Review of patient safety for children and young people
NPSA partnership work

Produce regular reports containing RLS data relating to children, and improve guidance for external stakeholders on reporting patient safety incidents

Support of the Patient Safety First Campaign (England) and the 1000 Lives Campaign (Wales)

Facilitate the development of a regional children’s risk management network

Address the issue of medication dosing errors for children and neonates

Increase the profile of the NPSA within primary care settings and subsequently increase the rate of reporting into the RLS from these areas

Endorse ‘Spotting the Sick Child 2’, a DH-approved e-learning package designed to help healthcare professionals spot children with serious illness

Develop a web-based learning resource for healthcare professionals working in A&E departments to assist in their recognition and management of young people presenting with mental health issues

Support and endorse the development of standards to ensure young people with mental health needs are cared for in a safe and appropriate environment if admitted to adult mental health wards

Pilot the use of patient-held records for children with complex care needs to aid communication and improve the safety of their care

Advocate and promote child friendly services, and the provision of appropriate and safe environments for children and their families in receipt of NHS-funded care

Appendix 1: NPSA definition of degree of harm

Appendix 2: Terminology

Appendix 3: Interpretation of RLS data

Appendix 4: How paediatric and neonatal incidents are currently identified in the RLS

Appendix 5: References

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• The National Children’s Bureau and Contact a Family who undertook consultations on patient safety issues with children and their families on behalf of the NPSA.
• All those organisations who are participating in child health patient safety partnership work streams with the NPSA.
Executive summary

Between April 2007 and March 2008 there were approximately 1.9 million hospital admissions of children under 14 years in England and Wales and approximately 57 million contacts by children with general practice services. Most children are treated safely. However, some are exposed to preventable adverse events.

This review highlights some of the patient safety issues for children, young people and their families, outlines current National Patient Safety Agency (NPSA) partnership work streams, and identifies key actions for stakeholders.

Measuring healthcare quality and safety for children and young people

Using a variety of sources, this review builds a comprehensive picture of patient safety issues for children and young people.

The results of a number of large scale international casenote reviews have shown adverse event rates of 2.1% to 10.8% (per admission) for patients aged 0 to 17.

The Confidential Enquiry into Maternal and Child Health (CEMACH) report Why Children Die found preventable factors in 26% of reviewed cases. Common factors included difficulty in the recognition of severity of illness and poor communication.

Two major studies of the quality of healthcare provision are also reviewed. In the US, McGlynn and colleagues (see page 13) examined quality of care provided against evidence-based standards and found that children, on average, received only 46% of the indicated care.

In 2007, a Healthcare Commission report reviewed the quality of care for children’s services in hospital. Amongst their findings were that 16% of paediatric inpatient units carried out less work with children than the recommended minimum level, and in 8% of trusts surgeons carrying out planned surgery did not work enough with children to maintain their skills.

Analysis of Reporting and Learning System data

There were 910,089 incidents reported to the NPSA’s Reporting and Learning System (RLS) over a one year period (1 October 2007 to 30 September 2008). Of these, 2% were found to relate to the care of neonates and 5% to the care of children.

Only 4% of all reported incidents involving children were reported from primary care settings. As the vast majority of children receive their healthcare in the community, improved reporting from this area is essential to improving analysis of patient safety issues for children and subsequent learning.

The majority of patient safety incidents involving children and neonates were reported to have resulted in no harm or low harm to the child.

‘Medication incidents’ were the most commonly reported incident type for children (17%), followed by ‘treatment/procedure’ (13%) and ‘patient accident’ (11%).

For neonates, ‘treatment/procedure’ was the most common incident type (17%), followed by ‘medication incidents’ (15%) and ‘access/admission/transfer/discharge’ (14%).

The age group 0–4 years had the second highest percentage of medication incidents of all age groups. Only the over 75 year age group had more medication incidents reported.

Administration of the incorrect dose or strength of medication was the highest reported medication incident type for both children and
neonates. Calculations involving decimal points have been considered a factor in the occurrence of 10-fold dosing errors within children’s and neonatal environments.

For ‘treatment/procedure’ incidents, ‘delay and failure in treatment’ was the most commonly reported sub-category, followed by ‘inappropriate or wrong treatment’. These findings appear to relate to one of the key findings of the CEMACH report: the difficulty by some healthcare practitioners, both in primary and acute care, in recognising serious illness in children.

Patient accidents were the third most commonly reported incident type for children, and ‘slips trips and falls’ made up over half of these incidents. Two thousand children a week are admitted to hospital with accident-related injuries. It can therefore be anticipated that children will also be at risk of accidents while in hospital, and appropriate safeguards should be in place to protect children from accidental injury while receiving healthcare.

For neonates, ‘access/admission/transfer/discharge’ was the third most frequently reported incident type. ‘Unplanned admission/transfer to specialist care’ was reported in over half these cases and ‘unexpected readmission/re-attendance’ in nearly a quarter. The high numbers of unplanned admissions to neonatal units highlights the difficulty in ensuring safe staffing levels on neonatal units due to the unpredictability of unplanned admissions.

Consultation with children and families
The NPSA commissioned the National Children’s Bureau (NCB) and Contact a Family (CAF) to facilitate consultations with children, young people and their parents to elicit their views on patient safety.

Key issues raised relate to the communication and listening skills of healthcare professionals. Building relationships with children and their families through the use of good communication and listening skills is seen as vital in providing supportive and safe care.

The Healthcare Commission’s review of services to children in hospital in 2006 found only 24% of nurses and 7–9% of surgeons and anaesthetists had received any type of communication training relating to children. Children with disabilities and complex needs, and their families, in particular expressed concern that they were often not listened to by healthcare professionals about a change or deterioration in their child’s condition. They also felt that some healthcare staff did not understand how to communicate with non-verbal children.

Children and families also raised concerns about documentation and record keeping, the provision of a safe and appropriate environment for children and young people, medication administration and safety issues relating to the provision of medical care by parents.

Some of the recommendations from children and families included the provision of more training for healthcare professionals around communication and listening skills, advocacy support for parents, improved, integrated, multidisciplinary working through the use of shared documentation and multidisciplinary meetings, and support for parents providing healthcare for their child in the community.

NPSA partnership work
The NPSA is currently engaged in a number of partnership work streams with stakeholders from a variety of care settings to address some of the issues highlighted in this review. These include:

• Production of regular reports containing RLS data relating to children, and improved guidance for external stakeholders on reporting patient safety incidents.
• Support of the Patient Safety First Campaign in England and the 1000 Lives Campaign in Wales.
Facilitating the development of a regional children’s risk management network.
Addressing the issue of medication dosing errors for children and neonates.
Increasing the profile of the NPSA within primary care settings and subsequently increasing the rate of reporting into the RLS from these areas.
Endorsement of ‘Spotting the Sick Child 2’, a DH-approved e-learning package designed to help healthcare professionals spot children with serious illness.
Development of a web-based learning resource for healthcare professionals working in Accident and Emergency (A&E) departments to assist in their recognition and management of young people presenting with mental health issues.
Support and endorsement for the development of standards to ensure young people with mental health needs are cared for in a safe and appropriate environment if admitted to adult mental health wards.
Piloting the use of patient-held records for children with complex care needs to aid communication and improve the safety of their care.
Advocating and promoting child friendly services, and the provision of appropriate and safe environments for children and their families in receipt of NHS-funded care.

Key messages
The key issues regarding quality and safety of healthcare for children and young people arising from this review are:
Difficulty in the recognition of severity of illness.
A high rate of reported medication administration errors, in particular, dosing error.
The under-reporting of patient safety incidents in primary care.
The lack of an integrated approach to children’s risk management that incorporates health, education and social care.
The need for improved communication and listening skills by healthcare professionals when they are providing healthcare to children, together with more effective inter-professional communication.
A lack of recognition and appropriate management of mental health issues in young people, including the provision of a safe and appropriate environment when they are admitted to hospital for treatment.

Action points:
Actions that can be taken by organisations to address the issues identified in this review are:

1. Use NPSA tools and resources
The NPSA provides a number of tools, guidance and resources to support organisations to better understand, and make changes to, their safety culture, and to reduce harm to patients, including:

   • Seven steps to patient safety – a best practice guide to key areas of activity to ensure patient safety is being addressed in your organisation. www.npsa.nhs.uk/sevensteps
   • The Manchester Patient Safety Framework (MaPSaF) – a tool that helps organisations measure their progress towards making patient safety a central focus within their organisation. www.npsa.nhs.uk/nrls/improvingpatientsafety/humanfactors/mapsaf/
   • Being open – the NPSA’s Being open policy and tools helps healthcare staff communicate honestly and sympathetically with patients and their families when things go wrong. www.npsa.nhs.uk/nrls/improvingpatientsafety/patient-safety-tools-and-guidance/beingopen/
   • Root cause analysis (RCA) – the RCA toolkit provides a framework for reviewing patient safety incidents. Investigations can identify what, how, and why patient safety incidents have happened. Analysis can then be used to identify areas for change, develop recommendations and look for new solutions. www.npsa.nhs.uk/rca
   • Incident Decision Tree (IDT) – the IDT tool has been created to compliment the NPSA’s RCA toolkit and to help NHS managers and
senior clinicians decide whether they need to suspend (exclude) staff involved in a serious patient safety incident and to identify appropriate management action.

www.npsa.nhs.uk/idt

• **Foresight Training** – this resource pack has been developed to improve awareness in nursing and midwifery of the factors that combine to increase the likelihood of patient safety incidents. The pack contains a range of training scenarios, paper and video-based, and supporting materials for use by a facilitator. www.npsa.nhs.uk/nrls/improvingpatientsafety/humanfactors/foresight/

2. **Register for the Patient Safety First Campaign or the 1000 Lives Campaign**
The Patient Safety First Campaign in England aims to change the culture within the NHS to one that makes the safety of patients the highest priority and makes all avoidable death and harm unacceptable: www.patientsafetyfirst.nhs.uk

The 1000 Lives Campaign in Wales aims to reduce risks to patients by implementing interventions developed by clinicians: www.wales.nhs.uk/sites3/home.cfm?orgid=781

Both campaigns have interventions that can be adopted to reduce avoidable risks and harm associated with healthcare.

3. **Make use of the Paediatric Global Trigger Tool**
The Paediatric Global Trigger Tool provides a measure of harm experienced by patients in terms of adverse events: www.institute.nhs.uk/safer_care/safer_care/paediatric_safer_care

4. **Ensure ‘Spotting the Sick Child 2’ is made available as a reference tool**
The DH-approved e-learning package, ‘Spotting the Sick Child 2’, should be available to all doctors who treat children in a healthcare setting. This resource will be available soon at: www.spottingthesickchild.com

5. **Review local standard operating procedures for medicines management**
This can help identify points of risk and implement appropriate risk reduction strategies. Also ensure the provision of competency training and assessment in relation to medicines administration.

6. **Ensure staff meet the National Service Framework for Children standard in relation to sharing information with children and parents**
Organisations should assure themselves that staff who provide healthcare for children and young people meet the National Service Framework for Children Standard in relation to sharing information with children and parents and can:
- communicate with children at various levels of development;
- enable children and their families to exercise choice;
- understand the concept of competence in giving consent;
- give bad news in a sensitive, unhurried fashion.

7. **Support training for all healthcare staff in the recognition of mental health issues in young people**
e-learning for healthcare (e-LfH) is a Department of Health Programme that, in partnership with the NHS and professional bodies, provides free training to the NHS workforce. e-LfH has developed an adolescent health programme that contains a number of modules relating to mental health issues in young people:
www.e-lfh.org.uk/

The NPSA is also piloting a web-based resource aimed specifically at A&E staff to assist in their recognition and management of young people presenting with mental health issues. A report on this pilot will be available in 2009/10.
Introduction

The purpose of this report is to review and highlight patient safety issues for children, young people\(^a\) and their families, utilising data that have been obtained from a variety of sources. These include the NPSA’s RLS, key patient safety quantitative studies, and external stakeholder consultations in which children and their families discussed patient safety issues.

This review will be of interest to those providing health services to children in acute, primary care and third sector settings, as well as those providing neonatal services, and provides some key action points for stakeholders.

\(^a\) For the purposes of readability, the term ‘children’ will be taken to mean ‘children and young people’ throughout this review.
The NPSA is committed to providing regular reports on issues and themes arising from RLS data, and this is the first such report to focus on patient safety for children.

Following this introduction to the background and context of the report, patient safety data pertaining to children from a number of sources at a national level, including casenote reviews, administrative data and observational data are outlined.

The next section broadly outlines the results of RLS data analysis on factors such as type of incident, level of harm, and care setting. A number of themes emerging from the data are then explored, including medication incidents, issues relating to access and admission, and deterioration in condition. In conjunction with these thematic analyses, several important papers and reports are referred to and briefly discussed.

The next section explores responses from children and their parents related to patient safety issues derived from a series of workshops, focus groups and surveys. The final section has details of NPSA partnership work streams aimed at addressing some of the patient safety issues highlighted.

The appendices provide further supplementary information, including definitions and terminology relating to patient safety.

Background and context to the healthcare safety agenda for children

“The first dimension of quality must be that we do no harm to patients...Safety must be paramount for the NHS. Public trust in the NHS is conditional on our ability to keep patients safe when they are in our care.”

High quality care for all

Lord Darzi’s NHS Next Stage Review High quality care for all® sets out a framework through which the NHS can focus on improving the quality of care it provides. This includes quality improvements in patient safety, the patient experience and the effectiveness of care.

More than 10 years ago, a public enquiry led the General Medical Council to pass judgment on surgeons undertaking paediatric cardiac surgery at Bristol Royal Infirmary. The report Learning from Bristol® identified the hospital as having a significantly higher mortality rate for complex paediatric cardiac surgery than other comparable units in England. It did not, however, focus on individual culpability, but pointed to systematic failings in clinical safety and accountability. The report also identified issues relating to professional culture and a failure to take into account patient rights, and made close to 200 recommendations.

“The NHS must root out unsafe practices. It must remove barriers to safe care. In particular, it must promote openness and the preparedness to acknowledge errors and to learn lessons.”

Learning from Bristol®

“For the future, children in hospital must be cared for in a child-centred environment, by staff trained in caring for children, and in facilities appropriate to their needs.”

Learning from Bristol®
The Department of Health publication *An organisation with a memory (OWAM)* brought attention to the scale of the harm to patients stemming from adverse events in the healthcare system. Based on 8.5 million NHS inpatient episodes, the authors identified the potential for 314,000–414,000 adverse events per year and urged the NHS to follow high risk industries, such as the aviation industry, in learning from these adverse events. **OWAM** identified the need for a more open culture in which errors or service failures can be reported and discussed, and a systematic approach to the challenge of preventing, analysing and learning from errors.

In response to **OWAM**, **Building a safer NHS for patients** set out the Government’s plans for promoting patient safety, including the establishment of the NPSA to collect and analyse information about adverse events and near misses from local NHS organisations. This was followed by the introduction of the RLS to collect data on patient safety incidents (as presented from page 16 of this review).

A number of other significant reports and policy initiatives on the quality and safety of healthcare services for children have since been published. These include:

- Department of Health. *You’re welcome quality criteria: making health services young people friendly* 2005
- Royal College of Paediatrics and Child Health. *Modelling the future II: reconfiguration and workforce estimates* 2008
- Professor the Lord Darzi of Denham. *High quality care for all: NHS Next Stage Review final report* 2008
- Department for Children, Schools and Families. *Children and young people in mind: the final report of the National Child and Adolescent Mental Health Service Review* 2008
- Department of Health. *Healthy lives, brighter futures – the strategy for children and young people’s health* 2009

These reports and initiatives are aimed at bringing about a change in the way services for children are delivered, providing a more integrated approach from professionals and subsequently improving health outcomes and patient safety for children.
Casenote reviews
The OWAM® report drew on the findings of large studies that assessed the incidence of adverse events in hospital patients using systematic retrospective casenote review methodology. These studies aim to determine the type, frequency and severity of adverse events using specific screening criteria as triggers for adverse events.

A recent review of eight such studies from a number of countries showed that the incidence of adverse events varied from 3–16% of hospital admissions; a range that could reflect differences in study perspectives and methodologies. Adverse events were identified as affecting nearly one in 10 hospital patients, with over 40% of these being preventable. The outcome for over half the patients was no harm or minor disability, but it was suggested that 14% suffered permanent disability or death.

Data from three of the studies were further analysed by age group. Results from the Harvard Medical Practice Study\textsuperscript{11,12} indicated an adverse event rate of 2.1% for children aged under 15 years (excluding newborns) compared with 3.7% for all patients. The Quality in Australian Health Care Study (QAHCS)\textsuperscript{13} identified an adverse event rate of 10.8% for children aged under 15 years compared with 16.6% for all hospital admissions. An exploration of paediatric data from a US study\textsuperscript{14} found an adverse event rate of 1% for patients aged under 21 years versus 3.2% for all patients.

Extracting data from QAHCS, the most frequent adverse event descriptors for children aged 1–17 years, are shown in table 1.

**Table 1: Most frequent adverse events for children aged 1–17 years**

<table>
<thead>
<tr>
<th>Adverse event</th>
<th>Total number of incidents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management/planning/education problem</td>
<td>19</td>
</tr>
<tr>
<td>Inadequate manipulation/reduction of fracture</td>
<td>12</td>
</tr>
<tr>
<td>Diagnosis – delay/no or wrong</td>
<td>6</td>
</tr>
<tr>
<td>Premature discharge</td>
<td>6</td>
</tr>
<tr>
<td>Breakdown/failure of repair/rejection</td>
<td>5</td>
</tr>
<tr>
<td>Infection – abscess/other</td>
<td>5</td>
</tr>
<tr>
<td>Infection – wound</td>
<td>5</td>
</tr>
<tr>
<td>Post-operative nausea and vomiting</td>
<td>5</td>
</tr>
<tr>
<td>Haemorrhage</td>
<td>4</td>
</tr>
<tr>
<td>Medication – allergy/idiosyncratic effect</td>
<td>4</td>
</tr>
<tr>
<td>Unnecessary operation</td>
<td>4</td>
</tr>
<tr>
<td>Delay in admission</td>
<td>3</td>
</tr>
<tr>
<td>Unsatisfactory functional/cosmetic result</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
</tr>
</tbody>
</table>
Analysis of the data from the three studies found that the likelihood of a patient suffering an adverse event increased with age and was highest for older people, who are likely to have complex health needs. In addition, all studies identified surgery as the hospital treatment with the highest rate of adverse events, and children are less likely to undergo surgery. It is notable, however, that the rate of diagnostic error in children was similar to or higher than that for adults aged under 65 years. The proportion of the adverse events identified as preventable in children was found to be similar to other age groups.

Developments in the understanding of patient safety have been accompanied by studies examining the quality of healthcare provision by comparing retrospective casenote review against evidence-based standards of quality. A major study on the quality of care for adults in the US was followed by work to assess the quality of care for children. This research, conducted between 1996 and 2000, systematically examined all healthcare records of 1,536 children in different clinical areas to assess adherence to quality indicators (see figure 1). On average, children received 46% of the indicated care; a similar rate to that for adults.

**Figure 1: Adherence to quality indicators according to clinical areas**

There was a greater adherence to standards of care for acute conditions (mean adherence rate 77%) than for preventive care or chronic conditions (mean adherence rate 57% and 41%, respectively). Examining the function of the care provided, the study found that children received 47% of the indicated care for diagnosis, 66% for treatment and 45% for follow-up care.

**Paediatric Global Trigger Tool**

Trigger Tools were developed by the Institute of Healthcare Improvement in the US. They utilise a structured and timed manual review of patient records to identify adverse events. Data from these reviews can help organisations understand their rate of harm, and enable them to measure the impact of system and process improvements tested to eliminate harm to patients. As part of their Safer Care programme, the NHS Institute for Innovation and Improvement has recently piloted a Paediatric Global Trigger Tool amongst nine paediatric healthcare providers in the UK and has launched an electronic version of the tool on their website: www.institute.nhs.uk/safer_care/safer_care/paediatric_safer_care

**Confidential Enquiry into Maternal and Child Health (CEMACH)**

The 2008 CEMACH report *Why children die* applied confidential enquiry methodology to deaths in children (aged 28 days to 17 years and 364 days) occurring in Wales, Northern Ireland and three regions of England in 2006. The enquiry consisted of a quantitative analysis of a core dataset (957 deaths) and the qualitative analysis of 126 of these deaths evaluated by 41 multidisciplinary panels. Avoidable factors were found in 26% of the cases reviewed. Most frequently this was an: “Identifiable failure in the child’s direct care by an agency, including parents, with direct responsibility for the child.”
CEMACH highlighted the following common themes when evaluating avoidable factors in the cases reviewed by the multidisciplinary panels:

- recognition of severity of illness (further broken down into a number of subthemes);
- compliance with appointments;
- poor communication;
- single service issues;
- public information (e.g. the use of seatbelts in the back of a car).

Notification of all perinatal deaths from 22 weeks’ gestation to 28 days after birth is provided to CEMACH via a standard data collection tool. Findings from this surveillance of fetal and neonatal deaths is presented in the report Perinatal mortality 2006. Notifications of deaths, along with postmortem reports, were used to identify causes of perinatal deaths. Only a small proportion of reported deaths (0.3%) were attributed to accident or non-intrapartum causes.

Healthcare Commission quality reviews

Improvements in the quality of healthcare provision for children in England and Wales are assessed by the Care Quality Commission (formerly the Healthcare Commission). In 2005/06, the Healthcare Commission carried out a major review to assess whether hospitals were meeting or making progress towards key requirements of the National Service Framework for Children, Young People and Maternity Services Standard for Hospital Services.

Their report Improving services for children in hospital judged the quality of national service provision on four criteria: 4% of organisations were found to be excellent, 21% good, 70% fair and 5% weak. The following specific issues were also identified:

- 99% of trusts ensured that children requiring inpatient care were cared for in a child-only ward, but this figure fell to 38% for A&E services and 46% for outpatient services;
- 20 hospitals admitted less than 1,800 children per year and were within 30 minutes’ drive of the next nearest hospital;
- in 8% of trusts, surgeons carrying out planned surgery did not work enough with children to maintain their skills;
- 16% of paediatric inpatient units carried out less work with children than the recommended minimum professional level;
- 12% of trusts had insufficient medical cover to ensure that effective life support was available, rising to 18% at night;
- 58% of services used by children did not meet the necessary child protection training standards;
- there were insufficient numbers of staff trained in the management of pain in children, particularly in day-case and outpatient care;
- only 24% of nurses and 7–9% of surgeons and anaesthetists had received any sort of communication training relating to children;
- 79% of hospital services used by children were making progress towards meeting environmental standards for children but only 14% had met them in full.

A follow-up report published in 2009 revealed that although there was some improvement in certain areas, the overall baseline for improvement was low in the services assessed. The results for each theme were:

- Child protection training for nurses, and consultant surgeons and anaesthetists in emergency care and day care: 29% of trusts still did not meet the basic minimum level of child protection training for staff working with children.
- Managing pain and administration of analgesia by nurses in emergency care and day-case care: only 59% of trusts had the equivalent of one nurse per shift trained to assess and treat pain in children.
- Training in life support for nurses, and consultant surgeons and anaesthetists: 74% of trusts’ scores did not meet the guidelines for this training.
- Maintaining the skills of staff in surgery and outpatient departments: 63% of trusts were categorised as ‘consistently low
performing’ in ensuring that surgeons and anaesthetists undertake sufficient work to maintain their skills.

Quality and patient safety indicators
The US Agency for Healthcare Research and Quality (AHRQ) has developed quality indicators (QIs) to assist in the measurement of healthcare quality. Patient safety indicators (PSIs) focus on the measurement of potentially avoidable complications of healthcare. Inpatient hospital administrative data is screened for a predetermined set of indicators that, if present, would indicate that an adverse event had occurred. Examples of PSIs are complications of anaesthesia, postoperative sepsis and postoperative haemorrhage.

In the US, the software produced by AHRQ for paediatric QIs was applied to inpatient data for 431,524 hospital discharges. Most patients were aged between one and 12 years. Significant excess length of stay was found in six of the 12 paediatric QIs, ranging from 2.8 days for accidental puncture and laceration to 23.5 days for post-operative sepsis (see table 2). There are currently no specific paediatric QIs in use in the UK.

<table>
<thead>
<tr>
<th>Patient safety indicator</th>
<th>Mean excess length of stay</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-operative sepsis</td>
<td>23.5</td>
</tr>
<tr>
<td>Infection because of medical care</td>
<td>22.4</td>
</tr>
<tr>
<td>Foreign body left in during procedure</td>
<td>14.3</td>
</tr>
<tr>
<td>Decubitus ulcer</td>
<td>8.1</td>
</tr>
<tr>
<td>Post-operative respiratory failure</td>
<td>4.8</td>
</tr>
<tr>
<td>Accidental puncture and laceration</td>
<td>2.8</td>
</tr>
</tbody>
</table>

Observational studies
Researchers undertaking structured observation in operating theatres, intensive care units and A&E departments have identified patient safety incidents and near misses, including medication incidents. Data from observational research have contributed to the assessment of teamwork and other factors that affect the performance of clinicians (known as human factors). Observation also has the potential to record the impact of steps taken by clinicians to ameliorate the effect of a patient safety incident.

The statistical analysis of observational data collected from 173 operations in 16 paediatric cardiac centres in the UK points to the following findings:

• the number of uncompensated major incidents per case had a major predictive relationship with death;
• the overall number of minor incidents was also associated with poor outcomes;
• appropriate compensation for major incidents had a positive effect on outcome (the study did not find any effect of compensation for minor incidents).
Analysis of RLS data

This section presents results of analysis of RLS data to determine:
• the number and location of patient safety incidents involving children;
• the impact of patient safety incidents for children and neonates;
• the key reported incident types and emerging themes for children and neonates;
• medication incidents;
• treatment/procedure incidents;
• patient accidents;
• incidents relating to access and admission.

The RLS (originally known as the National Reporting and Learning System) was set up in 2003 and had received three million incident reports by January 2009. It enables the NHS to understand why, what and how patient safety incidents happen, learn from these experiences and take action to prevent the occurrence of future harm to patients. It does this through a series of processes that collect, review, analyse and feedback data, learning and action (see figure 2) relating to patient safety risks to support local patient safety improvement activities.

Figure 2: RLS process summary

Identify hazards
Evaluate impact
Analyse hazards and set priorities
Develop and implement risk mitigation strategies

The RLS collates information about patient safety incidents that have occurred across the NHS in England and Wales. The vast majority (around 99%) of the incident reports received to date have been collected in local NHS-provider risk management systems, and are sent electronically to the RLS by organisations. A small proportion of incidents are reported directly to the RLS via electronic web-based forms, from NHS staff, independent contractors (such as GPs) or patients.

Incidents reported to the RLS as ‘severe’ or ‘death’ are individually reviewed by the NPSA to determine if an NHS-wide response is necessary.

The purpose of this section is to examine RLS incidents relating to the care of neonates and children and to determine themes for further exploration. This analysis has been based on incidents reported to the RLS that occurred between 1 October 2007 and 30 September 2008.

The following definitions are applied throughout this section:
• neonate: any infant aged 0–27 days who may or may not require care on a neonatal unit or any infant aged above 27 days who is an inpatient on a neonatal unit.
• child: any patient aged between 28 days and 17 years (and not receiving care on a neonatal unit).
Number of patient safety incidents reported

Incidents concerning the care of neonates and children have been identified in the RLS using the reported age of the patient, specialty fields (neonatology, community paediatrics, child and adolescent mental health, and paedodontics), paediatrics specialty flags and some free text fields.

A total of 910,089 incidents were reported to the RLS as having occurred during the time period under assessment. Of these, 19,307 (2.1%) were found to relate to care of neonates and 42,029 (4.6%) to care of children.

More details related to incident interpretation, methodologies and data extraction can be found in appendices 3 and 4.

Location of incidents

Of all reported incidents involving children, 79% occurred in an acute setting, with a further 10% occurring in mental health settings. Only 4% of incidents involving children were reported as having occurred in a primary care setting and a further 7% occurred in a residence or home, social care facility, community hospital or other setting.

The low number of incidents reported from primary care compared with acute care reflects differences in reporting culture, and the maturity of reporting systems. However, the vast majority of children receive their healthcare in the community. Therefore improving reporting from community and primary care settings is essential to improving analysis of patient safety issues for children.

Of all reported neonatal incidents, 94% occurred in an acute setting, accurately reflecting the profile of where care is delivered. Just 2% were reported as having occurred in a residence or home, and 1% were reported from a primary care setting.

Impact of incidents on patients

The majority of patient safety incidents involving children and neonates reported an outcome of no harm or low harm. Every death reported to the RLS is reviewed and validated to confirm that it was related to a patient safety incident.

The majority of neonatal and child deaths reported to the RLS have not occurred as a result of, or involved, a patient safety incident. This is because incidents are mapped to the RLS from local risk management systems. Perinatal deaths, including stillbirths and those that have occurred as a result of prematurity or congenital abnormality, are routinely reported whether or not they are patient safety incidents. Child deaths as a result of known complex medical problems or life-limiting illnesses are also recorded, as well as suicides and sudden unexpected deaths in infancy (SUDI).

The reported degree of harm for incidents involving children and neonates, where only the validated deaths are included, is shown in figure 3.

Figure 3: Degree of harm of incidents involving children and neonates

Source: Incidents involving children and neonates, reported to the RLS as having occurred between October 2007 and September 2008.

Note: incidents reported as deaths were reviewed by a clinical reviewer. Deaths were excluded from this report if they were found not to be patient safety incidents, or unrelated to patients receiving NHS care. Some deaths have been reclassified under an alternative degree of harm as indicated by the text of the incident.
Child deaths

Between 1 October 2007 and 30 September 2008, 133 child deaths were reported to the RLS. Of these, 94 were excluded by clinical reviewers and six deaths were recoded as another level of harm. The free text in the remaining 33 reported incidents (30% of all reported child deaths) contained indicators of avoidable factors where an unexpected or unintended incident appeared to have occurred. However, without assessment of patient casenotes or the outcome of a case review and root cause analysis, it is not possible to state conclusively that an unexpected or unintended incident was a key contributing factor in these deaths. Because most of the incidents are reported from acute care, many of the children were very ill and it is difficult to attribute the outcome to the patient safety incident.

A very sick child was admitted on x/x/2008 with pressured sepsis secondary to chicken pox. Concerns regarding recognition of serious illness, inadequate clinical management and delay in involving retrieval service and Paed Intensive Care resulting in significant deterioration of child condition which could have been avoided.

Paediatric oncology neutropenic patient admitted with fever on x/x/08. No recordings of BP following admission despite having high fever overnight. First documented BP was in the afternoon of x/x/08 when patient was hypotensive. Patient failed to respond to fluid challenges and became more hypotensive, acidotic, hypoglycaemic with deteriorating renal function and oxygen requirement. Had to move to PICU for resuscitation. Gram negative sepsis.

[anonymised extracts from incident reports to the RLS]

Neonatal deaths

A total of 218 neonatal deaths were reported to the RLS during the same time period. Of these, 175 were excluded by clinical reviewers because a patient safety issue was not evident within the available reported text. Four deaths were recoded as another level of harm. There were 39 validated incidents (20% of reported deaths) that contained some indicators of avoidable factors where an unexpected or unintended death appeared to have occurred.

There is a disparity between the numbers of neonatal deaths reported to the RLS where evidence from the report text indicates that a patient safety incident might have contributed to the death of a neonate, and the number of neonatal deaths attributed to accident or non-intrapartum causes reported in the CEMACH Perinatal mortality report. This reflects the different purposes and triggers used by the systems.

The CEMACH report provides information on neonatal deaths based on the recorded cause of death indicated on the CEMACH perinatal death notification form and the cause of death recorded may not be attributed to a patient safety incident. In the conclusion of the Perinatal mortality report, CEMACH state that: “More precision about the causes of deaths from an improved perinatal classification
system would increase the value of CEMACH perinatal surveillance reports to clinicians and epidemiologists.” Their data collection tool has been revised to support the improvement of the quality and completeness of data collected.

**Reported incident types**

‘Medication incidents’ were the most commonly reported incident type for children (17%), followed by ‘treatment/procedure’ (13%), and ‘patient accident’ (11%). Figure 4 shows the percentage of different types of incidents reported involving children and neonates. ‘Treatment/procedure’ was the most common incident type for neonates (17%), followed by ‘medication incidents’ (15%) and ‘access/admission/transfer/discharge’ (14%).

**Figure 4: Incidents involving children and neonates, incident type reported**

**Medication incidents**

Of all medication incidents reported to the RLS (in which an age is provided), nearly 10% involve patients aged between 0 and 4 years. Figure 5 shows the pattern of medication incidents reported from acute hospital settings, by age group. The age group 0–4 years accounts for the second highest percentage of incidents, similar to that of the oldest groups (those aged 75 years and over).

While a high number of incidents involving older patients is expected, given the higher proportion of this demographic receiving care, further study is required to determine the reasons for the high rate of reported medication incidents in the 0–4 age group.

The complexity of dose calculation for this younger age group or the high rate of medications administered in neonatal care could be contributing factors.

**Figure 5: Percentage of medication incidents reported to the RLS by age group**

Source: Incidents involving children and neonates, reported to the RLS as having occurred between October 2007 and September 2008.
Type of medication incidents
The type of medication incidents reported for children and neonates is shown in Figure 6. Apart from the non-specified incident types (the ‘other’ category), administration of the incorrect dose or strength of medication was the highest reported medication incident type for both children and neonates, making up 23% of the overall total of medication incidents for children and 18% for neonates. The second most commonly reported type of medication incident for both children and neonates involved the omission of a medicine or ingredient (10% for children and 18% for neonates). The third most common was the wrong frequency of treatment (8% for children and 13% for neonates).

Errors with drug dose calculation
The finding that dosing errors are the most common type of medication incident for children is consistent with other relevant meta-analyses.

A key contributing factor to dosing errors for children and neonates is the complexity of the dose calculation required. These calculations, based on the age, weight and clinical condition of the child, often require the clinician who is calculating the dose to use only part of a tablet or ampoule intended as an adult preparation. In addition, liquid preparations are often used enterally with younger children when it is not possible to use the oral route. These liquid preparations are available in various strengths thereby increasing the possibility of a dosing incident.

Some children’s medicines require the clinician to convert dose units from milligrams to micrograms due to the availability of drug preparations. This results in calculations involving decimal points, which have been considered a factor in the occurrence of 10-fold dosing errors within a children’s and neonatal environment. Wong et al. state: “This problem is clearly demonstrated by the examples of diamorphine and morphine injections in the UK. The lowest strength of licensed diamorphine and morphine injections are 5mg and 10mg respectively; one such ampoule is sufficient to cause a 10 or 100 times overdose in neonates.”

Other examples of commonly used drugs in paediatric and neonatal medicine where 10-fold overdoses have occurred are benzylpenicillin, theophylline, digoxin, tacrolimus, adrenaline and ciclosporin.
The following examples of incidents involving 10-fold errors were reported to the RLS:

**Pt was due a dose of oral morphine 220 micrograms. When the dose was checked by S/N ‘A’. S/N ‘B’ noticed that the dose on the bottle was 100mg/1ml instead of the normal stock bottle of 100 micrograms/1ml:**

This bottle had been in use since x and pt had been given his prescribed dose of 220 micrograms, 6 hrly since then. If this dose was calculated from the bottle labeled 100mg/ml it would mean that 0.0022ml would need to have been drawn up, which would have been impossible to do.

At 18:00 on x intravenous indomethacin was administered as prescribed after being checked by two neonatal nurses. At 11:00 on x neonatal pharmacist noticed that the amount prescribed was incorrect. The patient had received 10 times the usual dose. The ward manager and consultant informed.

**Errors with intravenous medicines**

The number of medication incidents involving intravenous medication preparation and administration is problematic. A multicentre audit concluded that the incidence of medication errors with intravenous medication preparation and administration is higher than with other forms of medicine.

The following incidents involving intravenous medication preparation and administration were reported to the RLS:

- **Intravenous vancomycin supposed to be given as an infusion over 60 minutes was administered as slow iv bolus over 5 min.**

- **Intravenous antibiotic given at 13.25 and signed for on drug card. further dose of the same antibiotic given and signed for at 14.25. (dose given twice).**

The NPSA issued an alert in 2007 to promote the safer use of injectable medicines. This highlighted the risks associated with the administration of injectable medicines and produced a multi-faceted solution approach, including risk assessment of procedures, pro formas for standard operating policies and audit tools. It also included training packages and competency assessments for staff.

**Gentamicin**

Gentamicin is an antibiotic widely used intravenously for the treatment of neonatal sepsis. It has a narrow therapeutic range; high trough concentrations may cause oto- and/or nephro-toxicity and low peak levels will effect efficacy. An analysis search of RLS data undertaken for the period April 2007 to March 2008 for neonatal medication incidents involving gentamicin found 400 relevant incidents. Of these, 66% were related to problems with administration, 23% prescribing and 6% monitoring.

Gentamicin is the subject of a joint project between the NPSA and the Royal College of Paediatrics and Child Health (RCPCH): ‘The Safer Practice in Neonatal Care – care bundle project.’ Care bundles are defined as: “A group of evidence-based interventions related to a disease or care process that, when executed together, result in better outcomes than when implemented individually.” One of the two care bundles piloted across neonatal units in England is related to the safe administration of intravenous gentamicin to neonates. Elements of this care bundle include:

- a policy of no interruptions during the prescribing, preparing, checking and administering process;
- the use of the 24-hour clock when prescribing;
- administration of the dose to be given within one hour either side of the prescribed time;
- a prompt checklist for nurses administering the drug.

The NPSA is working in partnership with the RCPCH to produce a Safer Practice Notice in relation to this care bundle.
Treatment/procedure
Incidents reported as ‘treatment/procedure’ incident type made up 13% of all reported patient safety incidents involving children and 17% of all reported incidents involving neonates.

Among those incidents for which a specific detailed category was reported ‘treatment/procedure – delay/failure’ was the most commonly reported sub-category: 33% for children and 17% for neonates. This was followed by ‘treatment/procedure – inappropriate/wrong’: 15% for children and 11% for neonates; and ‘infusion injury (extravasation)’: 4% for children and 8% for neonates.

The following examples of incidents involving treatment/procedure and children or neonates were reported to the RLS:

Treatment/procedure – delay/failure

Delay to transfusion as blood not ready.

Patient is a known haemophiliac, attended Children’s Emergency Department (CED) following an injury. Required treatment via his Vacuport, no one trained in CED to administer this. No one available on wards x, x, and x to administer treatment. Ward x contacted and nurses informed nursing staff they do not do paediatric procedures. Long delay for patient waiting for treatment.

Treatment/procedure – inappropriate/wrong

Preterm baby of insulin dependent mother admitted and guideline for term babies of insulin dependent mothers followed, therefore baby did not have blood sugar checked at admission, and when first blood sugar recorded it was 1.1mmol and baby was apnoeic and cyanosed. (It does not state on the guideline that it should be used for term babies only).

Patient was on the ENT theatre list for the morning but 7am milk feed given.

Infusion injury (extravasation)

Extradation around left shoulder/chest following continuous infusion of TPN and LIPID via short long line.

Nurse from night shift handed over that the patient had an extravasation wound develop over night. I was told it was a blister that was oozing but when reviewed burst and raw underneath, red surrounding. Blister size of 4cm/2cm with 2 smaller blisters: one above and one below.

A random sample of 100 ‘treatment/procedure – delay/failure’ incidents relating to both children and neonates was analysed for common themes. Examples of delays to treatment were lack of availability of equipment, cancellation of operation and unreported scan. Examples of failure of treatment were equipment or staffing issues, and failure to recognise and subsequently treat serious illness and deterioration.

One of the key findings of the CEMACH report Why children die³ was the difficulty some healthcare practitioners, both in primary and acute care, had in recognising serious illness in children. In addition, the review of hospital services for children by the Healthcare Commission⁴ established that 16% of paediatric inpatient units carried out less work with children than the recommended minimum professional level.

The CEMACH report identified best practice in this regard as ensuring that: “All healthcare professionals who treat sick children should have appropriate training and supervision...
such that their key skills and competencies can be demonstrated, standards maintained and performance assured.” It also identified that healthcare institutions should ensure that staff are aware of, and implement, national guidelines. In addition, all clinicians, particularly those in primary care and A&E departments, should empower and encourage parents to seek further advice if a child’s condition fails to improve or deteriorates following medical advice. The report recommended the introduction of an early warning score system to ensure early identification of children who are developing critical illness.

With regard to extravasation, a review of RLS data for this period identified over 400 reported extravasation incidents within neonatal care settings. The majority of these incidents were categorised as ‘no harm’ or ‘low harm’. The NPSA is currently scoping this issue in more detail and aims to work collaboratively with stakeholders to determine best practice care elements relating to the management of intravenous lines that could be considered to reduce the incidence of extravasation.

**Patient accident**

Patient accidents were the third most commonly reported incident type for children, though less common for neonates, as might be expected. Slips, trips and falls made up over half of the patient accident incidents involving children (54%). Other incidents involved collision or contact with an object (18%), and contact with sharps (4%). In 19% of cases, no further specific category was reported. Of all accidents reported for children, 96% were categorised as having an outcome of ‘low harm’ or ‘no harm’. There were no deaths associated with patient accidents.

The following examples of incidents of patient accidents involving children were reported to the RLS:

**Slips, trips and falls**

*Child walking down corridor tripped over own feet landing on all fours*

*Child fell off a bench when practicing balance skills.*

**Collision/contact with an object**

*Bumped head on Reception desk whilst running. No LOC awake and orientated now, sitting at a desk drawing with crayons. Parents advised on what to look for if he develops head injury problems.*

*Pt given mouth care when pt made a sudden movement forwards and banged his face on cot sides.*

**Other**

*Pt was attempting to force open the door of the nursing office, which was shut by staff, trapping her second finger*

Five children die every week in England from accidents and over 2,000 children a week are admitted to hospital because of accident-related injuries. It can therefore be anticipated that children will be at risk of accidents while in hospital and appropriate safeguards should be in place to protect children from accidental injury while receiving healthcare.

**Access/admission/transfer/discharge**

The third most frequently reported incident type involving neonatal patients was ‘access/admission/transfer/discharge’. A further breakdown of this incident type indicates that ‘unplanned admission/transfer to specialist
care unit’ was reported in over half of these cases (53%) and ‘unexpected readmission/re-attendance’ in nearly a quarter (23%).

The following examples of incidents involving access/admission were reported to the RLS:

**Access/admission – unplanned admission/transfer to specialist care unit**

*Emergency LSCS Code red under spinal for pathological CTG Apgars Colour deteriorated & breathing laboured. Emergency admission to SCBU.*

*Persistent low blood sugars necessitating admission to SCBU. Also noted to have renal dilation.*


**Access/admission – unexpected readmission/re-attendance**

*Baby readmitted with weight loss history of vomiting and not tolerating feeds.*

*Serum bilirubin taken in the community. SBR level – 358 – baby readmitted to ward – phototherapy commenced.*

The high number of unplanned admissions to neonatal units highlights the difficulty in ensuring safe staffing levels on neonatal units due to the unpredictability of unplanned admissions.
Consultation with children and their families

This section discusses the outcome of consultation with children with disabilities and complex healthcare needs, and their families and carers, to elicit their views on patient safety issues. The key issues raised were:

- communication and listening;
- documentation and record keeping;
- safe and appropriate environment;
- medication administration;
- safety issues relating to the provision of medical care by parents;
- workforce training.

In 2007, the NPSA commissioned the NCB and CAF to facilitate consultations with children and parents from vulnerable groups to elicit their views on patient safety.

The right of any child to express their views and have them given due weight in decisions affecting them, in accordance with their age and maturity, is protected within The United Nations Convention on the Rights of the Child (Article 12). These rights are also supported by standards contained within the National Service Framework for Children and Young People.

The NPSA recognises the importance of actively involving children and young people in gathering qualitative evidence about safety issues within healthcare settings, and ensuring that their views and recommendations help to shape future NPSA work streams.

The NCB is a charitable organisation that acts as an umbrella body for organisations working with children in England and Northern Ireland. NCB also works in partnership with Children in Wales, the national Welsh umbrella organisation for those working with children. CAF is a UK-wide charity providing advice, information and support to parents of disabled children.

The NCB held four events in England and Wales in which 40 children aged from six to 18 years participated. The participants were recruited from vulnerable groups, including children with disabilities, long-term conditions, mental health needs and parents whose children had received care in neonatal or intensive care units. CAF conducted two focus groups with 20 parents of disabled children in England and obtained 19 completed questionnaires from parents of disabled children living in Wales.

The key issues raised during both these consultations are discussed below.

Communication and listening

Young people participating in the consultation identified that communication using age-appropriate language, and the provision of full and clear explanations about their diagnosis, treatment and medication helped them to feel safe in a healthcare environment. Failure of healthcare professionals to listen to children and their parents was identified by group participants as a major concern and a possible cause of safety incidents. Building relationships with children and their families through the use of good communication and listening skills was seen as vital to providing supportive and safe care.

The provision of information in other languages when English was not spoken or understood, and an awareness of different cultural needs, was highlighted as important by a number of families. They felt this would allow them to participate more fully in decisions about their child’s healthcare.
The following are responses provided by some young people indicating how a lack of communication from healthcare professionals made them feel unsafe:

**Physical examination without explanation.**

**Using equipment without explanation as to what it did/how it feels.**

**If the doctor made you feel unsure e.g. not explain the situation, use complicated terminology.**

Safety issues relating to occasions where there appeared to be a lack of communication between different healthcare professions involved in the care of a child were also highlighted. For example, children being discharged from hospital and community staff receiving no information about their care needs.

A large number of parents who participated in the consultation had experienced occasions where they felt they had not been listened to by healthcare professionals in relation to their child’s medical condition, or a deterioration in or concern about that condition. They believed that, consequently, the safe provision of healthcare to their child had been compromised. Many parents had been providing 24-hour care for their child since their diagnosis, and felt that they were ‘experts’ in how their child was affected by that condition. They felt that they should be listened to by medical professionals when they raised concerns about a change or deterioration in their child’s condition.

**Doctors etc. must respect the parents/carers as experts in their child and be more supportive of them.**

**Nobody listens to me until I start becoming more aggressive. This is not part of my culture: I was brought up to respect people.**

Parents/carers know their children best. Please listen to us. Don’t assume we are all paranoid parents. These children fall into the most vulnerable group. They cannot speak for themselves. Please listen to us!

**Documentation and record keeping**

During the consultations, examples of incidents arising from medical notes being incorrect or unavailable were identified.

**Safe and appropriate environment**

The young people who had experienced in-patient care due to their mental health needs felt that there were many potential dangers within a hospital that needed to be addressed. The NCB report documents the following:

**One young person remembered seeing a knife which should have been removed from a ward as there were self-harmers there. Others felt that medical staff should take dangerous situations seriously, such as young people running away from wards, to ensure their future safety. They felt that they needed to be better protected against other violent patients in hospitals.**

Waiting areas were seen as places where patient safety incidents could potentially occur, particularly in relation to disabled children. Having accessible changing areas for wheelchair users in some healthcare settings was also identified as a safety requirement. One mother explained how her daughter was a wheelchair user and was too big to be changed on a normal baby changer:

**It is hard to change her in the disabled toilets as both hospitals do not have changing couches or hoists which are necessary. I was offered a desk in a room once.**
Medication administration
Some parents described medication safety incidents experienced by their child. Parents highlighted situations where mistakes had been made with medication administration. One parent stated that she checked the amount of medication that was about to be given to her child and discovered that it was double the prescribed amount. She went on to say that it was not the first time that this had occurred. Parents felt that mistakes were more likely to happen on night shifts and/or when agency staff were on duty.

Safety issues relating to the provision of medical care by parents
It was generally accepted that the majority of parents want to actively participate in the care of their child. However, some parents felt that safety issues sometimes arose as a result of an assumption by healthcare professionals that parents could provide for all a child's healthcare needs, often with very little training.

Concerns were also raised by parents about the safe provision of care for their child, for example, when cared for at home by an exhausted parent.

Workforce training
A significant number of parents reported occasions where they felt that a healthcare professional's lack of awareness about their child's disability had put their safety at risk. They expressed particular concern about healthcare staff not understanding how to communicate with non-verbal children or not demonstrating an understanding of the need for consistency of care for children with disabilities. Some parents felt that some healthcare staff only saw their child in relation to their condition, and failed to see them holistically.

I couldn't even leave him [in hospital] to get a cup of tea.

We phoned to make an appointment and explain that autism meant our child would be stressed by waiting. We arrived at the appointed time to then be kept waiting for 30 minutes by which time my child was so stressed the GP could not examine him. He has never seen a GP since.

...surely when a patient is without speech and with profound needs, it makes sense for the same nurses to care for them each time wherever possible? With special needs children, so much of looking after them is knowing what is normal for them and it puts a lot of pressure on the parents to be there to interpret for them the whole time.

Actually the times that [my son] was probably most at risk was at night, when I was caring for him. I had about 4 years of unbelievable sleep deprivation when he woke frequently all night, needing care. For much of that time I slept on a mattress on his bedroom floor because it was not worth going back to my own bed….

Health argued that [my son] didn’t generally need medical assistance at night and Social Services said there was no point in installing a carer who would need to wake me for meds. Finally when [my son] started unpredictably going blue, they decided we could have a nurse at night starting with one night a week. Slowly over the next years we got it up to 7 nights a week…. It was a terrifying responsibility and I felt he was frequently at risk because I was just too exhausted.
Recommendations from children and families on how safety could be improved

- Healthcare professionals should listen to the concerns of parents and allow them an opportunity to act as an advocate for their child.
- Healthcare professionals who work with children should be able to communicate with them in a way in which they can understand, explaining treatments and procedures to the child directly as well as the parents using age-appropriate language, and allowing them an opportunity to ask questions.
- Multidisciplinary working should be improved through the use of shared documentation and multidisciplinary meetings.
- Parents of children with disabilities should be provided with adequate support to care for their child in both acute and community care settings.
- Children with disabilities should be allocated a key worker to provide continuity of care.
- Independent advocates should be made available to families of children with disabilities.
- Training should be provided for healthcare professionals who care for children with disabilities, particularly relating to non-verbal communication skills, and more learning disabilities staff should be employed on children’s wards.
NPSA partnership work

The NPSA is currently engaged in a number of partnership work streams with stakeholders from a variety of care settings to address some of the issues highlighted within this report. These include acute and primary care, child and adolescent mental health, and third sector providers. Outlines of these work streams are described in this section.

Produce regular reports containing RLS data relating to children, and improve guidance for external stakeholders on reporting patient safety incidents

The NPSA produces a number of regular outputs which include a six-monthly report for reporting trusts that incorporates a breakdown of incidents by specialty. However, the NPSA also intends to publish a more detailed breakdown of specialty-level data. In addition, in order to improve reporting levels and the quality of data reported, the NPSA will produce guidance on reporting incidents to the RLS specifically aimed at organisations providing services for children and neonates. The NPSA will also introduce a ‘paediatric’ specialty RLS which will facilitate improved analysis of these incidents.

Support of the Patient Safety First Campaign (England) and the 1000 Lives Campaign (Wales)

Both of these campaigns aim to make sustainable changes to the way in which patient safety issues are addressed. The approach is to mobilise frontline staff and leaders to take positive action on saving lives and reducing avoidable harm. Both campaigns focus on key clinical and leadership interventions that have been proven to make a difference.

Patient Safety First is also linked with the NPSA’s Matching Michigan Project. This project stems from Lord Darzi’s *High quality care for all: NHS Next Stage Review* which recommended a national patient safety initiative to tackle central-line catheter related bloodstream infections. The project draws on a simple, successful and sustainable bundle of care demonstrated by Professor Pronovost and his colleagues in a state-wide study conducted in Michigan, USA and published in the *New England Journal of Medicine* in 2006. The World Health Organization, through the World Alliance for Patient Safety, is also supporting the adoption and implementation of this initiative internationally.

Unlike the original Michigan study, the Matching Michigan project is including paediatric intensive care units in the data collection and intervention. The data collection process is being piloted in four intensive care units in the North-East Strategic Health Authority between May and July 2009.

Facilitate the development of a regional children’s risk management network

Children’s risk management networks aim to produce an integrated approach to children’s risk management that incorporates incident analysis from health, education and social care. Analysis of the risks underlying incident reports is undertaken, leading to an improved system of learning from patient safety incidents that involve children.

Networks such as these could ensure that high levels of risk to children are reported to
trust and local authority boards, and to the RLS. Local and national solutions can then be addressed.

In conjunction with these regional networks, Patient Safety Action Teams and children’s services can develop an active network of staff. These staff will provide a package of safety presentations, training aids and case studies to increase awareness of safety in relation to children and focus on specific initiatives aimed at children and families. These could be targeted at local, regional and national conferences and also primary and acute care providers.

The NPSA is working in partnership with the Cheshire and Merseyside Child Health Development Programme Team to develop this work.

Address the issue of medication dosing errors for children and neonates

Medication incidents are the highest percentage reported incident type for children and the third highest reported incident type for neonates.

*High quality care for all* states that: “The first dimension of quality must be that we do no harm to patients. This means reducing avoidable harm such as excessive drug errors.” The NPSA report *Safety in doses*  highlighted drug dose calculation as one of its seven key recommendations to improve medication safety: “To provide information, training and tools for staff to make calculations of doses easier, and target efforts towards high risk areas such as children.”

The NPSA will work collaboratively with external stakeholders to devise and implement information, training and tools for staff to reduce medication dosing errors in children and neonates.

The NPSA will also look to produce a Safer Practice Notice in partnership with the RCPCH in relation to neonatal gentamicin care bundle.

**Increase the profile of the NPSA within primary care settings and subsequently increase the rate of reporting into the RLS from these areas**

Analysis of RLS data demonstrates that reporting from primary care settings accounts for just 4% of all patient safety incidents relating to children, despite most of the care being undertaken in this setting.

The NPSA will work to formulate a programme of measures to increase the profile of the NPSA and subsequently promote reporting into the RLS from primary care settings where children are cared for. This would take the form of training workshops, the production of appropriate information literature and the development of collaborative networks.

**Endorse ‘Spotting the Sick Child 2’, a DH-approved e-learning package designed to help healthcare professionals spot children with serious illness**

Analysis of RLS data and casenote reviews shows that undetected action or inaction related to deterioration continues to be an issue.

The CEMACH report *Why children die* and the Healthcare Commission report *Improving services for children in hospital* both highlighted occurrences where there were failures by healthcare professionals to identify and subsequently treat serious illness and deterioration in children. The CEMACH report included recommendations that: “Healthcare professionals who treat sick children should have appropriate training and supervision such that their key skills and competencies can be demonstrated, standards maintained and performance assured.” They also stated: “For paediatric care in hospital we recommend a standardised and rational monitoring system
with embedded early identification systems for children developing critical illness – an early warning score.”

The NPSA is endorsing the ‘Spotting the Sick Child 2’ tool, which is also supported by the Department of Health, The Faculty of A&E Medicine and the RCPCH. A comprehensive interactive resource has been designed to help healthcare professionals spot children with serious illness.

**Develop a web-based learning resource for healthcare professionals working in A&E departments to assist in their recognition and management of young people presenting with mental health issues**

*Why children die* raised concerns about the mental health of the children in the populations studied: “The majority of children who died following suicide or substance abuse were not in contact with mental health services. The review panels encountered situations where failure to follow published NICE guidelines (e.g. in respect of children who self harm) had adverse consequences.”

In addition, a national review of Child and Adolescent Mental Health Services (CAMHS) was published in 2008. This highlighted the following issues:

- when parents, carers and children require help and support regarding mental health issues, they need more rapid and effective input from practitioners within universal services (e.g. A&E or primary care settings) to address their needs;
- the availability of information for healthcare professionals about risk, protective factors and effective interventions needs to be improved.

The report recommended that universal services should play a pivotal role in promotion, prevention and early intervention in relation to mental health for children. In addition, they recommended that staff across these services should have a clear understanding of their roles and responsibilities, and have the appropriate range of skills and competencies to manage these needs.

The NPSA is working in partnership with external stakeholders to develop a web-based resource to improve the knowledge base of healthcare staff working in A&E settings on mental health issues for children and to assist in their management and support of these children.

**Support and endorse the development of standards to ensure young people with mental health needs are cared for in a safe and appropriate environment if admitted to adult mental health wards**

The lack of safe and appropriate accommodation for young people with mental health problems was highlighted in the Office of the Children’s Commissioner for England report *Pushed into the shadows* and in the consultations outlined in this report.

The College Centre for Quality Improvement at The Royal College of Psychiatrists has undertaken a project to develop a set of standards and measurable criteria to ensure that if young people are admitted to adult wards the environment there will be safe and appropriate to their needs. The standards have been established following broad stakeholder consultation and have taken into account the requirements of the amended Mental Health Act, the recommendations from the *Pushed into the shadows* and *Out of the shadows* reports, and the Quality Network for Inpatient CAMHS service standards.

The NPSA is supporting and endorsing these standards, currently being piloted across a number of mental health wards in England, which address a significant patient safety issue for young people.
Pilot the use of patient-held records for children with complex care needs to aid communication and improve the safety of their care

Consultations undertaken by CAF and NCB with children with complex needs and their families regarding safety and quality issues identified concerns with communication between the multidisciplinary team caring for this group. This qualitative evidence is supported by a study carried out in the US, which describes the incidence and outcomes of medical injuries amongst over 300,000 children hospitalised in Wisconsin. It demonstrated that: “Children with special needs or dependence on medical technology experienced significant higher rates of medical errors.”

The Welsh Assembly Government has identified improving communication amongst healthcare professionals caring for this vulnerable group of children as a priority. Standard 5.4 of the Welsh National Service Framework for Children, Young People and Maternity Services states a commitment to provide all disabled children with complex needs with a hand-held record to compliment the parent child health record. The use of these additional hand-held records for children with complex needs has been positively evaluated in Wales.

One of the priorities for children’s health services in England contained within Public Service Agreement (PSA) 12 is: “To improve parent’s experience of services for disabled children.” The NPSA aims to support this PSA and also address the concerns highlighted by children and their families following consultation. It is therefore supporting a local development project to develop and pilot a patient-held record for children with complex care needs and their families. This record will aid communication between these children and their families, and the healthcare professionals involved in their care. The record will hold information such as a medical summary of the child’s condition, an up-to-date care plan for the child and a medication record sheet. It will also allow healthcare professionals an opportunity to enter an update of care whenever they see the child. The project will be hosted by Richard House Children’s Hospice in Newham, and supported by Great Ormond Street Palliative Care Team.

Advocate and promote child friendly services, and the provision of appropriate and safe environments for children and their families in receipt of NHS-funded care

Consultations carried out on behalf of the NPSA by the NCB and CAF highlighted concerns about communication between healthcare professionals, and children and their families. In particular, concerns were raised about how verbal information was provided and how concerns expressed by children, young people or their families were not always fully listened to and addressed.

The Healthcare Commission report Improving services for children in hospital states that: “Effective communication between health professionals and children is extremely important.” It also recommends formal training in communicating with children as an essential part of ongoing training for all staff involved in the care of children. The Department of Health report You’re welcome quality criteria recommends that all staff who are likely to come into contact with young people receive basic training on communicating with young people, and meet standards established in the current NHS knowledge and skills framework. They also state that staff should receive training on Department of Health guidance on confidentiality and consent in relation to children.

The children and families taking part in this consultation also felt more confident that staff working in a child-friendly environment would take into account the needs of a child and their family, and practice would be safer as a result. Improving services for children in hospital
states that the care of children: “Should be provided in buildings that are accessible, safe and child- and family-friendly.”

The NPSA advocates the adoption of the quality criteria set out in You’re welcome quality criteria24 by all service providers who come into contact with children, within both acute and primary care. In addition, the NPSA supports the promotion of the Patient Advice and Liaison Service to children and their families to improve advocacy for them in all areas of their healthcare provision and to ensure that children, young people and their families feel supported in the reporting of patient safety concerns.
## Appendix 1

### NPSA definition of degree of harm

<table>
<thead>
<tr>
<th>Harm</th>
<th>NPSA definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>No harm</td>
<td>Impact prevented: any patient safety incident that had the potential to cause harm but was prevented, resulting in no harm to the person(s) receiving NHS-funded care.</td>
</tr>
<tr>
<td>Low harm</td>
<td>Any patient safety incident that required extra observation or minor treatment, and caused minimal harm to the person(s) receiving NHS-funded care.</td>
</tr>
<tr>
<td>Moderate harm</td>
<td>Any patient safety incident that resulted in a moderate increase in treatment, and which caused significant but not permanent harm to the person(s) receiving NHS-funded care.</td>
</tr>
<tr>
<td>Severe harm</td>
<td>Any patient safety incident that resulted in permanent harm to the person(s) receiving NHS-funded care.</td>
</tr>
<tr>
<td>Death</td>
<td>Any patient safety incident that directly resulted in the death of the person(s) receiving NHS-funded care.</td>
</tr>
</tbody>
</table>
Appendix 2
Terminology

Clarification on the definitions of terminology used throughout this review:

**Children and young people:** those aged under 18 years.

**Neonate:** any infant aged 0–28 days who may or may not require care on a neonatal unit, or any infant aged over 28 days who is an inpatient on a neonatal unit.

**Patient safety incident:** any unintended or unexpected incident that could have or did lead to harm for one or more patients receiving NHS care.

**Adverse event:** an injury related to medical management, in contrast to complications of disease. Medical management includes all aspects of care, including diagnosis and treatment, failure to diagnose or treat, and the systems and equipment used to deliver care. Adverse events may be preventable or non-preventable.

**Error:** the failure of a planned action to be completed as intended (i.e. error of execution) or the use of a wrong plan to achieve an aim (i.e. error of planning). Errors may be errors of commission or omission, and usually reflect deficiencies in the systems of care.

**Near-miss:** serious error or mishap that has the potential to cause an adverse event but fails to do so because of chance or because it is intercepted.

**System:** a set of interdependent elements (people, processes, equipment) that interact to achieve a common aim.

Appendix 3
Interpretation of RLS data

There are a number of notes of caution in interpreting data from the RLS:

- The RLS is a voluntary reporting system and therefore is not a clear indicator of the rate or type of incidents occurring within NHS healthcare settings.
- International research indicates significant under-reporting of patient safety incidents.
- Although most patient care takes place in the community, there is significant under-reporting to the RLS from primary care settings.
- Patient safety incidents are mapped to the RLS through local risk management systems. These local systems may not capture all types of incidents that occur.
- Incident reports are often made immediately following an incident but before an investigation to establish the cause and final outcome. Therefore reports to the RLS may not contain complete information about the incident.
- Some reports recorded in local risk management systems, and therefore forwarded to the RLS, may not be patient safety incidents. For example, stillbirths or unexpected deaths.
Appendix 4
How paediatric and neonatal incidents are currently identified in the RLS

Children
The RLS has the capability to capture incidents reported about care of children, and these were identified in four ways:

- **Specialty codes**: several codes relate to children’s specialties in the RLS, although there is not currently a specified ‘paediatrics’ specialty. These other specialty codes include ‘Community paediatrics’, ‘Paedodontics’, and ‘Child and adolescent mental health’. Any incidents coded or mapped to these categories were used in paediatrics analysis.

- **Patient age**: patient age is derived from date of birth and the date of the incident. To protect the confidentiality of the patient, the date of birth is removed from the final dataset. Any incidents where the age of the patient is recorded as 28 days or more, and less than 18 years were used in paediatric analysis.

- **Flags**: there are two paediatrics ‘flags’ in the RLS, which correspond to the following questions: ‘Did this incident take place in a paediatrics or adult specialty?’ and ‘Was the patient being cared for in a dedicated paediatric ward/department/unit?’. The quality of this flag has not been reliable therefore this flag is used in conjunction with a text search (described below) to identify incidents that relate to children.

- **Text fields**: not all local categories are mapped to the RLS, and at a local level there may be children-specific incident types, locations or specialties that do not map directly to a code in the RLS. This information is kept in text fields and may be searched using specific search terms. For this report, these text fields were searched for paediatric-specific terms.

Neonates
The RLS has the capability to capture incidents reported about care of neonates, and these were identified in three ways:

- **Specialty code**: ‘Neonatology’ exists in the RLS as a level 2 specialty category, which falls under the level one category ‘Medical specialties’. Any incidents coded or mapped to this category were used in neonatal analysis.

- **Patient age**: patient age is derived from date of birth and the date of the incident. To protect the confidentiality of the patient, the date of birth is removed from the final dataset, and for neonates converted to an age in days or a decimal in years. Any incidents where the age of the patient is recorded as less than 28 days were used in neonatal analysis.

- **Text fields**: not all local categories are mapped to the RLS, and at a local level there may be neonatal-specific incident types, locations or specialties that do not map directly to a code in the RLS. This information is kept in text fields and may be searched using specific search terms. For this review, these text fields were searched for neonatal specific terms.

The approach to extracting children and neonatal incidents has recently undergone a review and will be subject to periodic review and improvement. Future changes in the RLS dataset may change the approach to identifying incidents involving care of neonates and children.
Data quality improvement

Almost all the incidents within the RLS have been uploaded from local risk management systems. There is considerable variation in the quantity and quality of data reported by individual trusts, and while the NPSA works with trusts to improve reporting, the analysis and feedback that can be undertaken is, ultimately, limited by what trusts send to them.

Specific issues the NPSA are aware of are:

• age of patient – approximately 36% of reports to the RLS do not specify the age of the patient;
• specialty – level 2 is missing in approximately 12% of reports;
• age and specialty are at times inconsistently reported – reports in the neonatal category include incidents where the patient is older than one year (up to 85 years old).

Improvement in the quality of age and specialty reporting would allow improved analysis of incidents related to child and neonatal care.
Appendix 5
References

1. HES & Health Solutions Wales data. 2007/2008.


