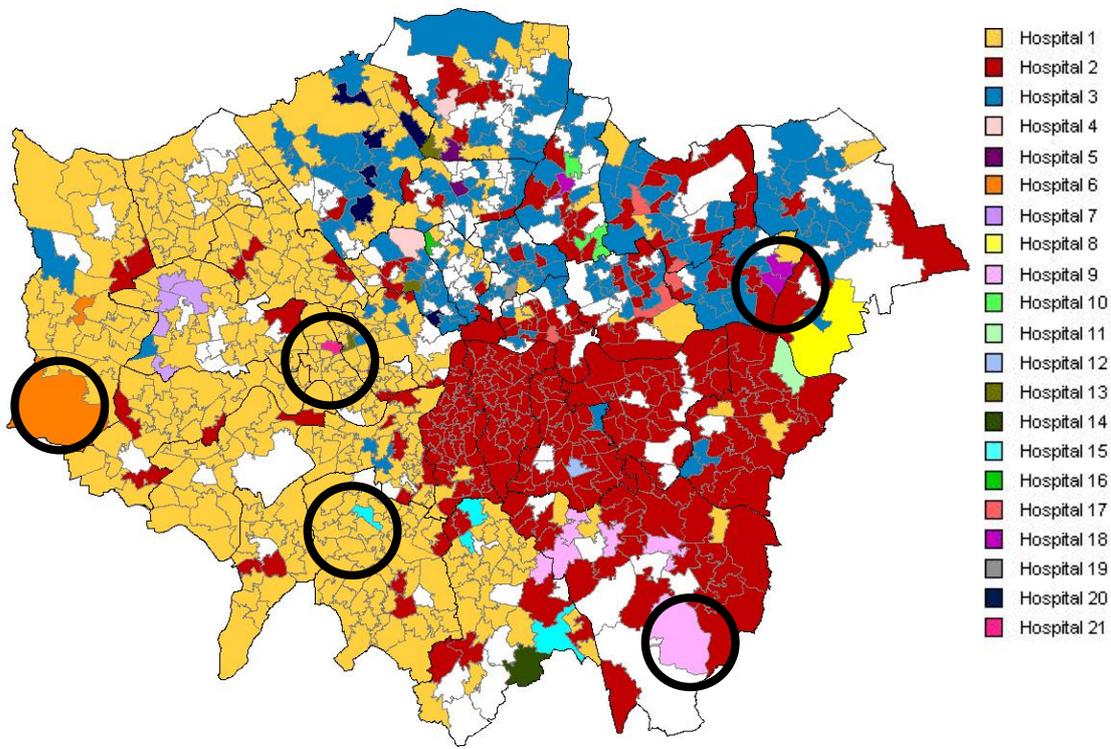
The fragmentation of service provision is likely to be due to the large number of hospitals providing the service and that no hospitals that have been identified to cover the service provision for defined areas of London. Based on provider service quality and outcomes. Further, there are no networks in place to establish guidance about referrals for treatments and manage the workload across a large but defined area.

Figure 4 shows the provision of another specialised service. Most patients in north west and south west London are receiving the specialist children’s service at the ‘yellow’ hospital, while south east London is mainly treated by the ‘red’ hospital, and north central and north east by the ‘blue’ hospital. There are many other patches of colours, indicating that more hospitals are providing the service to small parts of the



population. There are also unexplained areas where patients are being treated at different hospitals from the majority of adjacent areas (black circles).

Figure 4 – Paediatric cardiology provided across London



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Colours illustrate the variety of hospitals that residents of different areas are receiving treatment

The circles highlight examples of areas where the majority of patients should clearly be treated by the same hospital that is covering the majority of the work in surrounding areas.

Source: HES, 2005/06-2007/08

Not only do these individual maps show fragmentation within each specialised service, there is no coherence between these different services. Children and young people with multiple needs will often be treated at a variety of different centres for each specialised children's service. This disorganised picture is consistent across all the specialised services we analysed. Fragmentation is apparent within specialised children's services and between these services. There is little or no evidence that this pattern of service provision has been planned.

Networks could play a key role in ensuring that appropriate paths for referrals to tertiary centres, based on the patients' place of residence, are effectively managed. Such networks could ensure that specialised children's services are coordinated to meet necessary interdependencies across all specialties and that there are appropriate links among the individual specialties across London.



Key messages

Fragmentation of London's specialised children's services is widespread and service provision is largely unplanned. This ultimately has a critical bearing on the coordination of patients' care with a potential need for multiple transfers.

Given the spread of services across at least 18 hospital sites, 'critical mass' is not achieved for specialised children's services across London. This raises major concerns about the safety and sustainability of many of these services.

Fragmentation is of major concern when in the context of a limited high skilled workforce.

Fragmentation could be overcome in a new model of care through:

- Fewer hospitals to provide a comprehensive range of in-house specialised children's services covering defined geographical areas (critical mass/workforce must be considered).
- The establishment of a tertiary paediatric network(s) that would manage the coordination of specialised services in a defined area, including clinical standards, interdependencies, clear pathways, and when to accept and act on referrals.
- All specialised children's services must be provided as part of an integrated tertiary paediatric network.



3 Interdependencies

Case study

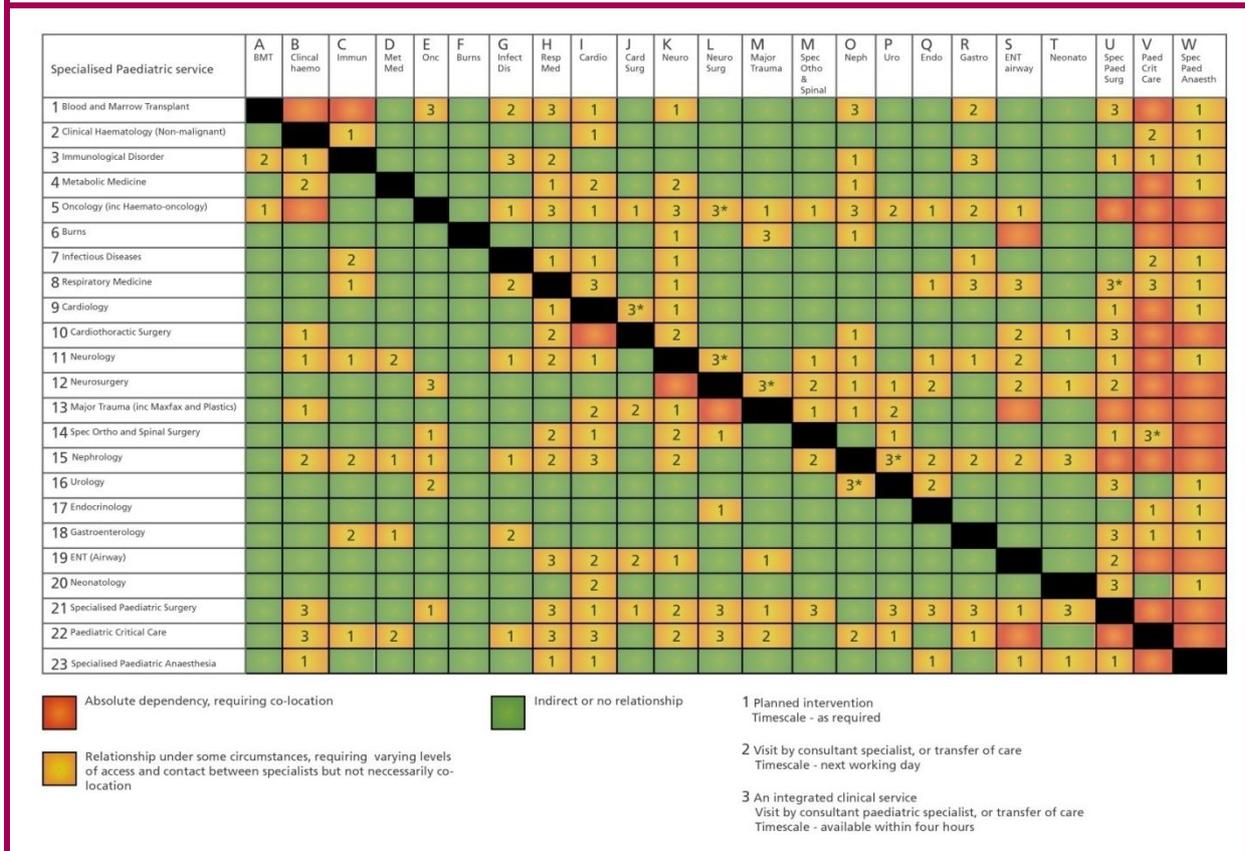
Baby K was born with Down's syndrome and was diagnosed shortly after birth with intestinal obstruction that required surgery. The patient was therefore transferred to a local paediatric surgery centre. There it was noted that the child was in heart failure, so he had to be transferred again to a paediatric cardiology centre at another hospital (which had no paediatric surgery or other paediatric specialities). The child was also found to have severe hypothyroidism and treated back at the first hospital; immunodeficiency that required investigation and management at third hospital; and renal dysplasia that required management at a fourth specialist hospital. A little while later, the child was noted to have a scoliosis, which required a period of assessment at fifth tertiary centre. The family meanwhile were also under a local general paediatrician, and a community neuro-developmental paediatrician, and because of possible seizures, also under a paediatric neurologist. The child is currently being managed by eight medical teams in six separate hospitals.

The 2008 report *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies*, comprehensively set out the argument that interdependencies must be accounted for when planning safe and sustainable specialised children's services. As it stated, services are 'complex and mutually dependent' and therefore to plan these in isolation from each other is not effective.

The report presented for the first time a clinically agreed framework that maps the interdependencies between specialised children's services. This is presented in Figure 5.



Figure 5 – Service interdependency matrix



Service interdependency matrix⁷

The Figure 5 matrix specifies “the nature of relationships between services” through using a colour coding system set out in the key above (note amber is further coded by number).

The survey of 28 trusts, referred to earlier, enabled a degree of analysis of how current configuration of services matches against the inter-dependency matrix. As Figure 7 (on page 20) shows, 14 of these hospitals delivering in-house specialised children’s services are not adequately meeting key interdependencies. This means that they do not provide one or more of the following four key services required to support other services they deliver:

- ear nose and throat (airway)
- paediatric critical care
- specialised paediatric anaesthesia
- specialised paediatric surgery

Figure 6 indicates the services that the acute hospitals surveyed said they do provide (in dark blue). Using the service inter-dependency matrix, only the red relationships between services have been considered – meaning those where there is an ‘absolute

⁷ Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008



dependency' between services and therefore requiring collocation. By way of example, a hospital provides specialised paediatric cardiology without paediatric critical care. According to the service inter-dependency matrix, cardiology has a 'red relationship' with paediatric critical care. Therefore, paediatric critical care has been made red and the number three (for cardiology) recorded in the box, to indicate that cardiology has a dependency on this service. However, once paediatric critical care (numbered 18) is required, this service also is dependent on others, including ENT, specialised paediatric surgery and specialised paediatric anaesthesia. So these have been highlighted in red, as well as the number 18 placed in the appropriate box to indicate the service dependent on it. Then these services themselves must be checked for which other services they are dependent on, and so on.



Figure 6 – Mapping of ‘red relationships’ between existing in house services at acute Trusts in London

Trust	1 Blood and marrow transplant	2 Burns	3 Cardiology	4 Cardiothoracic surgery	5 Clinical haematology (non-malignant)	6 Endocrinology	7 ENT (airway)	8 Gastroenterology	9 Immunological disorder	10 Infectious diseases	11 Major trauma (including maxfax and plastics)	12 Metabolic medicine	13 Neonatology	14 Nephrology	15 Neurology	16 Neurosurgery	17 Oncology (including haemato-oncology)	18 Paediatric critical care	19 Respiratory medicine	20 Spec ortho and spinal surgery	21 Specialised paediatric anaesthesia	22 Specialised paediatric surgery	23 Urology
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University College London Hospital																							
University Hospital Lewisham																							
West Middlesex University Hospital																							
Whipps cross hospital																							
Whittington Hospital																							

■ Specialised service provided at hospital
■ Specialised service has a red relationship with another service, indicated by a number

Source: Project survey of acute trusts, 2009

From this exercise, we can clearly see the gaps where critical interdependencies are not being met at acute hospitals by not having all the services in place to deliver safe care. It is likely that many of these gaps are managed through outreach services, adult services or transfers between sites, however, these arrangements do not meet required standards of care.



Further concerns are highlighted when we consider the interdependencies between services at a pan-London level. The number in each cell in Figure 7 shows how many hospitals do not provide critical and essential collocations on the same site for specific service inter-dependency. For instance, out of all hospitals that provide paediatric ENT, two did not ensure critical interdependency with paediatric intensive care and two with specialist paediatric anaesthesia, while four hospitals do not provide respiratory medicine on the same site.

Figure 7 – Critical and collocated interdependencies for specialised children’s services in London

	1 Blood and marrow transplant	2 Clinical haematology (non-malignant)	3 Immunological disorder	4 Metabolic medicine	5 Oncology (including haemato oncology)	6 Burns	7 Infectious diseases	8 Respiratory medicine	9 Cardiology	10 Cardiothoracic surgery	11 Neurology	12 Neurosurgery	13 Major trauma including 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
1 Blood and marrow transplant	0	2			2										3						2	2	
2 Clinical haematology (non-malignant)																							
3 Immunological disorder							2										1						
4 Metabolic medicine																						0	
5 Oncology (including haemato oncology)	1							1		1	2				4						1	1	1
6 Burns												1							0			0	0
7 Infectious diseases																							
8 Respiratory medicine									6									3	5		1	2	
9 Cardiology										2												1	
10 Cardiothoracic surgery								0													1	0	0
11 Neurology											4											1	
12 Neurosurgery				1							0		0									0	0
13 Major trauma (including maxfax and plastics)												3							2		0	1	0
14 Spec ortho and spinal surgery																						1	1
15 Nephrology								1								0				1	0	0	0
16 Urology															4						0		
17 Endocrinology																							
18 Gastroenterology																						2	
19 ENT (airway)								4														2	2
20 Neonatology																						4	
21 Specialised paediatric surgery	2							2			7		4	4	3	4	3			2		3	1
22 Paediatric critical care	2							1	4			4							2		1		0
23 Specialised paediatric anaesthesia																						4	

 Number of hospitals in London without critical interdependencies
 Number of hospitals in London without essential co-located paediatric services

Source: Project survey of acute hospitals, 2009



The report *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies*⁸ recognised that while interdependencies between different specialised children's services were important, there are also significant interdependency requirements between specialised children's services and secondary paediatric services, maternity services, neonatal services and specialised adult services. For some children there are also important interdependencies with community services and child mental health services.

Key messages

Interdependencies between services are poorly planned for by many hospitals in London, resulting in some critical gaps in services that should be provided in conjunction with others. This affects the safety and sustainability of services and leads to inappropriate patient transfers between sites.

Only three hospitals appear to be meeting interdependencies requirements when considering 'absolute dependency, requiring collocation' (red relationships).

Specialised ENT (airway), paediatric critical care, specialised paediatric anaesthesia and specialised paediatric surgery are the four core services that hold specialised children's services together. There are gaps in provision of these in the majority of London hospitals providing specialised children's services.

Interdependencies between services could be accounted for by:

- ensuring hospitals delivering specialised children's services meet all interdependencies, as per service inter-dependency matrix; and
- ending the provision of severely isolated services that are reliant on out-reach services or adult services to meet inter-dependency requirements.

⁸ Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008



4 Critical mass

In healthcare, a relationship between ‘volume’ of care (numbers of admissions or numbers of procedures) and ‘high quality’ is often assumed to exist. A key question which must be considered when discussing the future provision of specialised children’s services is the relationship of volume to outcome. In addition, whether critical mass achieved through amalgamations of services on one site or through strong networks, would bring about better patient experiences and health-related outcomes.

A recently published report⁹ scrutinised 135 published studies covering a range of 27 surgical procedures or clinical conditions, and looked at both hospital volume and doctor/surgeon volume for the condition studied. The report concluded that most studies indicated there was a direct relationship between volumes and improved outcome. This was most marked in complex or high-risk procedures such as complex surgery and cancer treatment. An important finding from a similar recent report¹⁰ is that the cumulative volume of surgery within a hospital or service has a positive effect on outcome. This is independent of the contribution of individual surgeon volume, and therefore suggests that expertise is developed in organisations or teams who support better outcomes.

Due to factors including the relatively low incidence of serious childhood illness and the diversity of childhood disease, with the exception of paediatric cardiac surgery¹¹ there are relatively few purely paediatric volume-outcome studies.

An independent review of available research literature¹² commissioned by the NHS *Safe and Sustainable* review team found that there is an association between volume and outcome for paediatric cardiac surgery. However, there is not sufficient evidence to make firm recommendations regarding the cut off point for minimum volumes. There is good evidence in a recent report from the USA which suggests that outcomes for paediatric cardiac surgery are consistently better in units treating a larger volume of cases compared to smaller centres¹³.

Berry et al¹⁴ demonstrated in the USA, using the Kids Inpatient Database, that children undergoing tracheostomy in a high volume institution were only half as likely

⁹ Halm EA, Lee C, Chassin MR. *Is volume related to outcome in health care? A systemic review and methodologic critique of the literature.* Ann Intern Med. 2002;137:511–520.

¹⁰ Chowdhury MM, Dagash H, Pierro A. *A systematic review of the impact of volume of surgery and specialization on patient outcome.* British Journal of Surgery 2007;94:145-161.

¹¹ Jenkins KJ, Newburger JW, Lock JE, et al. *In-hospital mortality for surgical repair of congenital heart defects: preliminary observations of variation by hospital caseload.* Paediatrics. 1995; 95: 323-30.

¹² Public Health Resource Unit, *The relation between volume and outcome in paediatric cardiac surgery: A literature review for the national specialised commissioning group*, 2009

¹³ Welke KF, O'Brien SM, Peterson ED et al. *The complex relationship between paediatric cardiac surgical case volumes and mortality rates in a national clinical database.* J Thorac Cardiovasc Surg 2009;137:1133-1140.

¹⁴ Berry JG, Lieu TA, Forbes PW, Goldmann, D.A. *Hospital volumes for common paediatric specialty operations.* Arch Pediatr Adolesc Med 2007;161: 38-43.



to have complications as those in low volume hospitals. Tracheostomy is a common procedure; however placement of a tracheostomy will mean ongoing complex multidisciplinary care. The institute's ability to deliver the care rather than the tracheostomy procedure will have the predominant impact on the outcome.

Smith et al¹⁵ have demonstrated that mortality and adverse discharge disposition rates for paediatric brain tumour craniotomy were lower when the procedure was performed at high-volume hospitals and by high-volume surgeons in the USA, from 1988 to 2000. There were trends toward lower mortality rates, greater centralisation of surgery, and more specialisation among surgeons during this period.

This evidence is cumulatively convincing and we can conclude that there is an association between higher volume and better outcomes, at least for complex healthcare interventions or treatments. This does not mean that excellent outcomes cannot be achieved in lower volume settings, but low volumes may not be cost effective, reproducible or sustainable.

The focus of volume-outcome relationships on individuals (for example, a surgeon,) is overly simplistic¹⁶. Whilst a surgeon may profoundly influence team performance, the whole care pathway from referral to discharge to community care is relevant to ensuring the best patient-focussed outcomes. Many important aspects of care are not considered by studies which focus on mortality or short-term process measures such as length of stay when discussing 'volume-outcome' issues.

Facilities associated with excellent outcomes are therefore most likely to be available or affordable in larger specialised centres. Whilst there is limited data relating specifically to children, there is no reason to suggest that the fundamental requirements for complex healthcare delivery for children are substantially different from those for adults with regard to models, structure or resources.

Regarding the principle of volume and outcome, Figure 8 shows the result of work undertaken to assess the varying levels of activity of a range of specialities at different trusts in London. Data was collected under each specialised service using the corresponding Health Resource Groups (HRGs). Whilst the data is often not a precise reflection of activity and can be difficult to refine to ensure absolute accuracy, it still clearly illustrates there is an unacceptable variance in the volumes of work under specialties delivered at different sites.

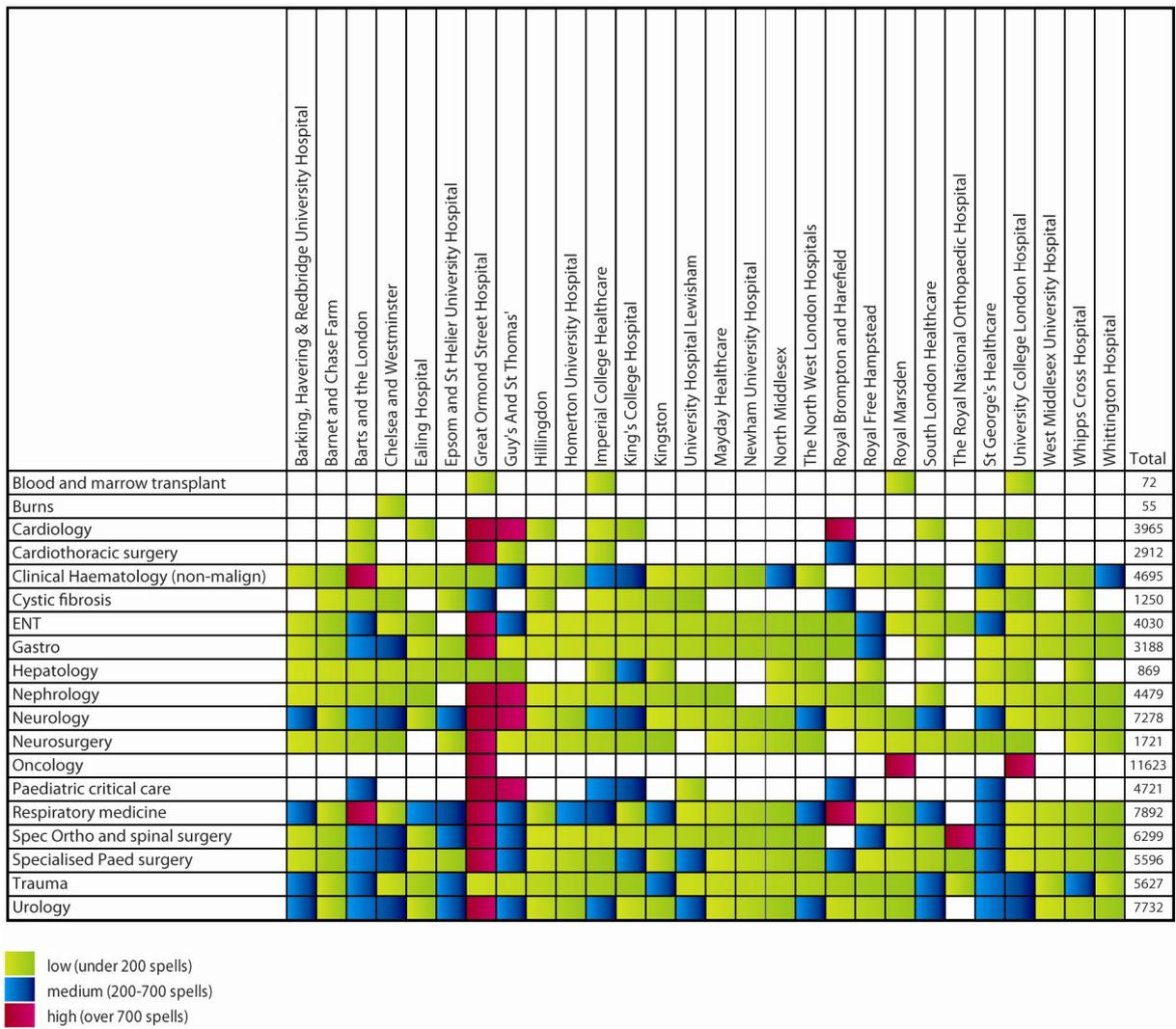
With the spread of the workload across 31 hospitals, it is clear that critical mass in most specialties is not achieved in most hospitals. We cannot be confident that this current distribution of activity is safe and sustainable. Much of the 'medium' and 'low levels' of activity needs to be accumulated in fewer sites to build a critical mass.

¹⁵ Smith ER, Butler WE, et al. *Craniotomy for resection of pediatric brain tumors in the United States, 1988 to 2000: effects of provider caseloads and progressive centralization and specialization of care*, Neurosurgery 2004; 54:553-565.

¹⁶ Carey J, Parker J, Brandeau C, et al. *The "occasional open heart surgeon" revisited*. J Thorac and Cardiovasc Surg 2008 135, 1254-1260



Figure 8 – Specialised activity levels for 0-17 year olds treated in London Trusts



Source: HES 2007/08, London SCG



Key messages

1. Levels of activity for specialised services vary across all sites – some providers perform large amounts of work, others perform small numbers, raising concern about safety and sustainability.
2. Only one or two providers perform large volumes of work across all specialties.
3. A few providers specialise in one particular service.
4. Specialists delivering low volumes of work within specialties in many trusts may not be able to maintain an effective skill level.
5. Organisation of services and workforce is not designed around the principle of critical mass.
6. Higher volumes of work are associated with better outcomes.
7. Workforce is stretched as workload is spread across too many sites.

Critical mass could be accounted for by:

- Assessing what would be an appropriate critical mass for specialties, as well as within a tertiary service.
- Ending clinically defined inappropriate low volumes of activity.



5 Workforce and training

The *London Children and Young People's Pathway Group report*¹⁷ produced in May 2008 was the culmination of work undertaken by a multi-agency and multi-disciplinary group of professionals working with children and young people from across London. Highlighted concerns were:

- workforce shortages in key specialties and European Working Time Directive requirements;
- the challenge of improving the experience profile of clinicians, with the requirement to undertake a sufficient minimum number of procedures to maintain sustainable, safe practice;
- re-configuration of adult services which fails to take account of links to specialised children's services;

Ensuring the effective arrangement of the medical workforce to best support specialised children's services is a crucial consideration for delivering improvements, especially regarding the safety and sustainability of services.

Research presented by the Children's Surgical Forum at the Royal College of Surgeons of England¹⁸, which indicated that amongst surgical specialties there has been an increase in work at tertiary centres, while there has been a decline at district general hospitals. As a result, specialised children's services are conducting an increasing number of routine surgical procedures.

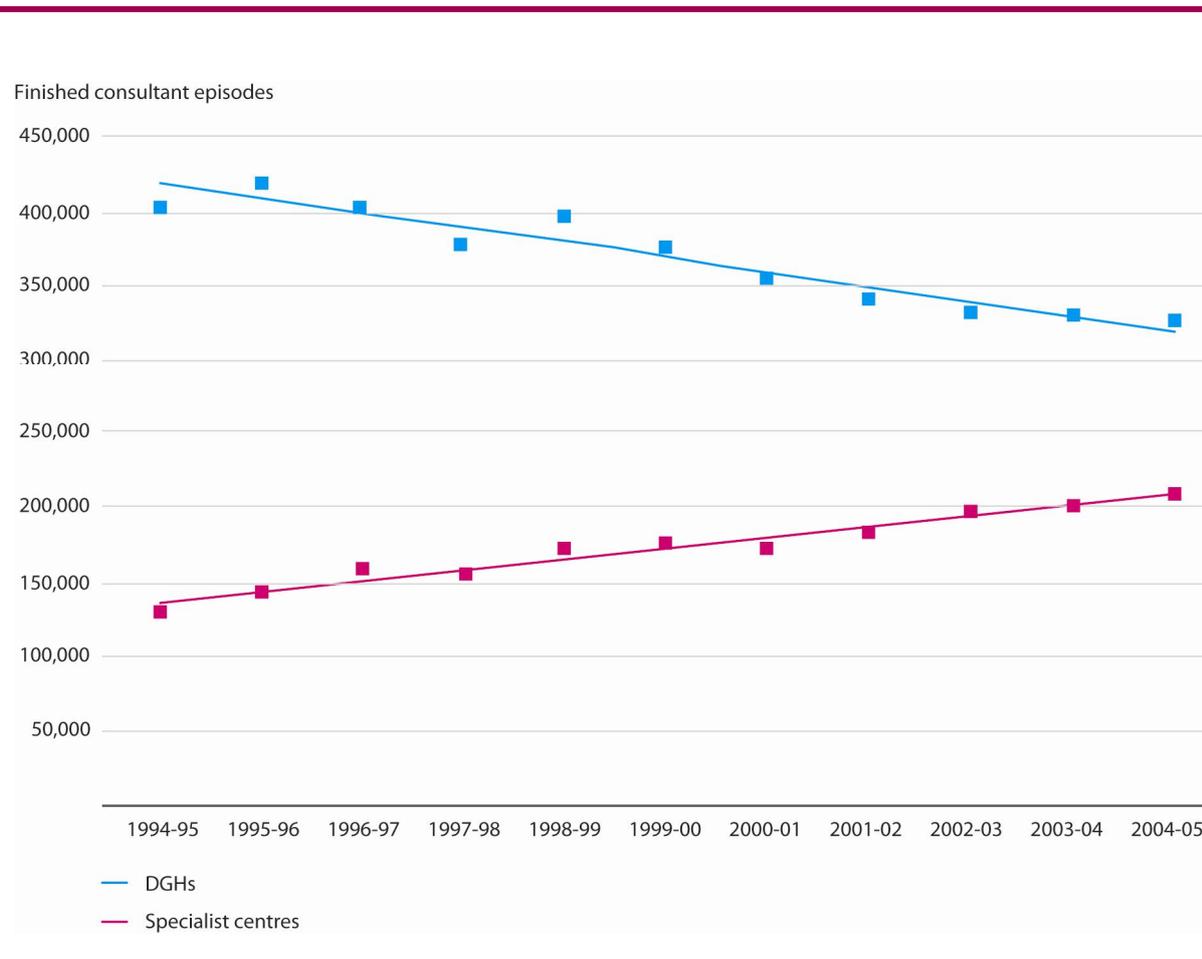
Figure 9 shows that in each year from 1994 to 2005 the number of operations carried out on children and young people across England in local hospitals decreased by approximately 9,700. This trend is concerning, considering that increasing work volumes at tertiary centres is jeopardising the capability of surgeons and anaesthetists at local hospitals to maintain optimal and safe skill levels.

¹⁷ Commissioning Support for London, *Final Report of the London Children and Young People's Pathway Group*, May 2008.

¹⁸ Children's Surgical Forum, Royal College of Surgeons of England, *Surgery for Children: Delivering a First Class Service*, July 2007



Figure 9 – Work trends in specialist hospitals and district general hospitals



The patient workload of tertiary centre surgeons should consist of those with complex and rare conditions, rather than routine elective or emergency surgery, as the latter can be treated effectively in a major hospital. Accordingly, there must be a more rigid assessment and standards in place to ensure that work referred to tertiary centres is appropriate, and work carried out in each setting of care is clear and adhered to.

It is well known amongst clinical staff that the current configuration of the workforce around an unplanned system of specialised children’s services equates to inefficiencies and risk. *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*¹⁹, emphasised the concerns about aspects of the specialised medical workforce. These are:

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

¹⁹ Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008



together with an outreach programme. This will mean fewer in-patient units for many specialties and a requirement to develop and strengthen clinical networks.

Working time directive (WTD) – providing the 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.

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.

For nurses, the following needs to be considered:

- Children and young people requiring tertiary paediatric care should be looked after by nurses and allied health professionals who are experienced and trained in the care of children (registered children's nurses, paediatric physiotherapists and occupational therapists).
- It is anticipated there will be a future shortage of experienced clinicians. This will be due to more experienced staff reaching retirement with less staff to replace them leading to a decrease in training focused specifically on paediatrics.
- More centralised specialised children's services can promote better outcomes of care for children through care being delivered by experienced staff at core sites, with community outreach provided by both specialist and generalist paediatric nurses.

Key messages

1. The current medical workforce is spread across too many sites. This is not sustainable given that there are already significant shortages in most paediatric specialties.
2. Doctors in training will require a larger caseload to develop their skills and will need to work in larger teams.

There is a need to:

- ensure the most efficient use of resources in the provision of services; and
- determine an appropriate organisation of the workforce that would take account of training needs.



6 Academic programmes

Clinical excellence and academic excellence are mutually interdependent. Plans to improve specialised services for children in London must take into account education and research if they are to deliver clinical excellence. There is a general perception that academic paediatrics is underdeveloped nationally^{20,21}. There are many causes for this, but fragmented and poorly organised clinical services without critical mass, is one of the principal reasons London academic paediatrics does not achieve its full potential. Effective clinical research programmes require a concentration of clinical work and scientific expertise, which cannot be achieved in small dispersed services. Successful education programmes require long-term investment in the workforce and a strong clinical base. Excellent educational programmes, undergraduate and postgraduate, are critical in attracting the highest quality staff into children's services.

Strong academic programmes drive clinical innovation and clinical excellence. They help attract the highest quality staff and ensure that the future workforce is trained to the highest standards. They will ensure that children and families in London have sustainable services of the highest quality and access to the latest developments in healthcare. Well-coordinated specialised services of sufficient critical mass provide the basis for academic development.

Key messages

1. There is a link between well planned clinical services and successful research and education programmes.
2. Academic paediatrics is underdeveloped in London and nationally.
3. Effective planning of services will support academic development, which will help drive clinical excellence.

Academic provision could be accounted for by:

- Specialised children's services networks planning and coordinating clinical services, as well as academic programmes.

²⁰ Weaver LT. *Academic Paediatrics*. Archives of Diseases in Childhood 2005; 90:991-992.

²¹ Winyard PJD, Cass HD, Stephenson TJ, et al. *Developing critical mass and growing our own academics*. Archives of Disease in Childhood 2006; 91:1027-1029.



7 The needs of patients and their families

In seeking the views of children and young people about their experiences of health services, the Children's and Young People's Project sought their input through a number of avenues. This included:

- A workshop with young people brought together through collaboration with the Greater London Authority, DareLondon and the UK Youth Parliament.
- Reviewing research undertaken by Great Ormond Street Hospital that involved collecting young patients' views.
- A workshop with members of the Evelina Pride group.

Overall, what has been most apparent from this engagement work is that children and young people value both the expertise and friendly nature of clinical staff.

This point is particularly significant as it highlights that for children and young people their experience of the health service starts first and foremost with their interactions with clinical staff. Furthermore, it suggests that effective paediatric care relies heavily on the availability of doctors and nurses who have been specifically trained in how to relate to and meet the needs of children and young people.

It is also evident that a strong relationship with one hospital and a group of clinical staff that knows the patient, their condition(s) and medical background in sufficient detail is the most favourable arrangement from the patient's perspective.

Through care being coordinated around the patients needs, they are able to build the appropriate relationships with staff in the one place, which in turn provides them with a greater sense of being in control of and educated about their circumstance of health. When their care is managed across a number of teams or sites, they feel the added responsibility of having to carry and re-communicate their medical background, which understandably creates a degree of anxiety and frustration.

"I would always prefer to be seen by one doctor who has got to know me. I have quite a rare condition and people rarely read my notes properly. They are too long! Knowing a bit about me saves a lot of time and misunderstanding. I'm also more confident about speaking up for myself around people I know." *Patient and attendee at Evelina Pride group workshop*

It is important that a new model of care for specialised children's services takes account of what avenues exist to ensure that commissioners and providers maintain an ongoing and effective dialogue with children, young people and their families. This will mean the quality of service and opportunities can be seized to better meet the care needs of patients first and foremost. The voice of children and young people must always be present in the discussion about how to best plan their care.



Services for adolescents

Specialised services for adolescents have received little consideration until recent years. The importance of age-appropriate care for children and young people, and the effective transition of care of adolescents into adult services has been acknowledged by the expert panel. Accordingly, it has been recognised that age-appropriate care is poorly developed. While there are isolated examples of good practice, most children growing up with long-term conditions are not cared for in age-appropriate services and many appear to face a poorly coordinated and uncertain transition to adult services.

Planning of specialised paediatric services must take into account the needs of children of all ages including adolescents, and the need for a managed transition to adult services. Services should be of sufficient size to have the resources in place, in terms of physical capacity and workforce, so that age-appropriate care can be provided for children and young people of all ages.



8 Conclusion – taking this forward

The intention of this case for change has been to present a strong and logical path towards the development of a new model of care for London's specialised children's services.

As identified in this document, a new model of care could incorporate the following elements to drive much needed improvements:

1. Fewer hospitals should provide a more comprehensive range of in-house specialised children's services, and cover defined geographical areas.
2. Establish a tertiary paediatric network(s) that coordinates specialised services in a defined area through the provision of clear pathways based on clinical standards and interdependencies.
3. All specialised children's services could be provided as part of an integrated tertiary paediatric network.
4. Ensure hospitals delivering specialised children's services meet all interdependencies, as described in the service inter-dependency matrix.
5. End the provision of severely isolated services that are reliant on out-reach services or adult services to meet critical clinical interdependencies.
6. Assess what would be an appropriate critical mass for individual specialties, as well as within a tertiary service.
7. End clinically defined inappropriate low volumes of activity.
8. Ensure the most efficient use of resources in the provision of services.
9. Determine an appropriate organisation of the workforce that takes into account training needs.
10. Specialised children's services networks to plan and coordinate clinical services, as well as academic programmes.
11. Effective collaboration with maternity services, neonatal networks, secondary paediatric care networks, child mental health services, and community services.
12. Ensure age appropriate care is provided including managing the transition of children with long-term conditions to adult services.

A model of care will propose to commissioners, a new framework, from those in London's tertiary paediatric community, for improving specialised children's services and outline how commissioners and providers can take forward its implementation. Proposals will take account of the developments emerging from the London Specialised Commissioning Group and those at the national level. Furthermore, proposals developed for specialised children's services



will integrate with that which has already been developed for primary, community and acute children's services.

A new model of care should be ambitious, and significant changes will need to occur. This process is not about jeopardising the excellence that already exists. Instead, it is to follow through on what London needs so that patients and their families can receive the best planned specialised children's care. It is about seizing an important opportunity to propel London towards being at the forefront of international standards – to lead the way and be the key example of excellence in specialised paediatric care.

For the past decade or more, London's specialised children's services have stood still and while change has been needed it has not been achieved. Numerous reports have recommended that these services urgently move forward into a better planned system of care. We have received a clear message from clinical staff – to stand still is not an option. Commissioners, providers and clinical staff must therefore work collaboratively to support the realisation of the changes that are essential, achievable and must be taken forward now.



Part two: A model of care



1 About the model of care

The recommendations from the July 2001 Kennedy Report²² into children's cardiac surgery in Bristol, disturbingly, have not yet been fully implemented some nine years on. In particular, the report contained the following important statement:

'Historically, it is a feature of the provision of healthcare in hospitals that the care is organised around the needs of the organisation or the healthcare professionals. This must change. Strategic guidance is needed ... as to which type of organisational model would best achieve 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.'

The objective of this model of care is to ensure patients receive the highest quality care, delivered by safe and sustainable specialised children's services, which are organised in an integrated manner based on standards of best practice.

The vision for patients of tertiary services is that they are able to easily access a seamless system of specialised services, which delivers the best possible patient experience and ensures the best achievable outcomes.

This model of care has been devised with input from the clinical expert panel, commissioners and health professionals at a stakeholder event, and patients and families at a series of workshops.

The 12 recommendations outlined in the case for change provide a robust steer for the development of a model of care. These are ambitious when considered against the current landscape of service provision. However, the work is grounded in a strong evidence base set out in the case for change to deliver a new system for specialised children's services that enshrines best practice.

Taking account of these recommendations, the expert panel articulated the following guiding principles for a model of care:

- Services are designed around the best interests of children and young people, as well as their families;
- All services are linked in an effectively planned system of care;
- All services are demonstrably safe and sustainable;
- The highest quality of care is achieved not only through clinical expertise but a clear and robust care pathway for patients;
- Resources are concentrated and more effectively utilised, especially the limited highly skilled workforce;

²² Bristol Royal Infirmary Inquiry, *Learning from Bristol: The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 – 1995* (The Kennedy Report), HM Government, July 2001



- Overall, providers work collaboratively to ensure London is in a position to lead and redefine world class clinical, education, training and research standards for specialised children's services.



2 Context for a new model of care

While the case for change acknowledged a number of current strengths within specialised children's services, it also revealed that commissioners and clinical staff are unequivocally of the view that major and urgent changes are needed in this area of paediatric care. This is especially true when the safety and sustainability of several specialised children's services across London is examined.

2.1 A model of care for primary and secondary paediatric services

At the same time as developing the specialised children's services' case for change and model of care, the programme has also developed *Meeting the health needs of children and young people: guide for commissioners*²³ for primary and secondary paediatric health services in London. The guidance sets out a framework to enable significant changes to the way primary and secondary paediatric health services are currently provided.

The guidance recommends rationalising the number of paediatric inpatient beds on to less hospital sites and the creation of an ambulatory care service at the front end of nearly every hospital in London. This service will take the form of urgent care services open 24/7 and paediatric assessment units open between 12 and 24 hours depending on the hospital and local need. There will also be a shift of much more planned care activity into the community, particularly outpatient appointments.

Through centralising paediatric inpatient units onto less hospital sites with all non-elective surgery performed here and a requirement that these hospitals develop HDU capacity, this will support a reduction in the fragmentation of tertiary services. It is expected hospitals that no longer have paediatric inpatient units will no longer carry out tertiary paediatric care.

2.2 Learning from other reconfigurations in major cities

Considering the unique and complex nature of London, particularly its culturally and diverse population, the expert panel identified it was not feasible to adopt an existing model of care from another major city and apply this to the capital.

Essentially, the case for change articulates what is required of a model that would best suit London. However, as part of the process of designing a new care model, the expert panel sought insight from reconfiguration work that has taken place in specialised children's services in other major international cities/countries. Reconfiguration work in Paris, Dublin, Manchester, Scotland, and the model used at SickKids in Toronto (which is recognised internationally as a leading paediatric centre), were investigated.

²³ Healthcare for London programme, *Meeting the health needs of London's children and young people*, November 2009



The key principles consistent within each major city's configuration of specialised children's services are:

- Improving quality of care through greater emphasis on understanding the patient's experience and meeting their needs.
- Planning of services on a pan-city basis.
- Rationalisation of services to improve integration, achieve critical mass, address shortages in workforce and improve cost effectiveness across the whole system of care.
- Focus on achieving effective critical mass in services to ensure safety and sustainability.
- Emphasis on taking account of interdependencies between services and accounting for these when planning the system of care.
- Creation of networks to ensure services and providers are linked to achieve stronger care pathways, enhanced communication, data sharing, and joint work.
- Importance of delivering age appropriate care and smooth transition to adult services.
- Where possible, delivering care closer to home within local settings.

Having regard for the political climate and its influence is important, however, at the outset, this should not constrain what needs to be achieved to reach standards of best practice.

It is recommended that the proposed care model is implemented in two phases. Details regarding what should occur in phase one and two are outlined in the following chapters.



3 Tertiary paediatric networks - Linking and integrating safe and sustainable services

It is proposed that implementation is phased over a three year period. Phase one will begin in 2010/11 for 18 months whereat phase two will be implemented from mid 2012 over a second 18 month period.

Key milestones in phase one:

- Ending of services that are clinically determined as not being safe, sustainable or are severely isolated, and appropriately integrate this clinical expertise into networks.
- The development of commissioned provider networks, referred to as 'tertiary paediatric networks'.
- Identifying other providers within networks who are able to deliver tertiary services.
- Creation of network boards.
- Development of strategies within networks to establish a clear care pathway for the network, as well as individual specialties.
- Establishment of protocols for referral of patients to networks, transfers and transport, as well as discharge to secondary or primary care settings.

Key milestones in phase two:

Phase two will focus on the tertiary paediatric network's achieving leadership in international standards of best practice. This will be achieved through building on the outcomes of phase one with an emphasis on:

- Advancing the further rationalisation and consolidation of services pan-London, to meet critical interdependencies.
- Reconfigure the patient pathway so that referral patterns ensure patients are treated within their appropriate geographical area.
- Ensuring sustained quality and improvement of services, focussing on clinical outcomes, patient safety and experience.
- Further workforce planning focussed on the needs of tertiary services and especially the development multidisciplinary teams.
- Enhancing training and education
- The development of internationally competitive research programmes.



3.1 Development of commissioned provider networks

In recognising the need to overcome the fragmentation of services, the expert panel agreed the most effective means of ensuring these are linked, appropriately planned and coordinated would be through all specialised services being delivered within commissioned provider networks. This recommendation is consistent with the 2010 review authored by Sir Ian Kennedy, which states *“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.”*²⁴

3.1.1 Number of networks

Deciding how many networks, covering differing geographical areas of London, was considered in detail at several expert panel meetings, and with further input from over 80 commissioners and health professionals that attended a stakeholder event held on 2 October 2009.

Expert panel discussions considered the following four options:

	Positives	Negatives
One Network	<p>Would ensure the network could provide a critical mass in all services</p> <p>Would provide integration of services to best meet clinical interdependencies</p> <p>Would provide strong opportunities for academic and educational development</p>	<p>Would be larger than any comparative international service</p> <p>Would reduce the opportunities for patient choice</p> <p>Would remove any element of competition</p> <p>Might reduce resilience of overall London provision for these services</p>
Two Networks	<p>Each network would be big enough to provide critical mass in all services</p> <p>Networks would be big enough to provide all clinical</p>	<p>Does not fit with sector model of London provision</p>

²⁴ Kennedy, Ian, *Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs*, September 2010



	<p>interdependencies</p> <p>Would provide an element of patient choice and some competition to drive clinical standards and innovation</p> <p>Would provide better resilience</p> <p>Large enough service to support strong academic and educational programmes</p>	
Three Networks	<p>Each network would be minimal size to meet critical mass and interdependencies</p> <p>Would provide patient choice and competition</p> <p>Would provide resilience</p>	<p>Unlikely that all networks would meet the critical mass and interdependencies satisfactorily</p> <p>Would not be easy to implement in the light of current distribution of services</p> <p>Does not fit with London sectors</p>
Four Networks	<p>Minimal change option</p> <p>More closely aligns with London's sectors</p>	<p>Very unlikely that all networks would meet the critical mass and interdependencies satisfactorily</p>

Having considered the above four options, the clinical expert panel recommended that two networks would be most appropriate for managing all specialised children's services across London. One network would cover North London, and the other South London. The proposed North / South configuration reflects the networked relationship already emerging in North and South London, respectively. It also reflects the geographical coverage of the two PICU transfer and retrieval services provided for North and South Thames.

The preferred two network option was based on the following:

Critical interdependencies: Importantly, a two network structure would be large enough to ensure that all critical interdependencies are met. Specialised ENT (airway), paediatric critical care, specialised paediatric anaesthesia and specialised paediatric surgery are the four core services that hold specialised children's services together. Two networks would ensure at least one hospital in each network delivering specialised children's services that meet all interdependencies.

Population and coverage: The coverage of each provider network and the tertiary paediatric services provided within it should match the population requirements. London's tertiary paediatric services serve a total



population of eight million in London and a population from outside of up to a further nine million. International evidence indicates that leading tertiary paediatric centres serve a population between three and a half and five million and in some instances up to 12 million²⁵.

This evidence suggests that the London population of eight million would support a maximum of two tertiary paediatric networks if the work was evenly distributed between them. The flow of patients from outside London would ensure that both networks would consistently meet the minimum critical mass of activity.

A larger sized network provides overall patient benefits through central efficiency gains, easier service developments and introduction of new treatments, an increased number of patients entered into clinical trials and easier internal benchmarking of clinical performance.

Three networks would be likely to meet the critical mass of activity, but this would be dependent on the inflow of work from outside London. If four networks were established there would be a considerable risk that one or more of these would not consistently achieve a critical mass of activity.

Tertiary paediatric activity: Fewer, larger provider networks, covering a larger geographical area and population, would allow a higher proportion of London's paediatric patients to receive their care within a single network. This should result in more consistent high quality care for more patients across a larger set of community types as a higher proportion of tertiary paediatric services would be managed and delivered by a single provider network. Fewer, larger provider networks would afford the opportunity of an increased managerial oversight of patient outcomes and could also lead to management efficiency savings.

3.1.2 Composition and function of tertiary paediatric networks

The following details the composition of tertiary paediatric networks. Each will have:

- a provider identified as the lead provider;
- a number of other providers that will deliver agreed tertiary paediatric services as part of the network;
- clear links with secondary and primary care paediatric services and mental health, in the network's geographical area;
- a clear working relationship with relevant commissioners of children's services.

²⁵ McKinsey & Company Inc (for the Health Service Executive, Ireland), *Children's health first: international best practice in tertiary paediatric services: implications for the strategic organisation of tertiary paediatric services in Ireland*, February 2006

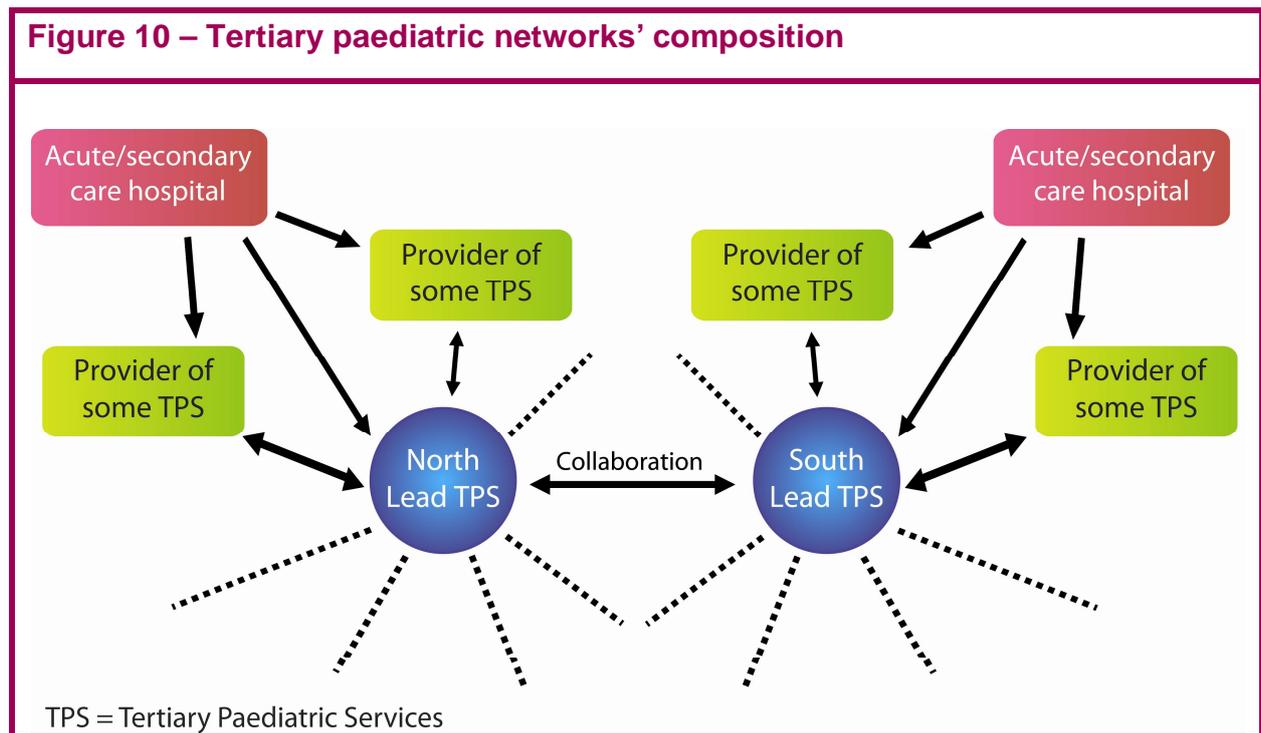


The function of networks will be:

- Establish an effective working relationship with, and define communication and reporting protocols with commissioners.
- Implement a process to assess and identify services in networks that are clinically determined as not being safe, sustainable, or are severely isolated. Provide the London Specialised Commissioning Group (SCG) with appropriate advice and proposals for how this activity and clinical expertise can be integrated into existing safe and sustainable services within the network.
- To provide and co-ordinate all the tertiary paediatric services for patients within a defined geographical area.
- To identify services where it is appropriate to be delivered on a site that is not the lead provider and make recommendations to commissioners.
- To manage clear clinical care pathways for each specialist service and ensure that care for children requiring multiple services is fully coordinated.
- To ensure that services are provided equitably across the geographical area served, providing services locally where possible and centralising only where clinically necessary.
- To ensure clear links with secondary and primary care paediatric services and mental health, in the network's geographical area.
- Where necessary - for very rare conditions - to work with providers outside the network to ensure children have access to these services.
- To collaborate with the other London tertiary paediatric network to ensure comprehensive and equitable provision of services and to ensure that, where appropriate, a pan-London approach is taken to planning individual services.
- To support the development and delivery of a comprehensive range of tertiary service education, and training for the clinical workforce.
- Work with academic institutions in London to encourage the development of related clinical research programmes and the translation of research findings into clinical innovation.
- To improve data gathering and its quality, achieve standardised data sets and shared records.
- To monitor and report on the quality of clinical care and clinical outcomes across the whole network.



Figure 10 sets out the composition of each tertiary paediatric network.



3.2 Lead tertiary paediatric service (lead provider)

A tertiary paediatric network would include a lead provider to:

- deliver a comprehensive range of tertiary paediatric services;
- ensure all of their services meet critical mass;
- meet critical interdependency requirements as detailed in the service inter-dependency matrix²⁶;
- provide the majority of tertiary beds for the network;
- work closely with other identified tertiary paediatric services within the network.

Children with complex needs requiring multiple tertiary services will generally be cared for at the lead provider. Children with less complex needs may be cared for at one of the other providers within the network. Care pathways will need to be developed within networks to clearly define where a child should be treated within the network.

²⁶ Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008



3.3 Other providers of tertiary paediatric services

Other providers in tertiary paediatric networks will deliver one or more tertiary paediatric services provided they:

- achieve critical mass
- meet critical interdependencies
- are equipped to offer the service(s) in collaboration with the lead provider.

It will be important for tertiary paediatric networks to ensure that duplication of specific services only occurs when there is agreement that it is clinically necessary to manage the workload across the network. In agreeing the duplication of services, the network must also have regard for ensuring that an appropriate critical mass is still maintained within each service delivering the same specialty.

While there will be a lead provider within each network, all providers should have equal responsibility in the network to engage in productive discussions and decisions about service provision across the whole of the network. The lead provider for the network will not always be the lead provider for individual tertiary paediatric specialties. In some cases it will be entirely appropriate to deliver services on another networked site.

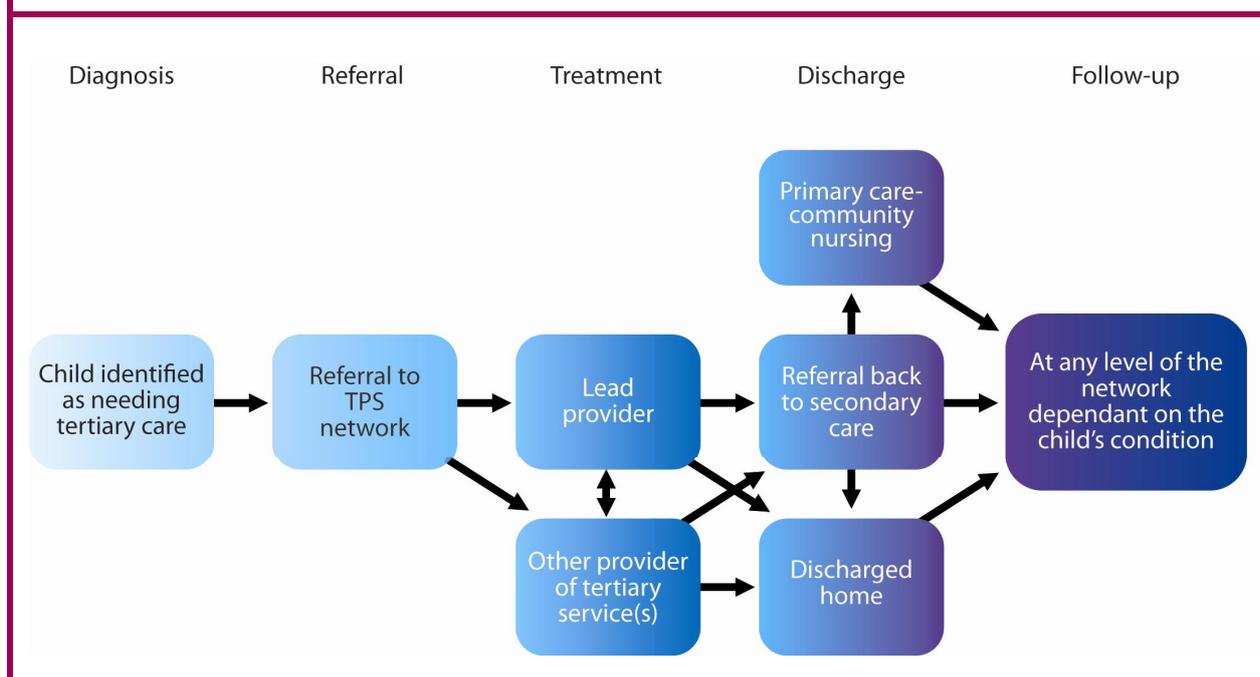
In this respect, all providers within the network have the capacity to influence the structure of service provision throughout the network so standards of best practice are reached.

3.4 Shared care and follow up

- The network will establish shared care arrangements and outreach clinics with secondary care hospitals for ongoing care and follow-up.
- For appropriate services links will need to be established with community services, particularly community paediatrics and community nursing teams, as well as mental health services, education and social care to ensure children receive the necessary ongoing support.
- Follow-up may be offered at either the lead provider, other providers within the network or in outreach clinics provided by the network at secondary care hospitals, as appropriate to each individual condition.



Figure 11 – Basic care pathway for a tertiary paediatric network



3.5 Patient and family representation within networks

The network board will be expected to monitor and report to the commissioning body on patient / family satisfaction with the service provided. It will also be expected to consult with children and families about proposed changes/improvements in service provision.

The following are suggestions of the ways needs of patients and families should be represented in the networks that were identified at the stakeholder event on 2 October 2009

- Involve patient/user representatives, primarily those linked to existing patient groups, charities and advocacy groups, so that they are able to offer a broad range of views and exchange information.
- Ensure representation reflects the diversity of the population.
- Network boards need good and direct links with patient associations.
- Important to discover needs rather than demands through effective consultation mechanisms.
- Need to enable patients to feel as though they can change things within the network.
- Build in real time user feedback into the process, as well as have a standard format for feedback.



- Need to develop an action plan based on feedback and demonstrate what tangible changes have resulted.
- Regular stakeholder engagement days.
- Develop useful information that can be distributed through a variety of mediums.
- Patients and families must be involved in the implementation of any changes.

Given the above, it is proposed that network boards should consider how patient/family groups can best participate in their meetings and/or work.

3.6 Transparency and high quality information

At the heart of the model of care is the collection and publication of high quality performance information. *Liberating the NHS* promises an ‘information revolution’. Providers will be under clear contractual obligations, with sanctions, in relation to accuracy and timeliness of data for use by commissioners and the public. It is vital that commissioners have access to high quality, contextualised data in order to make effective commissioning decisions. As more sophisticated measures are developed, quality metrics should be based on outcomes rather than inputs or process measures. The recently published *Transparency in Outcomes - a framework for the NHS*²⁷ is a consultation document to support the DH directive to refocus the NHS on the outcomes achieved for patients. The document proposes a set of national outcome goals which patients and the public can use to judge the overall performance of the NHS. The proposed outcome domains include reflecting the patient experience and treating patients in a safe environment, two key drivers for this proposed model of care.

Giving patients and the public a clear understanding of the quality of experience offered by their local providers is crucial to improving quality and informing choice. Ensuring patient choice is fundamental to the ambition to drive up the quality of services. The high quality information necessary for the commissioning and managing services and networks would be made available to the public to inform this choice.

London's Quality Observatory (LQO) is a new web-based information portal supporting the NHS quality agenda for London. It will serve commissioners, clinicians and provider organisations, offering one-stop access to robust, high quality data and information. The Quality Observatory provides a vehicle to increase participation in the quality metrics that emerge from the model of care and its role should effectively be the coordinating, enforcing and consolidating of data submissions.

²⁷ Department of Health, *Transparency in Outcomes - a framework for the NHS*, 2010



3.6.1 Quality accounts

Liberating the NHS sets out plans to extend existing methods which compel providers working for or on behalf of the NHS to publish quality accounts²⁸. These will be reports to the public on the quality of services they provide – looking at safety, experience and outcomes. Easy-to-understand, comparative information will be available on the NHS Choices website at the same time. To ensure the availability of transparent high quality performance information, London's provider networks should publish consolidated quality accounts. The content of these accounts will be developed in partnership with commissioners and standardised across the two networks. Reporting on performance should be by provider network and by institution. The consolidated quality account would profile both provider network quality and the performance of individual providers in each network.

Providers of tertiary paediatric care must be able to demonstrate that their service is comprehensive, safe, effective and research active. They must achieve these objectives within the context of a caring environment and provide the patient and family with a positive experience. Providers must have systems in place to measure and monitor their outcomes in these areas.

Indicators should also be developed that encourage collaborative working, such as targets for referral and repatriation times between acute and tertiary providers to ensure efficient transfers.

Liberating the NHS sets out plans for patients to be enabled to rate services and clinical departments according to the quality of the care they receive²⁹. Commissioners and provider networks should engage service users in the development of patient satisfaction measures for the quality accounts.

Liberating the NHS also restates the importance of patient generated information in realising its vision of an 'information revolution'³⁰. Patient reported outcome measures (PROMs) should be included as they are developed for tertiary paediatric services. Initially it might be necessary to use process and output measures as a proxy for quality metrics but ever more sophisticated measures should be used as they are developed through patient and public involvement.

Appropriate performance measures that are outcome focussed should be developed by the clinical steering group and form the basis of the consolidated quality accounts. Quality accounts would be assured by commissioners so that patients and the public can rely on them as a fair and accurate assessment. They would be published widely to allow patients and the public to make comparisons between services.

²⁸ Department of Health, *Equity and excellence: Liberating the NHS*, 2010

²⁹ Ibid, 2010

³⁰ Ibid, 2010



4 Implementation

By the end of phase two it is envisaged that:

- There will be two tertiary paediatric networks (one north, one south).
- There will be fewer providers of tertiary paediatric services in London, collocating critical interdependencies.
- Commissioning responsibility for tertiary paediatric services not already procured by London SCG, will transfer to the London SCG within the scope identified by the clinical steering group (this arrangement will be revisited in light of the NHS white paper³¹ which states that commissioning of regional specialised services set out in the Specialised Services National Definition Set will lie with the proposed NHS Commissioning Board).
- London SCG will be budget holders for the core service provider and tertiary paediatric element of the networks.

Any service reconfiguration decisions will be informed by the outcome of national reviews, for example, the National Paediatric Congenital Cardiac Review currently underway and the National Paediatric Neurosurgical Review; as well as the evolving landscape for primary and acute paediatric care.

Each tertiary paediatric network must function as an integrated, actively managed, single entity taking responsibility for governance of all children requiring treatment within the network. Each will be led by a network board that will comprise of representatives from all providers within the respective tertiary paediatric networks. All provider representatives will have an equal stake in the discussions and decisions of the network board. Consideration will also need to be given by network boards to include representatives from community paediatric services and patient and family groups.

The role of the network board will be to:

- Ensure that the composition and functions of the network set out in 3.1.2. are undertaken.
- Monitor and report on the quality of clinical care across the whole network.
- Develop and regularly review a strategic plan accounting for demographic changes, developments in treatments and changing service requirements.
- Identify services where it is entirely appropriate to be delivered on a site that is not the lead service provider and make recommendations to commissioners.

A key principle for implementation will be the clear separation of commissioner and provider functions. Each network board will report to the London SCG for specialised

³¹ Department of Health, *Equity and excellence: Liberating the NHS*, 2010



children's services in London. This will enable the London SCG to ensure consistency in developments across both networks, as well as compare outcomes when measuring improvements.

Full detail of proposed governance arrangements, including patient, public and GP engagement; and phased implementation over a three year period, is set out in a separate implementation plan.



5 Conclusion – making change happen

The programme's case for change in specialised children's services and this model of care, present a major opportunity to advance urgent and significant improvements within specialised paediatric services in London.

This model of care delivers a framework through which improvements can be realised, firstly, as a result of a stronger and active collaboration between commissioners, providers and health professionals. It also provides a much needed solution to the fragmentation of specialised children's services and sets out objectives that provide a trajectory for addressing other significant issues. Further, it proposes implementing improvements during distinct phases, rather than a 'top-down' imposition of immediate directives.

The two phases of implementation are captured as follows:

Phase one: Linking and integrating safe and sustainable services, through establishing commissioned provider networks that cover sensible divides of London's geography.

Phase two: The outcomes achieved in phase one will enable tertiary paediatric network's to achieve leadership in international standards of best practice in phase two. Emphasis is on further rationalisation of services, greater workforce planning, as well as enhancement of training, education and research programmes.



6 Appendices

6.1 Appendix 1. Overview of patient and clinical feedback

The needs of patients and their families

In seeking the views of children and young people about their experiences of health services, the children's and young people's project has sought their input through a number of avenues. This has included:

- A workshop with young people brought together through collaboration with the Greater London Authority, DareLondon and the UK Youth Parliament.
- Reviewing research undertaken by Great Ormond Street Hospital that involved collecting young patients' views.
- A workshop with members of the Evelina Pride group.

Overall, what has been most apparent from this engagement work is that children and young people value both the expertise and friendly nature of clinical staff. These skills go hand in hand in with delivering a service that meets the needs of children and young people.

This point is particularly significant as it highlights that for children and young people their experience of the health service starts first and foremost with their interactions with clinical staff. Furthermore, it suggests that effective paediatric care relies heavily on the availability of doctors and nurses who have been specifically trained in how to relate to and meet the needs of children and young people.

It is also evident that a strong relationship with one hospital and a group of clinical staff that knows the patient, their condition(s) and medical background in sufficient detail is the most favourable arrangement from the patient's perspective.

Through care being coordinated around the patients needs, they are able to build the appropriate relationships with staff in the one place, which in turn provides them with a greater sense of being in control of and educated about their circumstance of health. When their care is managed across a number of teams or sites, they feel the added responsibility of having to carry and re-communicate their medical background, which understandably creates a degree of anxiety and frustration.

"I would always prefer to be seen by one doctor who has got to know me. I have quite a rare condition and people rarely read my notes properly. They are too long! Knowing a bit about me saves a lot of time and misunderstanding. I'm also more confident about speaking up for myself around people I know." *Patient and attendee at Evelina Pride group workshop*

Our engagement with children and young people regarding specialised services highlighted the things they value:



- Clinical staff with good people skills and an ability to have fun from time to time.
- Clinical staff who can clearly explain what they are doing at all times and provide adequate information if the patient requests it.
- Ensuring that patients are equally informed about their condition(s) and care, as to that of their parents.
- Having an age appropriate environment to be cared for in.
- For hospitals not just to be a place where treatment is received but where patients know staff and they feel confident in getting to know other patients and staff.
- Having a school facility and 'chill out zone' available.
- Better visitor access.

The following points were made by patients and carers with regard to planned care:

"I like going to the same hospital because they know me and my medical background."

"It is good when the doctor at the local hospital knows me and my condition well."

"I don't think most of the staff at my local hospital know enough about my condition to give me information. It's usually the other way around!"

"If you are treated by new doctors or nurses you need to be an expert in your condition to explain to them everything they need to know."

"Travelling to different places can be difficult if you are not use to going there or if you have accessibility needs."

"My hospital care was shared between two different wards: neuro / metabolic and renal. The advantage to this is that I received specialist care. A disadvantage of this was the care on each ward was very specialised and didn't really cross over and did make getting to know the nursing staff more difficult as I wasn't always looked after on the same ward."

"Currently my care is shared between three different hospitals. The disadvantage of this is that there is less continuity of care. I sometimes feel as if I am the only one who knows everything. Communication isn't always as good as it could be. I do spend a lot of time seeing different people in different hospitals. I find it hard to find many advantages to the situation at the moment as I am caught between adult and children's care."

The following points were made with regard to adolescent care and the transition to adult services:



“As much as possible, you should be in a ward with people around your own age. Sometimes you can get stuck next to babies crying, which can be difficult.”

“As you get older it would be good to have more of a choice about when you have your appointments so they don’t interrupt your day so much. Maybe early morning or evening would be better.”

“In paediatric services I don’t mind mixed sex wards, but this probably isn’t appropriate in adult services.”

“I think that the nursing staff usually treat me in an age appropriate way. They always ensure my privacy and try to keep me away from the screaming babies and toddlers!”

“In adult services I’m always seeing different doctors and nurses, I don’t have the connection with the same staff as I did in paediatric services.”

“The environment where I am cared for is not suitable for my age group. I am still under the paediatric unit at my local hospital as the transition process is taking a very long time to work through”

“Lots of people talk about transition but not enough is actually being done... particularly for anyone who has a complex medical condition and continues to need inpatient admissions after the age of 16-18 years.”

“I worry about what will happen when I transfer to local adult services. Will I be waiting in A&E for hours before I am seen? My metabolic disease leads to de-compensation and early intervention is essential.”

What has been presented in this document is only a snapshot of a broad range of issues that must continue to be addressed through change and improvements within the health service. Given this, it is important that a new model of care for specialised children’s services take account of what avenues can exist to ensure that commissioners and providers maintain an ongoing and effective dialogue with children, young people and their families about the quality of service and what opportunities can be seized to better meet the care needs of patients first and foremost. The voice of children and young people must always be present in the discussion about how to best plan their care.

Assessment by clinical staff

The project’s work has been clinically led and relies heavily on the expert input and influence of a range of clinical staff from various disciplines and institutions. In addition to forming an expert panel to provide ongoing input and guidance, a wider cross section of views from clinicians has been sourced, as detailed below.

In December 2008, the nomination process for the clinical expert panel yielded a large range of viewpoints from almost 40 senior clinical staff that were required to comment on the strengths and challenges within specialised children’s care. Further, in May 2009, the children and young people’s project held a forum that captured the views and ideas of 70 commissioners, clinicians, nurses and other clinical staff.



The following is a summary of the major points that have been raised by clinicians to date:

- The strength of current specialised children's services
- A range of high quality services and institutions, which have international standing in attracting staff.
- Some strong academic links for research and teaching/training.
- Expertise of some clinical staff leading in their field, and diversity of 'collocated' specialists.
- Specialist/multidisciplinary teams – good outcomes from teams that are specialised.
- Some children's services collocated with relevant leading adult specialities.
- Foundation of networks already in place – some networks exist but are informal.
- Density of population – have the volume to 'get it right' when it comes to a new model of care.
- Challenges to current specialised children's services
- Fragmentation of service provision so that clinical developments are slowed, services are potentially unsafe and clinical governance sometimes weak.
- Some services provided by hospitals have a lack of comprehensive paediatric support facilities.
- Development of isolated specialised services (due to lack of commissioning framework) and further local and national fragmentation.
- Lack of a coherent network structure encompassing lead centres and referring hospitals enabling suitable support and work load structure.
- Lack of a robust commissioning model for many specialities.
- Organisational resistance to change – being able to look beyond organisational boundaries to see what is most needed and moving out of the 'bunker mentality.'
- Workforce – lack of recruitment and retention of the right people (especially specialist nurses), and investment in adequate training.
- Communication – poor information flows between tertiary services and local hospitals/community teams.



- Information technology – lack of efficient systems and poor data collection.
- Complexity of population mix/diversity, and growth in demand for services.
- Not getting the right message about services and care pathways across to parents and children.
- Failure to implement key strategies to date – perceived lack of coordination between multiple service reviews.

From engagement with clinical staff we have affirmed:

- The majority agree that the challenges are considerable, but that change is urgently needed to ensure that London's specialised children's services are sustainable - to do nothing is not a safe option.
- Clinicians recognise that the needs and views of patients and their families must be one of the key drivers for pursuing service excellence.
- Most are ready and willing to participate in making improvements and change genuinely happen now. If this opportunity for change is missed there is a risk that a degree of pessimism could emerge and flatten future clinical involvement in such processes.
- There is recognition that in order to achieve progress a collaborative approach between commissioners and providers will need to take place.
- Many recognise that effective and well led networks are the major means of addressing the current fragmentation of services and the vehicle for service redesign.



6.2 Appendix 2. Recognising input from organisations and individuals

The tertiary paediatric services clinical expert panel members:

Prof Ted Baker, Oxford Radcliffe Hospitals NHS Trust (formerly Guys and St Thomas' NHS Foundation Trust).

Ms Barbara Howe, London Specialised Commissioning Group

Dr Duncan Macrae, Royal Brompton and Harefield NHS Trust

Dr Mike Sharland, St George's Hospital NHS Trust

Dr Joanna Begent, University College London Hospital

Dr Ian Murdoch, Guy's and St Thomas NHS Foundation Trust

Dr Jane Deal, Imperial College Healthcare NHS Trust

Dr David McCormick, King's College Hospital Foundation Trust

Prof Andrew Pearson, Royal Marsden NHS Foundation Trust/Institute of Cancer Research

Ms Kate Khair, Great Ormond Street Hospital for Children NHS Trust

Dr Barbara Buckley, Great Ormond Street Hospital for Children NHS Trust

Dr Deborah Eastwood, Great Ormond Street Hospital for Children NHS Trust

Dr Gary Hartnoll, Chelsea and Westminster Hospital NHS Foundation Trust

Dr Simon Clarke, Chelsea and Westminster Hospital NHS Foundation Trust

Dr Sue Hobbins, South London Healthcare NHS Trust

Prof Inderjeet Dokal, Barts and the London NHS Trust

Ms Carol Sweeney, Ealing PCT / School Nutrition Action Group



Representatives from the following organisations attended the tertiary paediatric services forum on 5 May and provided input into this work:

Barts and The London NHS Trust

Chelsea and Westminster Hospital NHS Foundation Trust

Great Ormond Street Hospital for Children NHS Trust

Guy's and St Thomas' NHS Foundation Trust

Imperial College Healthcare NHS Trust

King's College Hospital NHS Foundation Trust

Royal Brompton & Harefield NHS Trust

Royal Marsden NHS Foundation Trust

Royal National Orthopaedic Hospital NHS Trust

St George's Healthcare NHS Trust

South East Coast Specialised Commissioning Team

South London Healthcare NHS Trust

University College London Hospitals NHS Foundation Trust

London Specialised Commissioning Group

NHS London

NHS Islington

Croydon Primary Care Trust

Ealing Primary Care Trust

School Nutrition Action Group (Ealing PCT)

Hillingdon Primary Care Trust

Sutton and Merton Primary Care Trust

