Welcome... from Paul Chumas, Chair of Safe and Sustainable’s Paediatric Neurosurgery Steering Group

It is my pleasure to introduce you to the latest newsletter about the Safe and Sustainable review of children’s neurosurgical services in England.

Thank you to everyone who participated in the workshops we held in November 2010 and shared their views. The valuable feedback we have gained - from both the workshops and the previous discussions we have had with parents, charity representatives and clinicians - continues to inform the review process.

The review team will seek further feedback from a range of stakeholders on the draft service standards and potential models of care.

We appreciate that some stakeholders may have concerns about what the review may mean for individuals and services going forward. While taking these concerns on board, I would urge you to continue to focus on the needs of the children and what will deliver the best outcomes for them in the future.

For all the latest news on the review visit our website: www.specialisedservices.nhs.uk/safeandsustainable
A number of important issues were raised at the 2009 stakeholder conference. The Models of Care Group was formed in response and has since focused on four key conditions that require children's neurosurgery. Their job: to review how children access the services they need, consider the available evidence and make recommendations for discussion. See page 3 for more details...

On page 6 you can read more about the centre visits that James Steers, retired neurosurgeon and past president of the Society of British Neurological Surgeons, and Sharon Stower, a senior children's nurse, nominated by the Royal College of Nursing, made to the children's neurosurgical centres...

... We want to gather as much information as possible about parents' experiences of current children's neurosurgical services. The centre visits included conversations with 44 families. See page 7 to read more and to see what Robert Hughes, Chairman of Anna's Hope, found when he listened to parents' views, opinions and concerns. In November, we also talked to parents about their views on the future of the service at a series of regional workshops...

...And engagement with a wide range of clinicians continues. In November over 200 clinicians gathered at a workshop focusing on children's neurosurgery and the linked services. See page 10 for a summary of the key topics covered at the workshop and some of the views and comments put forward...

Safe and Sustainable: what is it?

Safe and Sustainable is the name of this NHS review process. The aim is to identify the best way to organise children's neurosurgical services. What will deliver the best outcomes for children?

In future:
- care should be provided in line with national standards to ensure the service is high quality, safe and sustainable, and;
- centres will need to demonstrate compliance with the standards, which will be agreed by both professionals and commissioners (the people responsible for making decisions about services)

“It is clear that there is broad agreement on the need to seize the opportunity that the Safe and Sustainable review provides for addressing long-standing areas of concern and debate.”

James Steers and Sharon Stower, Report of the centre visits, September 2010
Your child’s care

Robert Hughes, Chairman of Anna’s Hope charity, is the patient and parent representative on the review’s Steering Group. He is also a lay representative on the Models of Care Group.

Anna’s Hope is a charity that provides support and rehabilitation to children and young people who have been diagnosed with a brain tumour.

“As a parent who has experienced first-hand the neurosurgical services on offer for children in this country, I have seen how important it is that parents and children are given consistent support and guidance throughout a difficult and extremely traumatic time for the whole family.

“The Models of Care Group was set up to first identify and then scrutinise the current and potential pathways and models of care for the four conditions that make up the majority of cases every year.

“In our work, we have considered many factors including the impact of the current network of care alongside cancer and trauma services; access; activity levels; staffing, and the patient and family experience. Part of our role is also to consider the need for 24/7 emergency services across the country, how patients are retrieved and transferred and the education and training of clinicians.

“We are using the evidence from our discussions with parents so far to inform our proposals on national standards and models of care. As the review continues we will keep listening to your views and feedback, which are vital in helping us to shape future services for our children.”

Robert Hughes, Chairman of Anna’s Hope charity

“ASBAH would support the principle of a 24/7 paediatric neurological service and would urge you to develop systems and guidelines that make this possible.”

Jackie Bland, Chief Executive of the Association for Spina Bifida and Hydrocephalus (ASBAH)
Who sits on the Models of Care Group?

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<thead>
<tr>
<th>Name</th>
<th>Title and Details</th>
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<tr>
<td>Teresa Moss (Chair)</td>
<td>Director of National Specialised Commissioning, NHS Specialised Services</td>
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<tr>
<td>Mr Paul Chumas</td>
<td>Consultant Paediatric Neurosurgeon, Leeds Teaching Hospitals NHS Trust</td>
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<tr>
<td>Professor Helen Cross</td>
<td>Consultant Paediatric Neurologist, Great Ormond Street Hospital for Children NHS Trust, and Head of Neurosciences Unit, UCL Institute of Child Health</td>
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<tr>
<td>Barbara Howe</td>
<td>Director of Specialised Commissioning, London Specialised Commissioning Group (SCG)</td>
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<td>Robert Hughes</td>
<td>Chairman, Anna's Hope</td>
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<td>Mr Andrew Kay</td>
<td>Consultant Neurosurgeon, Birmingham Children's Hospital NHS Foundation Trust</td>
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<td>Professor Colin Kennedy</td>
<td>Consultant Paediatric Neurologist, Southampton University Hospitals NHS Trust, and Professor in Neurology and Paediatrics, University of Southampton</td>
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<td>Dr Tom Kenny</td>
<td>Medical Adviser, NHS Specialised Services</td>
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<td>Mr Donald MacArthur</td>
<td>Consultant Neurosurgeon and Training Programme Director, Nottingham University Hospitals NHS Trust</td>
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<tr>
<td>Lindy May</td>
<td>Nurse, Great Ormond Street Hospital for Children NHS Trust</td>
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<tr>
<td>Dr Anthony Michalski</td>
<td>Consultant in Paediatric Oncology, Great Ormond Street Hospital for Children NHS Trust</td>
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<td>Mr James Palmer</td>
<td>Consultant Neurosurgeon, Plymouth Hospitals NHS Trust</td>
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<td>Mr Ian Pople</td>
<td>Consultant Paediatric Neurosurgeon, North Bristol NHS Trust</td>
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<td>Dr Brijender Rana</td>
<td>Consultant in Public Health, South East Coast Specialised Commissioning Group (SCG)</td>
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<td>Mr Owen Sparrow</td>
<td>Consultant Neurosurgeon, Southampton University Hospitals NHS Trust</td>
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<tr>
<td>Stephanie Stanwick</td>
<td>Programme Manager, NHS Specialised Services</td>
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<tr>
<td>Mr Dominic Thompson</td>
<td>Consultant Paediatric Neurosurgeon, Great Ormond Street Hospital for Children NHS Trust</td>
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<tr>
<td>Mr John Thorne</td>
<td>Consultant Neurosurgeon, Central Manchester University Hospitals NHS Foundation Trust</td>
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<td>Mr Philip van Hille</td>
<td>Consultant Neurosurgeon, Leeds Teaching Hospitals NHS Trust</td>
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<tr>
<td>Dr Amber Young</td>
<td>Consultant Paediatric Anaesthetist, North Bristol NHS Trust</td>
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We are grateful to both the individuals and professional bodies who have been involved in the work undertaken by the Models of Care Group and contributed to the process.
What are the four main conditions?

**Hydrocephalus**

Hydrocephalus is a condition where there is a build-up of fluid on the brain. The excess fluid can put pressure on the brain, which can damage it. The damage to the brain can result in a wide range of symptoms including:

- headache
- vomiting
- blurred vision
- difficulties walking

**Brain tumours**

A brain tumour is a growth of cells in the brain which multiply in an abnormal, uncontrollable way. There are two main types of brain tumour: malignant and benign.

Brain tumours are graded from 1 to 4 according to their behaviour, such as how fast they grow and how likely they are to spread.

A high-grade brain tumour - grade 3 or 4 - is malignant, which means it is cancerous and fast-growing. Malignant tumours invade other cells in the brain.

A benign brain tumour is a non-cancerous growth. It usually grows slowly in one place and does not invade other areas of the brain or spread to other parts of the body. It is an uncommon condition.

**Brain trauma**

A severe head injury can cause brain damage (referred to as brain trauma or brain injury). Even though the brain is protected by the skull, the surface of the brain can tear or bruise as it bumps against the skull. This can damage blood vessels and nerves.

These injuries can cause bleeding, blood clots or a build-up of fluid, which puts pressure on the brain. This can sometimes lead to brain trauma, which can be either temporary or permanent.

**Epilepsy**

Epilepsy is a condition that causes somebody to have repeated fits. The medical term for an epileptic fit is seizure.

Epilepsy is a relatively common condition, affecting around 456,000 people in the UK. Epilepsy usually begins during childhood, although it can start at any age. Around one in every 280 children is affected by epilepsy.

The cells in the brain, known as neurons, communicate with each other by using electrical impulses. During a seizure, the electrical impulses are disrupted, which can cause both the brain and the body to behave strangely.

Information sourced from NHS Choices website, November 2010

What is a child’s pathway?

A ‘pathway’ covers the whole treatment of a child’s neurosurgical condition over time - from diagnosis and treatment, to rehabilitation and aftercare.
Centre visits

In November 2009 the Society of British Neurological Surgeons (SBNS) agreed that visits be made to each provider of paediatric neurosurgery. The visits were carried out as a joint initiative by Safe and Sustainable and the SBNS. James Steers, retired neurosurgeon and past president of the SBNS, and Sharon Stower, a senior children’s nurse, nominated by the Royal College of Nursing, carried out the visits to each children’s neurosurgical centre.

Earlier in the year, each unit submitted detailed information about the service they provide. On each visit, James and Sharon were able to ask further questions and see the facilities first-hand, as well as talk to parents and staff, including clinicians from a range of disciplines.

What did they find?

- The ways in which centres are organised, both in terms of structure and staff, differs across the country. The services available, including access and support along the pathway for different conditions, can therefore vary considerably
- To improve children’s neurosurgical services for the future, 24/7 advice and support from a paediatric neurosurgeon needs to be readily available across a network of care
- High quality, effective, multi-disciplinary teams (MDTs) are crucial for a ‘world class’ service. MDTs are important for the whole pathway of care - from diagnosis, through to treatment and aftercare
- Rehabilitation in most areas is a significant concern: current rehabilitation services need urgent review
- Effective care arrangements are needed for children and young people moving to adult neurosurgical services
- The need for strong academic links and quality paediatric neurosurgical research and education
- Formally recognised training and education for staff working in neurosurgical teams.

The findings and data from the centre visits have fed into the review process.

“(The) visits highlight the different ways in which units are resourced both in terms of structure and personnel. There is no ‘perfect’ paediatric neurosurgical resource currently in the UK, hence the value of seeing ‘what works and what doesn’t’ to assist the …development of the service in the future to the benefit of neurosurgical children.”

James Steers and Sharon Stower, Report of the centre visits, September 2010

“The value of the visits was increased enormously by the excellent organisation and by all those who gave so freely of their time to help us with the understanding of the units - from the well completed visit template, the introductory meeting with the teams, through the tours of the unit and the mounds of documentation.”

James Steers and Sharon Stower, Report of the centre visits, September 2010

Parents’ point of view

What matters to parents?

Shock  Early diagnosis  Trust  Outcomes
Advice  Delays in treatment  Family impact
Car parking  Information  Quality  Communication
Distance  Child friendly environment  Rehabilitation
Accommodation  Qualified and skilled staff  Multi-disciplinary team
Open door access  Education

Alongside the work carried out on the centre visits, Safe and Sustainable also asked Robert Hughes, Chairman of Anna’s Hope, to gather parents’ views and experiences. His interviews with parents of children who have undergone neurosurgery provide valuable insights into how parents view the current service and what would make a difference.

What do parents say?

“I will go to our centre rather than go locally any day of the week. I feel confident in the staff. I know that if I pick the phone up any one of them will deal with my child.”

“I took my child into the local A&E and one nurse said: I can’t spell hydrocephalus let alone know what it is, you’d better take him somewhere else!”

“The nurses and...the neurosurgeons were brilliant. I was amazed by the ethos...the mission statement.”
What do parents say?

Robert’s interviews with parents uncovered a range of helpful observations, such as:

- **Delayed diagnosis**: parents commented that slow symptom recognition by GPs and local District General Hospitals (DGHs) often leads to a delay in diagnosis.
- **Having someone to talk to**: the majority of parents said that they lacked information about their child’s diagnosis and the journey they were about to embark upon, especially in the early stages.
- **How parents are treated**: many parents are in shock and fear for their child’s life. Open channels of communication are important so that questions and concerns can be heard.
- **The impact on the family**: the impact on the rest of the family should not be underestimated. Many issues were raised in this respect - from juggling day-to-day responsibilities, to travel and cost.
- **Lack of rehabilitation and specialist support**: the need for a range of support throughout the pathway was highlighted - parents mentioned how important it is to have a link between the paediatric neurosurgeons and the local teams providing care and support. Post treatment rehabilitation and support was emphasised as a particular issue. Examples of the support needed includes specialist liaison nurses, school support and access to clinical psychology for parents and their families.
- **Continuity of skills and care**: parents prefer to have a familiar team involved in their child’s care.
- **Information on the child**: many parents were keen for a ‘child’s file’ of written information. This could be used if visiting new hospitals or meeting new doctors. As well as saving time, this would ensure that there was clarity about the child and their treatment.

Our thanks go to all the parents who have taken the time to help us gather the information.


Robert continues to work closely with a selection of charities with an interest in children’s neurosurgical services. As the nominated patient representative on the Steering Group, Robert liaises with these charities regularly about issues raised and further news. Following a meeting with charities this summer, further meetings are scheduled for 2011.
The regional parent and charity workshops

We appreciate the fact that over 100 parents and charity representatives took the time to come and share experiences with us this November. Your contributions as parents are vital in helping us to shape future services.

A report on the workshops will be available on the website. The findings of the report will also be presented to the working groups of the Safe and Sustainable review team to inform their continuing work.

The workshops took place in London, Bristol, Southampton, Warrington, Leeds and Birmingham. Of course, we recognise that this does not cover all parents of children who have undergone neurosurgery – so please do get in touch if you would like to contribute to the review. Details of how to get in touch are on page 16.

Parents’ comments at the workshops

Here is a snapshot of parents’ comments:

“Her head was allowed to grow; no-one seemed to be doing anything. Then suddenly she had to have surgery. We knew it was a possibility but weren’t sure. After the surgery we felt ‘spat out’ of the hospital and left alone.”

“The co-ordination of the multi-disciplinary team (MDT) is so important – the surgeons and oncologists need to liaise and come to the parents with one diagnosis. At the moment, they don’t seem to have a discussion beforehand.”

“It’s difficult emotionally and exhausting when you have a child in hospital and have to try to balance that with your day-to-day life.”

“In terms of care, trust is very important. As parents we know our children best. All children act and react differently, so it’s important to feel that the ‘professionals’ trust your judgment and in turn you can trust them.”

“There need to be stronger voluntary support networks for both parents and children.”

“The facilities at specialist centres are not good enough - our minimum wish list would comprise books, a quiet room, a play room, a ‘bad news’ room.”

“My son needs physio to learn to walk but there is no rehab available to him. I would travel as far as needed if I could get him the right support.”

“I’m fed-up with having to repeat the same information to lots of different medical professionals all the time. I’ve therefore resorted to creating my own laminated document containing the most important information about my child’s condition, so that clinicians can find important information out at a glance.”

Read on to see how we shared some of the views from the parent workshops with clinicians.
Clinically-led process

Over 200 clinicians attended a workshop in November 2010. We are pleased that the delegates reflected the range of professionals involved in the care of children requiring neurosurgery, including: specialist nurses, anaesthetists, ambulance staff, neurosurgeons, paediatric neurologists, paediatric intensive care unit (PICU) staff, therapists, theatre staff, radiologists and oncologists.

What was the purpose of the workshop?

- To update clinical staff on progress and plans for the national review of paediatric neurosurgery in England
- To seek input and contributions to the development of the four draft care pathways: brain trauma; brain tumours; epilepsy; hydrocephalus
- To explore the implications for key professions of the potential changes to service provision

The Safe and Sustainable review team listened to a wide range of views, comments and opinions at the workshop. Children’s needs must be paramount. Clinicians told the conference that we need a world class paediatric neurosurgical service, including improvements for diagnosis and rehabilitation. But how does the NHS deliver that? Clinicians shared a range of strong views on how the service should be organised and delivered. Clinicians’ views will continue to inform the review process. In spring 2011, we will engage further on draft service standards and potential models of care.
The context and case for a review of paediatric neurosurgery

Professor Terence Stephenson, a practising paediatrician and President of the Royal College of Paediatrics & Child Health (RCPCH), opened the workshop reminding people that children are not small adults: they need appropriately tailored care.

Talking about the fact that most clinical staff already work in networks, he highlighted key issues, such as:

- The risk of not having appropriate cover out of hours and at weekends
- The increasing evidence that a certain volume of cases improves outcomes and training
- The fact that more staff and resources are not necessarily the solution to providing quality care
- The growing evidence that consultant-led care provides better quality services for patients - with fewer errors, more appropriate admissions and shorter waiting times in hospitals.

Aside from workforce and quality issues, Professor Stephenson spoke of the importance of measuring services by outcomes - what is the end result for the patient? - and not processes. Work is underway to develop outcome measures for children and these will tie in with the areas already identified by the Government: long term conditions, acute illness/ injury, patient experience (this includes parents), safety and mortality.

Encouraging clinicians to focus on the overall framework needed for the future development of services and clinical pathways, Professor Stephenson asked:

“What kind of service would you want for your child or grandchild if they were ill today? What does a quality, safe, sustainable service look like?”
Paul Chumas, Chair of the Steering Group, closed the morning session with his review of national and international evidence and experience. Over the past year the review team has been looking at the following data:

- Hydrocephalus – Shunt BPNG (British Paediatric Neurosurgical Group) data
- Brain tumours – Cancer Registry
- Brain trauma – PICANet (Paediatric Intensive Care Audit Network)

Taking into account the key elements of the review - whether services are safe, sustainable and world class - Mr Chumas suggested that safety is not currently a concern at any of the centres. He called for a debate around what the available evidence could tell us about safety, sustainability, outcomes and models of care.

Developing the care pathways

“We’re hugely supportive of the intention of the review, which is obviously to improve the care of children and families that require neurosurgical interventions. But we’re also concerned about the quality of the care and decision making before the neurosurgical episode and also the quality of the rehabilitation services after.”

Dr Simon Lenton, Consultant Paediatrician and Chair of BACCH (British Association for Community Child Health)

Professor Colin Kennedy, Consultant Paediatric Neurologist and Professor in Neurology and Paediatrics, addressing clinicians on behalf of a British Paediatric Neurology Association (BPNA), said:

“The views of paediatric neurologists on the ‘Safe and Sustainable Paediatric neurosurgery review’ has been mixed since the initial proposals for the revised model of care are seen by some as a threat to the overall delivery of care. The proposals for the standards of care, on the other hand, are, in most cases, seen as an opportunity to improve care. The... report [based on the centre visits] has been well received by paediatric neurologists who particularly welcome the emphasis on the central role of the multi-disciplinary team, the difficulties around rehabilitation and the barriers that current arrangements sometimes create for rehabilitation. There is a clear implication that children’s rehabilitation should be commissioned as a specialised service. This in turn opens up a more general discussion about how to move forward from the current model of specialist care for children with neurological problems.”
Ray Flux, facilitator for both the clinical workshop and the regional parent and charity workshops, shared some of the views from the recent parent workshops. He asked clinicians to consider how they might tackle some of the issues raised by parents.

**Parents wanted to know – how can we?**

- Help GPs to achieve earlier diagnosis of brain tumours
- Give difficult news skilfully and gently
- Ensure that GPs show more understanding and respect for parents making decisions about their child
- Offer information on the condition, its causes and effects; prognosis, treatment options and risks; available support – and at times and in ways that parents can use
- Develop care plans in discussion with parents
- Co-ordinate support for parents and children who have long periods in regional centres
- Organise prompt follow-up and support for parents at home
- Improve information transfer between regional and local clinical teams
- Develop passports to fast-track patients through local gatekeepers
- Develop parent-held electronic patient records
- Work with voluntary sector and other support groups.
What are the implications and opportunities of the proposed care pathways?

Opening the afternoon session, Anne Moore, President of the Society of British Neurological Surgeons, said that it is important that the network and the system works for all paediatric neurosurgical cases and covers all related conditions.

Referencing Paul Chumas’ earlier presentation on evidence and outcomes, she said that giving patients the best possible care is a top priority.

She went on to say: “However good the care is we currently provide, it is hard to argue a case against trying to improve it. We should all be trying to improve the care we give and we want to make it the best care in the world.”

Delegates tested out four draft care pathways and discussed: standards; networks; workforce; research, development and training. Here are some of the comments:

What standards and service improvements could be applied now?

- Data on patient outcomes should be collected centrally, routinely analysed and published
- Ensuring we have long term quality of life measures – especially for brain tumours
- Introducing a paediatric neurosurgical nurse specialist to all units
- Parents should have easy access to the ward

Improving rehabilitation services

A delegate said: “It’s great that rehabilitation has finally been recognised, but it’s a huge piece of work and we feel there should be a lot more interdisciplinary involvement. From a nursing and therapeutic point of view, we should have more of a say and an input.”

What could we do to improve networks now?

- Making it easier to share scans and images
- Ensure that there are clear protocols for the local area, including a central contact point
- Introduce patient (parent)-held information

Research, development and training

- Outcome data to be formally reviewed; also standardised data sets for international comparisons
- Create research networks; encourage more academic research
- Give more thought to training and revalidation; consider non-operative skills and support and mentoring for junior surgeons
Lessons and insights from the trauma network

Professor Keith Willett, National Clinical Director for Trauma Care, gave an overview of his review into trauma services. He spoke about the importance of networks based on patient needs, local expertise, geography, facilities and transport options.

The next phase of his review will consider how children’s trauma services could be networked. The Safe and Sustainable review team continues to work alongside Professor Willett’s team to ensure that any proposals developed take into account the objectives of both reviews.

Putting forward proposals on standards for children’s neurosurgical services, Professor Willett suggested that:

- Paediatric neurosurgery consultants should be available for the network 24/7
- A management plan for children with severe brain trauma should be in place within one hour of a CT (scan)
- Ongoing care of children with brain trauma should be in a paediatric neurosciences centre, irrespective of the need for surgery.

Professor Willett also spoke extensively about rehabilitation and noted his wish for every child to leave the trauma network with a ‘prescription for rehab’.

Summing up the workshop,

Teresa Moss, Director, National Specialised Commissioning, said:

“The Safe and Sustainable review is focusing on the whole package of care, not just neurosurgery. This is a review led by standards, with the firm objective of improving the quality of services. We must put children first and that means continuing to work with clinicians, but also listening to parents, families and the charities that support many of them.

“There is agreement on the need for 24/7 access to advice from a consultant paediatric neurosurgeon - something we are not able to deliver at the moment. We need to continue working with you to find out how we can move that forward and change in a pragmatic and safe way; this also applies to the other vital parts of the pathway, such as rehabilitation.”

“As the new President of the Society of British Neurological Surgeons, I look forward to working with colleagues on the NHS Safe and Sustainable team. The workshop reinforced the fact that there are tough decisions to be made about children’s neurosurgery - but these decisions are essential ones if we are to ensure that our neurosurgery and related services are fit for purpose for the children who will rely on them in the future.”

Anne Moore, President of the Society of British Neurological Surgeons
Review timeline

What’s already happened?

- An overview of current arrangements and services: James Steers and Sharon Stower
- Developed draft service standards: Standards Group
- Developed draft proposals for a national model of care (four care pathways): Models of Care Group
- Design priorities based on parents’ experience: Robert Hughes and Sharon Stower
- Tested out potential models of care at workshops with parents, charity representatives and clinicians (November 2010)

Key dates:

- 2011: Engagement with stakeholders - from staff working in children’s neurosurgery centres, to parents and charities supporting families - on draft service standards and potential models of care; formal assessment of centres
- 2012: Outcome of assessment visits; public consultation on any proposed service changes
- 2013: Decision early 2013

Staying in touch

For the latest news and information about Safe and Sustainable, please log on to www.specialisedservices.nhs.uk/safeandsustainable

We want to hear your views on the future of the national service. If you have any comments, views or suggestions, you can contact Stephanie Stanwick, Programme Manager for Safe and Sustainable Children’s Neurosurgery Programme:

- Email: Stephanie.Stanwick@nsct.nhs.uk
- Write to her at: NHS Specialised Services, 2nd floor, Southside, 105 Victoria Street, London SW1E 6QT
- Telephone 0207 932 3958 and ask to speak to Stephanie Stanwick

For further details about Safe and Sustainable go to: www.specialisedservices.nhs.uk

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