

Are We There Yet?

A review of organisational and clinical aspects of children's surgery



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A report by the National Confidential Enquiry into Patient Outcome and Death (2011)

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Foreword

This is the third study that NCEPOD has undertaken on surgery and anaesthesia in children^{1,11} In view of the changes in the NHS and the introduction of the National Service Framework for children the time was right to revisit the care of these patients. This is both the largest case-based peer review study of children who died after surgery that has ever been done in the UK, and the first wide-ranging organisational survey of the hospitals carrying out those operations. As such it provides a valuable snapshot of the service that the sickest of our children receive, warts and all.

The reader who is familiar with recent reports from NCEPOD will be struck by the general conclusion that 71% of the patients received good care (see page 48) in most previous NCEPOD studies less than 50% of cases have satisfied this test. If more of the patients in this study received better treatment than others we have studied, one is tempted to offer at least one hearty cheer at the outset.

As usual, by good care we do not mean that it is outstanding or excellent, simply of a standard that our advisors would accept from themselves or their institution. NCEPOD makes determined efforts to ensure that these judgements by its Advisors represent mainstream opinion. I do not know whether we should say that 71% is a good figure, or whether it is an outrage that over a quarter of a group of children who died following surgery received care that the Advisors would not accept from themselves and considered there to be room for improvement in aspects of care. In the two previous NCEPOD reports concerning surgery and anaesthesia in children the conclusion of the assessors was that overall assessment of care received was “excellent” or “doing most things well”.

The majority of deaths occurred in Specialist Centres with very few in the District Hospital and most babies and children were transferred for their surgery. This has

not changed over the last 10 years. Much time is spent organising these transfers and delays on occasion were judged to have had an effect on the patient’s outcome. Cases were frequently complex, and the surgery and anaesthesia recognised as high risk. Yet on occasion the documentation of discussions about these risks with parents and carers by sufficiently senior personnel were sadly lacking. All this is disappointing given that the very same issues were noted in our 1999 report¹¹. In that report we also suggested the need for care to be organised more overtly into regional networks, particularly as far fewer surgeons and anaesthetists were caring for children.

If the purpose of NCEPOD is, as I believe, to describe the territory that lies between what is, and what the profession believes should be happening in our hospitals, this may suggest that we have not made the progress that one would hope for in the last 20 years. Given that this report studied events occurring between April 2008 to April 2010, at the end of the 7 years of fiscal growth triggered by the Wanless Report in 2001, this is especially disappointing. This was the end of what we may look back on as the halcyon era for NHS funding and it is going to be especially difficult to apply the lessons in the more difficult times since we started to feel the pendulum swing back in response to what is now described as the Nicholson Challenge.

The most disappointing features of the findings in this report to my mind are in the organisation of care. Unlike the case review data, which mainly concerned events in the Specialist Tertiary Paediatric Centres because so many of the sample were extremely ill, the organisational data was collected from every hospital that declared it undertook surgery in children. As I say this is the first time anyone has reported on this and I want to highlight the results because I think many readers will tend to concentrate on NCEPOD’s comments on the cases,

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whereas this report illustrates how valuable the data on the organisation of care can be. In every area that the authors studied they found room for improvement, reflecting a failure to meet the organisational standards that our children are entitled to expect.

For example, audit and morbidity and mortality discussions are an intrinsic part of clinical care yet we now find that only 53% of our respondent hospitals were doing audits and morbidity and mortality meetings. In addition, from the review of the case notes, the clinical discussion was evidenced in only a third of the notes, 126 of 378 cases (page 68): I would particularly like to draw attention to the authors' view that the conclusion should be recorded in the clinical notes and the record of the patient is incomplete if they are omitted. The record is a vital part of the means by which the institution shows that it is discharging its duty of candour and the absence is a sign that all is not well in that department. The proposition that "if it isn't written it did not happen" leaves something to be desired in respect of clinical care generally, but it seems perfectly apt to describe a failure to record for all to see what the M&M Meeting concluded after a child has died within 30 days of an operation. The composition of the record - "What shall we agree to say about this?" - is often an essential part of the shaping of the conclusion.

All through the organisational section there are similarly disappointing findings. Why are so few hospitals part of managed clinical networks? Of 267 hospitals that answered, 160 admitted that they were not included in a network (Table 2.4). It is vital that we emphasise the importance of cooperation between hospitals so that the pressures in favour of competition do not result in damage to the quality of care across the Service as a whole. This report is also timely when the NHS is considering the Safe and Sustainable programme, since many of the lessons that programme is seeking to build upon in cardiac and neurosurgery apply equally to these patients. Clinically managed networks with clear accountability and clinical governance may provide the most valuable model of care for many of these patients. There are changes ahead which may increase the necessity for functioning clinical networks⁹.

One area of particular concern to those of us who handle negligence cases brought against hospitals is the number of places that do not have policies for identifying sick children or resuscitation policies (page 36). So many of our recent studies have reported that the ability to recognise the sick patient of any age is a diminishing skill and as the doctors in training become less experienced, they need all the help they can get. The absence of satisfactory arrangements for acute pain management in children who have undergone operations is particularly unfortunate (pages 37-40). It is important to acknowledge that the deficiency does not tell us that these children were in pain, but it does suggest that post operative pain management is not valued as highly as it should be. This report should be eagerly read by managers as well as clinicians for it is constructive and hard headed, putting forward suggestions that are not radical, controversial or expensive. They require primarily the will to respond to a problem that has been clearly described by our authors, applying yardsticks that are already accepted by the professions.

More than ever, I want to express on behalf of the NCEPOD Trustees our gratitude to all of those who have helped to make this report possible. Our organisation is itself going through difficult times. As a result of problems with which we are all familiar, we have to cut our coat according to cloth that is much shorter than ever before.

To respond to this challenge we are dependant upon the enthusiasm of our experts, advisors and other volunteers who come together to make these studies possible. Whilst paying tribute to those who have worked on this report, I must stress that we will need more of you in the future. Please do respond to our calls for Advisors to help us. We have a programme of enormously valuable work ahead, as you can see from the list of future studies on the website and I hope you will think as I do that it is a privilege to be a part of the team undertaking this work. With many thanks to all who respond and everyone who has already played a part.



Mr Bertie Leigh, Chair of NCEPOD

Principal Recommendations

Organisation of care

Clinical networks for children's surgery

There is a need for a national Department of Health review of children's surgical services in the UK to ensure that there is comprehensive and integrated delivery of care which is effective, safe and provides a high quality patient experience. *(Department of Health and Devolved Administration Governments)*

National NHS commissioning organisations including the devolved administrations need to adopt existing recommendations for the creation of formal clinical networks for children's surgical services. These need to provide a high quality child focused experience which is safe and effective and meets the needs of the child^{8,18,26,27}. *(National Commissioners)*

Specialised staff for the care of children

Children admitted for surgery whether as an inpatient or an outpatient must have immediate access to paediatric medical support and be cared for on a ward staffed by appropriate numbers of children trained nurses. *(Clinical Directors)*

Management of the sick child

All hospitals that admit children as an inpatient must have a policy for the identification and management of the seriously ill child. This should include Track & Trigger and a process for escalating care to senior clinicians. The National Institute for Health and Clinical Excellence needs to develop guidance for the recognition of and response to the seriously ill child in hospital. *(Medical Directors, National Institute for Health and Clinical Excellence)*

Peer Review

Inter-hospital transfer

Hospital teams working in both specialist and non specialist centres should be in a state of readiness for transfer of babies and children requiring emergency surgery, and be prepared to provide high level and timely support for these transfers. Surgical emergencies may require rapid triage, simultaneous with resuscitation and communication with tertiary care providers. *(Medical Directors and Clinical Directors)*

Consent and information for patients & parents

In surgery which is high risk due to co-morbidity and/or anticipated surgical or anaesthetic difficulty, there should be clear documentation of discussions with parents and carers in the medical notes. Risk of death must be formally noted, even if difficult to quantify exactly. *(Consultants)*

End of life care

National guidance should be developed for children that require end-of-life care after surgery. *(Department of Health, Royal Colleges, appropriate specialist societies)*

Confirmation that a death has been discussed at a morbidity and mortality meeting is required. This should comprise a written record of the conclusions of that discussion in the medical notes. *(Medical Directors)*

Specific care reviews

Necrotising enterocolitis

This survey and the advice from our specialist Advisors have highlighted the difficulties in decision-making during both medical management and the decision to operate in babies with NEC. A national database of all babies with NEC might facilitate this aspect of care and generate data upon which to base further research. *(Department of Health, Specialist Societies)*

Under embargo until 00.01 27th October



Introduction

The delivery of surgical services for children in the United Kingdom has changed in the last 20 years. Since the first NCEPOD report about standards for the surgical and anaesthetic care of children¹ there have been a number of other documents with both direct and indirect effects on the totality of care for children in the health service including the National Service Framework for children²; the Healthcare Commission's 'Improving Services for Children in Hospital'³; the Every Child Matters programme⁴; the Children's Plan⁵; the NHS Next Stage Review⁶; the joint Department for Children Schools and Families/Department of Health⁷ strategy for children and young people; Sir Ian Kennedy's report on children's services⁸; and a report by the Royal College of Paediatrics and Child Health⁹. As a result there has been both clinical and organisational change to health care provision for children. These include specialisation and centralisation of children's services, and modifications of staff training. There is direct evidence that there has been a reduction in the number of DGH's providing children's surgery. Even so the majority of operations are still undertaken in this setting¹⁰.

Twenty-one years ago the first NCEPOD report which reviewed deaths in children within 30 days of surgery¹ showed that there were deficiencies in the skills of health care professionals who cared for surgical children and in the facilities available. This was thought to be especially so in District General and Single Specialty Hospitals. Recommendations were made that surgeons and anaesthetists should not undertake occasional paediatric practice and that consultants who have responsibility for children need to maintain their competence in the management of children. The 1999 NCEPOD report,

'*Extremes of Age*', recommended a regional approach to the organisation of paediatric surgical services¹¹. These recommendations along with others have resulted in considerable debate on the best model for children's surgery in the UK both in terms of skills of health care professional and the appropriate facilities¹²⁻¹⁴.

There has been a decline in the number of children who have surgery performed in District General Hospitals (DGHs) from more than 410,000 children under 18 years in 1994/1995 to 325,000 in 2004/2005. This is a complex situation and some of this reduction reflects changes in practice (e.g. general reduction in ear, nose and throat procedures). However, there has been an increase in referrals to tertiary centres, particularly in the areas of general and also orthopaedic surgery without any shift of resources¹. Whilst in principle this may encourage greater paediatric specialisation and concentration of expertise there is a perception amongst some clinicians and anecdotal evidence that this has been detrimental to children's surgical services in DGHs¹⁵. There is a concern regarding the deskilling of surgeons and anaesthetists in DGHs who care for children which may limit their ability to manage critically ill children who present at their hospital¹⁶. The development of clinically managed networks for children's surgical and anaesthetic care has been recommended as a solution to this problem¹⁷⁻²⁰ but as yet has not been fully implemented. There is a risk of reaching a tipping point in the surgical and anaesthetic care of children in DGHs and several professional bodies have been calling for an urgent national review of paediatric surgical and anaesthetic services.

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Whilst there have been national reviews of some subspecialty paediatric surgical services such as cardiac²¹ and neurosurgical services²², there has been no similar review of those paediatric surgical services which provide the majority of care to children in the UK.

With these factors in mind, this study aims to provide valuable data on the current state of paediatric surgical and anaesthetic practice which can be used to inform and provide recommendations for those planning the future direction of surgical and anaesthetic services for children.

1 – Method and data returns

Aims

To explore remediable factors in the processes of care of children aged 17 and younger, including neonates, who died prior to discharge and within 30 days of emergency or elective surgery.

The aims were to look in detail at: 1. The organisational structure of services provided and 2. The quality of care received by individuals.

Expert group

A multidisciplinary group comprising consultants from surgery and anaesthetics (both paediatric general and cardiac), intensive care, nursing, a representative from the Centre for Maternal and Child Enquiries, a lay representative and a scientific advisor contributed to the design of the study and reviewed the findings.

Objectives

The Expert Group identified objectives that would address the overall aim of the study and these will be addressed throughout the following chapters:

- Organisational structure of care
- Pre-operative care and admission
- Inter-hospital transfer
- Networks of care
- The seniority of clinicians
- Multidisciplinary team working (including the involvement of paediatric medicine)
- Delays in surgery
- Anaesthetic and surgical techniques
- Acute pain management
- Critical care
- Comorbidities
- Consent

Hospital participation - organisational data and peer review data

All National Health Service hospitals in England, Wales and Northern Ireland as well as hospitals in the independent sector and public hospitals in the Isle of Man, Guernsey and Jersey were expected to participate if they undertook surgery in children aged 17 and younger.

Within each hospital, a named contact, referred to as the NCEPOD Local Reporter, acted as a link between NCEPOD and the hospital staff, facilitating case identification, dissemination of questionnaires and data collation.

Population

Organisational data: All hospitals undertaking surgery in children were asked to return an organisational questionnaire.

Peer review data: All patients aged 17 years and younger, who died within 30 days of a surgical procedure (defined by the giving of a general or regional anaesthetic) between 1st April 2008 and 31st March 2010 were included in the study. For the purposes of the study, this also included patients who underwent interventional procedures or radiology either in the operating theatre or elsewhere. Throughout the report the term 'operation' refers to both surgery and interventional procedures.

Exclusions - Peer review data

1. A number of procedures were excluded where performed in isolation (See Appendix 4 on the website);
2. Patients undergoing surgery without the use of general or regional anaesthesia;
3. Patients transferred alive to another Trust following surgery, who subsequently died.

Organisational questionnaire

Data on a hospital by hospital was basis collected to provide information on the facilities provided at all hospitals that undertook surgery in children irrespective of whether cases were included in the peer review aspect of the report. Data collected concerned networks of care, arrangements for the transfer of patients, critical care facilities, hospital facilities, acute pain management, pre-admission facilities, surgical facilities, and audit. Respondents were asked to categorise their hospital type. However, there were some inconsistencies in this designation, e.g. a hospital selecting both University Teaching Hospital and Specialist Tertiary Paediatric Centre and when a respondent categorised their hospital to be in more than one category it was allocated to the most appropriate category based on existing data on hospital types^{11,18}. The fact that some respondents did not know how to define their hospital's purpose suggests that clearer definitions, or clearer communication of existing definitions is required. To ensure consistency with other similar datasets further cross-checking was undertaken to ensure robust categorisation for the purpose of analysis.

The organisational questionnaire was sent to the Local Reporter for completion in collaboration with the relevant specialties. The Medical Director was also asked to contribute where appropriate.

Case ascertainment - peer review data

Cases were identified using OPCS codes. The NCEPOD Local Reporter identified all patients who died within their hospital(s) during the study period, within 30 days of the primary surgical procedure. The information requested for each case included the details of the surgeon and anaesthetist who carried out the procedure. All cases identified to NCEPOD with an included OPCS code were included in the study. Data concerning the type of anaesthetic administered was also requested but since this was not routinely recorded it was rarely available.

Clinical questionnaires and case notes

Two questionnaires were used to collect data for the peer review aspect of this study, a surgical questionnaire and an anaesthetic questionnaire per case included.

Surgical and anaesthetic questionnaire

The surgical questionnaire was sent to the surgeon who carried out the primary procedure of the patient's final admission. The anaesthetic questionnaire was sent to the anaesthetist who was responsible for the patient during the primary procedure of the final admission. These questionnaires covered all aspects of patient care from admission, to specific information around the procedure, to death. As the anticipated sample size was small, the number of questionnaires was not limited per surgeon. Where a surgeon or anaesthetist had more than one questionnaire to complete, extra time was given. These questionnaires were either sent directly to the surgeon or via the Local Reporter for dissemination, depending on the Trust's preference. It was also suggested that anaesthetists and surgeons liaised closely with neonatal/paediatric intensive care unit colleagues to answer some of the questions.

Case notes

For each case, the following case note extracts were requested to enable peer review:

- Inpatient and outpatient annotations from pre-admission (birth where applicable) to death;
- Integrated care pathways;
- Nursing notes;
- Drug charts;
- Imaging reports;
- Paediatric Intensive Care/Special Care Baby Unit charts;

- Fluid balance charts;
- Operation notes;
- Notes from multidisciplinary team meetings;
- Consent forms;
- Pathology results;
- Haematology and biochemistry results;
- Incident report form and details of outcome;
- Discharge summary;
- Operation notes;
- Anaesthetic charts;
- Pre-anaesthetic or pre-admission protocols/ checklists;
- Recovery room records;
- Do Not Attempt Resuscitation documentation;
- Post mortem report.

Advisor groups

A multidisciplinary group of Advisors was recruited to review the case notes and associated questionnaires. The group of Advisors comprised: paediatric general/urological surgeons, paediatric cardiac surgeons, paediatric otolaryngology surgeons, paediatric orthopaedic surgeons, paediatric neurosurgeons, paediatric cardiologists, specialist and non-specialist paediatric anaesthetists, paediatricians, neonatologists, emergency medicine physicians, paediatric intensivists, paediatric radiologists, and children's nurses.

All questionnaires and case notes were anonymised by the non-clinical staff at NCEPOD who removed all patient, clinician and hospital identifiers. The Clinical Co-ordinators at NCEPOD, and the Advisors had no access to such identifiers.

After being anonymised each case was reviewed by one Advisor within a multidisciplinary group. At regular intervals throughout each meeting, the chair (an NCEPOD Clinical Co-ordinator) allowed a period of discussion for each Advisor to summarise their cases and ask for opinions from other specialties or raise aspects of a case for discussion.

The grading system below was used by the Advisors to grade the overall care each patient received.

Good practice – a standard that you would accept for yourself, your trainees and your institution
Room for improvement – aspects of **clinical** care that could have been better
Room for improvement – aspects of **organisational** care that could have been better
Room for improvement – aspects of both **clinical and organisational** care that could have been better
Less than satisfactory – several aspects of **clinical and/or organisational** care that were well below satisfactory
Insufficient data – insufficient information submitted to assess the quality of care

Quality and confidentiality

Each case was given a unique NCEPOD number so that cases could not easily be linked to a hospital.

The data from all questionnaires received were electronically scanned into a preset database. Prior to any analysis taking place, the data were cleaned to ensure that there were no duplicate records and that erroneous data had been entered during scanning. Any fields in an individual record that contained spurious data that could not be validated were removed.

Data analysis

The qualitative data collected from the Advisors' opinions and free text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. The data were reviewed by NCEPOD Clinical Co-ordinators and Clinical Researchers to identify the nature and frequency of recurring themes. Case studies have been used to illustrate particular themes.

All data were analysed using Microsoft Access and Excel by the research staff at NCEPOD. The findings of the report were reviewed by the Expert Group, Advisors and the NCEPOD Steering Group prior to publication.

Data returns

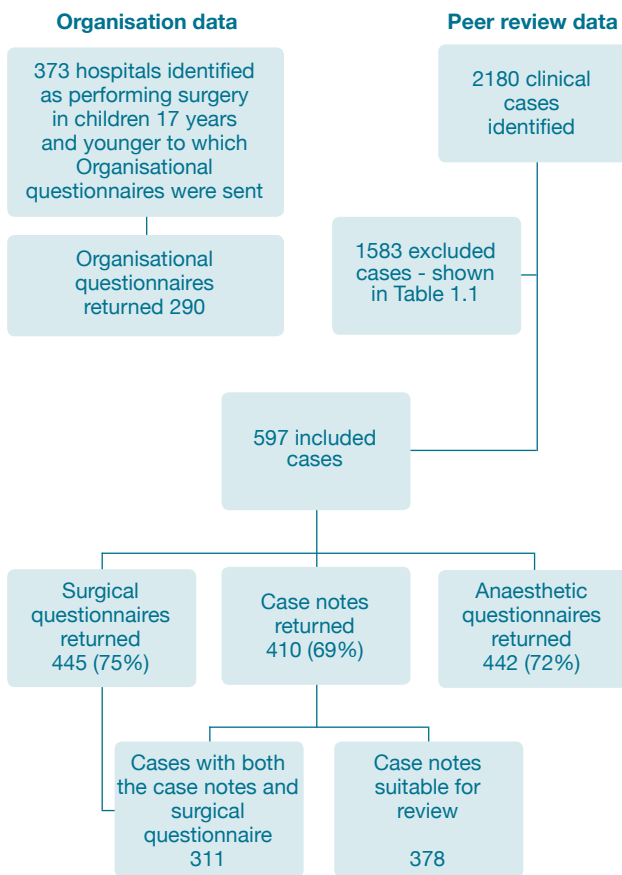


Figure 1.1 The data returns for the study

Over the two year period 2180 cases were reported, of which 1583 were excluded. The main reasons for exclusion are presented in Table 1.1.

Table 1.1 Reasons for exclusions

Reason for exclusion of case	Total
Excluded as the operation code was not included in the study	1154
Death not within 30 days	287
Did not undergo a procedure	64
Did not have an anaesthetic	55
Reason not recorded	18
Discharged alive	5
Total	1583

In a number of cases questionnaires were returned unanswered to NCEPOD or problems with regard to questionnaire completion were notified to the office; the most common reasons for this were case notes being lost or difficulty in retrieving case notes, and the consultant in charge of the patient at the time of their surgery no longer being at the hospital. The returns for the study are summarised in Figure 1.1.

It should be noted that case note retrieval proved much more difficult in this study compared to previous NCEPOD reports. The NCEPOD staff committed considerable time and effort to this but several Trusts were unable to locate the clinical records. Thus not all hospitals are adhering to relevant NHS information governance standards²³.

Study sample denominator data by chapter

Within this report the denominator used in the analysis may change for each chapter and occasionally within each chapter. This is because data has been taken from different sources depending on the analysis required. For example in some cases the data presented will be a total from a question taken from the surgical, anaesthetic or organisational questionnaire only, whereas some analyses may have required a clinician questionnaire plus the Advisors' view taken following case note review.

2 - Organisation of Care

How hospitals organise the delivery of surgical services for children will depend on the number children cared for, the subspecialty mix and the degree of specialisation of children's surgical services required. In the UK most children's surgery is provided by non specialist District General Hospitals and University Teaching Hospitals¹⁰ while more specialised children's surgery is provided by Specialist Paediatric Centres and Single Specialty Hospitals. Furthermore some Private Hospitals provide a surgical service for children. Regardless of the degree of paediatric surgical specialisation and number of children cared for it is important that these hospitals provide the appropriate environment, facilities, infrastructure and skill mix of personnel for the care needs of the children. In this chapter of the report these essential elements for the safe and effective delivery of surgery for children have been reviewed.

Types of hospital where children have surgery

For the purpose of this study the hospitals that returned an organisational questionnaire, indicating that they undertook surgery in children, were divided into District General Hospitals (DGHs) <500 beds, District General Hospital >500 beds, University Teaching Hospitals (UTHs), Specialist Tertiary Paediatric Centres (STPCs) (these may include children's units within a University Teaching Hospital), Private Hospitals (PHs) and Single Specialty Hospitals (SSHs) such as orthopaedic units, cardiac units, ear nose and throat and ophthalmic units. Each respondent self designated which category best described their hospital. However as stated previously there were some inconsistencies in this designation and when a hospital appeared to be in more than one category it was allocated to the most appropriate category based on existing data on hospital types^{10,18} NCEPOD recognises that there may be some overlap in these categories.

Of the 373 hospitals that were identified as performing surgery in children and were sent an organisational questionnaire 290 were returned. Table 2.1 shows the number in each category.

Table 2.1 Hospital category

Hospital category	Total	%
DGH <500 beds	65	22.4
DGH >500 beds	59	20.3
STPC	27	9.3
UTH	27	9.3
PH	92	31.7
SSH	20	6.9
Total	290	

The majority of the organisational questionnaires were returned from DGHs and this fact must be borne in mind when reviewing the data.

Most NHS hospitals admitted children as an emergency (Table 2.2) and 88% (171/194) undertook both elective and non-elective surgery in children. Few Private Hospitals admitted emergency patients.

Table 2.2 Hospital type to which children were admitted as an emergency

Hospital category	Yes	No	Subtotal	Not answered	Total
DGH <500 beds	61	4	65	0	65
DGH >500 beds	56	3	59	0	59
STPC	27	0	27	0	27
UTH	23	4	27	0	27
PH	4	87	91	1	92
SSH	11	8	19	1	20
Total	182	106	288	2	290

Surgical workload

Each hospital was asked to supply figures for the number of operations and interventional procedures undertaken on children between 1st April 2008 and 31st March 2009. Although 32/290 hospitals were unable to provide this information, the reason for this is not known. It is essential that information systems to determine the number of patients treated within a hospital for monitoring, clinical governance and financial purposes are adequate. In the remaining 258 hospitals 426,218 operations were performed. The proportion from each category of hospital is shown in Figure 2.1.

Two-thirds (64%) were undertaken in DGHs and UTHs compared to STPCs and SSHs. This is similar to data collected from other studies¹⁰ thus indicating that the non specialist children's hospitals undertake more surgical procedures in children than STPCs. It is important that these hospitals have the necessary environment, facilities and skill mix to meet the needs of children. Furthermore good links to STPCs are essential. The volume of cases undertaken per annum will to some extent determine the resources hospitals may apply to various aspects of care for children and this may be a useful marker to measure against organisational aspects of care in this dataset (Figure 2.1 and Table 2.3).

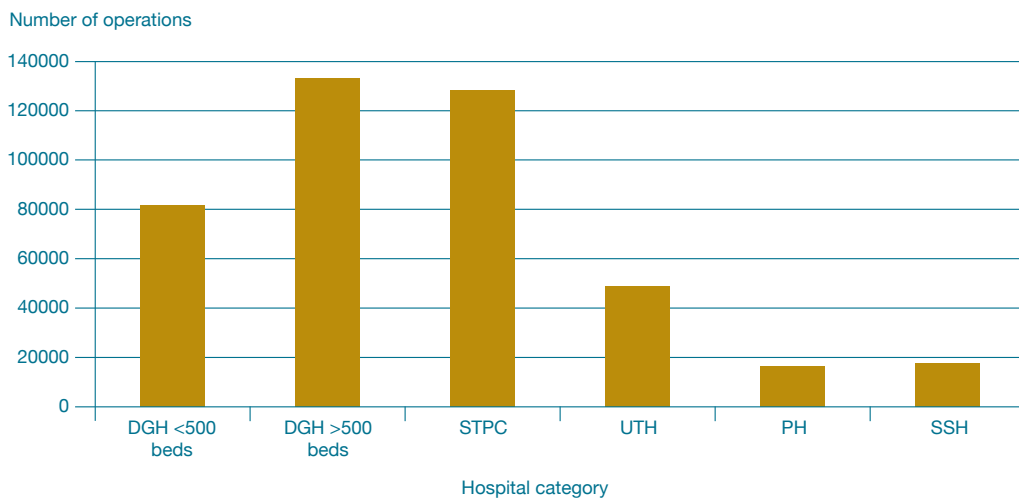


Figure 2.1 Total number of operations performed in children by hospital category during 2008-2009

Table 2.3. Volume (in ranges) of operations (in 0-17 year olds) performed per annum by hospital category

Number of operations	DGH <500 beds	DGH >500 Beds	STPC	UTH	PH	SSH	Total
1-100	2	0	0	1	37	3	43
101-500	8	3	0	3	38	3	55
501-1000	16	5	0	5	2	4	32
1001-2000	24	17	7	6	3	5	62
2001-4000	9	19	4	7	0	1	40
4001-10000	2	6	11	3	0	1	23
>10000	0	1	2	0	0	0	3
Subtotal	61	51	24	25	80	17	258
Not answered	4	8	3	2	12	3	32
Total	65	59	27	27	92	20	290

In 98 hospitals less than 500 operations were performed a year and some of these hospitals performed very few procedures. These hospitals may need to review their children’s surgical service to ensure a good quality of care.

Clinical networks for children’s surgery

The concept and function of managed clinical networks is well established in the NHS^{24,25}. The principles underpinning managed clinical networks for children,

including surgical services, have been defined by the Department of Health and several subspecialty groups^{8,18,26,27}. These describe the relationship between a Specialist Tertiary Paediatric Centre and a series of hospitals within an agreed region in order to provide a safe and effective child focused surgical service for children (see Figure 2.2).

The possible functions of formal managed clinical network for children’s surgery are shown in Figure 2.3.

INFORMAL NETWORKS

‘A collaboration between health professionals and/or organisations from primary, secondary and/or tertiary care, and other services, aimed to improve services and patient care, but without specified accountability to commissioning organisations’.

THESE INCLUDE:

Clinical Association: An informal group that corresponds or meets to consider clinical topics, best practice and other areas of interest.

Clinical Forum: A group that meets regularly and has an agenda that focuses on clinical topics. There is an agreement to share audit and formulate jointly agreed clinical protocols.

Developmental Network: This group is a Clinical Forum that has started to develop a broader focus other than purely clinical topics, with an emphasis on service improvement.

Formal Networks (Managed Clinical Network)

‘A collaboration between health professionals and/or organisations from primary, secondary and/or tertiary care, and other services working together in a coordinated manner with clear accountability arrangements’. This network, which includes the function of a Clinical Forum, has a formal management structure with defined governance arrangements and specific objectives linked to a published strategy.

Figure 2.2: Types of clinical networks of care:

Adapted from: [Department of Health (2005). A guide to promote a shared understanding of the benefits of managed local networks. Accessed from <http://www.dh.gov.uk/assetRoot/04/11/43/68/04114368.pdf> ²⁶

Collaborative multidisciplinary working between children’s surgical service providers within a defined geographical region focused around a Specialist Tertiary Paediatric Centre. The clinical network has the following responsibilities:

Patient safety

- Development of standards for clinical and operational care
- Agreed thresholds for patient transfer between hospitals for elective and emergency care.
- Determine, enhance and maintain the appropriate skill mix and competencies of health care professionals within the network
- Clear routes of communication
- Clear governance and accountability arrangements

High quality patient experience

- Transparent and unified mechanisms of referral

- Agreed standards for a child friendly hospital environment

Clinical effectiveness

- Contractual agreements that specify service requirements and outcomes
- Appropriately resourced on an administrative and financial basis
- Clear definition of services provided based on competencies and facilities available
- Multidirectional flow of services within the network
- Provides training and Continuing Professional Development

Figure 2.3. Functions of a managed clinical network for children’s surgery ^{8,18,26,27}

With these factors in mind an assessment was made on how well developed clinical networks for children’s surgery were amongst hospitals in England, Wales, Northern Ireland, the Channel Islands. For the purposes of this analysis the term ‘clinical network for children’s surgery’ encompasses both informal and formal types of networks as described in Figure 2.2.

In total 37% (107/284) of hospitals indicated that they were part of a clinical network for children’s surgery; however, when Private Hospitals were excluded from

the analysis 49% (96/194) of NHS hospitals were found to be part of a network (Table 2.4). Just under half of SSHs were part of a network and very few (11/90) Private Hospitals were incorporated into networks. It has been argued that all hospitals in which surgery in children is undertaken, particularly non specialist paediatric hospitals, should be included in a managed clinical network. As two thirds of hospitals included in this study were not part of such a network this demonstrates considerable scope for development ^{8,18,26,27}.

Table 2.4 Hospital category and whether they were included in a network

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500	24	35	4	63	2	65
DGH >500	28	27	3	58	1	59
STPC	22	4	0	26	1	27
UTH	13	13	1	27	0	27
PH	11	70	9	90	2	92
SSH	9	11	0	20	0	20
Total	107	160	17	284	6	290

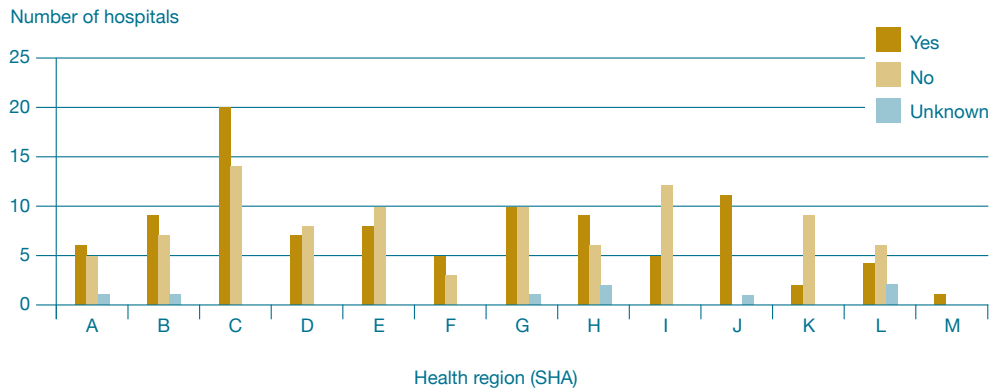


Figure 2.4 Health regions by presence of NHS hospitals included in a children's surgical network

These data were further examined with reference to Strategic Health Authority regions in England and the Health Regions of Wales and Northern Ireland (Figure 2.4 and Table 2.5). For confidentiality the identity of each Health Region has not been revealed.

From this dataset no inference can be made between the availability of networks of care for children requiring surgery and the quality and standards of care provided. However, at the very least it indicates inconsistency between Health Regions in the uptake of the recommendations of professional organisations and the DH^{8,18,26,27}.

These data reveal that there is considerable variation in the inclusion of hospitals in networks between health regions.

Table 2.5 Proportion of NHS hospitals within each health region from which a questionnaire was returned

Health region	Number of hospitals from which a questionnaire was received	Number of hospitals identified that performed children's surgery
A	12	13
B	17	22
C	34	43
D	15	17
E	19	32
F	10	15
G	20	25
H	17	23
I	18	25
J	12	21
K	11	14
L	12	14
M	1	2
Total	198	266

Data were requested from each hospital with regard to which surgical specialties were included in a clinical network (Table 2.6). The most common specialty was paediatric general surgery, followed by ear, nose and throat, orthopaedics and urology.

Few surgical networks included paediatric anaesthesia. It may be that there are separate paediatric anaesthesia clinical networks, which were not specifically identified as part of this study. However there may be advantages for children's surgical clinical networks to include paediatric anaesthesia or at least closely liaise with a separate paediatric anaesthetic network if it exists.

For each hospital where it was stated that it was included in a network of surgery for children, details were requested regarding its structure and function (Tables 2.7-2.13).

Table 2.6 Specialities included in networks

Specialities included	n
Paediatric general surgery	63
Ear, nose and throat	48
Orthopaedics	42
Paediatric anaesthesia	35
Urology	34
Paediatric cardiology	28
General surgery	27
Maxillo-facial surgery	27
Ophthalmology	25
Plastic surgery	24
Other	17
Neurosurgery	17
All surgical specialties	16
Paediatric cardiac surgery	14
Gynaecology	9

**Answers may be multiple (n/106)*

Table 2.7 Type of network See definition of formal and informal network (Figure 2.2)

Hospital category	Formal	Informal	Subtotal	Not answered	Total
DGH <500 beds	5	15	20	4	24
DGH >500 beds	11	11	22	6	28
STPC	11	8	19	3	22
UTH	3	9	12	1	13
PH	2	5	7	4	11
SSH	5	3	8	1	9
Total	37	51	88	19	107

Table 2.8 Presence of clinical leads for networks

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	10	6	4	20	4	24
DGH >500 beds	11	6	3	20	8	28
STPC	15	3	1	19	3	22
UTH	4	7	1	12	1	13
PH	5	1	1	7	4	11
SSH	5	3	1	9	0	9
Total	50	26	11	87	20	107

Table 2.9 Presence of network held educational meetings

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	9	7	4	20	4	24
DGH >500 beds	9	8	3	20	8	28
STPC	16	2	1	19	3	22
UTH	2	10	0	12	1	13
PH	3	3	1	7	4	11
SSH	7	2	0	9	0	9
Total	46	32	9	87	20	107

Table 2.10 Presences of policies for clinical care in hospitals

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	14	4	2	20	4	24
DGH >500 beds	15	4	0	19	9	28
STPC	14	4	1	19	3	22
UTH	7	2	2	11	2	13
PH	7	0	0	7	4	11
SSH	7	2	0	9	0	9
Total	64	16	5	85	22	107

Table 2.11 Types of policies for clinical care

Types of policies	n
Elective transfers	43
Emergency transfers	55
Management of critically ill child	46
Management of specific surgical conditions	7
Other	6

* Answers may be multiple (n/63)

These data reveal that most hospitals were in networks that were informal, without specific accountability or clinical governance arrangements. Only 20/79 hospitals that responded stated that they received funding for networks. Many did have clinical leads and undertake educational meetings with agreed policies for clinical care although few of these included specific surgical conditions. Furthermore a minority of hospitals undertook network based multidisciplinary team meetings, audit or morbidity and mortality meetings. It is difficult to see

Table 2.12 Use of network based multidisciplinary team meetings to agree clinical management by hospital category

Hospital category	Yes	No	Unknown	Subtotal	Unanswered	Total
DGH <500 beds	4	12	4	20	4	24
DGH >500 beds	5	14	1	20	8	28
STPC	10	9	0	19	3	22
UTH	1	9	1	11	2	13
PH	4	2	1	7	4	11
SSH	4	5	0	9	0	9
Total	28	51	7	86	21	107

Table 2.13 Presence of network based audit and Morbidity and Mortality meetings by hospital category

Hospital category	Yes	No	Unknown	Subtotal	Unanswered	Total
DGH <500 beds	1	9	7	17	7	24
DGH >500 beds	4	11	5	20	8	28
STPC	10	9	0	19	3	22
UTH	1	9	1	11	2	13
PH	2	4	1	7	4	11
SSH	3	6	0	9	0	9
Total	21	48	14	83	24	107

without having these important elements in place, how a clinical network for children's surgery can function to provide an integrated and comprehensive level of care.

Transfer of children

Children who require either elective or non-elective surgery may require transfer from one hospital to another for definitive care. In many cases this may be from a non specialist paediatric hospital such as a DGH to a STPC. However, in some circumstances patient transfer of care may be in the opposite direction for example during the recovery and rehabilitation phase of an illness when less specialised care is required. There are nationally agreed guidelines and targets for the inter-hospital transfer of the seriously ill child to paediatric intensive care units. Furthermore some health regions have dedicated neonatal and paediatric third party transfer teams^{16,28-32}. However there is less guidance for the transfer of children who do not require intensive care. It is therefore the responsibility of both the referring and accepting hospitals to have policies in place for the safe transfer of children.

Responses from the majority of hospitals in this study indicated that they had a policy for the transfer of children to another hospital, 93.3% (266/285). However, ten DGHs, four UTHs and one STPC stated that there was no such policy. This is a critical clinical governance issue for these hospitals that needs to be addressed. For those hospitals that did have a policy, most were agreed locally or in conjunction with regional policies (Table 2.14).

Table 2.14. Level at which transfers policies are agreed

If YES, these were:	n
Local policies	137
Local policies and regional policies	52
Regional policies	35
Local policies and national policies	21
Local policies, regional policies and national policies	12
National policies	7
Regional policies and national policies	1
Not answered	1
Total	266

The Paediatric Intensive Care Society has produced standards for elements that should be included in every transfer policy²⁹. Whilst most hospitals had a transfer policy for emergency cases, it is of note that several important elements were not included. Only 130/259 hospitals included staffing arrangements for transfers and only 127 included family support. Furthermore 188/259 included communication procedures, 174/259 included equipment provision and 195/259 included transport arrangements. It is clear from these data that whilst most hospitals do have a policy on the transfer of children these are not as comprehensive as they should be.

Team working

In the provision of surgical services for children effective multidisciplinary team working is an important part of hospital practice^{32,33}. Hospitals should have a multidisciplinary group which has responsibility for ensuring the safe, effective and child friendly provision of children's services. Information was requested on hospital policies for multidisciplinary team working and operational activities (Table 2.15). Despite national recommendations there was considerable variation amongst hospitals on the inclusion of many of these policies for surgery and anaesthesia in children^{1,11,17,18,32}.

Table 2.15 Presence of operational policies for surgery for children by hospital category

Policies:	DGH <500 (n=65)	DGH >500 (n=59)	STPC (n=27)	UTH (n=27)	PH (n=92)	SSH (n=20)	Total (n=290)
The referral of surgical patients to hospital	33	34	19	9	62	11	168
Who can operate on children	40	35	19	14	70	11	189
The management of emergency surgery for children	36	31	22	14	22	9	134
Pre-operative preparation of children	43	47	26	18	79	16	229
Out of hours medical cover for children	37	37	25	15	41	8	163
Admission criteria for surgical patients	36	34	20	13	82	14	199
Who can anaesthetise children	47	45	22	19	66	15	214
The management of emergency anaesthesia for children	35	35	21	12	16	10	129
Handover between clinical teams	35	25	24	9	31	11	135
The named consultant who has overall clinical responsibility of children who undergo surgery	36	31	25	15	51	12	170
Answered YES to all policies	14	10	15	4	9	2	54
Not answered at all	1	2	0	1	3	1	8

(*answers may be multiple)

Multidisciplinary team meetings

Multidisciplinary team (MDT) meetings are an integral part of modern health care and they have a valuable role in determining the best management for individual patients. Whilst for most children requiring surgery the factors that influence best treatment are straight forward, for complex clinical cases this may not be the case. The use of a MDT meeting in these situations is of the greatest benefit. Furthermore, it might be that performing a larger number of operations or more specialised surgery would place a greater emphasis on the need for MDT meetings. Data were requested on whether MDT meetings for children who required surgery took place at each hospital as shown in Table 2.16. It can be seen that MDT meetings occurred less commonly in UTHs and DGHs compared to

STPCs. The fact that MDT meetings were less common in non-specialist paediatric hospitals may reflect the fact the more straight forward surgical cases in children are performed in these hospitals. However, it is surprising in SSHs where it would be expected that relatively complex surgery in children would be undertaken that only just over half held MDT meetings.

From Tables 2.17 and 2.18 it can be seen that some hospitals that had a high volume of children's surgical activity did not always hold MDT meetings. Whilst these hospitals may only undertake straight forward cases there is a risk that this implies that some important management decisions are being made by individual surgeons without formal discussion with colleagues in these hospitals.

Table 2.16 Category of hospital that undertook MDT meetings

Hospital type	Undertake MDT meetings					Total
	Yes	No	Unknown	Subtotal	Not answered	
DGH <500	7	50	6	63	2	65
DGH >500	14	42	3	59	0	59
STPC	27	0	0	27	0	27
UTH	6	20	1	27	0	27
PH	4	82	3	89	3	92
SSH	7	12	1	20	0	20
Total	65	206	14	285	5	290

Table 2.17 Number of operations performed per annum and use of MDT meetings

Number of operations	Yes	No	Unknown	Subtotal	Unanswered	Total
0-100	0	39	3	42	1	43
101-500	3	48	1	52	3	55
501-1000	4	25	3	32	0	32
1001-2000	17	41	3	61	1	62
2001-4000	16	21	3	40	0	40
4001-10000	15	8	0	23	0	23
>10000	3	0	0	3	0	3
Subtotal	58	182	13	253	5	258
Not answered	7	24	1	32	0	32
Total	65	206	14	285	5	290

Table 2.18 Hospitals that do not hold MDT meetings by number of operations performed per annum by hospital category

Hospital category	Do not hold MDT Meetings						Total
	DGH <500	DGH >500	STPC	UTH	PH	SSH	
Number of operations per annum							
0-100	1	0	0	1	33	3	39
101-500	7	3	0	3	34	2	48
501-1000	12	5	0	4	1	3	25
1001-2000	20	12	0	5	2	2	41
2001-4000	4	13	0	4	0	0	21
4001-10000	2	4	0	1	0	1	8
Subtotal	46	37	0	18	70	11	182
Not answered	4	5	0	2	12	1	24
Total	50	42	0	20	82	12	206

Clinical governance and audit

Clinical governance and audit is now embedded in every aspect of health care. Hospitals are required to adhere to guidelines on clinical governance and medical practitioners are required to undertake regular review of clinical practice^{32,34,35}.

Data were collected on whether audit and/or morbidity and mortality meetings were undertaken which included children who had undergone surgery. Of the 276 responses from hospitals 53% (147) stated that they did have such meetings. Thus just under half of hospitals (116) did not undertake these activities. This would

appear to be a particular issue in smaller DGHs and PHs (Table 2.19). These data were further analysed by the volume of cases undertaken per annum (Table 2.20). Four of the 26 hospitals with a high volume of surgical cases appeared not to undertake such meetings. It is difficult to understand why this essential component of clinical practice was not performed. It is possible that some hospitals did include children in adult morbidity and mortality meetings but misinterpreted this question believing that NCEPOD required data for children only meetings. Regardless of this possibility, all hospitals should review their procedures to ensure that audit and mortality and morbidity meetings are held to review the quality of care for children who receive surgery.

Table 2.19. Presence of audit and morbidity and mortality meetings that included children, by hospital category

Hospital category	Morbidity and Mortality meetings undertaken				Not answered	Total
	Yes	No	Unknown	Subtotal		
DGH < 500 beds	33	22	4	59	6	65
DGH >500 beds	38	15	5	58	1	59
STPC	27	0	0	27	0	27
UTH	16	8	2	26	1	27
PH	19	65	2	86	6	92
SSH	14	6	0	20	0	20
Total	147	116	13	276	14	290

Table 2.20 Number of operations performed per annum, by presence of audit and morbidity and mortality meetings which included children

Number of operations	Yes	No	Unknown	Subtotal	Not answered	Total
0-100	8	29	2	39	4	43
101-500	17	33	0	50	5	55
501-1000	20	10	1	31	1	32
1001-2000	38	17	3	58	4	62
2001-4000	27	7	6	40	0	40
4001-10000	19	4	0	23	0	23
>10000	3	0	0	3	0	3
Subtotal	132	100	12	244	14	258
Not answered	15	16	1	32	0	32
Total	147	116	13	276	14	290

The acquisition of good information on clinical outcomes is crucial for effective audit and clinical review. This is often best managed by the routine collection of clinical information in a managed database. Hospitals were asked if such databases were used for children who undergo surgery. Almost 40% (101/273) of hospitals did not manage this information in a database particularly in smaller DGHs and PHs. One would expect PHs to hold most of this procedural data within a database for billing purposes and it may be that these hospitals do not undertake sufficient numbers of surgical procedures to warrant such a database; although these data should be available in some format. Although small numbers might be the case in Private Hospitals, DGHs undertake the majority of surgery in children and should therefore have adequate systems to collect clinical information.

Pre-operative assessment of elective paediatric surgical patients

Children who require elective surgery should have an appropriate clinical assessment prior to surgery. This is often most easily performed by the use of a pre-admission clinic³⁶. In this study 80% (228/284) of hospitals had pre-admission clinics and this was consistent in all of the categories of hospital (Table 2.21).

Prior to admission for surgery parents and children should receive both verbal and written information on various aspects of the health care that is to be given^{17,37,38}. This includes the operation to be performed, the types of anaesthesia and the facilities for families and accommodation. Data from the questionnaire identified whether any written information was provided and the nature of this (Table 2.22). Whilst 90% (240/267) of

Table 2.21. Existence of surgical pre-admission clinics for children by hospital category.

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	48	15	1	64	1	65
DGH >500 beds	49	8	0	57	2	59
STPC	24	3	0	27	0	27
UTH	18	7	1	26	1	27
PH	76	13	1	90	2	92
SSH	13	7	0	20	0	20
Total	228	53	3	284	6	290

Table 2.22 Type of written information provided prior to admission

Information provided	n
No written information	4
The operation that is to be performed	240
The family facilities and accommodation	166
The types of anaesthesia	149
Other	63
Not answered	23

**answers may be multiple (n/267)*

hospitals provided written information about the surgery, only 56% (149/267) provided written information about the anaesthesia despite the promotion of this by the Royal College of Anaesthetists^{39,40}.

Theatre scheduling for children

In the scheduling of elective surgery for children every effort should be made to separate children from adults. Ideally this would be in the form of children only operating theatre lists^{2,17,41}. This may not be practicable depending on the number of children requiring surgery and the subspecialty. In these circumstances designated time for children on adult operating lists should be scheduled, ideally at the start of such lists. National recommendations state children should not be mixed with adults within an operating list^{2,17,41}.

For children who required elective surgery, data were requested as to whether the hospital had one or more

dedicated children's operating theatres. Of the 288 hospitals from which a response was received 55 (19%) indicated that such theatres were employed. Analysing the data by category of hospital, STPCs had more of these theatres than DGHs. One might expect a DGH not to have the resources to have dedicated children's operating theatres whilst STPCs should have such theatres. Thus it is perhaps surprising that two STPCs did not have these theatres (Table 2.23). Whilst these hospitals existed as part of a UTH they both stated that high volumes of cases per annum were undertaken. Furthermore, nine other hospitals of all categories that reported a high caseload did not have dedicated children's operating theatres (Tables 2.24 and 2.25).

Table 2.23 Presence of one or more dedicated children's operating theatres by hospital category

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH<500 beds	4	60	0	64	1	65
DGH >500 beds	8	51	0	59	0	59
STPC	25	2	0	27	0	27
UTH	7	19	0	26	1	27
PH	3	88	1	92	0	92
SSH	8	12	0	20	0	20
Total	55	232	1	288	2	290

Table 2.24 Presence of dedicated children's operating theatres by number of operations performed per annum

Number of operations	Yes	No	Unknown	Subtotal	Not answered	Total
0-100	0	42	1	43	0	43
101-500	2	52	0	54	1	55
501-1000	3	29	0	32	0	32
1001-2000	16	46	0	62	0	62
2001-4000	9	30	0	39	1	40
4001-10000	15	8	0	23	0	23
>10000	2	1	0	3	0	3
Subtotal	47	208	1	256	2	258
Not answered	8	24	0	32	0	32
Total	55	232	1	288	2	290

Table 2.25 Hospitals that did not have dedicated children's operating theatres by number of operations per annum and hospital category

Hospitals that did not have dedicated children's operating theatres							
Hospital category	DGH <500 beds	DGH >500 beds	STPC	UTH	PH	SSH	Total
Number of operations per annum							
0-100	2	0	0	1	36	3	42
101-500	7	3	0	3	36	3	52
501-1000	16	5	0	4	2	2	29
1001-2000	22	14	0	6	2	2	46
2001-4000	8	17	0	4	0	1	30
4001-10000	2	3	2	1	0	0	8
>10000	0	1	0	0	0	0	1
Subtotal	57	43	2	19	76	11	208
Not answered	3	8	0	0	12	1	24
Total	60	51	2	19	88	12	232

Even if a hospital does not have dedicated children's operating theatres, it is important that there is appropriate scheduling of children and this may include having a regular children only operating list. Hospitals were asked how elective surgery for children was incorporated into the operating theatre schedule (Table 2.26). Whilst most hospitals separated adult and children's operating, in 64 hospitals children were mixed into adult operating lists at times in no particular order. This even occurred in five STPCs (Table 2.27) where one would expect at least some segregation of children from adults.

For those children who require non-elective (urgent or emergency) surgery scheduling may be more difficult; however when possible these children should be accommodated within hours into existing elective operating lists or dedicated emergency lists. Out of hours the provision of non elective children's surgical operating will depend on the provision of children's surgical services in each hospital. For example one would expect STPCs that have a substantial children's surgical practice and a large workload to either have dedicated children only emergency lists or at least rapid access to general emergency lists.

Table 2.26. Scheduling of children's elective surgery

How children are incorporated	n
Children only operating lists	166
Adult operating list with a segregated time slot for children	191
Mixed into an adult operating list in no particular order	64
Other	11

*Answers may be multiple (n/283)

Table 2.27 Scheduling arrangements for children's elective surgery

Scheduling arrangements for children's surgery	DGH <500 beds	DGH >500 beds	STPC	UTH	PH	SSH	Total
Children only operating lists	44	44	27	21	19	11	166
Adult operating list with a segregated time slot for children	45	46	12	13	67	8	191
Mixed into an adult operating list in no particular order	15	13	5	6	22	3	64
Other	0	2	2	1	2	4	11

**Answers may be multiple*

Table 2.28 shows how hospitals incorporate non-elective cases in children into "in hours" operating schedules. A greater proportion of DGHs added emergency cases to general emergency lists compared to STPCs. Out of hours most hospitals added non elective children's cases to

general emergency lists. In 14/27 of STPCs there were out of hours children only emergency lists. Of note five of the remaining STPCs undertook between 4,000 and 10,000 cases per annum however it is unknown what proportion were non-elective cases. There may be good

Table 2.28 Scheduling of "in hours" non-elective cases by hospital category

Hospital category	Separate emergency list for children	Added to elective children only lists	Separate emergency list (all ages)	Added to adult elective list	Other	Not answered
DGH <500 beds	0	7	45	20	10	5
DGH >500 beds	3	13	50	20	5	1
STPC	17	15	17	10	5	0
UTH	0	9	18	6	2	4
PH	0	3	0	4	26	60
SSH	0	4	3	5	4	6
Total	20	51	133	65	52	76

**Answers may be multiple*

operational reasons for these hospitals not to have dedicated out of hours children only emergency operating lists. Nevertheless, these children may be better served if they had children only emergency lists.

Following the immediate recovery from surgery and anaesthesia children should be cared for in a Recovery area which is separate from adults to ensure that their emotional and physical needs are met^{2,17}. Of the 282 hospitals that responded 99 (35%) stated that they did not have a separate children's recovery area. This comprised 35/124 DGHs, 3/25 STPCs, 7/25 UTHs, 43/90 PHs and 11/20 SSHs (Table 2.29).

Who operates on and anaesthetises children

There has been considerable debate over the last two decades about who should operate and who should anaesthetise children in the UK^{1,12,15,32,42}. It is clear there needs to be a balance between the concentration of expertise and the demand for surgical and anaesthetic services for children. Furthermore it is essential that the basic skills and competencies of consultants are maintained. Having a co-ordinated plan as to how the services of individual hospitals and geographical regions across the UK provide best care to children who require surgery is a priority. Components of this debate are the need for consultant emergency on-call rotas for children and discussion about the minimum age of children for whom hospitals will undertake surgery.

Table 2.29 Presence of a recovery ward separate from adults

Hospital category	Yes	No	Subtotal	Not answered	Total
DGH <500 beds	43	20	63	2	65
DGH >500 beds	44	15	59	0	59
STPC	22	3	25	2	27
UTH	18	7	25	2	27
PH	47	43	90	2	92
SSH	9	11	20	0	20
Total	183	99	282	8	290

Table 2.30 shows whether there were separate paediatric consultant emergency on-call rotas for surgery, anaesthesia and radiology. Overall there were a greater number of separate consultant rotas for children's anaesthesia compared to surgery and radiology. One can see that most STPCs, nearly half of SSHs and very few other hospitals had a separate on-call emergency rota for paediatric anaesthesia. There was a similar picture for paediatric surgery. However for paediatric radiology, where there were few separate consultant on-call emergency arrangements, fewer than half of the STPCs had separate paediatric radiology consultant on-call rotas.

2 - ORGANISATION
OF CARE

Table 2.30 Number of hospitals with separate specialist on-call emergency rotas for children

Hospital category	Paediatric surgery			Paediatric anaesthesia			Paediatric radiology			Total
	Consultant on-call rotas	Subtotal	Not answered	Consultant on-call rotas	Subtotal	Not answered	Consultant on-call rotas	Sub-total	Not answered	
DGH <500 beds	0	61	4	0	62	3	0	60	5	65
DGH >500 beds	2	59	0	1	56	3	2	59	0	59
STPC	24	26	1	24	26	1	11	26	1	27
UTH	4	25	2	8	25	2	2	25	2	27
PH	2	86	6	12	84	8	1	84	8	92
SSH	3	19	1	9	20	0	1	18	2	20
Total	35	276	14	54	273	17	17	272	18	290

For those hospitals that did not have separate consultant on-call emergency rotas for children, data were obtained on the lower age limit that consultants

would anaesthetise, operate and undertake radiological procedures for children (Figure 2.5).

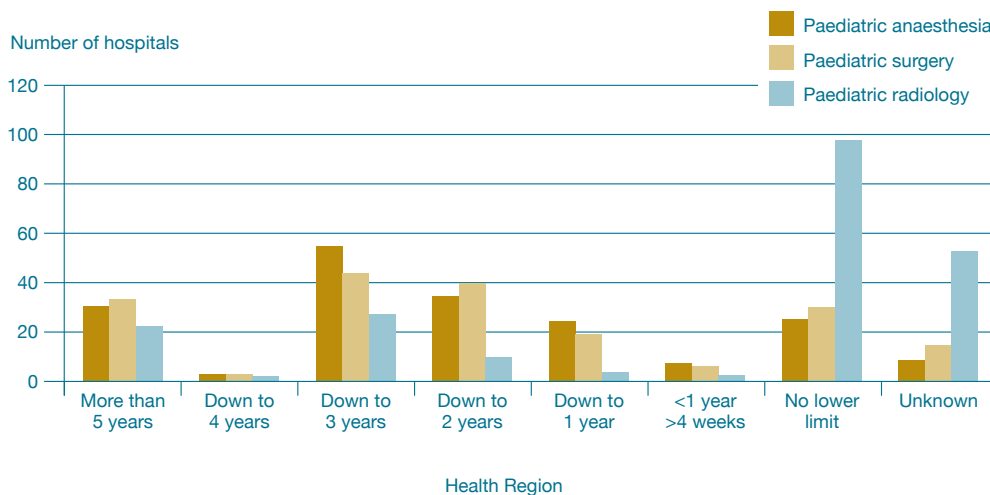


Figure 2.5 Lower age limits for anaesthesia, surgery and radiology if no on-call emergency rota for children by number of hospitals

Many hospitals did not provide information on consultant on-call emergency rotas or age limits (39 paediatric anaesthesia, 55 paediatric surgery, 72 paediatric radiology) and thus these data must be interpreted with caution. Without being able to verify the skill mix of consultants in these hospitals and the volume of emergency surgery in children by age it is difficult to draw firm conclusions. Nevertheless it is important that hospitals and clinicians are confident that they have the necessary infrastructure, facilities, experience and competencies to treat children who present for surgery in an emergency.

Furthermore it is clear that there are few hospitals, including less than half of STPCs that had separate on-call emergency rotas for paediatric radiology. There are many surgical conditions in children that require skilled and experienced paediatric radiologists for diagnostic and interventional procedures. It is important that there is access to this level of expertise 24 hours a day in hospitals that perform such procedures.

Hospital facilities for children

Hospitals in which children are cared for who require surgery need to ensure that they provide the necessary environment and facilities that meet standards set out by the National Service Framework for children and adhere to the recommendations of the Royal College of Surgeons and Royal College of Anaesthetists^{2,17,32,41}.

In providing an appropriate environment and facilities for older children and adolescents the NSF for children states that they should be *“located alongside other people of their age who are more likely to meet their need for social interaction and this makes it is easier for staff to meet their needs for different forms of entertainment, education and additional privacy”* and that *“Separate adolescent units may be the best solution, but this will*

*not always be the case, and many hospitals will address their needs quite adequately by grouping them together in separate bays in the paediatric ward”*². This is particularly important for older children and adolescents as privacy and social issues may impact on surgical conditions. Table 2.31 presents the ward provision for older children and adolescents in hospitals. In 16 hospitals there was a separate adolescent ward, 29% (82/281) had a designated area on a children’s ward whilst 36% (101/281) mixed children of all ages together on a children’s ward. If the latter data is subdivided by the category of hospital then over a third of DGHs and a half of STPCs and UTHs did not have separate provision for older children and adolescents.

Table 2.31 Ward provision for older children and adolescents

Type of provision for adolescents	n	%
All ages mixed together	101	35.9
Separate adolescent ward	16	5.7
Designated area on a children’s ward	82	29.2
Other	82	29.2
Subtotal	281	
Not answered	9	
Total	290	

When a child is admitted to hospital it is important that the needs of their family are also taken into account. This should include suitable sleeping accommodation, recreational facilities and access to bereavement services if required. Data were collected on whether such arrangements were present. Whilst the majority (253/277) of the hospitals did have family accommodation, nine DGHs, six PHs and seven SSHs did not. Furthermore it was found that only 135/261 (51.7%) of hospitals, from which a response was received, had a bereavement service for the family members of children who have

died. The number of such bereavement services by hospital category is shown in Table 2.32. It may be that those hospitals that did not have family bereavement services do not treat many children who are likely to die or these services may be combined with the Trust's adult bereavement service. However access to such services is set out as in the NSF for children².

Table 2.32 Presence of a bereavement service for the family members of children who have died

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	38	18	5	61	4	65
DGH >500 beds	38	13	4	55	4	59
STPC	25	1	0	26	1	27
UTH	15	6	3	24	3	27
PH	11	62	3	76	16	92
SSH	8	10	1	19	1	20
Total	135	110	16	261	29	290

Specialised staff for the care of children

Regardless of the location in the hospital that children have surgery it is essential that they are cared for by health care professionals who have the appropriate training, experience and competencies for their needs. Some standards for these requirements are set out in the NSF for children and health care professional organisations^{2,17,43,44}.

In 37/278 (13%) hospitals surgery or interventional procedures requiring anaesthesia was undertaken on a site remote from the inpatient paediatric beds. Of these, provision was made in 30 hospitals to ensure onsite paediatric medical support was available if required. However six hospitals (two small DGHs, one UTH, two PHs and one SSH) undertook surgery on a separate site remote from the paediatric inpatient beds without any paediatric medical support (doctors with specific training for the care of children). These children may be at

significant risk if an untoward event occurred and urgent paediatric medical support was required. Review of the provision for onsite trainee medical cover for children who required inpatient surgery showed that in 23/223 (10.3%) hospitals that responded cover was provided by trainees from an adult surgical specialty only.

It was asked whether there was at least one Registered Children's Nurse per nursing shift on the non critical care ward which admitted children for surgery. In 23/275 (8.3%) of hospitals this was not the case. Looking at these data by hospital category it can be seen that thirteen PHs, four UTHs, four DGHs and two SSHs did not have this level of children's nursing cover. These hospitals fell well below existing national standards which state that a minimum of two Registered Children's Nurses per shift should be on duty 24 hours a day in all children's wards and departments^{43,44}. These hospitals need to review the nursing provision and ensure appropriate levels to meet national standards.

In the operating theatre department the surgeons and anaesthetists who care for children need to be supported by nursing staff and operating department professionals who have the appropriate child-oriented competencies. Whilst for adults some standards of care and competencies for nurses and operating department practitioners exist^{16,45,46,48} no specific national competencies for the care of children have been

developed. However many hospitals in the UK have created “in-house” competencies for various aspects of the care of children⁴⁹.

Tables 2.33-2.34 show whether there was 24 hour availability of a theatre nurse, anaesthetic assistance and recovery room anaesthetic assistance deemed to have competencies in the care of children by hospital category.

Table 2.33 Presence of at least one theatre nurse with competencies in children’s surgery 24 hours a day (for hospitals that provide non-elective surgery for children)

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	20	25	7	52	5	57
DGH >500 beds	29	21	3	53	2	55
STPC	23	3	1	27	0	27
UTH	9	8	4	21	0	21
PH	3	2	0	5	0	5
SSH	4	6	0	10	1	11
Total	88	65	15	168	8	176

Table 2.34 Presence of at least one anaesthetic assistant with competencies in children’s anaesthesia 24 hours a day (for hospitals that provide non-elective surgery for children)

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	26	21	6	53	4	57
DGH >500 beds	37	14	2	53	2	55
STPC	24	1	2	27	0	27
UTH	12	5	4	21	0	21
PH	4	1	0	5	0	5
SSH	5	6	0	11	0	11
Total	108	48	14	170	6	176

Table 2.35 Presence of at least one recovery anaesthetic assistant with competencies in recovery of children 24 hours a day (for hospitals that provide non-elective surgery for children)

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	27	19	6	52	5	57
DGH >500 beds	31	17	4	52	3	55
STPC	20	3	2	25	2	27
UTH	11	5	4	20	1	21
PH	5	0	0	5	0	5
SSH	5	5	0	10	1	11
Total	99	49	16	164	12	176

Caution is required in interpreting these data in the absence of nationally agreed competencies in these disciplines and each hospital may have interpreted these questions differently. However, there is a need for those professional organisations responsible for peri-operative nursing, and operation department practitioners, to create specific standards and competencies for staff that care for children in the operation theatre department. At the very least these staff should have basic paediatric airway, breathing and circulation management skills.

Management of the sick child

All hospitals in which children requiring surgery are cared for should have policies and procedures in place

for the management of those who have suffered critical illness and trauma. This includes the identification of the critically ill child, resuscitation and stabilisation followed by transfer to another hospital for specialist paediatric care if necessary^{2,17,18,50,51}.

Data were collected on whether hospitals had a policy for the identification and management of the seriously ill child. Of the responses received 78.2% (216/276) of hospitals, where the question was answered, indicated that they had a policy and 51 (18.5%) did not. Table 2.36 shows these data by category of hospital. It can be seen that 20 DGHs, three STPCs, one UTH, 22 PHs and five SSHs did not have these policies in place. It is difficult to explain why this was the case and this poses a major risk to the welfare of the children in these hospitals.

Table 2.36 Presence of a policy for the identification and management of the seriously sick child by hospital category

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	49	9	2	60	5	65
DGH >500 beds	43	11	4	58	1	59
STPC	24	3	0	27	0	27
UTH	24	1	1	26	1	27
PH	64	22	1	87	5	92
SSH	12	5	1	18	2	20
Total	216	51	9	276	14	290

Table 2.37 Use of paediatric track and trigger systems by hospital category

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	38	18	4	60	5	65
DGH >500 beds	34	22	3	59	0	59
STPC	20	5	0	25	2	27
UTH	15	7	3	25	2	27
PH	40	46	2	88	4	92
SSH	8	9	1	18	2	20
Total	155	107	13	275	15	290

Whilst there are specific national guidelines on the management of adult inpatients who become critically ill^{52,53}, no similar guidance exist for children. However various hospitals are developing and piloting early warning scoring systems for children to help identify the critically ill child although these require validating⁵⁴⁻⁵⁶. To determine the extent that hospitals used track and trigger (paediatric early warning scoring) in clinical practice this information was requested from the hospitals. Of those that replied 56.4% (155/275) used such a tool. The proportion that used these tools across the different hospital categories is shown in Table 2.37.

As many hospitals have developed systems for the identification and management of the critically ill and injured child there is now a real opportunity to gather an evidence base to develop guidance in this important clinical situation.

If a child's condition deteriorates such that they require cardiopulmonary resuscitation, it is essential that the health care professionals that are in attendance have the necessary competencies and experience to manage the child appropriately. The presence of onsite resuscitation teams is a prerequisite for all hospitals⁵⁷. Furthermore, hospitals that care for children should have a resuscitation policy that includes children. Of the 289 hospitals from which a response was received 282 indicated that they had an onsite resuscitation team for

any age of patient, and six did not (in one it was unknown). Of those that did not, three were DGHs and three PHs. It was also determined that 5% (15/277) of hospitals that replied did not have a resuscitation policy that included children. Further analysis determined that these were three DGHs, four UTHs, five PHs, and three SSHs. Finally data were requested as to whether hospitals had at least one member of the resuscitation team that attended children with up to date paediatric advanced life support training including European Paediatric Life Support or Advanced Paediatric Life Support. Of the 282 hospitals that had a resuscitation team, 16 stated that this was not the case (four were small DGHs, three large DGHs, one UTH, two PHs and six SSHs).

Overall these findings are encouraging, but there were some hospitals that undertook surgery in children which did not have contingency arrangements to care for the child that may become suddenly or unpredictably seriously unwell.

Paediatric acute pain management

Hospitals that undertake surgery in children must have appropriate arrangements in place to ensure that postoperative pain and discomfort is minimised. How this is achieved will depend on the type and volume of surgery undertaken and the category of hospital.

There should be appropriate funding with hospital wide protocols for the management of postoperative pain in children which include, (depending on the type of surgery performed), the use of simple and complex analgesia and tools to assess pain and the side effects of analgesia drugs. The efficacy of these elements needs to be audited. Regular education programmes are required for doctors and nurses in pain management for children. Depending on the category of hospital and paediatric case load this may be best achieved by having a multidisciplinary team of health care professionals which includes a consultant anaesthetist supported by clinical nurse specialists, (Acute Pain Nurses) who have responsibility for acute pain management in children. This could be delivered via a dedicated children's acute pain service or within the remit of a combined service for adults and children^{2,17,33,58-60}.

In the 284 hospitals from which a response was received 152 (53.5%) stated that there was a multidisciplinary acute pain service which included children. Excluding PHs most of which do not have an acute pain service, 137/198 (69%) of NHS hospitals had such a service. Of the 50 (25%) NHS hospitals that did not have a multidisciplinary acute pain service that included children many performed less than 1000 operations in children a year (Table 2.38) and thus it may be difficult for these hospitals to justify having such a service. The presence of an acute pain service was further analysed by hospital category (Table 2.39). There were some hospitals undertaking 4001 to 10,000 operations a year that did not have such a service which included children (Table 2.40).

Table 2.38 Presence of an acute multidisciplinary pain service that included children by number of operation per annum

Number of operations	Yes	No	Unknown	Subtotal	Not answered	Total
0-100	9	32	1	42	1	43
101-500	10	40	3	53	2	55
501-1000	16	13	2	31	1	32
1001-2000	44	14	4	62	0	62
2001-4000	34	5	0	39	1	40
4001-10000	20	3	0	23	0	23
>10000	3	0	0	3	0	3
Subtotal	136	107	10	253	5	258
Not answered	16	15	0	31	1	32
Total	152	122	10	284	6	290

Table 2.39 Presence of an acute pain service that included children by hospital category

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	42	20	1	63	2	65
DGH >500 beds	47	9	1	57	2	59
STPC	24	1	2	27	0	27
UTH	18	6	3	27	0	27
PH	15	72	3	90	2	92
SSH	6	14	0	20	0	20
Total	152	122	10	284	6	290

Table 2.40 Hospitals that did not have an acute pain service that included children by number of operation per annum and hospital category.

Hospital category	Hospitals that did not have an acute pain service						Total
	DGH <500 beds	DGH >500 beds	STPC	UTH	PH	SSH	
Number of operations per annum							
0-100	2	0	0	1	27	2	32
101-500	4	1	0	2	30	3	40
501-1000	5	4	0	0	1	3	13
1001-2000	6	2	0	1	2	3	14
2001-4000	2	1	0	1	0	1	5
4001-10000	0	1	1	1	0	0	3
Subtotal	19	9	1	6	60	12	107
Not answered	1	0	0	0	12	2	15
Total	20	9	1	6	72	14	122

A named consultant with specific responsibility for acute pain management of children was present in 106/278 (38%) hospitals. However of these 39 had no allocated sessions, 19 had one or more allocated sessions and 48 did not answer the question.

Only a quarter (69/271) of hospitals reported that they had an Acute Pain Nurse with responsibility for children. There was a greater proportion of Acute Pain Nurses in STPCs (Table 2.41). Even so, five STPCs did not have an Acute Pain Nurse with responsibility for children.

Table 2.41 Presence of an Acute Pain Nurses responsible for the management of postoperative pain in children

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	12	48	0	60	5	65
DGH >500 beds	18	39	0	57	2	59
STPC	20	5	2	27	0	27
UTH	5	17	3	25	2	27
PH	13	70	0	83	9	92
SSH	1	18	0	19	1	20
Total	69	197	5	271	19	290

In addition it was found that 14% (38/272) of hospitals did not have protocols for the management of postoperative pain in children and only 48% (131/273) of hospitals provided regular education programmes for doctors and nurses in acute pain management in children. Those categories of hospitals that provided education are shown in Table 2.42. Clearly very little training is provided in Private Hospitals or Single Specialty Hospitals.

Epidural analgesia for children is a specialised form of analgesia which is of most value following major surgery. Overall 63/277(23%) hospitals used this form of analgesia and the data collected is shown in Table 2.43, where it can be seen that this modality of analgesia was mainly undertaken in STPCs. Of the 63 hospitals that use epidural analgesia 48 had pre-prepared analgesic solutions. Pre-prepared analgesic solutions reduce the risk of drug error and lower infection risk⁵⁹.

Table 2.42 Hospitals that provide regular education programmes in acute pain management

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH<500 beds	35	23	4	62	3	65
DGH >500 beds	36	20	0	56	3	59
STPC	24	1	2	27	0	27
UTH	11	11	4	26	1	27
PH	19	62	2	83	9	92
SSH	6	12	1	19	1	20
Total	131	129	13	273	17	290

Table 2.43 Use of epidural analgesia by hospital category

Hospital category	Yes	No	Unknown	Subtotal	Not answered	Total
DGH <500 beds	4	57	2	63	2	65
DGH >500 beds	14	42	2	58	1	59
STPC	26	1	0	27	0	27
UTH	7	12	1	20	7	27
PH	6	83	1	90	2	92
SSH	6	12	1	19	1	20
Total	63	207	7	277	13	290

Pain and sedation were routinely assessed in children following surgery in 264/277 (95%) hospitals that responded to this question. However, many hospitals did not have fully developed acute pain management systems for children despite clear national guideline and standards on acute pain management.

Key Findings - Organisation of Care

Surgical workload

Thirty two hospitals from which an organisational questionnaire was returned were unable to provide important data on the number of operations undertaken in children.

Clinical networks for children's surgery

Less than half of NHS hospitals in which surgery in children was undertaken stated that they were part of a surgical clinical network for children and there was uneven distribution of hospitals included in networks between health regions in England, Wales and Northern Ireland.

Few surgical clinical networks for children included paediatric anaesthesia.

More than half of hospitals that were in surgical clinical networks had no specific funding and many did not include elements that would suggest effective functioning; such as leadership, education, clinical care policies, multidisciplinary team meetings, clinical governance and accountability arrangements.

Transfer of children

93% (266/285) of hospitals had a policy for the transfer of children to another hospital. However many of these policies did not include staffing arrangements for the transfer or family support during the transfer.

Team working

Not all hospitals had comprehensive operational policies on surgery and anaesthesia for children as recommended by various national bodies^{17,18}.

Clinical governance and audit

53% (147/276) of hospitals that undertake surgery in children reported that they held clinical audit and

morbidity and mortality meetings for children although these may not have included children discussed in wider departmental audit meetings.

Pre-operative assessment of elective paediatric surgical patients

80% (228/284) of hospitals that undertook surgery in children had pre-admission assessment clinics for children, however, only 56% (149/267) provided written information for children and parents about anaesthesia.

Theatre scheduling for children

Despite national recommendations stating that surgery on children should be undertaken either on children only operating theatre lists and where this is not feasible have a segregated time slot on adult lists, some hospitals mix children and adults in no particular order within operating lists^{2,17,41}.

Nine hospitals that had a large case load for children's surgery did not have dedicated children's operating theatres.

There was considerable variation for the provision of non-elective surgery for children both in hours and out of hours.

In 35% (99/282) of hospitals, children were recovered following surgery and anaesthesia in a Recovery area which was not separated from adults. This is contrary to national recommendations^{2,17}.

Hospital facilities for children

In 36% (101/281) of hospitals children of all ages were mixed together on a children's ward with no special provision for older children and adolescents. This goes against recommendations of the National Strategic Framework for Children which states that older children and adolescents should be grouped together in separate bays on the paediatric ward or on separate adolescent wards to help meet their social needs².

Specialised staff for the care of children

Six hospitals undertook surgery on a separate site remote from the paediatric inpatient beds without any paediatric medical support (doctors with specific training for the care of children).

In 10% (23/223) of hospitals trainees from an adult only surgical specialty provided medical cover for inpatient children.

In 8% (23/275) of hospitals that undertook surgery in children there was not at least one children's registered nurse per shift on non critical care wards. This does not comply with national standards^{43,44}.

There was considerable variation in the level of appropriate child orientated competencies of peri-operative nurses and operation department practitioners between hospitals that undertook surgery in children.

Management of the sick child

In 18.5% (51/276) of hospitals that undertook surgery in children there was no policy for the identification and management of the seriously ill child.

Some hospitals that undertook surgery in children did not have the minimum measures in place to provide for the child that might require cardiopulmonary resuscitation. These include a resuscitation policy that includes children and on-site resuscitation teams that include staff with advanced training in paediatric life support.

Paediatric acute pain management

Not all hospitals that undertake surgery in children had the necessary measures in place to provide effective pain control following surgery. In many hospitals there was lack of consultants and specialist acute pain nurses with sessional commitments for acute pain management and a paucity of protocols and educational programmes in the management of post operative pain.

Recommendations - Organisation of Care

Surgical workload

All hospitals that undertake surgery in children must have the necessary information systems in place to determine the number of patients that are treated within their hospital for monitoring, clinical governance and financial purposes. *(Trust Chief Executives)*

Clinical networks for children's surgery

There is a need for a national Department of Health review of children's surgical services in the UK to ensure that there is comprehensive and integrated delivery of care which is effective, safe and provides a high quality patient experience. *(Department of Health and Devolved Administration Governments)*

National NHS commissioning organisations including the devolved administrations need to adopt existing recommendations for the creation of formal clinical networks for children's surgical services. These need to provide a high quality child focused experience which is safe and effective and meets the needs of the child^{8,18,26,27}. *(National Commissioners)*

Transfer of children

All hospitals that admit children should have a comprehensive transfer policy that is compliant with Department of Health and Paediatric Intensive Care Society guidance and should include; elective and emergency transfers, staffing levels for the transfer, communication procedures, family support, equipment provision and transport arrangements. *(Medical Directors)*

Team working

All hospitals that provide surgery for children should have clear operational policies regarding who can operate on and anaesthetise children for elective and emergency surgery, taking into account on-going clinical experience, the age of the child, the complexity of surgery and any co-morbidities. These policies may differ between surgical specialities. *(Medical Directors)*

Clinical governance and audit

All hospitals that undertake surgery in children must hold regular multidisciplinary audit and morbidity and mortality meetings that include children and should collect information on clinical outcomes related to the surgical care of children. *(Medical Directors)*

Pre-operative assessment of elective paediatric surgical patients

Hospitals in which surgery in children is undertaken should provide written information for children and parents about anaesthesia. Good examples are available from the Royal College of Anaesthetists website^{39,40}. *(Clinical Directors in Anaesthesia)*

Theatre scheduling for children

Hospitals that have a large case load for children's surgery should consider using dedicated children's operating theatres. *(Clinical Directors in Surgery and Anaesthesia and Medical Directors)*

Hospitals in which a substantial number of emergency children's surgical cases are undertaken should consider creating a dedicated daytime emergency operating list for children or ensure they take priority on mixed aged emergency operating lists. *(Clinical Directors in Surgery and Anaesthesia and Medical Directors)*

Specialised staff for the care of children

Children admitted for surgery whether as an inpatient or an outpatient must have immediate access to paediatric medical support and be cared for on a ward staffed by appropriate numbers of children trained nurses. *(Clinical Directors)*

There is a need for those professional organisations representing peri-operative nursing and operating department practitioners to create specific standards and competencies for staff that care for children while in the operating theatre department. *(British Anaesthetic and Recovery Nurses Association, College Operating Department Practitioners, Association for Perioperative Practice, Royal College of Nursing)*

Management of the sick child

All hospitals that admit children as an inpatient must have a policy for the identification and management of the seriously ill child. This should include Track & Trigger and a process for escalating care to senior clinicians. The National Institute for Health and Clinical Excellence needs to develop guidance for the recognition of and response to the seriously ill child in hospital. *(Medical Directors, National Institute for Health and Clinical Excellence)*

All hospitals that admit children must have a resuscitation policy that includes children. This should include the presence of onsite paediatric resuscitation teams that includes health care professionals who have advanced training in paediatric resuscitation. *(Medical Directors and Resuscitation Leads)*

Paediatric acute pain management

Existing guidelines on the provision of acute pain management for children should be followed by all hospitals that undertake surgery in children^{2,17,58,59}. *(Medical Directors)*

Under embargo until 00.01 27th October



3 – Peer Review Data

Introduction

The following chapters describe the peer reviewed data and details of care of 378 babies and children who died within 30 days of a surgical or interventional procedure under anaesthesia in the period (April 2008-March 2010). A detailed assessment of clinical care in these cases has been provided. This dataset is different to that described in the previous chapter on organisational care. The data in Chapter 2 is based on the results of the Organisational Questionnaire which focused on the way care was provided across all hospitals that undertook surgery in children. However, whilst the majority of surgery in childhood occurs across all types of hospitals, the majority of deaths analysed in this part of the study occurred in major centres, reflecting the specialties located in these hospitals (paediatric surgery, cardiac surgery, neurosurgery etc.), and a policy of transferring critically ill children from smaller or less well resourced institutions.

Descriptive data

Very few peri-operative deaths occur in babies and children compared to adults and there is evidence that death rate is decreasing in certain diagnostic groups⁶¹.

NCEPOD last looked at 112 deaths in children aged 0-16 years over a one year period from April 1997 to March 1998¹². This study excluded cardiac surgical deaths. The current study reviewed all deaths within 30 days of surgery in all specialties operating on children over a two year period.

From Figure 3.1 it can be seen that the vast majority of paediatric surgical deaths occurred in infants aged less than one year (250/378, 66%). Of these, 135/215(63%) were born prematurely (at less than 37 weeks gestation). There were relatively few deaths in older children and young people, but with a small increase in late teenage years. In almost all age groups males were over represented. This pattern is reflected in other studies which also include non surgical cases in children^{50,62}.

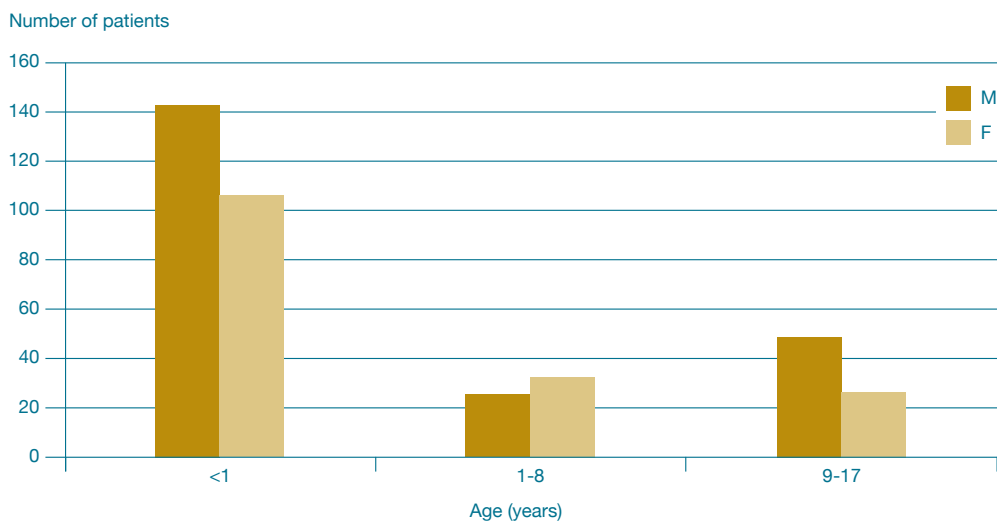


Figure 3.1 Age of patients

Most deaths occurred in STPCs where surgery had also taken place, with a minority in DGHs and SSHs (Table 3.1). In the previous NCEPOD study in 1999¹² classification of centres differed and cardiac surgical cases were not included, but similarly a minority of operations occurred in DGH's (7/112).

Table 3.1 Location of deaths by category of hospital

Hospital type	n	%
DGH <500 beds	3	0.9
DGH >500 beds	5	1.5
STPC	281	84.6
UTH	36	10.8
PH	2	0.6
SSH	5	1.5
Subtotal	332	
Not answered	46	
Total	378	

Specialty of Admitting Consultant

The largest admitting teams were neonatology (including neonatal intensive care), paediatric surgery and paediatric cardiology, followed by paediatric intensive care (PIC) and neurosurgery (Figure 3.2). This pattern reflects both the age profile and level of acute illness of the population, with significant requirement for Level 2 and 3 intensive care.

Overall 125 cases had the direct input of paediatric surgeons (NEC and congenital paediatric general surgery, and the majority of cases were coded as general paediatric surgery i.e. 18/22) (Table 3.2). More detail will be presented on cardiac surgery, NEC, trauma and neurosurgical cases in Chapter 4.

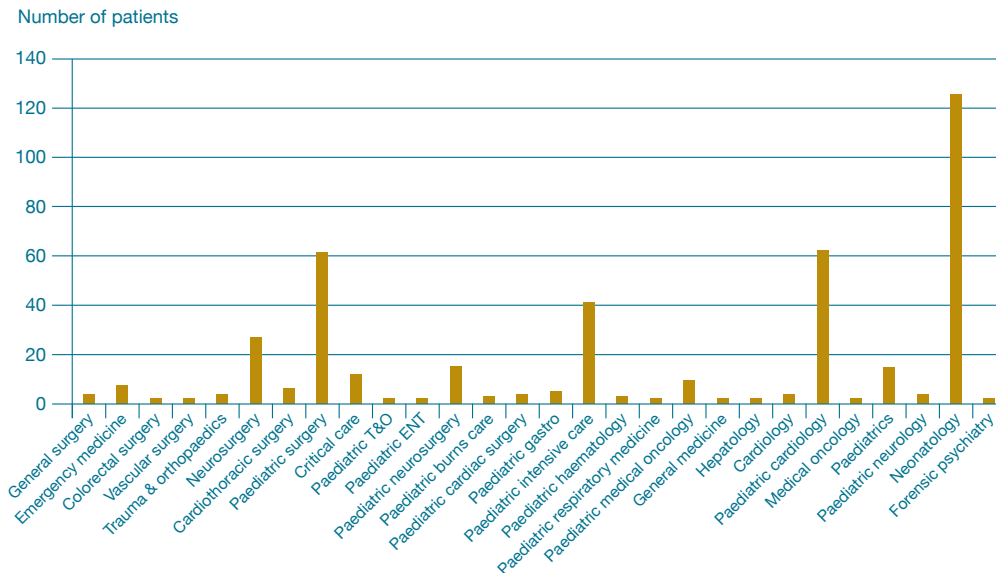


Figure 3.2 Specialty of admitting consultant

Table 3.2 Diagnostic category

Case type	n	%
Congenital paediatric general surgery	22	7.1
Ear, nose and throat	10	3.2
General paediatric (not congenital) surgery	22	7.1
Trauma- including head injury	25	8.0
Neurosurgical - non trauma	36	11.6
Necrotising enterocolitis (NEC)	103	33.1
Congenital cardiac surgery	62	19.9
Unknown	7	2.3
Other	24	7.7
Subtotal	311	
Not answered	67	
Total	378	

Surgeons were requested to define the urgency of the admission. In 254/309 (82%) cases patients were admitted as emergencies, with just 50 elective admissions. In a further five cases urgency was unknown and in 69 cases the question was not answered or no surgical questionnaire was returned with the clinical notes (Table 3.3).

Table 3.3 Urgency of admission

Urgency of admission	n	%
Elective	50	16.1
Emergency	254	82.3
Unknown	5	1.6
Subtotal	309	
Not answered/No surgical questionnaire	69	
Total	378	

It is well known that ASA grade is a relatively crude estimate of peri-operative risk, and this may be particularly so in babies and children. This was noted in the 1999 NCEPOD study on children¹², but a suitable alternative is yet to be defined. However it can be seen from Table 3.4 that most cases fell into the ASA 3/4/5 categories, with the majority being ASA 4 and 5 (261/308, 84%). It should be noted that anaesthetists decided on these ASA grades in retrospect as they were completing the questionnaires. Of note is the fact that 85/308 (27.5%) babies and children were designated as ASA 5 (defined as “a moribund patient who is not expected to survive 24 hours with or without an operation”). Accepting the limitations of assigning ASA grade in retrospect, anaesthetists would generally have also recorded this at the time of surgery. It could be questioned as to whether all these operations were appropriate if patients were correctly classified.

Table 3.4 ASA grade as defined by the attending anaesthetist

Health status prior to operation	n	%
ASA 1: A normal healthy patient	8	2.6
ASA 2: A patient with mild systemic disease	5	1.6
ASA 3: A patient with severe systemic disease	34	11.0
ASA 4: A patient with severe systemic disease that is a constant threat to life	176	57.1
ASA 5: A moribund patient who is not expected to survive the operation	85	27.6
Subtotal	308	
Not answered/ No anaesthetic questionnaire	70	
Total	378	

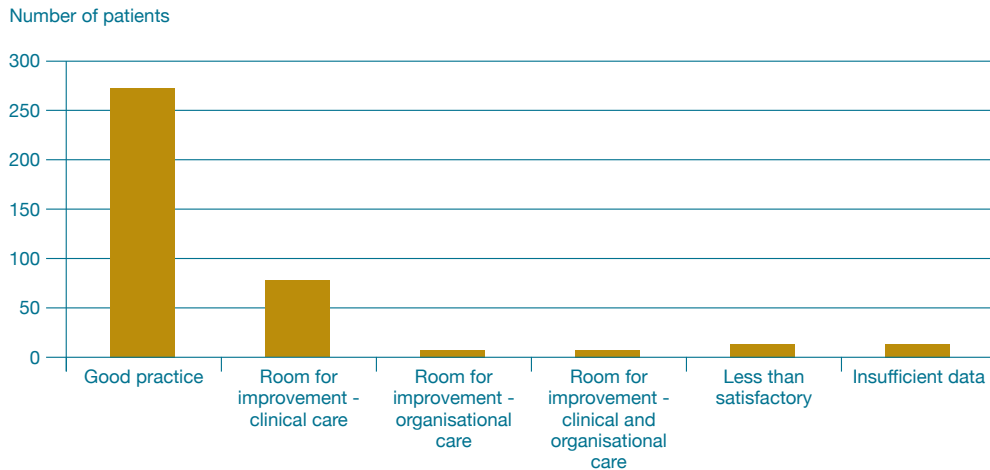


Figure 3.3 Overall assessment of care - Advisors' opinion

Overall assessment of care

After reviewing all aspects of care provided (not outcome) of 378 cases, Advisors were asked to provide an overall quality of care assessment of the case, based on a five point scale. As Figure 3.3 shows 71% of cases reviewed were judged by the Advisors as good care; demonstrating that there is a high level of good quality care, on both a clinical and organisational level, being delivered to children undergoing surgery. This is likely to reflect the fact that the majority of the sample described came from specialist centres.

However, there is still scope for improvement and it is these areas that will be concentrated on in the next sections. In 20% of the sample there was believed to be room for improvement in clinical care, 2% in organisational care, and 2% in both clinical and organisational care. Three percent of patients (11) were deemed to have received care which was less than satisfactory.

In a further 3% (11 cases) Advisors did not have enough information in the case notes provided to make a valid assessment.

Pre-operative care

Whilst the overall assessment was that quality of care in this population was generally satisfactory; those areas where it was less than good were examined. In order to do this the care pathway of the population of children prior to surgery is described in detail.

Timing of admission and surgery

The case notes were examined to ascertain whether there was a particular time of the day when patients were admitted (Table 3.5) and operated on (Table 3.6).

Table 3.5 Time of admission

Time of admission	n	%
08:00-17:59	159	43.6
18:00-23:59	84	23.0
00:00-07:59	122	33.4
Subtotal	365	
Insufficient data	13	
Total	378	

Table 3.6 Time of surgery

Time of operation	n	%
08:00-17:59	207	66.3
18:00-23:59	71	22.8
00:00-07:59	34	10.9
Subtotal	312	
Insufficient data	66	
Total	378	

At least 206 paediatric surgical patients were admitted between 18:00 and 07:59 (a greater number than during the normal working day). Many were transferred for urgent surgical opinions and/or paediatric intensive care (PICU) or neonatal intensive care (NICU). This has important implications for the staffing and safe delivery of the service. It is noted that operations also occurred relatively often out of hours (105/312 cases Table 3.6). Even in a children's hospital setting it is accepted that there are generally fewer personnel and reduced availability of facilities out of hours^{9,63,64}. Since surgery and anaesthesia in babies and children is typically performed by consultants, who are not generally part of shift working, this can have major implications for fatigue, staff well being and retention. It is important to note that time of admission could not be identified easily or was not recorded in a further 13 cases, and in 66 no time of surgical procedure was discoverable. Both time points are important to define clearly when cases are reviewed either internally or externally.

Inter-hospital transfer

Based on the opinion of the Expert Group at the start of the study, and the findings of the NCEPOD 1999 study¹² it was anticipated that many babies and children would be transferred between centres. Neonatal networks now exist in the UK for transfer of babies between units

with different designations of care. Dedicated transfer teams generally support these networks and this is also considered in recent national recommendations^{65,66}.

Since the last NCEPOD report on surgery in children, there have also been major changes in the delivery of paediatric intensive care for older babies and children²⁸ which is provided in fewer centres and is supported in networks by transfer teams²⁹. Surgical babies and children benefit from these services should they also require intensive care. However, systems may not be so robust for the transfer of non intensive care patients, and where a referring unit is required to urgently transfer the patient without the assistance of a dedicated and relatively senior team. Recommendations on the immediate transfer of the paediatric neurosurgical patient have recently been clarified⁶⁷.

In this study, 246/373 (66%) patients in this study were transferred from another hospital before they underwent their primary operation. Seventy two percent (178/246) of those transferred were infants under one year of age. One hundred and six babies who were transferred had been born at less than 37 weeks gestation i.e. prematurely. A further analysis of the patients aged less than one year of age that were transferred showed that 84 (56.4%) had a diagnosis of NEC, 30 (20%) cases had congenital cardiac problems, and 13 (8.7%) had congenital paediatric surgical problems. It would be expected that many of the babies suffering from NEC would also have been suffering an associated level of cardio-respiratory compromise, as well as their prematurity and abdominal sepsis. The need to transfer such babies has increased over the last 10 years because of clearer recommendations on designation of care and survival of many more extremely small and preterm babies⁶⁸.

3 - PEER REVIEW DATA

In the 1999 NCEPOD report on surgery in children (which excluded cardiac surgery), it was noted over the one year of the study that there were 53 transfers, 33 being under the age of one year. It is probable that the volume of cases requiring transfer has increased in the interim, and this probably relates to multiple factors including further regionalisation of paediatric surgical work as well as improved survival of very preterm infants.

Most of the patients who were transferred required emergency admission (Table 3.7).

Table 3.7 Transferred patients by urgency of admission

Urgency of admission	n	%
Elective	13	6.5
Emergency	182	91.0
Unknown	5	2.5
Subtotal	200	
Not answered/ No surgical questionnaire	46	
Total	246	

The Advisors were asked to determine whether there was deterioration in the patients' condition between the decision to transfer and arrival in the receiving hospital (Table 3.8).

Table 3.8 Deterioration in patients' condition on transfer - Advisors' opinion

Deterioration occurred	n	%
Yes	28	13.8
No	175	86.2
Subtotal	203	
Insufficient data	43	
Total	246	

In 28 cases (13.8%) the condition of the patient deteriorated prior to arrival in the receiving unit. Whilst

this was not entirely unexpected given the acute nature of the patients being cared for, it was also noted that on occasion this was preventable.

In 11 cases transfer had been undertaken by the referring unit, in nine the patient was "retrieved" and in eight cases this was unknown or not answered. Deterioration during transfer does not necessarily imply that the care delivered was poor. Given the extreme nature of the underlying condition requiring rapid transfer it may have been that this was the main factor dictating outcome. However it is known that the number of critical incidents during transfer relates to the seniority/training of the transfer team⁶⁹⁻⁷¹.

In 1999 NCEPOD reported that 53/85 patients, in whom notes were sufficiently complete, were transferred as an inpatient from another hospital¹². In 19 cases in the 1999 report it was believed that the patient's condition on admission was unsatisfactory, and two cases were transferred without a medical or nursing escort. It was recommended that a rigorous audit of paediatric transfers was maintained. In the current study, care during transfer was judged by Advisors to be appropriate for the majority. However, it is also true to say that in many cases documentation on transfer was very poor, making audit and subsequent comment impossible.

The Advisors were asked specifically about the appropriateness of the care given to the patient during transfer (Table 3.9).

Table 3.9 Appropriateness of the care given to the patient during transfer - Advisors' opinion

Care appropriate	n	%
Yes	163	97.0
No	5	3.0
Subtotal	168	
Insufficient data	78	
Total	246	

In the majority of cases where data were available (163/168) the care given during transfer was judged to be appropriate, with just five where it was not. Three of those were patients that deteriorated during transfer. Again lack of clear documentation of care and observations during transfer made it impossible to comment in a further 78 cases. It is unacceptable that transfer notes are not part of the full medical record as they form a very important description of the patient pathway and record of care.

Examples of substandard care in this group included poor monitoring and lack of attention to temperature maintenance. An example of such a case is presented in case study 1.

Case study 1

Poor care during transfer

A small child presented to the local DGH with a reduced conscious level and a GCS of 8 after a fall. An early CT scan revealed an acute subdural cerebral bleed. Transfer by the local team was arranged. Blood gases on arrival at the tertiary centre revealed that ventilation had been inadequate for some time (pCO₂ 13.8, pH 6.99). In theatre as well as a large bleed, there was considerable oedema and a “non-pulsatile” brain was noted by the neurosurgeon. The prognosis was considered hopeless, and after full review and discussion, treatment was withdrawn.

Advisors commented that whilst the outcome may well have been very poor, substandard management on transfer with failure to maintain basic ventilation clearly worsened the prognosis of this very serious injury.

Whilst standards exist for monitoring during paediatric transfer, as well as quality of documentation during transfer²⁹, it is clear that the information provided within the patients’ main medical records may give insufficient detail on which to base an opinion.

Advisors identified that delays occurred during transfer in 34 cases. However in 70/246 cases they were unable to answer as documentation was incomplete (Table 3.10). Delays occurred as often when the method of transfer was the referring hospital team (in 12 cases) as in a further 13 cases where the patient was retrieved.

Table 3.10 Transfer delayed at any stage - Advisors’ opinion

Transfer delayed	n	%
Yes	34	19.3
No	142	80.7
Subtotal	176	
Insufficient data	70	
Total	246	

If there was a transfer delay the Advisors were asked whether this affected the patient’s outcome. In the majority of cases these delays were believed not to have affected outcome, but they did in 7/23 (in a further 11 cases Advisors were unable to answer). Of these seven cases, three were acute neurosurgical cases. In six the need for surgery by the time transfer occurred had risen to ‘immediate’ and in one case ‘urgent’. In 2/7 cases the level of urgency changed from urgent to immediate. In one a delay in receiving specialist surgical advice occurred and in the other it was judged by Advisors that surgery should have been available locally. In many others, whilst transfer delay was not deemed to have affected outcome, transition times were sometimes many hours in duration. Table 3.11 shows the time taken in hours from decision to transfer to admission in the receiving hospital.

Table 3.11 Time taken from decision to transfer to admission in receiving hospital

Time taken	n	%
Within 3 hours	25	15.7
Within 6 hours	43	27.0
Within 12 hours	25	15.7
Within 24 hours	54	34.0
More than 24 hours	12	7.5
Subtotal	159	
Not answered/ No surgical questionnaire	87	
Total	246	

In 91/159 cases the child took more than six hours to reach the receiving hospital. Of those, 84 were emergency admissions. Whilst in the majority of cases Advisors did not feel that the time taken to implement this transfer materially affected outcome, they may have been a factor in the distress caused to the patient and family. The commonly cited reasons for delays were reviewed and they involved all parts of the care pathway, but particularly organising ambulance transfer and securing a Level 2 or 3 bed.

There are several surgical conditions in children where rapid access to surgical care is absolutely critical to providing good outcomes, and in preventing serious morbidity and/or mortality. Pathways must be in place well in advance of emergencies presenting to allow triage to occur simultaneously with investigation, resuscitation and communication with tertiary care providers. These pathways need to be agreed regionally and scenarios rehearsed regularly (preferably in extended teams) so that all members are clear of their role⁵¹.

Diagnosis, referral and review

In 347/362 cases the Advisors stated that the pre-operative preparation of the patient was adequate (16

cases unable to answer or not answered). Examination of the 15 cases where pre-operative preparation was suboptimal highlighted cases of lack of resuscitation (fluids and inotropes), radiology, and blood tests.

Pre-operative tests/investigations/planning

Weight was recorded in 331/372 cases (89%). Whilst this was considerably better than many adult studies, care of babies and children in the absence of weight measurement is problematic as fluid and drug calculations or estimations are generally based on this information. Weight estimates using surrogates (e.g. Broselow system)⁷² are an alternative which must be agreed for use in the emergency situation.

Most patients (351/378) underwent radiological examination. In total 216 underwent chest X-ray, 132 a CT and/or MRI scan and 81 ultrasound. In total 268 more complex investigations/interventions were performed.

Most babies and children having a surgical intervention/procedure in this study were in larger centres. However, the availability of specialist paediatric radiology, particularly out of hours is limited even in some University Teaching Hospital settings. The organisational data presented in this report (Chapter 2) also notes that less than half of Specialist Tertiary Paediatric Centres stated that they had a separate on-call rota for paediatric radiology. Telemedicine links may facilitate specialist interpretation and discussion of images.

Echocardiography

One hundred and thirty one cases underwent pre-operative echocardiography. Whilst the majority of patients requiring echocardiography were undergoing cardiac surgery, it is also an essential tool to assist in decision making in other paediatric surgical patients, and in particular those neonates with complex syndromes/associations²¹.

Management planning

Use of Multidisciplinary Team (MDT) Meetings

In this study a pre-operative MDT was carried out in 37.9% (113/298) cases (Table 3.12). It has already been noted that more than 80% of cases were admitted as emergencies and most were being prepared for urgent surgery. In 134 of the 185 cases where there was no MDT meeting, emergency surgery was involved. A further 17 cases were elective, and in 33 cases there was no surgical questionnaire returned or the question was not answered.

In the 17 elective cases the type of surgery undertaken was examined. Whilst some surgery was relatively minor (e.g. endoscopy), other cases were complex and included five cardiac surgical procedures and four involving general paediatric surgery. Multidisciplinary team working should

be regarded as core to a high level service for children, and is implicit within the recently published consultation on Safe and Sustainable Standards for Congenital Heart Surgery in England²¹.

Where there was no evidence of an MDT the Advisors were asked to assess whether cases had been discussed with clinicians at an appropriate level. This was documented in 124/127 cases, with a further 58 cases where this could not be answered. A clear record of such discussions is extremely important.

In the vast majority of cases (333/359) there was evidence of an adequate management plan in the notes. In the 26 cases where this was not noted Table 3.13 shows what was thought to be missing by the Advisors.

Table 3.12 Evidence in the case notes that a pre-operative MDT was undertaken - Advisors' opinion

Urgency of admission	Evidence in the case notes of a pre-operative MDT meeting					Total
	Yes	No	Subtotal	Insufficient data	Not applicable	
Elective	22	17	39	7	4	50
Emergency	68	134	202	7	45	254
Unknown	3	1	4	0	1	5
Subtotal	93	152	245	14	50	309
Not answered/ No surgical questionnaire	20	33	53	9	7	69
Total	113	185	298	23	57	378

Table 3.13 Management plans - Information that was missing - Advisors' opinion

Missing information	n
A clinical summary	6
A differential diagnosis	3
A differential management option	6
A treatment plan	5
A list of investigations to be performed	8
Unable to answer	2
Other	8

*Answers may be multiple (n/26)

Given the large number of teams involved in the care of many patients it is not surprising that difficulties in communication sometimes arose, and were apparent to the Advisors in review of cases (Table 3.14).

Table 3.14 Communication difficulties - Advisors' opinion

Communication difficulties	n	%
Yes	35	9.5
No	333	90.5
Subtotal	368	
Insufficient data	10	
Total	378	

In the 35 cases where communication difficulties noted by the Advisors the source of problems were in the main (13/31 cases) between specialty teams and in 8/31 with parents/carers (insufficient data in 4 cases). This demonstrates that when communication problems occurred they were sometimes in multiple areas. Case study 2 provides an example of this.

Decision making process for treatment/surgery

Whilst there was delay in referral to surgeons in 28 cases (Table 3.15) this was not thought by Advisors to affect outcome in the majority. In 9/28 cases there was a delay in a surgical referral that may have affected outcome.

Table 3.15 Delays in the referral of the patient to the surgical team - Advisors' opinion

Delays in referral	n	%
Yes	28	8.0
No	322	92.0
Subtotal	350	
Insufficient data	28	
Total	378	

Case study 2

Poor communication

A baby with a major gut anomaly received care by neonatologists, paediatric surgeons, paediatric anaesthetists and a paediatric gastroenterologist. The baby underwent early surgery but had very poor urine output after the operation which was technically difficult, and this quickly resulted in post-operative renal failure. Review and recognition of this complication by the surgical team was delayed. The baby required transfer to a PICU at a second hospital for haemofiltration but died a week later.

Advisors commented that at several points in care there was evidence of poor multidisciplinary team working at the unit where surgery took place. Documentation of poor communication between medical and nursing staff was noted, as was lack of parental involvement in discussions. These problems were further compounded by poor liaison with the receiving PICU. Complex cases involving several teams are not unusual in paediatric surgical practice, and advisors commented that clear verbal and written communication is particularly important when complications arise.

There were also examples of cases where there was delay in transfer of care to the specialty ultimately performing surgery (Table 3.16).

Table 3.16 Delay in the transfer of the care of the patient to the specialty performing surgery - Advisors' opinion

Delay in transfer to specialty	n	%
Yes	32	8.7
No	321	87.2
Not applicable	15	4.1
Subtotal	368	
Insufficient data	10	
Total	378	

In 9/32 cases where there was a delay in the transfer to specialty, outcome was thought by Advisors to have been affected (Table 3.17).

Table 3.17 Delays in transfer of care to specialty performing surgery where outcome affected - Advisors' opinion

Outcome affected	n
Yes	9
No	13
Subtotal	22
Insufficient data	10
Total	32

Three cases where outcome was affected (two of which were neurosurgical) are represented in both Table 3.16 and Table 3.17 i.e. there were delays thought to result in poorer outcome arising from both delayed surgical referral and delay in transfer to specialty. Neurosurgery cases will be discussed further in Chapter 4.

Delays in surgical referral and transfer of care are important to rectify. Referrals may be facilitated by provision of clear management pathways for common surgical conditions⁷³, and senior input into early review and diagnosis. It has been demonstrated that some surgical emergencies in babies and children may be difficult to diagnose with trainees even in a dedicated paediatric emergency department seeing very few cases in their training⁷⁴. Ready availability of skilled surgical assistance on site is not universal as general surgeons increasingly have no specific paediatric competencies^{19,41} and/or may not feel confident to diagnose and operate on children⁴¹. All these factors may compromise a unit's ability to diagnose and manage acute surgical problems in children and can lead to delays.

Case study 3

Lack of ability to diagnose and operate on an acute surgical problem

A child presented to their local hospital with a short history of abdominal pain. Local paediatricians referred the patient to general surgery who in turn asked for an urgent anaesthetic assessment as they believed that the patient was in need of pre-operative resuscitation. After this occurred surgeons requested transfer to the tertiary hospital which occurred after a 10 hour delay. The patient was found to have a gangrenous appendix at surgery. Following this transfer the patient developed multi-organ failure and died one week later.

Advisors were concerned that the local team was insufficiently confident to operate on this child and that despite appropriate attempts at resuscitation subsequent transfer was delayed.

In 21/364 cases there was a delay or undue haste in diagnosis (Table 3.18). In a further 14 cases it was impossible to tell from case notes whether this was the case. It was judged by Advisors that this affected outcome in 9/21 cases.

Table 3.18 Time taken to make the primary pre-operative diagnosis - Advisors' opinion

Time to diagnosis	n	%
Yes, appropriate time was taken	343	94.2
No, there was a delay in diagnosis	19	5.2
No, diagnosis was made in undue haste	2	<1
Subtotal	364	
Insufficient data	14	
Total	378	

Where the Advisors had sufficient information to decide, there was a delay in consultant review in nine cases. However in a further 117 cases the question could not be answered. In 319/343 (93%) of cases the decision to operate was made by a consultant, and in 24 cases by a trainee or SAS grade. In 35 cases it was impossible for Advisors to determine this from questionnaires/notes review. When the surgeon making the decision was not a consultant in only one case was it judged by the Advisors to be inappropriate.

Decisions to undertake surgery were agreed in the main to be timely (Table 3.19). In the 23 cases where there was clear evidence of delay or undue haste, Advisors believed that it affected outcome in nine patients, and were unable to say in a further three.

Table 3.19 Appropriate time taken for the decision to perform the primary operation - Advisors' opinion

Appropriate timing to first operation	n	%
YES, timing of decision to undertake surgery was appropriate	338	93.6
NO, decision to undertake surgery was delayed	15	4.2
NO, decision to perform surgery was taken with undue haste	8	2.2
Subtotal	361	
Insufficient data	17	
Total	378	

All these cases were emergencies, and six involved intra-abdominal pathology. Of note is the fact that in a proportion of the cases, where outcome was affected by delay in the surgical diagnosis this involved a mid gut volvulus in a small baby. Whilst neonatal volvulus (secondary to congenital gut malrotation) is rare, it is a life threatening condition, and presents in an otherwise normal baby with distension and bile stained vomiting and/or with shock secondary due to the effects of

gut ischaemia. Resuscitation and surgery should be performed with the utmost urgency when it is suspected. Case studies 4 and 5 highlight cases of undue haste and delay to surgery.

Case study 4

Undue haste

Following a road traffic accident a child arrived in hospital intubated, with severe lower limb and pelvic injuries. A CT scan of the abdomen showed splenic contusion, and head CT showed a subdural bleed and midline shift. During the CT their systolic blood pressure dropped to 85mmHg, and the child was taken immediately to theatre for emergency splenectomy without consultant anaesthetic input. There was a turbulent intra-operative course and the patient required inotropes to support blood pressure. No central venous line was used for pressure monitoring and there were also problems with intraoperative ventilation.

Advisors commented on the undue haste in taking the child to theatre. Even though outcome may still may have been poor due to the low Glasgow Coma Score, there was no clear evidence at laparotomy that the hypotension was related to splenic bleeding, the Advisors believed it to be more likely related to the pelvic fractures; and splenectomy is not generally required to manage contusion.

In 50 cases surgery was delayed or postponed (Table 3.20). In 25/49 cases this was because there was a need for a further period of resuscitation. In four cases this was due to a lack of operating theatre time. Rarely did it relate to a lack of a PICU bed (three cases) or availability of an appropriate surgeon or anaesthetist (five cases), and in only one case was it related to lack of appropriate theatre personnel. It should be noted that this information relates only to the cases reviewed which in the main occurred in specialist centres.

Case study 5

Unexpected mortality and delay to surgery

A small child who had previously undergone surgery for mid-gut malrotation was re-admitted with abdominal pain and distension. Abdominal X-rays were said to show colonic dilatation but attempted decompression was unhelpful. After three weeks the on-call consultant proceeded to laparotomy and found an internal hernia with perforations of the large intestine. Two segments of bowel were resected and primary anastomoses performed. An intestinal fistula formed and a second laparotomy was performed that revealed irreversible ischaemia of the entire small bowel. An end of life care pathway was then instituted.

The Advisors stated that there was room for improvement in clinical care on the basis of a prolonged period of conservative management before the first laparotomy; radiological review of abdominal X-rays suggested small not large bowel dilatation and no other imaging was performed: performing a primary anastomoses at the operation without planned re-laparotomy and delay in performing the second laparotomy despite clinical deterioration.

Table 3.20 Delayed or postponed surgery - Advisors' opinion

Surgery was delayed or postponed	n	%
Yes	50	13.7
No	316	86.3
Subtotal	366	
Insufficient data	12	
Total	378	

Anaesthetic review

The vast majority of patients were reviewed by an anaesthetist prior to surgery (290/299) (Table 3.21). However in 79 cases Advisors were unable to answer as documentation was missing or insufficient. The anaesthetic record is an extremely important part of the patient record, should be completed legibly, and readily available from medical notes.

Table 3.21 Patient was reviewed by an anaesthetist prior to surgery

Reviewed by an anaesthetist	n	%
Yes	290	97.0
No	9	3.0
Subtotal	299	
Insufficient data	79	
Total	378	

Consent and information for patients & parents

In the majority of cases consent was obtained from the parent or carer, with a relative minority involving the patient themselves (Table 3.22). Whilst the age range of this study included children and young people who under normal circumstances should have been actively involved in the consent process, the majority of patients were less than a year old.

Table 3.22 Consent obtained - Advisors' opinion

Who gave consent	n	%
Patient	9	2.4
Parent	272	72.0
Next of kin	21	5.6
Guardian	17	4.5
Other	27	7.1
Consent form not returned in notes	32	8.5
Total	378	

However, in the 65 cases of children aged 10 and older, only four gave their own consent, 36 were consented by their parent/ guardian/ next of kin and in six cases no consent form was included in the notes. In 19 cases consent was not obtained due to the urgency of surgery or the fact that many patients had reduced conscious level due to illness or sedation/analgesia, which may well have made it difficult or impossible to fully involve them. The law differs slightly in different parts of the UK, but the principle of involving competent children and young people in decision making must be upheld⁷⁵⁻⁷⁸.

Written consent provides some evidence that procedures and risk were adequately discussed, but the Advisors were also asked to comment on additional documentation in the medical record of discussions that had occurred (Table 3.23).

Table 3.23 Documented evidence of a discussion with the parents/legal guardian and/or child regarding the operation prior to the operation - Advisors' opinion

Documented evidence of discussion with parents/guardian	n	%
Yes	269	80.8
No	64	19.2
Subtotal	333	
Insufficient data	45	
Total	378	

In 64 cases there was no (additional) documentation of discussion of the surgery with parents/legal guardian or the patient. Many of these cases were emergencies (46/55) (Table 3.24). In at least 13 cases this was extremely difficult as the patient was unconscious, no parent was present and surgery was lifesaving and needed to proceed. In these circumstances it is important that the surgeon appends a supplementary note in the main record.

Table 3.24 Urgency of the case where there was no documentation of additional discussion

Urgency of admission	n
Elective	8
Emergency	46
Unknown	1
Subtotal	55
Not answered/ No surgical questionnaire	9
Total	64

In 209/278 cases, and in the opinion of Advisors, the doctor obtaining consent was capable of performing the operation unsupervised. In 13 cases it was done

by someone who had only previously observed the operation. Unfortunately in 100 cases Advisors were unable to answer this question from the documentation available to them (Table 3.25)

Table 3.25 Doctor obtaining consent - Advisors' opinion

Doctor obtaining consent	n
Capable of performing the operation unsupervised	209
Capable of performing the operation with an experienced assistant	45
Someone who had only observed the operation previously	13
Other	11
Subtotal	278
Insufficient data	100
Total	378

The view of Advisors, the GMC and of NCEPOD is that consent should be taken by someone with sufficient knowledge of the proposed operation and understands the risks involved, and that the grade of this person should be recorded on the consent form. However, it is accepted that in some situations (e.g. extremely urgent surgery) this may be difficult as the (senior) surgeon is fully occupied caring directly for the patient. In these circumstances other senior clinicians should assist in discussions with parents, e.g. paediatrician, paediatric cardiologist.

The detail of these cases reveals that whilst many were emergencies, they also included several elective/scheduled highly complex surgical conditions (for examples of surgical diagnosis of these cases, see Table 3.29). It would be expected that these cases required, and should have received extremely detailed pre-operative discussion. The incorporation of high quality patient and parent information is to be encouraged, and is now widely available in different media and formats. It is regarded as an important standard of care and a part of the consent process⁷⁹.

Documentation of risk of death discussions

The Advisors were asked whether the risk of death should have been documented (Table 3.26). Advisors believed that in most cases in this study (316/373, (85%) cases) the risk of death should have been documented in the consent process. Of these it was documented in just 205 (65%) cases. It was not documented in 58 cases, and the Advisors were unable to answer or did not answer in a further 53 cases.

Table 3.26 Risk of death should have been documented - Advisors' opinion

Risk should have been documented	n	%
Yes	316	84.7
No	57	15.3
Subtotal	373	
Not answered	5	
Total	378	

In those cases where the Advisors thought that death should have been documented, and was not (58), the Advisors were asked to provide an assessment of that risk (Table 3.27).

Table 3.27 Risk of death - Advisors' opinion

Risk	n
Small Risk (<5%)	12
Major Risk (5-25%)	16
High Risk (25-50%)	11
Probable (50%)	15
Subtotal	54
Insufficient data	4
Total	58

This demonstrates that the Advisors thought that even if the risk of death was relatively small, it should generally be documented. Whilst all these judgements are made in retrospect it is important to note that in over half of the cases where the risk of death was not documented Advisors judged it to be in the order of one in four to one in two, i.e. very major risk of death which was not discussed and/or not documented.

Discussing the risk of death with parents and carers, particularly prior to urgent and emergency surgery in a baby or child is an extremely difficult task. It requires particular skill, and the detailed knowledge of the surgical procedure and possible outcomes. Clear numerical values cannot necessarily be attached to the risk, but the lack of these should not prevent proper discussion and documentation.

The consent process was reviewed in more detail in cases where the Advisors thought that risk of death should have been documented.

For those cases where risk of death was not discussed and the Advisors agreed that it should have been, the person who took consent was considered (Table 3.28).

Table 3.28 Doctor obtaining consent where risk of death was NOT documented and SHOULD have been - Advisors' opinion

Doctor obtaining consent	n
Capable of performing the operation unsupervised	22
Capable of performing the operation with an experienced assistant	10
Someone who had only observed the operation previously	5
Other	3
Subtotal	40
Unable to answer	18
Total	58

In many cases where Advisors thought that death should have been stated as a risk factor, a senior surgeon took consent. However this was not universal and someone who had only observed the case took consent in five cases.

The surgical diagnosis was examined in more detail in the eight cases where consent was taken by someone who had only observed the operation or "other" (Table 3.29).

Table 3.29 Profile of cases where consent was taken by a doctor who was not capable of undertaking the operation

Malrotation + volvulus
NEC (necrotising enterocolitis)
Oesophageal atresia and tracheo-oesophageal fistula
Volvulus
Atrial septectomy and pulmonary artery band
Intracerebral haematoma
MRI brain followed by insertion of peritoneal dialysis catheter
Transplant

The Advisors agreed that it was not surprising that risk discussions were limited if a less experienced person was given this responsibility. The cases described in Table 3.29 were mostly very major surgery, with associated high risks and complications. It is of concern that more senior individuals were not involved in the consent process.

Risk assessment

In 84 cases as judged by the Advisors the risk of death from the operation was small (72 cases) or very low (Table 3.30).

Table 3.30 Risk of death from the operation - Advisors' opinion

Risk	n	%
Totally unexpected	12	3.5
Small risk (5%)	72	20.9
Major risk (5 - 25%)	108	31.3
High risk (25 - 50%)	78	22.6
Probable (>50%)	75	21.7
Subtotal	345	
Insufficient data	33	
Total	378	

Conversely there were only 25 cases where surgeons stated that death was totally unexpected or small (<5%). However, the answer to this question was dependent on whether death had been documented as a risk at consent, and this was very poorly completed. We looked again at 40/84 of the cases where Advisors felt risk of death was low or non-existent. In 9 of these 40 cases we felt that the risk might reasonably have been described as low/unexpected or small. Whilst we cannot present the detail of these cases here they all vividly illustrated serious and unforeseen complications. However, the majority were ASA 3, 4 and 5 infants and children, having very major surgery, in whom NCEPOD Clinical Co-ordinators believe that the risks of death were potentially substantial. This again illustrates the difficulty in quantifying risk even by experienced individuals.

Surgery and Postoperative Care

The majority of deaths analysed in this study occurred in major centres reflecting the specialties located in these hospitals (paediatric surgery, cardiac surgery, and neurosurgery), the resulting case mix and a policy of transferring critically ill children from smaller or less well resourced institutions. This is also reflected by the age of children who died, the overwhelming majority being six months or less. There was a further much smaller peak in the late teenage years.

Underlying cause of death

Table 3.31 indicates the broad diagnostic categories in children who were included in the study.

Table 3.31 Diagnostic categories for children included in the study

Case type	n	%
Congenital paediatric general surgery	22	7.1
Ear, Nose and Throat	10	3.2
General (not congenital) paediatric surgery	22	7.1
Trauma: including head injury	25	8.0
Neurosurgical: non-trauma	36	11.6
Necrotising enterocolitis (NEC)	103	33.1
Congenital cardiac surgery	62	19.9
Unknown	7	2.3
Other	24	7.7
Subtotal	311	
Not answered/ No surgical questionnaire	67	
Total	378	

Time between operation and death

The interval between surgery and death is shown in Figure 3.4. It is apparent that 50% of deaths occurred within two days, which may reflect the proportion of children with NEC who underwent an "open and close" laparotomy, and those admitted with major trauma with or without a fatal head injury. In the 1999 NCEPOD report, Extremes of Age¹², the median time to death was 3.5 days. The subsequent pattern of death was identical to that of the 1999 report.

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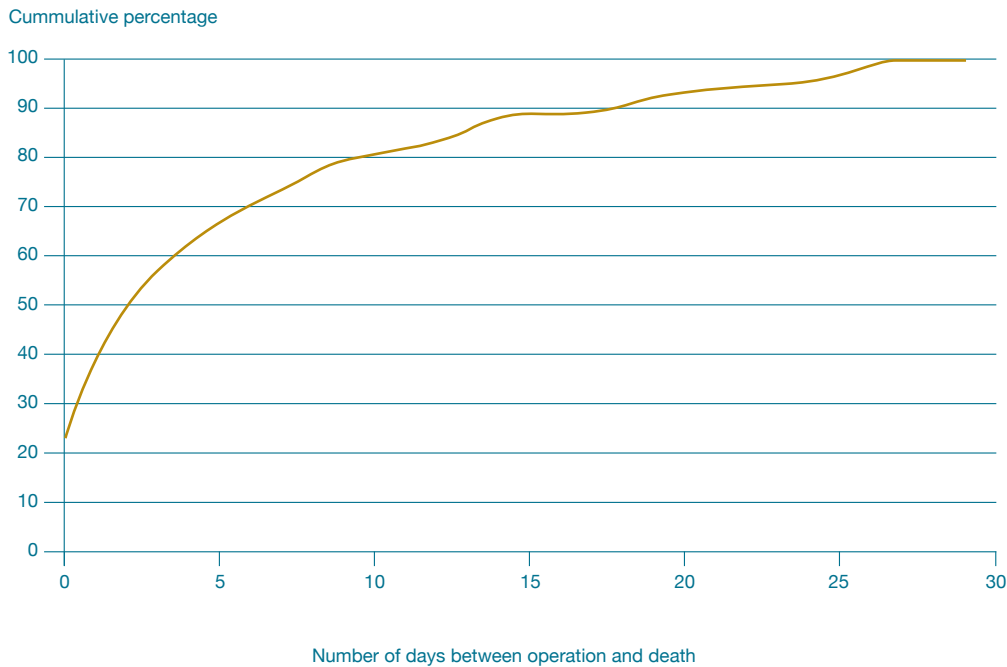


Figure 3.4 Number of days between surgery and death

Surgical Care

This part of the review reports on some of the generic aspects of care given to children who died during data collection for this report.

Grade of surgeon and choice of operation

The grade of surgeon performing surgery is shown in Table 3.32. Consultants performed the majority of operations. Of the remainder, senior specialist trainees performed most. A small proportion of operations were undertaken by other non-consultant grades including junior specialist trainees and basic grade doctors. Although the Advisors stated that this was sometimes inappropriate (4) it was agreed that this probably did not influence outcome in these patients.

Table 3.32 Grade of surgeon performing the surgery - Advisors' opinion

Grade	n	%
Consultant	297	85.3
Staff grade or associate specialist	3	0.9
Senior specialist trainee	32	9.2
Trainee with CCT	2	0.6
Junior specialist trainee	2	0.6
Basic grade	12	3.4
Subtotal	348	
Insufficient data	30	
Total	378	

Of the 51 operations performed by non-consultant grades the Advisors considered that the level of supervision was inappropriate in 4/27 cases where it was possible for them to express a definite view. These data are summarised in Table 3.33.

Table 3.33 Advisors opinion on whether the level of supervision was appropriate when a consultant did not perform surgery - Advisors' opinion

Grade of surgeon was appropriate	n
Yes	23
No	4
Subtotal	27
Insufficient data	24
Total	51

In these cases the Advisors commented: "should have been a consultant"; "There was no supervision"; "Very junior surgeon for such a catastrophic situation"; "In my view a consultant neurosurgeon should have been present. Unstable, high chance of death".

Aside from the grade of surgeon the Advisors also expressed an opinion as to the appropriateness of the operation that was performed (Table 3.34).

Table 3.34 Appropriateness of the operation performed - Advisors' opinion

Appropriate operation	n	%
Yes	348	96.2
No	14	3.8
Subtotal	362	
Insufficient data	16	
Total	378	

Case study 6

Appropriateness of the grade of surgeon

A child was admitted to their local hospital with symptoms that were correctly interpreted as representing raised intracranial pressure. A CT scan confirmed an intra-ventricular haemorrhage. Following deterioration in the GCS the patient was intubated and underwent delayed transfer to a neurosurgical unit. At the receiving hospital assessment and consent were undertaken by a junior specialist trainee who indicated that surgery (insertion of a shunt) was of low risk. Unfortunately decompression performed by the same trainee did not salvage the situation due to coning. The child died.

The Advisors stated that "the surgeon was very junior for such a catastrophic situation" and that the duty consultant should have been involved". This case also highlights problems with assessment (the situation was probably irretrievable) and the consent process. On a positive note clear protocols for the transfer of such patients were established following a Morbidity & Mortality review of this case.

The Advisors further commented as to the influence of inappropriate surgery upon outcome. In five cases where they could express an opinion they indicated that there had potentially been an adverse impact.

Anaesthetic Care

Grade of anaesthetist

A consultant anaesthetist was present for 269/289 operations where this was known (Table 3.35). It is of some concern that information on the grade of anaesthetist could not be determined in so many cases. For some it may reflect an incomplete dataset but in many it reflects poor documentation on the anaesthetic chart.

Table 3.35 Proportion of operations where a consultant anaesthetist was present - Advisors' opinion

Was the most senior anaesthetist a consultant?	n	%
Yes	269	93.1
No	20	6.9
Subtotal	289	
Insufficient data	89	
Total	378	

When a consultant anaesthetist was not present (20/289) the level of supervision of the trainee administering the anaesthetic varied. Unfortunately this information was only available for just over half of the cases. Where it was, it is apparent that a consultant was only contactable by telephone in eight of 11 cases (Table 3.36).

Table 3.36 Nature of trainee supervision when a consultant was not present - Advisors' opinion

If not a consultant, what was the level of supervision?	n
In theatre	1
In hospital	2
By telephone	8
Not documented	9
Total	20

In 7/8 cases (one not known) where the senior anaesthetist was providing cover by telephone, patients were undergoing emergency neurosurgical procedures. For one of these an Advisor commented: *"I think most people would consider emergency posterior fossa surgery for bleeding a 'consultant' case"*. Whilst this might be generally true it is possible that the trainee administering the anaesthetic possessed the appropriate competencies to manage the case. For the remainder it was agreed that the level of cover was satisfactory and that it had no adverse impact upon outcome. Interestingly, in the eight cases where an anaesthetic trainee was covered by a consultant available by telephone, a trainee surgeon also performed the surgery in 6/8 children.

Anaesthetic technique

Advisors were also asked to comment on the technical aspects of anaesthesia. In 307 patients this was considered appropriate but inappropriate in 10. They were unable to comment in 61 cases.

In the 10 children where it was considered that a modification of the anaesthetic technique might have been appropriate the Advisors believed that the outcome of surgery might have been affected in four (unaffected in one, unable to answer in five).

Anaesthetic monitoring

As with other aspects of anaesthetic and surgical management the Advisors were asked to comment upon the appropriateness of the intra-operative monitoring during anaesthesia. Table 3.37 reflects their opinions.

Table 3.37 Appropriateness of the intra-operative monitoring - Advisors' opinion

Monitoring appropriate	n	%
Yes	316	94.0
No	20	6.0
Subtotal	336	
Insufficient data	42	
Total	378	

The reasons why anaesthetic monitoring was considered inadequate are summarised in Table 3.38.

Table 3.38 Advisors' reasons for considering that anaesthetic monitoring was inadequate.

Reason	n
Absence of arterial line	7
Lack of temperature monitoring	5
Inadequate recording of blood pressure	4
Absence of central venous line	3
No monitoring of cerebral oxygenation	1
No monitoring of cardiac output	1
No monitoring of end-tidal CO ₂	1
No monitoring	1

**answers may be multiple (n/20)*

It should be recognised that absence of an arterial catheter or central venous line does not necessarily reflect an adverse standard of care since often these cannot be inserted because of the size of the child or urgency of the operation. Nevertheless, following review of these cases the Advisors considered that inappropriate monitoring contributed to an assessment of "room for clinical improvement" in 4/20. One of these was the child in whom no monitoring of end-tidal CO₂ was noted, although in mitigation the operation was

performed in NICU because of lack of theatre space. Nevertheless, recommendations from the Royal College of Anaesthetists National Audit Project 4 promotes its use in all intubated patients⁸⁰.

Peri-operative temperature management

Maintenance of a normal or adequate temperature proved difficult in a significant number of patients in this cohort (55); (no problems in 246, unable to answer 77). In one case it was noted that the incubator had been turned off during surgery and this resulted in a cold baby at transfer. In five other children the Advisors commented that it was not clear what warming methods had been employed during surgery.

The importance of maintaining normothermia in the peri-operative period has been highlighted in the publication *Reducing Harm in Perioperative Care*⁸¹ which aims to meet a standard where 95% of all (adult) surgical patients maintain a body temperature within the normal range during surgery and in the post operative phase. Unfortunately this document did not address the problems of temperature control in children which are clearly significant. From this review it would appear that a similar target cannot be met in the majority of neonates and babies with the currently available technology and in most of the children included in this study it seems that all efforts were made to maintain body temperature. Despite this, cooling occurred. Whilst this may have been detrimental to the chances of survival there may have been little opportunity to overcome the problem. Nevertheless, it is an important aspect of management that should not be overlooked.

Postoperative Care

Initial level of care

The majority of children were admitted to a Level 3 facility following surgery (Table 3.39). However, according to the data returns, 18 children were transferred to a normal ward (Level 1).

Table 3.39 Initial level of care provided postoperatively - Advisors' opinion

Level of care	n	%
Level 1	18	5.1
Level 2	11	3.1
Level 3	314	88.2
Other	13	3.6
Subtotal	356	
Not applicable	22	
Total	378	

Of the 13 children in whom the post-operative destination was described as "other" three were cared for in an adult ICU, three died before transfer to a post-operative facility, and one each went to a paediatric burns or haematology unit. In five instances the destination was unknown.

The Advisors were also asked to comment upon the appropriateness of the ward destination following surgery. For the majority this was the case (329/336) but in seven children the Advisors thought that an alternative should have been chosen (unable to answer in 42). However this only affected the outcome in one child who had undergone an invasive cardiological procedure and should have been admitted to a PICU rather than Level 1 care due to critically poor leg perfusion.

Postoperative analgesia

The Advisors agreed that, where it could be assessed the postoperative analgesia provided was appropriate, with only eight cases where this was not believed to be the case. However, in 118 cases there was insufficient data for the Advisors to assess the case (Table 3.40), again this points to a lack of documentation in this area.

Table 3.40 Appropriate postoperative analgesia was administered - Advisors' opinion

Appropriate analgesia	n	%
Yes	252	96.9
No	8	3.1
Subtotal	260	
Insufficient data	118	
Total	378	

Peri-operative complications

In the last 10 years there have been several initiatives promoting the reporting and recording of complications and critical incidents in secondary care⁸². In paediatrics in general critical incidents are relatively common and many relate to drug and fluid calculation errors, as well as procedural difficulties such as misplaced nasogastric tubes. Those specifically relating to anaesthesia have been reviewed more recently by multidisciplinary groups such as the Safety in Anaesthesia Liaison Group⁸³.

As might be anticipated complications were common in children included in this study, occurring in 254/368 patients (none in 114, unable to answer in 10).

Whilst these were managed appropriately in 220 children, the Advisors considered that they might not have been in 22 cases (unable to answer in 12). These have been classified into a number of groups as shown in Table 3.41. In 8/10 poor management of the complication was considered to have affected outcome (no in two, unable to answer in 12).

Table 3.41 Principal reasons for considering that complications were inadequately managed - Advisors' opinion

Reason	n
Inadequate monitoring or investigation (late recognition)	9
Inadequate treatment	2
Delayed or inadequate resuscitation	2
Failure to institute appropriate support (ECMO, ventilation)	6
Sepsis	1
Dislodged tracheostomy	1
Unknown	1
Total	22

The range of complications for which poor management affected outcome were no different to those described in Table 3.41 and there was no common theme upon which to make any specific recommendations.

Critical incidents were also reported in a relatively large proportion of the children included in the study (Table 3.42). The majority were related to cardiorespiratory events (cardiac arrest, accidental extubation, blockage of endotracheal tubes, bleeding). Although rare, miscalculation of drug doses remains an issue.

Table 3.42 Peri-operative critical incidents

Critical incidents	n	%
Yes	101	30.0
No	236	70.0
Subtotal	337	
Not answered	41	
Total	378	

In 80/101 children these were well managed, in 14 the Advisors were unable to express an opinion, and in 7 they agreed that care was suboptimal.

End of life care and Do Not Attempt Resuscitation (DNAR) orders

The Advisors were asked to consider if an end-of-life care pathway should have been considered for the children included in this study. Whilst this was not applicable in 76 children, they thought it appropriate in 235 patients. Full details are included in Table 3.43.

Table 3.43 Consideration given to end of life care planning - Advisors' opinion

EOLC should have been considered	n	%
Yes	235	64.6
No	76	20.8
Not applicable	53	14.6
Subtotal	364	
Insufficient information	14	
Total	378	

In reality such plans were only implemented for 112/235 children, some of whom were subject to more than one of the management options described in Table 3.44. Thus the consideration and delivery of formal end-of-life care seemed to be absent in more than half of the children where this would have been appropriate. This is disappointing and perhaps reflects a lack of input to this issue by the Department of Health and relevant Royal Colleges and specialist societies. Whilst the DH has published standards for palliative care in children and young people⁸⁴ the problems identified in this report were undoubtedly outside the remit of that document.

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Table 3.44 Nature of end-of-life care for children included in the study

End of life care plans	n
Advanced directive	15
End of life pathway	26
Involvement of a palliative care team	13
DNAR order	75
Withdrawal of ITU care	40

**answers may be multiple (n/112)*

As far as DNAR orders were concerned, these were almost universally discussed with the child or the relatives as shown in Table 3.45.

Table 3.45 Involvement of patient and relatives in the implementation of DNAR orders

DNAR discussed with:	n
The patient	4
The patient/relatives	1
The Relatives	68
Subtotal	73
Not answered	2
Total	75

Discussion with parents/guardians after death

The Advisors were asked to identify, from the medical notes, whether there had been a discussion with the parents or carer after death. Their opinion is shown in Table 3.46.

Table 3.46 Evident from the case notes that a discussion between the parents/carer and the surgical team occurred after death - Advisors' opinion

Discussion had taken place	n
Yes	266
No	36
Subtotal	302
Insufficient data	76
Total	378

Although it seems unusual that the surgeon did not meet the family after death in 36 cases, it is possible that medical staff from other specialties met the parents (paediatric cardiology, paediatricians, trauma team, intensivists etc). Of greater concern is the fact that it could not be established whether a meeting had occurred with any doctor in 76/378 of the deaths, thus highlighting important deficiencies in documentation.

Morbidity and Mortality meetings

This study also attempted to identify the frequency with which deaths were discussed at a morbidity and mortality (M&M) meeting. Again the Advisors derived their information from a review of the medical notes. In 126/184 cases the Advisors were able to confirm that an M&M discussion took place. However, in 194 cases documentation was not good enough to assess this (Table 3.47).

Table 3.47 Evidence of a morbidity and mortality discussion following death - Advisors' opinion

Morbidity and mortality discussion	n	%
Yes	126	68.5
No	58	31.5
Subtotal	184	
Insufficient data	194	
Total	378	

Documentation of an M&M discussion in the medical notes should be considered best practice. Certainly if information is subsequently required by the Coroner, Trust Clinical Governance Department, for research or even NCEPOD a record of the M&M discussion is particularly helpful.

Key Findings - Peri-operative care

Overall quality of care in the majority of patients was good (71%), with room for improvement in aspects of care in 26%. In 11 cases (2.9%) care was less than satisfactory.

Inter-hospital transfer

Most babies and children in this study were admitted as an emergency and were transferred to another hospital prior to surgery taking place.

Delays in transfer occurred in 34/176 cases. In 7/23 where an opinion could be made this was believed to affect outcome. In 91/159 cases where it could be determined it took more than six hours from the time of decision to transfer to being received in a centre where surgery took place.

Documentation of transfer events/detail and time of admission is poor within paediatric medical records.

Pre-operative care

Pre-operative investigation and preparation were generally performed in a full and timely manner.

There was a frequent requirement for both basic radiology (216 investigations) and more complex investigation/interventions (268 episodes) in the patients in this study.

Delays in surgical referral and diagnosis, and senior review were relatively unusual, but there were a few cases of both delay and undue haste in the decision to operate some of which affected outcome.

MDT meetings prior to surgery were performed in just over a third of this population. Where this was not the case senior clinician involvement of an appropriate level was generally apparent. However documentation of this involvement was lacking in 58/185 cases.

Consent and information for patients & parents

Consent was not always taken by surgeons who were fully conversant with the operation performed and documentation of seniority was poor.

Risk of death was often not formally noted or quantified during the consent process or documented in discussions with patient/parents and carers.

Even in retrospect surgeons and Advisors had difficulty quantifying risk.

Surgical care

The majority (297/348) of operations were performed by consultant surgeons. 51/348 were performed by other grades and where this was the case it was considered inappropriate in 4/51 cases.

The Advisors considered that an appropriate operation had been performed in 348/362 cases. When this was not the case the outcome may have been affected in 5/14 operations.

Anaesthetic care

There was a good level of cover by consultant anaesthetists (269/289) where this was known.

In only 10/317 procedures did the Advisors consider that the anaesthetic technique was inappropriate. This may have affected the outcome in four children. Overall the provision of anaesthetic services seems to have been very satisfactory.

Postoperative care

In the main the level of care (Levels 1, 2 and 3) provided postoperatively was appropriate.

Complications were common (254/368). In 22/254 instances the Advisors were of the opinion that management was sub-optimal and definitely affected the outcome in 8/10 children in whom it was possible to make a judgement. However given the range of specialties involved in the care of these children there did not appear to be a common theme upon which to base recommendations for reducing this incidence.

End of life care

End-of-life care planning was absent in at least 50% of children in whom it would have been appropriate.

Following the death of at least 36 children there was no discussion between the surgical team and the parents. Poor documentation prevented the assessment of this in a further 76 deaths.

Documentation that confirmed that the death was discussed at a morbidity and mortality meeting was only present in the case notes of 126/378 children although such information may have been recorded elsewhere.

There were many other instances of poor documentation that need to be addressed including name and grade of both surgeon and anaesthetist, end of life care planning and discussions with parents after death.

Recommendations - Peri-operative care

Inter-hospital transfer

National standards, including documentation for the transfer of all surgical patients, irrespective of whether they require intensive care need to be developed by regional networks. (*Network Leads*)

Hospital teams working in both specialist and non specialist centres should be in a state of readiness for transfer of babies and children requiring emergency surgery, and be prepared to provide high level and timely support for these transfers. Surgical emergencies may require rapid triage, simultaneous with resuscitation and communication with tertiary care providers. (*Medical Directors and Clinical Directors*)

When a decision to transfer a patient for (less urgent) surgical care has been made, this should be expedited. Transfer method and personnel should be agreed in advance. (*Clinical Directors*)

Pre-operative care

Expertise in paediatric radiology is an essential adjunct to the running of a service for children requiring surgery.

Multidisciplinary team meetings for complex cases should be undertaken pre-operatively except when this is predicated by the urgency of the case. Documentation of inter-professional discussions is essential even if written in retrospect. (*Medical Directors and Clinical Directors*)

Consent and information for patients & parents

Consent by a senior clinician, ideally the one performing the operation should be normal practice in paediatrics, as in other areas of medicine and surgery. Documentation of grade confirms that this process has occurred. This is already a national recommendation. *(Medical Directors and Clinical Directors)*

In surgery which is high risk due to co-morbidity and/or anticipated surgical or anaesthetic difficulty, there should be clear documentation of discussions with parents and carers in the medical notes. Risk of death must be formally noted, even if difficult to quantify exactly. *(Consultants)*

End of life care

National guidance should be developed for children that require end-of-life care after surgery. *(Department of Health, Royal Colleges, appropriate specialist societies)*

Clinicians must ensure that appropriate records are made in the medical notes of all discussions that take place with a child's parents or relatives after death. In addition it is mandatory that the name and grade of clinicians involved at all stages of care are clearly recorded in the medical notes and on anaesthetic and operation records. *(Guidelines from Royal Colleges/specialist societies and Medical Directors)*

Confirmation that a death has been discussed at a morbidity and mortality meeting is required. This should comprise a written record of the conclusions of that discussion in the medical notes. *(Medical Directors)*

Under embargo until 00.01 27th October



4 – Specific care reviews

Specialist paediatric general surgery (excluding NEC)

Patients who died under the care of specialist paediatric surgeons most often underwent surgery for gastroschisis, exomphalos and malrotation (10). The remainder had a variety of congenital abnormalities. In non-congenital cases there was no common theme, with a variety of diagnoses ranging from apparently benign conditions (adhesive obstruction, inguinal hernia, appendicitis) to more complex pathology (adrenal neuroblastoma, relapsing Ewing's sarcoma). However, the commonest groups requiring care, in this study, were for necrotising enterocolitis, neurosurgery and cardiac surgery. This chapter provides an overview of the care of children within these three specific specialities.

Necrotising Enterocolitis (NEC)

NEC is a problem that has evolved alongside the introduction of modern neonatal intensive care and many believe that it is associated with the use of enteral feeding whilst breast milk appears protective. It does not occur in a sterile gastrointestinal tract and rarely develops until 8-10 days after birth. This suggests an important aetiological role for microbial colonisation of the gut (enteral aminoglycosides may have a preventative role) and whilst no individual organism appears to be particularly virulent, unusual gut bacteria and a reduction in the number of different organisms in the gut seem significant.

A recent review from the USA indicates that the prevalence of NEC in low birth-weight babies (500-1500g) is around 7%, with a mortality of 20-30%. The prognosis for babies requiring surgery is poor and

even for survivors the outlook may be dismal with a high risk of neurodevelopmental delays⁸⁵. This, and the high cost of treatment has promoted extensive but largely unsuccessful research on preventative measures, although this must be the key to future management. Currently a large UK study is examining the role of probiotics in prevention, an intervention for which some evidence of efficacy exists^{86,87}. However, given a policy of resuscitating babies as young as 23-24 weeks it is unlikely that any preventative measures will be universally effective.

Although early recognition and intervention is crucial to a successful outcome, this can be very difficult since many low birth-weight babies have symptoms and signs consistent with early NEC (as described by the Bell Classification⁸⁸) and its subsequent modifications for other reasons. If medical management (abdominal decompression, bowel rest, broad spectrum antibiotics, intravenous nutrition) fails then surgery is indicated. Currently the decision to operate on these infants may be very difficult unless perforation has occurred. Although a rising C-reactive protein level, reduced platelet count, deteriorating biochemistry, and the presence of immobile "fixed" loops of bowel on repeated abdominal X-rays suggest the need for surgery, this is rarely supported by objective investigations. The uncertainty around this important decision and the choice of intervention might be reduced if data were available from a detailed audit of both the medical and surgical management of babies with NEC.

Perforation is usually associated with a marked deterioration in clinical status. Although laparotomy is perhaps the management of choice this may be hazardous in these extremely low birth weight babies. It has therefore been suggested that insertion of a

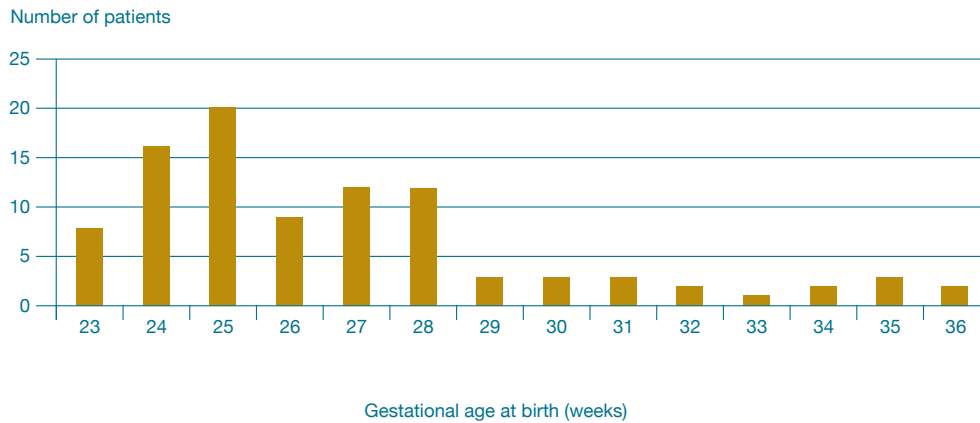


Figure 4.1 Gestational age of babies with NEC

peritoneal drain may allow a period of resuscitation prior to open surgery. Rarely this might even prove successful as the definitive procedure. Data on the use of peritoneal drains were not collected in this study, as they are not usually inserted in an operating theatre and not associated with an OPCS code from which patients could be identified.

The use of a peritoneal drain has been the subject of considerable debate. A meta-analysis of data from non-randomised studies has suggested a 50% increased mortality for simple drainage over laparotomy. Perhaps of greater importance was the finding that subsequent developmental progress appeared better in the laparotomy group⁸⁹. Nevertheless, the vagaries of meta-analysis of non-randomised data, which is subject to reporting bias, should not be forgotten. The controversy has also been addressed in two multicentre trials both of which were underpowered to show a difference between the two approaches and thus the findings that drain insertion was of no benefit were not robust^{90,91}. Currently, the NEST Trial in the USA is re-examining this question⁹². Further research should establish quality standards and pathways of care for babies with NEC in line with the NICE quality standards programme for specialist neonatal care⁹³.

In the current study 97% of babies undergoing surgery for NEC were premature (born at <37 weeks). Indeed the greater proportion had a gestational age of 28 weeks or less (Figure 4.1). As such these children comprised the 25% or so of sufferers in whom a fatal outcome occurs.

Delays

When considering the management of babies included in this study the Advisors found little evidence of delays in referral to the surgical team (Table 4.1). In the nine babies in whom some delay occurred this may have affected outcome in one.

Table 4.1 Advisors' opinion on delays in referral to the surgical unit

Delay in referral to specialty (NEC)	n
Yes	9
No	91
Not applicable	1
Subtotal	101
Insufficient data	2
Total	103

There were 84/103 babies who were transferred from the hospital to which they were first admitted for surgery, and the Advisors reported that there was deterioration in the clinical status during the transfer process in 5/71 babies (13 insufficient data) (Table 4.2).

Table 4.2 Deterioration in clinical status during transfer - Advisors' opinion

Deterioration between decision to transfer and arrival (NEC)	n
Yes	5
No	59
Unknown	7
Subtotal	71
Insufficient data	13
Total	84

In 9/84 babies the Advisors were of the opinion that the transfer was delayed (no delay in 54, unknown in 21) and in 2/9 they thought that the delay might have influenced outcome (Table 4.3).

Table 4.3 Delay in transfer potentially affected outcome - Advisors' opinion

Affected outcome (NEC)	n
Yes	2
No	6
Unknown	1
Total	9

Multidisciplinary team meetings

The Advisors also considered the role of an MDT in deciding the management of these children. Given that many were transferred urgently for surgery from other hospitals it is not surprising that an MDT discussion did

not take place in the majority (Table 4.4). Of the 60 cases where there was no formal MDT discussion 48 were transferred from another hospital. The questionnaires that were used for collecting data for this study were not designed to provide any other information on the decision-making processes prior to surgery.

Table 4.4 Management of the baby was discussed at an MDT prior to surgery - Advisors' opinion

MDT discussion (NEC)	Total
Yes	23
No	60
Subtotal	83
Insufficient data	20
Total	103

One area of good practice was evident in relation to obtaining consent for surgery with this task generally undertaken by either consultants or experienced trainees (Table 4.5).

Table 4.5 Clinical ability of surgeon obtaining consent - Advisors' opinion

Doctor obtaining consent (NEC)	n
Capable of performing the operation unsupervised	41
Capable of performing the operation with experienced assistant	25
Only previously observed the operation	3
Other	1
Subtotal	70
Insufficient data	33
Total	103

Where this information could be determined Advisors felt that the risk of death should have been but was not documented on the consent form in 21/86 babies (Table 4.6).

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Table 4.6 Risk of death was documented on the consent form - Advisors' opinion

Risk of death documented (NEC)	n
Yes	65
No	21
Unknown	13
Total	99

This is of some concern given that the Advisors considered that the risk of death was major or high in the majority of babies (Table 4.7).

Surgery was nearly always performed by a consultant surgeon (93/97) with the remainder undertaken by a staff grade surgeon or senior trainee with their CCT. For six children the grade of the operating surgeon was not documented. A summary of the operative details is shown in Table 4.8.

As with all patients included in this report the Advisors were asked to provide an overall assessment of the quality of care afforded to babies with NEC.

Table 4.7 Advisors' view of risk of death during peri-operative period

Risk	n
Unexpected	0
<5% Small	9
5-25% Major	30
25-50% High	33
>50% Probable	27
Subtotal	99
Insufficient data	4
Total	103

Table 4.8 Operative details for babies with NEC

Type of surgery (NEC)	Number
Laparotomy, resection ± stoma	25
Laparotomy with stoma formation	18
"Open and close" laparotomy	20
Unknown	40
Total	103

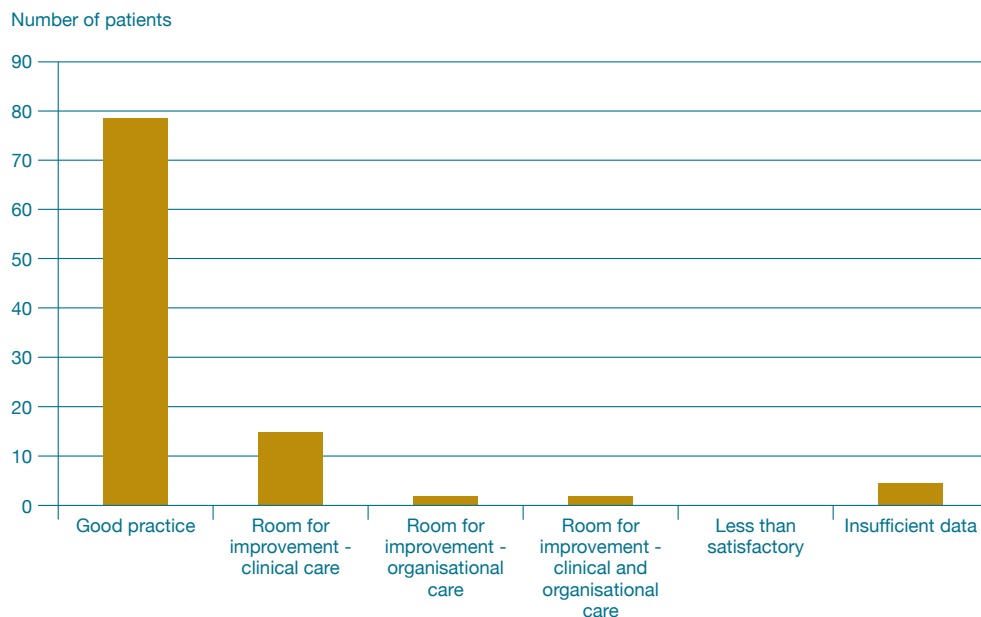


Figure 4.2 Advisors' assessment of the quality of care for babies with NEC

Table 4.9 Aspects of management identified by Advisors that contributed to an overall assessment of “Room for improvement – clinical” or “Room for improvement - clinical & organisational” in babies with NEC.

Reason	n
Delayed diagnosis	2
Delayed referral	1
Delayed surgery	2
Intubation, airway or ventilator problems	3
Surgical technique	2
Failure to monitor intra-operative temperature	1
Poor post-operative fluid and inotrope management	1
Delayed recognition of intra-arterial placement of long line	1
Inappropriate prolongation of treatment	1
Inadequate discussion with parents	1
Poor medical notes	4
Unknown	1
Total	20

Whilst they considered that the management was good in 78/103 babies they thought that there was room for improvement in the clinical management in 20/103. The reasons for this are shown in Table 4.9.

The difficulties in diagnosis have been commented upon earlier and these are likely to have contributed to five of these cases. Of the remainder many could be considered “unavoidable” complications but poor record keeping and failure to communicate with the baby’s parents are inexcusable.

Congenital cardiac surgery

Following the Kennedy Inquiry⁹⁴, which reviewed the care of children receiving complex cardiac surgery at the Bristol Royal Infirmary between 1984 and 1995, there has been considerable concern regarding the care of children with congenital cardiac disease. A review of congenital

cardiac services in the UK made proposals on how the recommendations from the Kennedy Inquiry should be put in to practice⁹⁵. A series of standards were proposed which included development of regional team working, systematic clinical accountability and national audit, child centred care, clinical assessment and consent, and medical and surgical care. The Department of Health has recently completed a review of congenital cardiac services with a view to improving standards of care. The outcome of this has not yet been published²¹.

Analysis of the results for surgery for congenital heart defects (CHD) is problematic: there are 149 internationally “recognised” procedures, although the UK Central Cardiac Audit Database only calculates survival data for 36 more commonly performed surgical and 12 interventional radiology procedures. In 2008-2009 analysis of the data showed a 2% mortality after 30 days (180 children) for this type of surgery⁹⁶.

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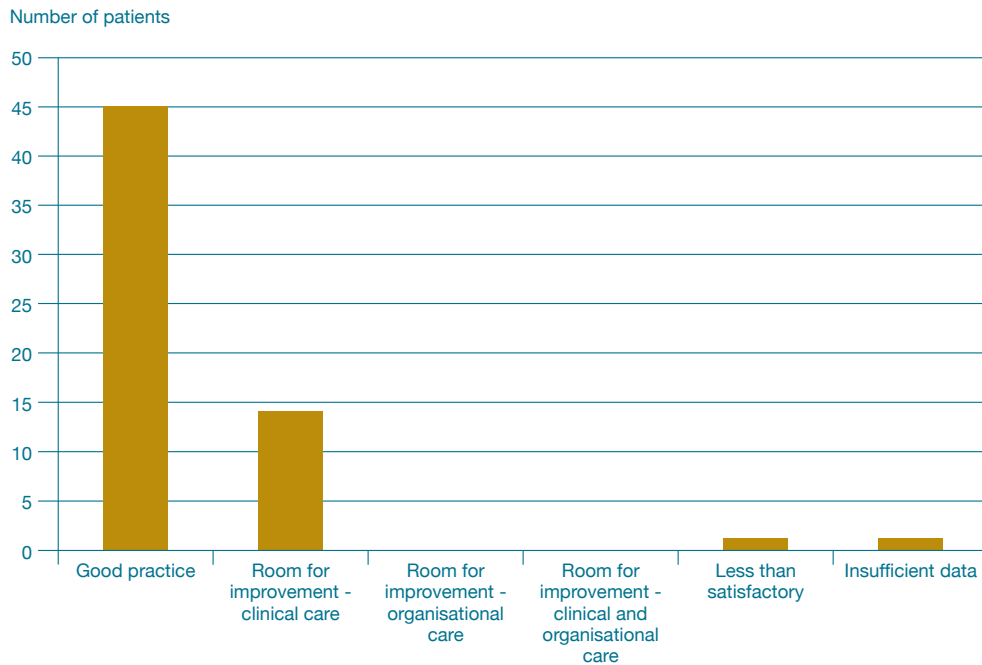


Figure 4.3 Advisors' assessment of the quality of care in children with congenital heart disease

Successful outcomes for congenital heart surgery require a high level of technical skill, good organisational care and teamwork. These factors are difficult to measure using traditional quantitative data analysis.

The underlying diagnosis in this group of children included a variety of anomalies. Overall however a third of these babies (19/54 in whom an accurate diagnosis was available) had hypoplastic left heart syndrome. Closure of the foramen ovale and ductus after birth effectively shuts down the systemic circulation, causing right heart failure and death within a few days. Successful treatment of this condition was initially developed in the 1980's when Norwood and his colleagues conceived a 3-stage reconstructive operation⁹⁷ that subsequently achieved survival rates of >60% albeit with some morbidity in respect of reduced exercise tolerance and impaired cognitive function following perinatal cerebral ischaemia⁹⁸.

A Norwood (or modified Norwood) procedure was performed in 15/19 children with hypoplastic left ventricle included in this report. A further four babies underwent a more recently developed hybrid procedure that combines stenting of the ductus arteriosus and surgical banding of the branch pulmonary arteries. This is largely regarded as a temporising and less invasive intervention in particularly sick babies. Interestingly however, a recent study has shown no reduction in the incidence of NEC with this less invasive procedure. Necrotising enterocolitis develops in >10% of neonates undergoing major cardiac surgery with more than a third dying from this complication⁹⁹.

Although detailed information about individual cases is difficult to derive from this type of study the Advisors were able to comment on wider issues relating to congenital cardiac surgery. In particular they made an assessment of the overall quality of care given to these children. This is summarised in Figure 4.3.

In the majority of children care was considered to have been good (45/62) but in 14/62 they considered that there was room for improvement and in one case they indicated that care was less than satisfactory. This assessment is consistent with that of the report as a whole in which it was considered that there was room for improvement in clinical care in 19.8% of children with a further 2.9% receiving less than satisfactory care.

Table 4.10 shows the reasons for Advisors suggesting that there was “room for improvement in clinical care”. In the single case where treatment was considered less than satisfactory a minimally invasive procedure was performed rather than a Norwood operation for hypoplastic left heart syndrome.

Table 4.10 Advisors’ reasons for considering that there was room for improvement in clinical care in children with congenital heart disease

Reason
Missed NEC pre-operatively
Should have been discussed at an MDT
Inadequate consent
Inappropriate to operate in view of general condition
Delay in performing surgery
Should have considered an alternative procedure
Management of post-operative complications and failure to use extracorporeal membrane oxygenation
Problem with drug infusion
Wrong destination post-procedure (should have gone to paediatric intensive care)

Although the assessment described above may cause concern there were certainly areas of good practice by the cardiac surgeons who submitted cases to this review. The consultant almost always undertook both consent and surgery and the risk of death was clearly documented on the consent form.

Overall in this group 38/62 cases were discussed at an MDT meeting. In 47/54 cases the consenting doctor was capable of performing the operation unsupervised (consultant). In 4/62 cases the Advisors were of the opinion that there was a delay in transfer.

Neurosurgery: trauma (including head injury) and non-traumatic diagnoses

Taken together this formed the second largest group and thus neurosurgical units had a major input to the care of children in this study.

At the time of writing the NHS Medical Director has commissioned a review (Safe and Sustainable Review of Children’s Neurosurgical Services)²² aimed at delivering:

- national standards and models of care to ensure optimum care for all children needing neurosurgery;
- a balance between convenient local services and the need for high quality specialist surgery;
- a suitably qualified and expert workforce with surgeons undertaking collaborative research into future treatments and clinical developments;
- specialised support services, expert multi-disciplinary professional skills and rehabilitation following surgery.

The review will assess centres against agreed standards to ensure that they are providing sustainable and consistent high quality services within appropriate networks of both local services and specialist centres.

1) Trauma (including head injuries)

Nineteen of the 25 trauma deaths were primarily the result of a head injury and four were a component of multiple trauma including abdominal injury. This is in keeping with other studies involving major trauma, where head injury is the main cause of death in children⁶⁵. Figure 4.4 shows the age and gender of children who sustained a major head injury.

Worthy of note is the high proportion of young people aged 15 years or more (12/25). These deaths were related to all types of trauma, with road traffic accident being the most common.

About half the cases were admitted and required surgical intervention out of hours with six operations commencing after midnight. Further, many of those that commenced after 18.00 would also have finished after midnight. This has obvious implications for transfer teams (including

DGH anaesthetists), and receiving anaesthetists, surgeons and ward teams. Virtually all cases required immediate surgical intervention (Table 4.11).

Table 4.11 Urgency of procedure - Advisors' opinion

Urgency of procedure (Trauma/head injury)	n
Immediate	18
Urgent	6
Expedited	0
Elective	0
Subtotal	24
Not answered	1
Total	25

Although the numbers are small, when Advisors were asked to assess the quality of care that these children received and there was a trend to suggest that it was a little worse than that of the other patient cohorts included in this study. In 8/25 cases they considered that care could have been improved or was less than satisfactory and this was largely for clinical reasons (7 cases). These data are summarised in Figure 4.5.

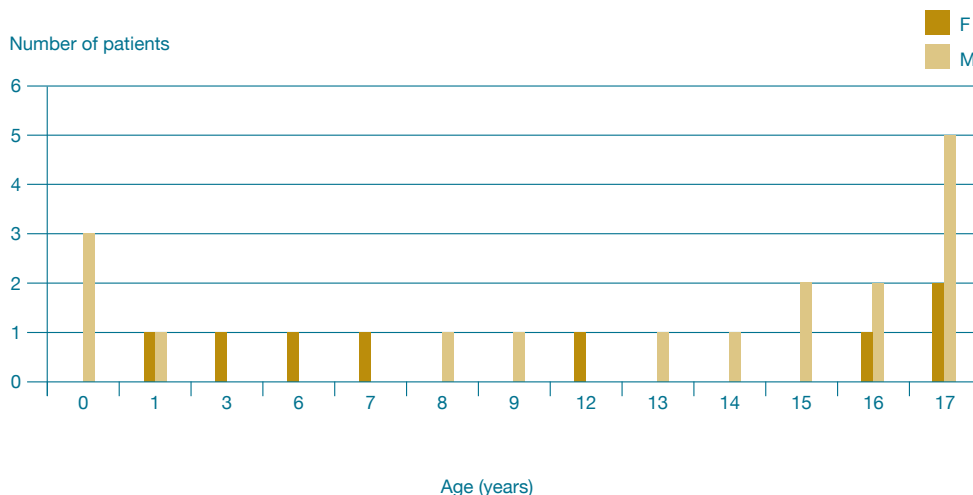


Figure 4.4 Age and gender of trauma/head injury cases

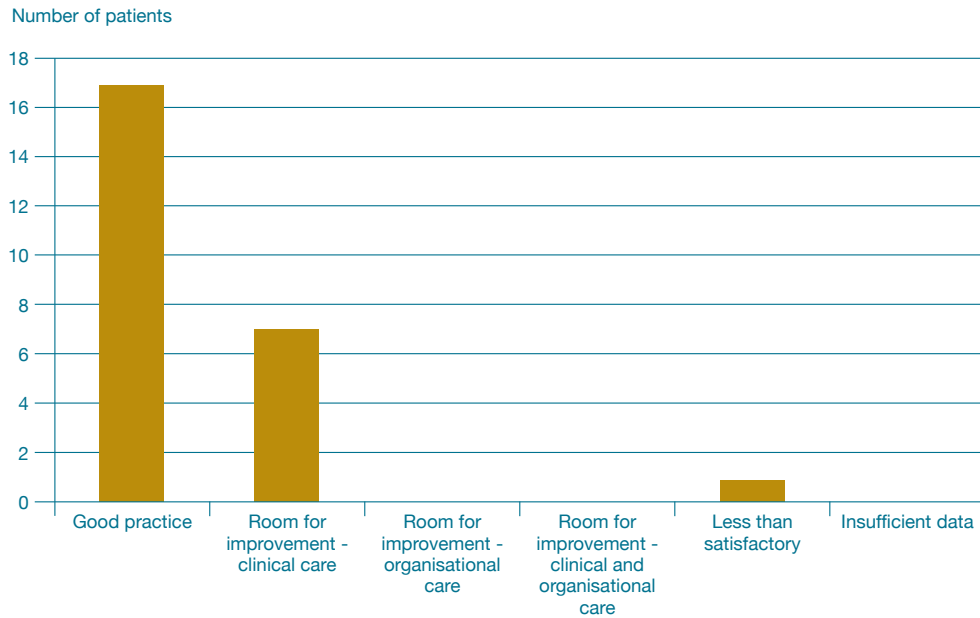


Figure 4.5 Advisors' assessment of the quality of care in trauma/head injury cases

Whilst in 23/25 cases the diagnosis was made within an appropriate time there was a delay in transferring the patient in five cases (Table 4.12). In a further 15 cases this question was not answered by Advisors because documentation was inadequate.

Table 4.12 Transfer delay - Advisors' opinion

Transfer delayed (Trauma/head injury)	n
Yes	5
No	5
Subtotal	10
Insufficient data	15
Total	25

In those five cases where a clear delay occurred the reasons for this were examined (Table 4.13).

Table 4.13 Examples of transfer delay

Examples of delay (Trauma/head injury)
Delay in finding a paediatric intensive care bed at the receiving hospital
No beds available in neurosurgical centre
Patient unstable and appropriately required further treatment at the referring hospital before transfer
Delay of >2hours in obtaining results of a CT scan
Unable to contact neurosurgeon (in theatre)
Unable to transfer CT images to neurosurgical centre
Delay in obtaining Factor VIII from National Blood Service: unlikely to have affected outcome

**answers may be multiple (n/112)*

Advisors believed that the outcome was affected in one patient, was not in two but were unable to comment in a further two.

Seniority of surgeons and anaesthetists

In the majority of cases the surgeon and anaesthetist were a consultant (Tables 4.14 and 4.15).

Table 4.14 Senior anaesthetist was a consultant - Advisors' opinion

Senior anaesthetist was a consultant (Trauma/head injury)	n
Yes	16
No	5
Unknown	4
Total	25

Table 4.15 Grade of surgeon

Grade of surgeon (Trauma/head injury)	n
Consultant	18
Staff grade	1
Senior specialist trainee	5
Trainee with CCT	1
Total	25

2) Non-trauma neurosurgical cases

As with head injury and trauma deaths these peak during infancy and the teenage years, as well as small numbers throughout childhood (Figure 4.6).

The urgency with which surgery was required in this group is shown in Table 4.16.

Table 4.16 Urgency of procedure (neurosurgery)

Urgency of procedure (Neurosurgery)	n
Immediate	21
Urgent	10
Expedited	3
Elective	2
Total	36

For the non-trauma cases of which there were 36, almost half (14) underwent a drainage procedure for raised intracranial pressure that was most often secondary to either a tumour or intra-cerebral bleed due to a congenital vascular anomaly. The remaining deaths also had a similar underlying pathology in most instances and underwent various procedures (evacuation of haematoma, tumour biopsy, decompressive craniotomy).

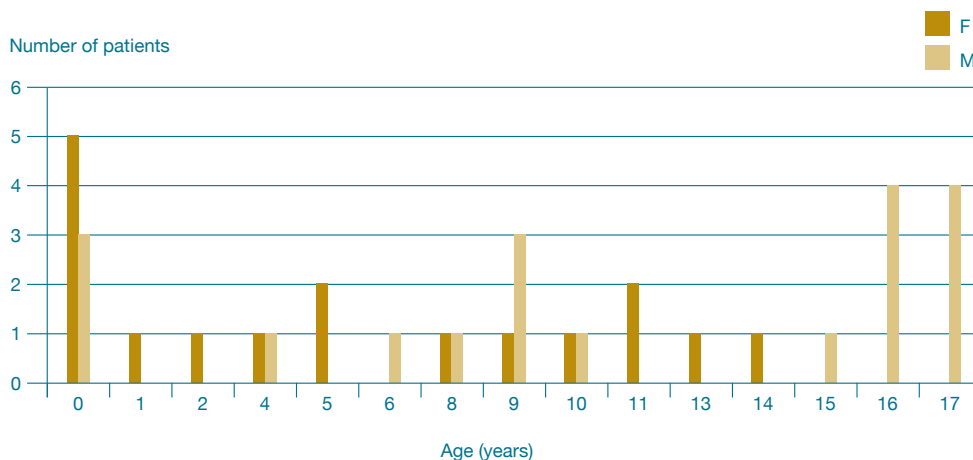


Fig 4.6 represents the age and gender profile of all (non-trauma related) neurosurgical cases

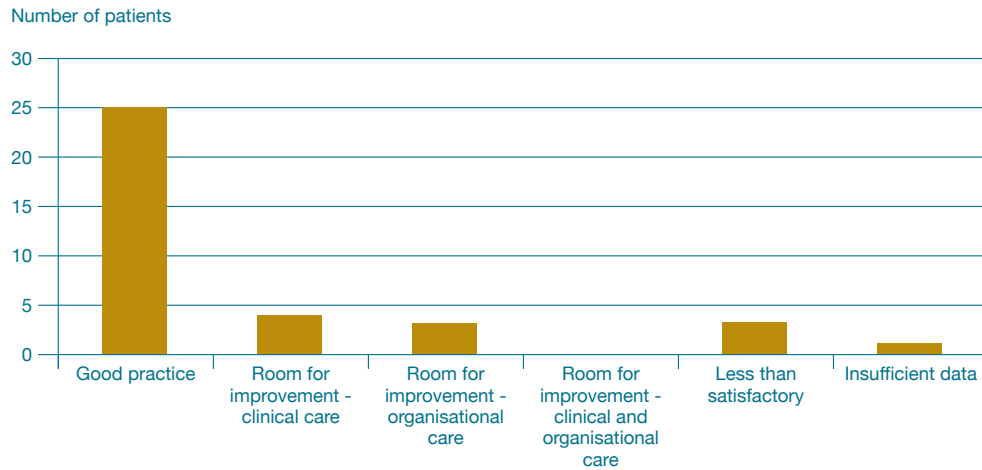


Figure 4.7 Advisors' assessment of the quality of care in non-trauma neurosurgical cases

As with traumatic deaths there seemed to be a trend that suggested that overall care in this group was less good with 7/36 where there was room for improvement and three cases where it was unsatisfactory (Figure 4.7). In some instances this was related to delays in referral and subsequent transfer to a neurosurgical unit.

There was a trend towards more junior medical personnel managing these cases (Tables 4.17 and 4.18) which may reflect the emergency nature of presentation that often occurred out of hours.

Table 4.17 Grade of surgeon

Grade of surgeon (Neurosurgery)	n
Consultant	16
Senior specialist trainee	11
Junior Specialist Trainee	2
Trainee with CCT	1
Other	2
Unknown	4
Total	36

Table 4.18 Grade of anaesthetist

Senior anaesthetist was a consultant (Neurosurgery)	n
Yes	15
No	9
Unknown	12
Total	36

Non trauma - neurosurgery delays

As with deaths in all surgical categories, delays were seen in a small number of cases at all stages of the referral process. Delays in referral to the surgical team were less common (3/34) than delays in the transfer of care to the specialty (6/35) (Table 4.19). Delays at some stage in transfer itself occurred in 8/23 cases (unable to answer in 13 cases).

**Table 4.19 Delay in transfer of care to neurosurgeons -
Advisors' opinion**

Delay in transfer of care to neurosurgeons	n
Yes	6
No	27
Not applicable	2
Subtotal	35
Insufficient data	1
Total	36

In England, the Safe and Sustainable review of Neurosurgery services for children will focus on delays in treatment in quality standards.

In all patients where there was a delay in transfer, urgent or immediate surgery was required.

Intra-cerebral bleeding

Intra-cerebral bleeds made up a relatively large number of the non-trauma neurosurgery admissions. These often occurred in older teenagers/young people where it may be less clear whether referral should be directed to adult or paediatric services. Whilst a poor outcome may be inevitable, there were concerns by the Advisors about the process of care, which on occasion revealed unsatisfactory delays. An example of this is shown in Case study 7.

Neuroradiology

Access to emergency CT scanning is an extremely important part of the neurosurgery and trauma pathway. Despite availability of technology that enables rapid transfer of images between hospitals there were several examples of delays in this process. There were also examples of misinterpretation of CT scans by junior members of staff that led to critical delays in treatment. An example is shown in Case study 8.

Case study 7

Delay in the case of an intra-cerebral bleed

A teenager with an acute intra-cerebral bleed presented to their local DGH with a GCS of 4 and was rapidly intubated, ventilated and underwent a CT scan. Notes revealed the following cause for delay in referral "I have discussed with the neurosurgical SpR at [another hospital]. They discussed this with their consultant who has advised that we seek admission to an adult unit"

Advisors commented that whilst this may have been a reasonable plan, it introduced an additional delay in the referral process.

Case study 8

Delay in obtaining specialist review

A teenager presented with a history of headache, weight loss and had a GCS of 14. A head CT was performed the next day and revealed a possible cerebral abscess or tumour. The neurosurgical unit advised antibiotics and an MRI was requested. The patient deteriorated and despite transfer to the neurosurgical unit they died.

Comment from the consultant neurosurgeon who completed the surgical questionnaire was that "the diagnosis of an abscess was made immediately, and correct advice given. However, it is notable that the referral occurred at a handover period, and no consultant neurosurgeon was involved in the management decisions."

Advisors commented that this was a totally unacceptable level of care. Waiting for an MRI scan when the CT scan at the local hospital showed clear pathology was unnecessary and urgent specialist review and surgery was required.

Key Findings - Specific care reviews

Necrotising enterocolitis

There was a delay in surgical referral in 9/101 babies with NEC perhaps reflecting the difficulties in both diagnosis and decision-making in respect of surgical intervention. In a further nine babies there was a delay in transfer to the hospital where surgery was performed.

Although consent was generally obtained by an appropriately experienced surgeon, documentation of the risk of death either on the consent form or in the medical notes was poor. The latter was a factor that was also noted in babies where the Advisors considered that there was “Room for improvement in clinical care”

Consultant surgeons performed the majority (93/103) operations in these babies.

Congenital cardiac surgery

Obtaining consent (including documentation of the risk of mortality) and surgery was almost always performed by a consultant surgeon.

The level of care for children with congenital heart disease was generally good and reflected that of the study as a whole.

Neurosurgery/Trauma

Important delays occurred in both investigation and transfer in a number of cases.

The level of care overall was less satisfactory for neurosurgical cases than in the remainder of the study.

Recommendations - Specific care reviews

Necrotising enterocolitis

Medical notes for babies with NEC require careful audit to ensure that the views and decisions of all members of the multi-disciplinary team are accurately recorded. (*Medical Directors*)

This survey and the advice from our specialist Advisors have highlighted the difficulties in decision-making during both medical management and the decision to operate in babies with NEC. A national database of all babies with NEC might facilitate this aspect of care and generate data upon which to base further research. (*Department of Health, Specialist Societies*)

Neurosurgery

Urgent completion of the “Safe and Sustainable Review of Children’s Neurosurgical Services” is required with implementation of the appropriate pathways of care that this is likely to recommend. This should be followed by a further audit to ensure compliance with national standards and models of care for all children requiring neurosurgery.

Under embargo until 00.01 27th October



5 – Autopsy and pathology

NCEPOD has not critically reviewed paediatric surgery autopsy reports since the 1999 report *'Extremes of Age'*, although there were a few such autopsies in the 2006 report *'The coroner's autopsies: do we deserve better?'*. Thus the 12-year interval permits an assessment of how matters related to the autopsy have changed.

In 1999, only 22 cases (coronial and hospital consented) autopsies were evaluated, without stratification by type of clinical pathology. The standard of reports was 'generally good'; there was criticism of the lack of histopathology sampling and the uninformative brevity in the coronial case autopsy reports. (These points were echoed strongly in the general review of coronial autopsy reports in 2006). Fewer than half the autopsies were performed by specialist paediatric pathologists.

In the present study there were 49 autopsy reports available: (Table 5.1).

Table 5.1 Cases undergoing autopsy

Neonatal enterocolitis (NEC)	19
Post-cardiac surgery	7
Traumatic brain injury	3
Non-injury neurosurgery	4
Other thoraco-abdominal surgery	16

Necrotising enterocolitis

All but one autopsy were performed by specialist paediatric/perinatal pathologists, and the reports were very comprehensive. Two of the 19 were coronial, the others hospital consented autopsies. They all included histopathology and microbiological sampling, and 8/19 included genetic karyotyping. Full clinico-pathological correlation was the norm, and one centre routinely included full literature references to the condition in the

reports. The only less than excellent autopsy had the odd conclusion that death was from 'Pseudomonas pneumonia' rather than the evident underlying prematurity and NEC.

The majority of the babies had had a laparotomy before death, with or without resection of bowel. The autopsy reports did not include the surgical histopathology of the resected bowel (and none had placental histopathology). This reflects the non-availability of such material when sick children are transferred between centres. However, none of this detracts from the Rolls-Royce service that perinatal pathologists appear to be providing to the neonatal clinicians.

Post-cardiac surgery

The children who died following one or more episodes of cardiac surgery were nearly all diagnosed in utero by scanning and had palliative or first-series operations within a few days. The autopsies were coronial in 5/7 cases, and were performed by paediatric pathologists – excellently – and concluded that the patients died of too-severe congenital heart disease and/or expected rapid complications of this type of surgery, with no indication of substandard surgical practice. In one case, the report specifically stated that the autopsy was instructed by the coroner because the family were unhappy about the care: the surgery was satisfactory but an intravenous line had become infected with staphylococci.

Traumatic brain injury and non-injury neurosurgery

The three cases of intracranial haemorrhage following falls and burr hole surgery were examined, under a

coroner, by neuropathologists or forensic pathologists. This is their proper field, and all the examinations were excellently reported. All four non-injury cases had detailed coronial autopsy examinations, with histopathology and microbiology, by neuropathologists and paediatric pathologists (in one case both). These excluded specific conditions and proved others, some unexpected – see Case study 9.

Other thoraco-abdominal surgery

Eleven out of the 16 cases were surgery for congenital malformations. All the autopsies were coronial or consented; they were all done by paediatric pathologists very thoroughly. Detailed commentaries that would have assisted clinicians and coroners, and helped to assuage parents, were standard.

As an anecdotal observation, in comparison to what most pathologists present in adult hospital or coronial autopsy reports, the range of clinico-pathological commentary in many of these reports encompassed much more detail and informed opinion. The non-survivability of the inherited conditions was emphasised, as when there had been a displaced tracheal tube that was the final cause of death.

The children who had non-congenital disease were older, and their autopsies were done – yet again very comprehensively - by (mainly) paediatric, adult or forensic pathologists. In one case the autopsy was a joint effort between a forensic and a paediatric pathologist and resulted in a 12 page report. There appeared to be a desire to explain what happened to account for the death. In one case of death during pelvic laparoscopic surgery, the conclusion that venous gas embolism was the most likely cause of death emerged from a chronological clinical review, combined with the autopsy which showed no alternative pathology. Completing this particular account, the morphological suspicion of hypertrophic obstructive cardiomyopathy, as well, was to be followed up.

Conclusion

When the right type of pathologist is on the job, even coronial autopsies can be routinely done very well, to benefit the family, clinicians, coroners, and public health. Compared to recent NCEPOD reviews of adult autopsies, particularly those commissioned by coroners, it is possible that children are regarded as 'special' in the sense that more attention is paid to getting the correct diagnosis; and explaining what actually happened to cause death.

If this sample is representative, then the quality of paediatric autopsy pathology has improved in this millennium. The main driver, from analysis of the types of pathologists involved, has to be specialisation. Nearly all of them were paediatric pathologists, who called in neuropathologists or forensic pathologists as appropriate.

A secondary factor appears to be the absence of any inhibition in sampling tissues for histopathology (as well as for microbiology, biochemistry and genetics). With one exception, all the autopsies considered here included histopathology. Whilst the Human Tissue Act 2004 and the exhaustive guidelines from the Human Tissue Authority seem to put fright into coroners and consenters when dealing with adults, they did not do so here.

If only the overall care demonstrated in paediatric autopsy pathology was matched by similar performance in the adult arena, the prognosis for quality UK autopsy pathology would be much more positive than is the case at present.

Case study 9

The benefit of a thorough autopsy

A term baby had an unexpected intracerebral bleed of unknown cause, a craniotomy was performed. The coronial autopsy, utilising histopathology, electron microscopy and genetic analysis, found the unusual aetio-pathogenesis: congenital nephrotic syndrome causing intracranial sino-venous thrombosis and intraparenchymal haemorrhage. A true learning exercise.

References

1. Campling EA, Devlin HB & Lunn JN. *The 1989 report of the National Confidential Enquiry into Perioperative Deaths*. 1990. NCEPOD, London.
2. Department of Health. *Getting the right start: National Service Framework for Children, Young People and Maternity Services Part 1: Standard for Hospital Services*. 2003. Crown Copyright.
3. Healthcare Commission. *Improving services for children in hospital*. 2007. Commission for Healthcare Audit and Inspection.
4. Department of Health. *Every Child Matters in the Health Service*. 2006. Crown Copyright.
5. Department for Children, Schools and Families. *The Children's Plan; Building Brighter Futures*. 2007. Crown Copyright.
6. Shribman S. *Children's health, our future: a review of progress against the National Service Framework for Children, Young People and Maternity Services 2004*. London: Department of Health; 2007.
7. Department of Health. *Healthy Lives, brighter futures – The strategy for children and young people's health*. 2009. Crown Copyright.
8. Kennedy I. *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs*. 2010. Department of Health. Crown Copyright.
9. Royal College of Paediatrics and Child Health. *Facing the Future: Standards for Paediatric Services*. 2011. RCPCH.
10. Cochrane H & Tanner S. *Trends in Children's Surgery 1994 – 2005: Evidence from Hospital Episodes Statistics Data*. London: Department of Health; 2007.
11. National Confidential Enquiry into Patient Outcome and Death. *Extremes of Age, The 1999 report of the National Confidential Enquiry into Peri-operative Death*. 1999. NCEPOD, London.
12. The Audit Commission for England and Wales. *Children first: a study of hospital services*. London: HMSO; 1993.
13. Atwell JD, Spargo PM. The provision of safe surgery for children. *Archives of Disease in Childhood*. 1992; 67(3):345-349.
14. Arul GS, Spicer RD. *Where should paediatric surgery be performed? Archives of Disease in Childhood*. 1998; 79(1): 65-72.
15. Pye JK. Survey of general paediatric surgery provision in England, Wales and Northern Ireland. *Annals of the Royal College of Surgeons of England*. 2008; 90(3); 193-97. doi:10.1308/003588408X285766.
16. Department of Health. *The acutely or critically sick or injured child in the District General Hospital - a team response*. http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/Closedconsultations/DH_4124412.
17. The Royal College of Anaesthetists. *Guidance on the Provision of Paediatric Anaesthesia Services*. 2010. Royal College of Anaesthetists.

REFERENCES

18. Children's Surgical Forum. *Ensuring the provision of general paediatric surgery in the district general hospital: Guidance to commissioners and service planners*. 2010. The Royal College of Surgeons of England.
19. Association of Paediatric Anaesthetists, Association of Surgeons for Great Britain and Ireland, British Association of Paediatric Surgeons, Royal College of Paediatrics and Child Health, Senate of Surgery for Great Britain and Ireland. *Joint Statement on General Paediatric Surgery Provision in District General Hospitals in Great Britain and Ireland*. London: BAPS; 2006.
20. Children's Surgical Forum. *General Paediatric Surgery*. Survey of Service Provision in District General Hospitals in England. 2010.
21. National Specialised Commissioning Group. *Children's Congenital Cardiac Services in England - Service Standards*. <http://www.specialisedservices.nhs.uk/document/paediatric-cardiac-surgery-standards> (accessed 31 July 2011).
22. NHS Specialised Services. *Safe and Sustainable-Children's Neurosurgical Services*. <http://www.specialisedservices.nhs.uk/document/children-neurosurgical-specification-standards-may-2011>.
23. Department of Health. *Records Management: NHS Code of Practice*. London: Department of Health; 2006.
24. NHS Networks. *Connecting people and ideas for better health*. <http://www.networks.nhs.uk>
25. National Services Division – Commissioning for Scotland's Health. *National Managed Clinical Networks*. <http://www.nsd.scot.nhs.uk/services/nmcn/index.html>
26. Department of Health. *A Guide to Promote a Shared Understanding of the Benefits of Managed Local Networks*. <http://www.dh.gov.uk/assetRoot/04/11/43/68/04114368.pdf>
27. Royal College of Paediatrics and Child Health. *A Guide to Understanding Pathways and Implementing Networks*. 2006. Royal College of Paediatrics and Child Health.
28. Department of Health – Health Services Directorate. *Paediatric Intensive Care "A Framework for the Future" - National Coordinating Group on Paediatric Intensive Care: Report to the Chief Executive of the NHS Executive*. 1997. Crown Copyright.
29. The Paediatric Intensive Care Society. 4th Edition, version 2. *Standards for the Care of Critically Ill Children*. London: The Paediatric Intensive Care Society; 2010.
30. The Association of Anaesthetists of Great Britain and Ireland. *AAGBI SAFETY GUIDELINE - Interhospital Transfer*. London: The Association of Anaesthetists of Great Britain and Ireland; 2009.
31. Clinical Resource Efficiency Support Team. *Protocol for the inter hospital transfer of patients and their records*. Clinical Resource Efficiency Support Team, Northern Ireland; 2006.
32. Emergency Surgery: Guidance for providers, commissioners and service planners. Standards for unscheduled surgical care. The Royal College of Surgeons of England. London. 2011.
33. Children's Surgery – A First Class Service Report of the Paediatric Forum of The Royal College of Surgeons of England May 2000 Review date 2005
34. Good Medical Practice. *Guidance for doctors*. General Medical Council. 2010.

35. Compliance Framework 2010-11. Monitor 2010.
36. Pre-operative Assessment and Patient Preparation. The Role of the Anaesthetist. Safety Guideline. AABGI. 2010.
37. Child patient rights and responsibilities. Patient Liaison Group. Royal College of Surgeons, London 2003.
38. Reference guide to consent for examination or treatment. Second edition. Department of Health 2009 (Crown copyright).
39. Royal College of Anaesthetists. *Your child's general Anaesthetic*. <http://www.rcoa.ac.uk/index.asp?PageID=1494>.
40. Royal College of Anaesthetists. *Anaesthesia information for children and young people*. <http://www.rcoa.ac.uk/index.asp?PageID=1520>.
41. Royal College of Surgeons of England. *Surgery for Children: delivering a first class service*. Roy Coll Surg Eng, London 2007 www.rcseng.ac.uk/rcseng/content/publications/docs/CSF.html
42. Lunn JN. Implications of the National Confidential Enquiry into Perioperative Deaths for paediatric anaesthesia. *Paediatric Anaesthesia* 1992; 2: 69-72.
43. Department of Health. *Welfare of children and young people in hospital*. 1991b. London: HMSO.
44. Health care service standards in caring for neonates, children and young people. London. Royal College of Nursing. 2011.
45. The role and responsibilities of the advanced scrub practitioner. Perioperative Care Collaborative. 2007.
46. Benchmark statement: Health care programmes. Operating department practice. Quality Assurance Agency for Higher Education 2004.
47. Portfolio of Core Competencies for Anaesthetic Assistants. Nursing, Midwifery and Allied Health Professions NHS Education for Scotland. 2007.
48. Association of Anaesthetists Working Party. *UK National Care Competencies for Post Anaesthetic Care*. 2011. In press.
49. Personal communication with Clinical Advisors and Expert Group.
50. Confidential Enquiry into Maternal and Child Health. *Why Children Die: A Pilot Study 2006, England (South West, North East and West Midlands), Wales and Northern Ireland*. London: 2008.
51. NHS East Midlands: Towards Excellence. Management of Children with Major Trauma: NHS Clinical Advisory Group Report. NHS East Midlands: Towards Excellence; 2011.
52. National Institute for Health and Clinical Excellence. *Clinical Guideline 50: Acutely ill patients in hospital - Recognition of and response to illness in adults in hospital*. <http://www.nice.org.uk/nicemedia/live/11810/35950/35950.pdf>
53. National Patient Safety Agency. *Safer care for the acutely ill patient: learning from serious incidents – The fifth report from the Patient Safety Observatory*. London: National Patient Safety Agency; 2007.
54. Healthcare Workforce Portal. *Paediatric Early Warning Tool*. http://www.healthcareworkforce.nhs.uk/wtd_pilot_pages/liverpool_pilot/paediatric_early_warning_tool.html

REFERENCES

55. Duncan HP. Survey of early identification systems to identify inpatient children at risk of physiological deterioration. *Archives of Diseases in Childhood*. 2007; 92 (9):828. doi:10.1136/adc.2006.112094.
56. Egdell P, Finlay L & PedleyDK. The PAWS score: validation of an early warning scoring system for the initial assessment of children in the emergency department. *Emergency Medicine Journal*. 2008;25(11): 745–749. doi:10.1136/emj.2007.054965.
57. Department of Health. HSC 2000/028: *Resuscitation policy*. http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH_4004244
58. Association of Paediatric Anaesthetists of Great Britain and Ireland (APA). *Good practice in post-operative and procedural pain*. London: APAGBI, 2008.
59. Faculty of Pain Medicine of The Royal College of Anaesthetists. *Best practice in the management of epidural analgesia in the hospital setting*. London: The Royal College of Anaesthetists; 2010.
60. Macintyre PE, Scott DA et al (eds.). *Acute Pain Management: Scientific Evidence* (3rd Edition). Melbourne: Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine; 2010. <http://www.anzca.edu.au/resources/books-and-publications/Acute%20Pain%20-%20final%20version.pdf>
61. Aylin P, Bottle A et al. Paediatric cardiac surgical mortality in England post Bristol: a descriptive analysis of hospital episode statistics 1991-2002. *British Medical Journal*, 2004; 329(7470): 825.
62. National Confidential Enquiry into Patient Outcome and Death. *Deaths in Acute Hospitals: Caring to the End?* http://www.ncepod.org.uk/2009report2/Downloads/DAH_report.pdf
63. National Patient Safety Agency. *Hospital at Night- Patient Safety Risk Assessment Guide*. NPSA, 2005. Gateway Ref. 4533.
64. Royal College of Paediatrics and Child Health. *Modelling the Future II: Reconfiguration and Workforce Estimates*. 2008. RCPCH.
65. NHS & Department of Health. *Toolkit for High Quality Neonatal Services*. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107845
66. British Association of Perinatal Medicine. *Standards for hospitals providing neonatal intensive and high dependency care*. http://www.bapm.org/publications/documents/guidelines/BAPM_Standards_Final_Aug2010.pdf
67. Joint statement from the Society of British Neurological surgeons (SBNS) and the Royal College of Anaesthetists(RCoA) regarding the provision of emergency paediatric neurological services, June 2010. www.rcoa.ac.uk
68. Academic attainment in Ex preterm children at 11 years. EPICure study Arch 2009 Foetal and Neonatal ed 94:F283-289.
69. Wallen E et al. Intrahospital transfer of critically ill paediatric patients. *Critical Care Medicine*. 1995; 23(9):1588-1595.
70. Britto J, Nadel S et al. Morbidity and severity of illness during interhospital transfer –impact of a specialised paediatric retrieval team. *British Medical Journal*. 1995; 311(7009):836-9.

71. Rowney DA, Simpson DL. Stabilisation and transport of the critically ill children. *Anaesthesia and Intensive Care Medicine*. 2006; 7(1):16-21.
72. Rosenberg M, Greenberger S et al. Comparison of Broselow tape measurement versus physician estimations of paediatric weights. *The American Journal of Emergency Medicine*. 2011; 29(5): 482-8.
73. Better health, better care. National delivery plan for children and young people specialist services in Scotland. General Surgery of Childhood-Care pathways for Surgical emergencies. NHS Scotland 2008. www.specialchildservices.scot.nhs.uk
74. McDonald IAR , Beattie TF. Intussuseption presenting to a paediatric accident and emergency department. *JAEM* 1995; 12, 182-186.
75. British Medical Association. *Consent, Rights and choices In healthcare for Children and Young people*. 2001.
76. British Medical Association. *Consent Toolkit*, 2009 (5th edition), www.bma.org.uk
77. Department of Health England. *Consent –what you have a right to expect –a guide for Children and young People*, 2001. www.dh.gov.uk
78. Department of Health, Social Services and Public Safety (Northern Ireland). *Good practice in Consent*, March 2003, <http://www.dhsspsni.gov.uk/consent-guidepart1.pdf>
79. General Medical Council. *Consent, patients and doctors-making decisions together*. 2008. www.gmc-uk.org
80. Royal College of Anaesthetists. *National Audit Project 4*. www.rcoa.ac.uk
81. Patient Safety First. *The ‘How to’ Guide for Reducing Harm in Perioperative Care*. 2009 www.patientsafetyfirst.nhs.uk
82. National patient Safety Agency. *National Reporting and Learning Service*. www.nrls.npsa.nhs.uk
83. Royal College of Anaesthetists. *Safety in Anaesthesia Liaison Group*.
84. Department of Health. *Commissioning Children and Young Peoples Palliative Care Services: A Practical Guide for the NHS Commissioners*. 2005. Crown Copyright.
85. Neu J, Walker WA. Medical progress: necrotising enterocolitis. *New England Journal of Medicine*. 2011; 364(3):255-264.
86. National Perinatal Epidemiology Unit. PiPS: *Trial of probiotic administered early to prevent infection and necrotising enterocolitis*. <https://www.npeu.ox.ac.uk/files/downloads/pips/PIPS-Protocol.pdf>
87. AlFateh K, Anabrees J and Bassler D et al. Probiotics for prevention of necrotizing enterocolitis in preterm infants. *Cochrane Database of Systematic Reviews*. 2011. Issue 3. Art No CD005496.D01;10,1002/14651858.CD005496.pub3.
88. Bell MJ, Ternberg JL et al. Neonatal necrotizing enterocolitis: therapeutic decisions based upon clinical staging. *Annals of Surgery*. 1978; 187(1):1-7.
89. Sola JE, Tepas JJ et al. Peritoneal drainage versus laparotomy for necrotising enterocolitis and intestinal perforation: a meta-analysis. *Journal of Surgical Research*. 2010; 161(1):95-100.

REFERENCES

90. Rees CM, Eaton S et al. Peritoneal drainage or laparotomy for neonatal bowel perforation?: A randomized controlled trial. *Annals of Surgery*. 2008; 248(1):44-51.
91. Moss RL, Dimmitt RA et al. Laparotomy versus peritoneal drainage for necrotising enterocolitis and perforation. *New England Journal of Medicine*. 2006; 354(21):2225-34.
92. ClinicalTrials.gov. *Laparotomy vs. Drainage for Infants with Necrotising Enterocolitis (NEST)*. <http://clinicaltrials.gov/ct2/show/NCT01029353>.
93. National Institute for Health and Clinical Excellence. *Quality Standards Programme*. <http://www.nice.org.uk/media/6F6/2B/DevelopingNICEQualityStandardsInterimProcessGuide.pdf>
94. Department of Health. *Learning from Bristol: The Department of Health's Response to the Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 – 1995*. 2002. Crown Copyright.
95. Department of Health. *Report of the Paediatric and Congenital Cardiac Services Review Group*. 2003. Crown Copyright.
96. Central Cardiac Audit Database, Healthcare Commission, Society for Cardiothoracic Surgery in Great Britain and Ireland, British Congenital Cardiac Association, and British Cardiovascular Society. (Information retrieved July 2009). <http://www.ccad.org.uk/002/congenital.nsf/0/E70012E407EC5741802575EF0001521F?OpenDocument?Summary>. Central Cardiac Audit Database.
97. Norwood WI, Lang P & Hansen DD. Physiologic repair of aortic atresia - hypoplastic left heart syndrome. *New England Journal of Medicine*. 1983; 308(1):23-6.
98. Wernovsky G. The paradigm shift toward surgical intervention for neonates with hypoplastic left heart syndrome. *Archives of Paediatrics and Adolescent Medicine*. 2008; 162(9):849-54.
99. Luce WA, Schwartz RM et al. Necrotizing enterocolitis in neonates undergoing the hybrid approach to complex congenital heart disease. *Paediatric Critical Care Medicine*. 2011; 12(1):46-51.

Appendices

Appendix 1

Glossary

CT	Computed Tomography
CVP	Central Venous Pressure
DH	Department of Health
DNAR	Do Not Attempt Resuscitation
Factor VIII	Blood clotting factor
GCS	Glasgow Coma Score
MDT	Multidisciplinary Team Meeting
MRI	Magnetic Resonance Imaging
NEC	Necrotising Enterocolitis
OPCS	Office of Population, Censuses and Surveys Classification of Surgical Operations and Procedures
PH	Private Hospital
PICU	Paediatric Intensive Care Unit
SCBU	Special Care Baby Unit
SPR	Specialist Registrar
SSH	Single Specialty Hospital
STPC	Specialist Tertiary Paediatric Centre
Surgical Clinical Network	See Figure 2.2
Track and Trigger	A mechanism to track physiological status and trigger a response if they change significantly
UTH	University Teaching Hospital

Appendix 2

Corporate structure and role of NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is an independent body to which a corporate commitment has been made by the Medical and Surgical Colleges, Associations and Faculties related to its area of activity. Each of these bodies nominates members on to NCEPOD's Steering Group.

The role of NCEPOD

The role of NCEPOD is to describe the gap between the care that should be delivered and what actually happens on the ground. In some ways it is a glorious anachronism: an exercise by the professions themselves to criticise the care that they deliver in the cause of improving the quality of the Service.

The process is simple but effective. We begin with an idea. Subjects can be suggested by anyone, but most come from the professional associations. It is a measure of how deeply the medical profession are committed to the improvement of their service that they should be voluble and enthusiastic about having the care that they deliver assessed and criticised by their peers.

To run the study robustly the staff and Clinical Co-ordinators, together with an Expert Group work up the study design so as to get the raw material that they think they will need to explore the quality of care. They identify a given group of cases and design the study and the questionnaires.

The NCEPOD Local Reporters – our precious eyes and ears in every Trust - are then asked to identify all the cases falling within that cohort. We then send all the Consultants responsible for those cases a questionnaire and elicit the key data that we need. We also ask the Trusts for copies of the notes.

Our staff then go through the notes laboriously anonymising them so that the Advisors and Authors cannot identify the patient, the hospital or the staff involved. Inevitably from time to time a perspicacious Advisor will recognise a colleague's handwriting, or even a case from a hospital they have worked at: they are trusted to quietly replace it on the pile and draw another. The Advisors are specialists in the areas of the study but they are emphatically not members of the expert group and play no part in the design of the study. They may have no prior connection with NCEPOD but wish to contribute to the over-riding aim of improving care in their specialty. They are trained, being put through dummy runs together with our Co-ordinators, so as to develop the necessary consistency of approach. Their assessment of the cases is done in our premises, in group meetings. Most cases will only be read by one Advisor who fills in a questionnaire, but they work together and discuss striking features as they come across them, so that the finished report and the vignettes do not represent idiosyncratic opinions. As you can see from our Acknowledgements they are a multidisciplinary group of distinguished professionals. The final report is compiled by the Co-ordinators and our staff from the material and the judgements made by them, for which we are deeply grateful.

Steering Group as at 27th October 2011

Members

Dr I Wilson	Association of Anaesthetists of Great Britain and Ireland
Mr F Smith	Association of Surgeons of Great Britain and Ireland
Mr J Wardrope	College of Emergency Medicine
Dr S Bridgman	Faculty of Public Health Medicine
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Observers

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Dr R Hunter	Coroners' Society of England and Wales
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Clinical Co-ordinators

The Steering Group appoint a Lead Clinical Co-ordinator for a defined tenure. In addition there are seven Clinical Co-ordinators who work on each study. All Co-ordinators are engaged in active academic/clinical practice (in the NHS) during their term of office.

Lead Clinical Co-ordinator	Dr G Findlay (Intensive Care)
Clinical Co-ordinators	Dr D G Mason (Anaesthesia) Dr K Wilkinson (Anaesthesia) Dr A P L Goodwin (Anaesthesia) Professor S B Lucas (Pathology) Mr I C Martin (Surgery) Professor M J Gough (Surgery)

Supporting organisations

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The Benenden Hospital Trust
The Horder Centre
The Hospital Management Trust
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