

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	170106S
Policy Title	Open fetal surgery to treat fetuses with open spina bifida
Accountable Commissioner	
Clinical Reference Group	Paediatric Neurosciences
Which stakeholders were contacted to be involved in policy development?	<ul style="list-style-type: none"> • NHS England Paediatric Neurosciences Spina Bifida Specification Working Group; • Paediatric Neurosciences CRG Members and Stakeholders; • Specialised women's Services CRG Members and Stakeholders; • Belfast Health and Social Care Trust; • British Association of Paediatric Medicine; • British Maternal Fetal Medicine Society; • British Paediatric Neurosurgery Group; • MMC Specification Working Group including SHINE Charity; • Neonatal Operational Delivery Networks – circulated to all in England; • Royal College of Midwives; • Royal College of Obstetricians and Gynaecologists; • Royal College of Obstetric Anaesthetists; • Royal College of Paediatrics and Child Health.
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	As above

<p>Which stakeholders have actually been involved?</p>	<p>Sixteen responses were received in total: Four clinicians responding as individual clinicians rather than in an organisational capacity. A patient and public voice representative from the Specialised Women’s Services Clinical Reference Group. A clinical representative of the Specialised Women’s Services CRG. Two clinicians who are members of the NHS England Spina Bifida specification Working Group: (i) King’s College Hospital (Neurosurgery Department; Fetal Medicine Unit; Department of Paediatrics) and Evelina/King’s Spina Bifida clinic and (ii) Consultant Neuroradiologist, The Portland Hospital; Hon Senior Lecturer, UCL Great Ormond Street Institute of Child Health; Member of NHS England Spina Bifida Specification Working Group. Birmingham Women’s & Children’s Hospital NHS Foundation Trust – joint clinician response. North Bristol NHS Trust British Academy of Childhood Disability British Maternal Fetal Medicine Society British Paediatric Neonatal Association. Children’s Hospitals Network, Oxford University and Southampton University Hospitals. Leeds Teaching Hospitals Trust University Hospitals Plymouth NHS Trust</p>
<p>Explain reason if there is any difference from previous question</p>	<p>Some consultees did not response to the consultation invite. The British Association of Paediatric Medicine asked for permission to share the draft specification with its members and followers via Twitter – but it was noted that this is more appropriate at public consultation stage as the range of comments could be from a wider group than members of the organisation.</p>
<p>Identify any particular stakeholder organisations that may be key to the policy development that you have approached that have yet to be engaged. Indicate why?</p>	<p>Not applicable (N/A)</p>
<p>How have</p>	<p>SHINE were represented on the Specification Working Group. The</p>

<p>stakeholders been involved? What engagement methods have been used?</p>	<p>Working Group held 1:1 stakeholder meetings, group teleconferences, and emailed draft documents for comment over a period of months.</p> <p>In addition, there were representatives from the Paediatric Neurosciences CRG and Specialised Women’s CRGs on the Specification Working Group and members of the CRG have commented on the document on two occasions.</p>
<p>What has happened or changed as a result of their input?</p>	<p>Comments were collated into a draft report, circulated to members of the NHS England Paediatric Neurosciences Spina Bifida Specification Working Group ‘the SWG’, including NHS England commissioners, for consideration and discussion on a joint teleconference.</p> <p>A number of additions and changes were made to the specification as a result. Where points made were outside the scope of the specification, this was also noted.</p> <p>The key changes made to the specification were:</p> <ul style="list-style-type: none"> i) that there should be “true co-location” of staff and facilities, with all specialities involved housed in same building and that fetal surgery should take place in a unit which has a Level 3 Neonatal intensive care unit on site; ii) that the service will be delivered in a shared care pathway together with existing local units / Regional Fetal Medicine Units and local maternity units; that good communication between the Fetal Surgery Centres and these units will be key to ensuring high quality care; it should be taken into account that there are some local experts who can support women as part of their care pathway; iii) that it is appropriate for service staff to note fetal surgery as part of discussions on options, on condition that (1) it is completely clear that it is only a possibility depending on meeting the criteria and (2) that potential negative outcomes are articulated at that point (e.g. there may be no improvement in the child’s condition, or even other complications resulting in other severe impairment (view of SHINE the patient charity); iv) that wording changes and wording additions should be made, such as being more explicit about the risks to the woman from uterine surgery; v) that current local and regional arrangements for pre and post-operative care will continue to apply; vi) that consideration should be given to the numbers of centres to be selected and current expertise (this will be taken into account as part of the provider selection process if the proposed service is approved for commissioning); vii) that individual circumstances should be taken into account when clinical discussions take place regarding whether inclusion/exclusion criteria have been met; viii) minor refinements to the inclusion/exclusion criteria;

	<p>ix) that there should be standardised and protocolised follow up, assessment and data capture (in Regional Units) as set out by the service until children are aged at least 18 – to support robust outcome monitoring and effectiveness of the surgery – the service will support this via clear clinical guidelines;</p> <p>x) the pathway should be simplified (actioned);</p> <p>xi) that arrangements for research and clinical governance should be set out at the same time that the service is developed.</p> <p>The key points made that were outside the scope of the specification concerned recommendations that the fetoscopic (laparoscopic) surgical approach should be permitted as an option for women as part of counselling discussions. It was noted that a separate policy application could be made to NHS England for that approach – which would include an evidence review of the available, published and peer-reviewed evidence base.</p>
<p>How are stakeholders being kept informed of progress with policy development as a result of their input?</p>	<p>Outcomes were published as part of the public consultation.</p>
<p>What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?</p>	<p>Half of the stakeholders considered 6 weeks to be appropriate and half 12 weeks. However, given the wide scope of comments already received, the Women and Children Programme of Care may wish to consider a different timescale and the likelihood of additional questions from other stakeholders which have not yet been put forward.</p>