REPORT BY THE ACUTELY ILL THEMED GROUP
Background

Throughout childhood from conception through to the teenage years and adulthood, families need to know how and where to get health advice, how to access care quickly and effectively, and to be confident that their child will receive effective care if they require transfer to more specialised services. In spite of improvements in facilities and technical equipment, and with designated training programmes for some professionals dealing with children, the UK is slipping behind other European countries in important child health outcomes:

- The all-cause mortality rate for children and young people in the UK has dropped from average to the worst in Europe over approximately the last decade and child death rates from specific causes that are amenable to healthcare such as asthma, pneumonia and meningitis are higher in the UK than in European countries. Half of children subsequently found to have meningococcal infection are sent home from the first primary care consultation and approximately 75% of hospital admissions of children with asthma could have been prevented with better primary care;
- These illnesses rely on early recognition when first contact is made with a health professional, for example, in the primary care and emergency care setting;
- Many children, in particular infants, are receiving care in hospital when they may be more appropriately looked after in the primary care setting. Given that fewer than half of all GPs in this country have been formally trained in child health, it is not a surprise to find that vital signs in acutely ill children are uncommonly measured in general practice;
- There is over 4 fold variation in the numbers of children attending emergency departments in England from equivalent general practices, and a 4–6 fold variation in admissions to hospital for bronchiolitis or asthma;
- Recent evidence indicates that increasing numbers of children are being taken to facilities such as walk in and urgent care centres, where there are often insufficient numbers of staff formally trained in child health;
- Of all medication incidents reported to the NPSA from acute hospital settings (in which an age is provided), nearly 10% involved patients aged between 0 and four years, the second highest group (highest was patients over 75 years);
- The results of a number of large scale international case note reviews have shown adverse event rates of 2.1% to 10.8% (per admission) for patients aged 0-17. 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.

In addition to better quality evidence and improved consistency of care for the child and family, there are drivers in the new commissioning structures to encourage care closer to home, or in a community setting, with implications for better quality of care as well as potential savings when compared to unnecessary acute trust attendance or re-attendance.

2 Thompson MJ et al Using vital signs to assess children with acute infections; a survey of current practice British Journal of General Practice 58(4) p236-41
Children who require emergency surgery may sometimes require transfer to a hospital which is distant from his/her home where there are appropriately trained surgeons and anaesthetists on site. Children who have experienced major trauma or critical illness need to be transferred to centres where there is the expertise to deal with their complex problems, and any delay can have a worse outcome for the child. The NCEPOD report in 2011 highlighted that there were problems transferring children from a local to specialist sites for definitive care, that hospitals were not necessarily part of effective networks for surgical provision and noted that children did not always have effective management of their pain.

We also know that despite a range of initiatives such as lesson plan resources for primary and secondary schools, developed by the NHS Institute for Innovation and Improvement and local schemes including patient experience surveys, the genuine views of children and young people are not captured and used to inform service design and delivery. More, and appropriate, information should be made available for children, young people, parents and carers in relevant and appropriate formats so that they know how to recognise illness, know when to seek help, and where to take their child.

Key Principles

The acutely ill themed group was made up of a range of people from medical, nursing and managerial backgrounds. Appendix 1 lists our membership and describes our methodology in detail.

We agreed that there were five fundamental principles central to successful and successfully delivery of improved health activities:

- networks are integral to the delivery of pathways of care. Networks help to deliver standards and measure outcomes for all children and young people from all backgrounds whether they require medical or surgical assistance;
- children and young people and their families must be involved in the development of the outcomes and services necessary to deliver them;
- health outcomes must be linked to the schools and colleges and connect with measures of the educational readiness/attainment and attendance of children and young people at school or college, and of their participation in normal activities;
- having an aligned Informatics Strategy in which there are two key standards –
  - having clear and effective data collections for quality assurance and quality improvement purposes, excellent (but safe) sharing, communication and secure information management systems; and
  - modernising how information is communicated to children and young people and families, providing meaningful information to children and young people and families so, for example, they have the confidence to recognise and manage illness and make safe decisions to access the health system appropriately.
- the outcomes will all have implications for the education and training of all staff that are involved with child health and will be required to keep up their skills. There will be gaps, skills and competence of the workforce, which must be addressed through NHS workforce planning. The scope and magnitude of problems must be identified in order to best inform workforce planning and training.
Forum Website Themes

During the consultation period, interested parties were invited to comment on the Forum’s website. Examples of the themes which were recorded are captured in the concept ...’right team, right place, right time and with least risk ‘and show the need for integrated care across the acute and community settings, and with partner agencies when required.

- caring for children and particularly teenagers in the right place;
- better partnership working and integrated pathways between medical and social care;
- the increase in paediatric admissions due to a lack of confidence in primary care settings, or poor access, creating an overwhelming burden in acute hospitals;
- acutely ill children and young people need access to specialist knowledge, rapid assessment of treatment, admission avoidance, shorter length of stay, with community children’s nursing teams( CCNTs) managing acutely ill children;
- acute care ( especially Out of Hours) built round the needs of patients and keeping them at home wherever possible;
- too little continuity between acute and community services;
- lack of joined up commissioning – NHS direct, GPs, walk in centres, A&E depts;
- more collaborative services via networks;
- improved access to children’s nurses in emergency/admission units and to community children’s nurses ( there are too few of them);
- improved transition to adult services;
- patient and parents reported outcomes measures need to be developed for children;
- poor knowledge base of parents/professional group to manage the acutely ill child. Some GPs have adequate training and experience to assess and manage decisions about the seriously ill or unwell child;
- access point to acute care for a child with special needs e.g. autism or Asperger’s syndrome – staff need to be experienced to ensure children and young people and their families receive the right access, communication and management plans – this applies to all health care settings;
- key outcomes must include death rates;
- parental education on all aspects of life pathway , particularly when discharged from neonatal units;
- parents/children and young people have a right to access good experienced health advice;
- communication strategies to be clear;
- the importance of the role of therapists in care of children and young people; and
- more thought to children and young people in the NHS cascades down to all of their relationships and their future independence.
Children & Young People’s Views

Children and Young People’s views must underpin the work to develop the outcomes. Excerpts from feedback from children and young people were taken from the draft document produced by the National Children’s Bureau (Listening to children’s view on health; a rapid review of evidence; National Children’s Bureau 2012).

The domains and outcomes in the existing frameworks that children and young people rate as of most importance are as follows:

<table>
<thead>
<tr>
<th>NHS Domain</th>
<th>Quality</th>
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<tr>
<td></td>
<td>Patient Experience</td>
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<td>Public Health Outcomes</td>
<td>Premature Death</td>
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<td>NHS Outcomes Framework</td>
<td>Premature Mortality</td>
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<td></td>
<td>Reducing deaths in babies and young children</td>
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<td></td>
<td>Health related quality of life for those with long term conditions</td>
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</table>

Evidence supporting outcomes and indicators

The indicators are presented here, with proposed allocation to both the NHS outcomes domains and the developing NHS Commissioning Outcomes Framework.

Key to the classification of the changes is below:

1. No change to existing outcomes framework indicator
2. Extension of existing indicator reflecting the life course
3. Adaptation of the indicator to make it more relevant to children and young people
4. New indicator or area to be included in the framework

Please note colour code for the assessment of indicator readiness:

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<thead>
<tr>
<th></th>
<th>Description</th>
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<tbody>
<tr>
<td>Red</td>
<td>New data source required (or adaptation to existing data source)</td>
</tr>
<tr>
<td>Amber</td>
<td>Data available, definition needs development</td>
</tr>
<tr>
<td>Green</td>
<td>Indicator readily available</td>
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<tr>
<td>Blue</td>
<td>Indicator in, or being developed for, existing outcomes framework</td>
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<tr>
<td>Domain</td>
<td>Description</td>
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<tr>
<td><strong>Domain 1 – Preventing People from Dying Prematurely</strong></td>
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<td></td>
<td>Infant mortality</td>
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<td></td>
<td>Neonatal mortality and stillbirths</td>
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<td></td>
<td>Mortality in childhood and young people</td>
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<td></td>
<td>Time from presentation at NHS setting to (i) definitive diagnosis; (ii) of initiation treatment: for set of exemplar conditions</td>
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<td></td>
<td><strong>NHS Commissioning Framework</strong></td>
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<td></td>
<td>Childhood mortality for specific conditions (meningococcal, septicaemia; asthma; LRTIs, diabetes and epilepsy)</td>
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<tr>
<td><strong>Domain 2 – Enhancing Quality of Life for People with Long Term Conditions</strong></td>
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<td></td>
<td>Unplanned hospitalisation for children and young people with asthma, diabetes and epilepsy</td>
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<td><strong>NHS Commissioning Framework</strong></td>
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<td></td>
<td>Percentage of patients diagnosed with diabetes, who are later admitted due to Diabetic Ketoacidosis (DKA).</td>
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<td><strong>Domain 3 – Helping People to recover from episodes of ill health or following injury</strong></td>
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<td>Emergency admissions for acute conditions that should not usually require hospital admission</td>
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<td>Emergency readmissions within 48 hours of discharge from hospital for children and young people</td>
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<td>PROM to measure outcomes from planned procedures for children and young people</td>
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<td></td>
<td>Emergency admissions for children and young people with LRTI</td>
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<td></td>
<td>Measure of functional recovery 1 year after injury for children and young people with severe traumatic brain injury</td>
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<td><strong>NHS Commissioning Framework</strong></td>
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<td></td>
<td>Percentage of admitted children and young people with a length of stay of less than 24 hours</td>
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<td>Average length of stay in hospital for children and young people</td>
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<td>Day case rates (for certain procedures – to be determined)</td>
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<td></td>
<td>Disability-free survival at 2 years of age for babies born at &lt;30 weeks of gestation</td>
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<td></td>
<td>Time from decision made to transfer a child from Trauma unit to major treatment centre</td>
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<td></td>
<td>Incidence of moderate/major trauma as measured by index severity score &gt;=9</td>
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<td></td>
<td>Time from arrival in Emergency Department to receive CT scan for infants, children and young people with serious head injury</td>
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<td></td>
<td>Emergency department attendances for children and young people defined per age</td>
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<td><strong>Domain 4 – Ensuring that People have a Positive Experience of Care</strong></td>
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<td></td>
<td>Children and young people’s experience of healthcare in all settings</td>
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<td></td>
<td><strong>NHS Commissioning Framework</strong></td>
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<td></td>
<td>Percentage of children and young people who report that their pain was managed</td>
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<td><strong>Domain 5 – Treating and caring for people in a safe environment and protecting them from avoidable harm</strong></td>
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<td>Incidence of hospital acquired infection i MRSA ii C.Difficile iii. Late onset blood stream infections in children</td>
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<td></td>
<td>Incidence of medication errors for children and young people that reach the patient</td>
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<td></td>
<td>Admission of full-term babies to neonatal care</td>
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<td></td>
<td>Incidence of harm to children and young people due to ‘failure to monitor’</td>
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<td></td>
<td>Rates of admission to age inappropriate environments for children and young people</td>
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<td></td>
<td><strong>NHS Commissioning Framework</strong></td>
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<td></td>
<td>Rate of catheter-associated and catheter-related bloodstream infections (CABSiS &amp; CREBSiS)</td>
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<td></td>
<td>Number of unexpected cardiac arrests for children and young people in hospital</td>
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<td></td>
<td>Paediatric Early Warning System in place and being acted on for children and young people</td>
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<td>Number of SUs reported (physical and mental health)</td>
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<td></td>
<td>Emergency admissions of home births and re-admissions to hospital of babies within 14 days of being born, per 1000 live births</td>
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Conclusions and Findings

We noted a number of issues which were common to all of the work stream groups. Some of these points had already been highlighted by our group within the 5 underpinning principles (page 3) in order for the outcomes to be brought to life:

- lack of data on patient experience for children and young people and families;
- poor transitional arrangements at all stages in the life course;
- a need to strengthen communication and information sharing, particularly for the vulnerable groups of children and young people;
- the right care needs to be provided to the right children and young people at the right time and in the right place; and
- health outcomes for children and young people must be linked to their educational attendance and attainment.

It was clear that a number of our proposed outcomes could be included with expansion and development into the existing NHS and Public Health Outcomes Frameworks. We noted that, for example, the bundle of indicators, which could be used to measure the impact of traumatic brain injury, would be well placed in the developing NHS Commissioning Framework.

We ask for a regular review of the Outcomes Frameworks so that the outcomes and indicators can be adapted in the future when there is more evidence available. Some examples are seen in the work of Safe and Sustainable Neurosurgery (http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-neurosurgical-services) and in the further development of the quality dashboard for paediatric intensive care. These outcomes must be embedded in the NHS Outcomes Framework in due course. Networks will be able to develop more specific indicators so that further service improvements can be made.

Some of the outcomes and indicators have been selected as single proxy measures of high-quality care within a complex system (a system which often encompass a range of care components across the health, education and social care). For example, reduction in attendance at emergency departments requires a suite of programmes to improve primary care availability, children and young people and parent/carer information, school based management, and self-management by young people.

Recommendations

We have six recommendations to support the acutely sick child and young person.

1. **High quality safety net advice for children, young people and families**

   Good consistent safety net advice is crucial in the current triage and assessment systems that have developed to respond to acute illness in children. If children and young people are to be able to access the right services at the right time, they and their families need access to a safety net of information in a form that they can understand which enables them to determine whether or not they can care for their sick child at home, or require health care. They need to be able to act on this information without fear of criticism. Before this, however, it is necessary to develop the evidence base which addresses the psychosocial drivers for service use around the reasons for increased paediatric admissions and service use in general.
2. *Children and young people are effectively cared for in the new NHS system design*

At all levels of commissioning, provision and regulation, there need to be leads for children and young people. In addition, the NHS CB, as part of its operational structure, should have an overarching strategic children’s network for children and young people which is dedicated to overseeing the commissioning of services for infants, children and young people, and that there is representation on this strategic network from public health, social care and the education sectors.

3. *Networks*

Children need to receive care close to home as possible but those requiring highly specialised care need to access this when necessary and networks of care are the effective way in ensuring equity of access.

Existing Networks must continue to be funded and developed. More networks need to be established where there is a patient need. The development of networks and the delivery of pathways through networks for children and young people need to be led by the NHS CB without delay.

Networks are key to providing the required standards of care through a pathway approach in order to meet the needs of infants, children and young people. Networks can also evaluate and act on care / clinical outcomes. They must continue to be an integral part of the NHS system, and should not be time limited unless there are clinical grounds for this. The role of networks within the current complexity of commissioning, and their ability to monitor outcomes and performance in the current design and structure of the NHS CB will need clarity. It must also be possible for some networks in development to demonstrate their added value in order to become managed clinical networks. To make networks effective, commissioning of care for a pathway of an infant, child or young person is essential. There is also a potential beneficial impact on reducing cost of health care when networks deliver the whole pathway of care. Cost savings may not be realised within the locus of the organisation investing in changes to services but across the whole life-course public sector cost – support for implementation must therefore be across sectors and integrated with a shared belief in the longer term benefits of collaborative working. Networks are the key to the success of integrated care and collaborative working for children and young people.

4. *Research*

We have to establish why we have the worst health outcomes with respect to amenable mortality in Europe (Wolfe I et al BMJ 2011). This is an absolute ‘must do’, and we need to see much more in the way of funded research into health systems/outcomes, for example through the National Institute for Health Research, and the academic institutions. We therefore recommend that there is a national child health research strategy. Research for both clinical and health services and systems must be supported and funded on a national wide basis. Currently there are excellent examples of clinical research relating to children and young people through organisations such as the Medicines for Children Research Network (www.mrcn.org.uk). Another useful reference is the RCPCH Turning the Tide.⁶

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⁶ [http://adc.bmj.com/content/early/2011/08/23/archdischild-2011-300721.extract](http://adc.bmj.com/content/early/2011/08/23/archdischild-2011-300721.extract)
5. Workforce

We must have a competent workforce equipped to address the needs of babies, children and young people. Collaboration must be of the highest standard with a consistent approach to delivery of care across the professions.

*We want, and need people to do the best, not just their best*

It is vital that staff caring for children and young people work collaboratively to deliver sustainable outcomes that are comparable with the best international health care providers in the world. We need to be consistent in our advice given to parents and in the care which we provide across the acute care pathway.

All staff that care for infants, children and young people must have the knowledge, skills and competence to care for them, and measures must be in place to ensure that they keep their skills up to date. This must apply to all settings where they need urgent care, ranging from the GP practices to walk-in centres/urgent care centres, ambulance services, the emergency department, inpatient ward, and intensive care unit. Furthermore, the training of staff must be shaped to meet the needs of babies, children, young people and their families through the various stages of the life path. The training needs to ensure that the cultural diversities of our society are understood and that staff have the right skills and competencies to look after infants, children and young people in their family context. This recommendation becomes an integral part of the quality assurance mechanisms in place to monitor the outcomes. This should be the responsibility of Health Education England.

6. Monitoring the outcomes

In addition to the NHS regulatory framework measures, we suggest the application of the NHS change model which has been created to support the NHS to adopt a shared approach to leading change and transformation. The model provides a systematic and sustainable approach to improving quality of care. It brings together a collective improvement knowledge and experience from across the NHS into eight key components. Through applying all eight components change can happen.

www.changemodel.nhs.uk

The model can be used by the on an annual basis for at least 3 years by an appropriate group so that the benefits and challenges of the implementation of the outcomes can be evaluated and fed back to stakeholders. Most importantly, we want children and young people and families to be involved in the implementation phase.
Appendix 1

Work stream discussion document and supportive evidence for Outcomes

Membership of acutely ill work stream

- Professor Sir Cyril Chantler, Chairman, UCL partners
- Dr Ronny Cheung, Registrar in Paediatrics, Evelina Children’s Hospital, London.
- Dr Carol Ewing, (Co – Lead), Consultant Paediatrician, Royal Manchester Children’s Hospital
- Dr Eric Kelly, GP (Co – Lead) – GP/ Chair of Doncaster Clinical Commissioning Group
- Sir Ron Kerr, Chief Executive, Guys and St Thomas’s Hospital
- Christine Outram, Managing Director, Medical Education England/ SRO Health Education England
- Fiona Smith, Advisor in Children and Young People’s Nursing, Royal College of Nursing
- Roly Squire, Consultant Paediatric Surgeon, Spire Leeds Hospital
- Professor Terence Stephenson, Nuffield Professor of Child health, Institute of Child Health, University College London

Methodology

In this report, a health outcome is taken to mean a measure which reflects some aspect of health status and an Indicator defines a quantity that describes an aspect of health.

The objective of the group has been to develop a list of outcomes and indicators for situations where infants, children and young people, and their parents and carers, require ‘urgent’ advice, and highlight those outcomes where improvement would make the greatest difference to their lives. The outcomes and indicators should apply consistently and equally for any infant, child or young person at any stage of his/her life, and particularly should represent the needs of vulnerable groups and at stages of transition e.g. infancy to childhood, childhood to teenage years and teenage years to adulthood.

Furthermore we recommended outcomes and indicators, or expanded existing ones in the NHS and PH Outcomes Frameworks which would be relevant in primary, secondary or specialist health care settings, and to accommodate both medical and surgical needs.

The group began their task with a blank page and each member listed up to 10 outcomes which they considered to be important indicators of a good acute care service. The group used published evidence wherever possible to support the development of the suggested outcomes. Also listed are outcomes where there was consensus among the group, or with the relevant stakeholders, that these should be developed. A generic list of references is attached in Appendix 2, and there are more...
specific references included under the discussion and evidence section used to develop the outcomes outlined in Appendix1.

The group have had weekly meetings/teleconferences and we have been supported by ‘critical friends’ with specific expertise and to whom we offer a very special thanks.

By the 29th March, the list had been condensed and divided into 3:

- most likely (applying SMART principles)
  - Significant
  - Measurable
  - Attainable
  - Relevant
  - Timely
- already in PH or NHS Outcomes Frameworks but the indicators might need more work; and
- showing potential as an outcome measure, but requiring further discussion, or which could be relevant to another/all work streams.

By May 2012, with the support of the DH analyst, Alison Kirby, the outcomes were shaped to answer a number of questions drawn up by the Forum which could be asked by children and young people and their families, and which should be applicable to a children and young people’s life path.

The group were also advised, for example, as to the ways in which HES (Hospital Episode Statistics http://www.hesonline.nhs.uk?Ease/servlet/ContentServer?siteID=1937) data could be used in collection of data and how indicators such as patient experience measures could be developed. There is a range of emergency and urgent care indicators from HES data which it is possible to breakdown by age.

The group were informed that there are no indicators relating to children’s care on the NHS Choices website (http://www.nhs.uk/Pages/HomePage.aspx) but that this organisation may be interested in using some of the measures that come out of our work, for example the indicators around day case rates.

We also learned that The NHS Information Centre have a set of indicators called the Indicators for Quality Improvement – a set of clinical quality indicators sourced from a range of different places. http://www.ic.nhs.uk/services/measuring-for-quality-improvement. Currently, they do not have any that are for acutely ill or injured children.

The outcomes and indicators were further refined by working with the other work streams and they were then allocated either to one of the five NHS Outcome Domains, or for them to be included in the developing NHS Commissioning framework. The latter was particularly important, for example, where indicators are being developed and collected through networked arrangements e.g. for the Paediatric Trauma or Intensive Care Networks. We also noted a number of standards documents, several of which have been developed by intercollegiate working groups e.g. the PIC Standards document which contains sections pertaining to ED wards, HDU and anaesthesia for children and young people and which are listed in appendix 2.
In addition to shaping the outcomes and indicators, the work stream has contributed to a number of other cross-cutting work – streams for the Forum such as:

- Education, training and workforce
- General Practice
- Informatics
- The new NHS operational framework
- Safeguarding
- Looked After Children
Appendix 2
Key Reference documents


RCPCH – Developing Quality indicators

RCPCH response to Transparency in Outcomes in the NHS Frameworks –
http://www.rcpch.ac.uk/system/files/protect/consultation/Response%20FINAL.pdf

RCPCH response to for a Public Health Outcome Framework


Quality and Safety Standards for small and remote units May 2011 RCPCH

Improving paediatric radiology services – an Intercollegiate report
http://www.rcr.ac.uk/docs/radiology/pdf/BFCR(10)12_Paediatric_IR.pdf

DH Spotting the Sick Child https://www.spottingthesickchild.com/?

RCPCH Bringing Networks to Life – www.RCPCH.ac.uk/networks


Guidance for Commissioners and providers on the provision of general paediatric surgery in the District General Hospital, RCSE 2010 http://www.rcseng.ac.uk/service_delivery/children2019s-surgical-forum/general-paediatric-surgery/

Standards for Children and Young People in Emergency care settings
www.rcpch.ac.uk/emergencycare
Right Care Right Place First Time – intercollegiate statement on commissioning young people’s emergency care
http://www.rcpch.ac.uk/news/right-care-right-place-first-time


Getting it right for children and young people. A review by Professor Sir Ian Kennedy.

Managing the acutely ill child. James HA Cave.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2277104/

Every Child Matters

The Munro Review of Child Protection
http://www.education.gov.uk/munroreview/downloads/8875_DfE_Munro_Report_TAGGED.pdf

The Government Response to the Munro Review
http://www.education.gov.uk/munroreview/downloads/8875_DfE_Munro_Report_TAGGED.pdf

The Munro Review of Child Protection: Moving forward towards a child centred system

The Early Years: Foundations for life, health and learning
An Independent Report on the Early Years Foundation Stage to Her Majesty’s Government Dame Clare Tickell
http://media.education.gov.uk/MediaFiles/B/1/5/%7B15EFF0D-A4DF-4294-93A1-1E1B88C13F68%7DTickell%20review.pdf

The NHS Outcomes Framework 2012/13

Modelling the future I,II,III – Safe and sustainable integrated health services for infants, children and young people
http://www.rcpch.ac.uk/sites/default/files/MTFIIIDec09_0.pdf

NHS Institute for Innovation & Improvement (2010) Focus On: Children and Young People Emergency and Urgent Care
http://www.institute.nhs.uk/quality_and_value/high_volume_care/focus_on%3a_emergency_and_urgent_care_pathway.html

NHS Institute for Innovation & Improvement (2011) A whole system approach to improving emergency and urgent care guide.

NHS Institute for Innovation & Improvement (2010) Young People’s Emergency & Urgent Care Health & Social Care Lesson Plan

www.ukpics.org.uk/documents/PICS_standards.pdf