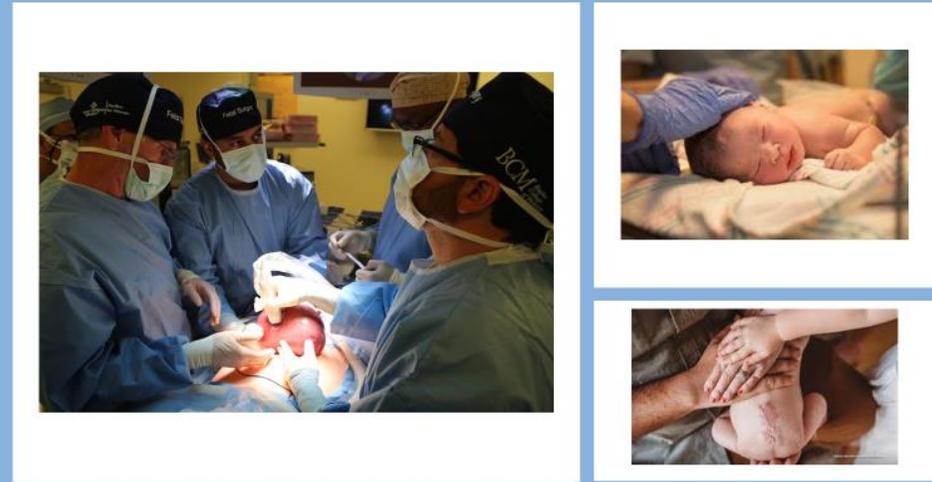
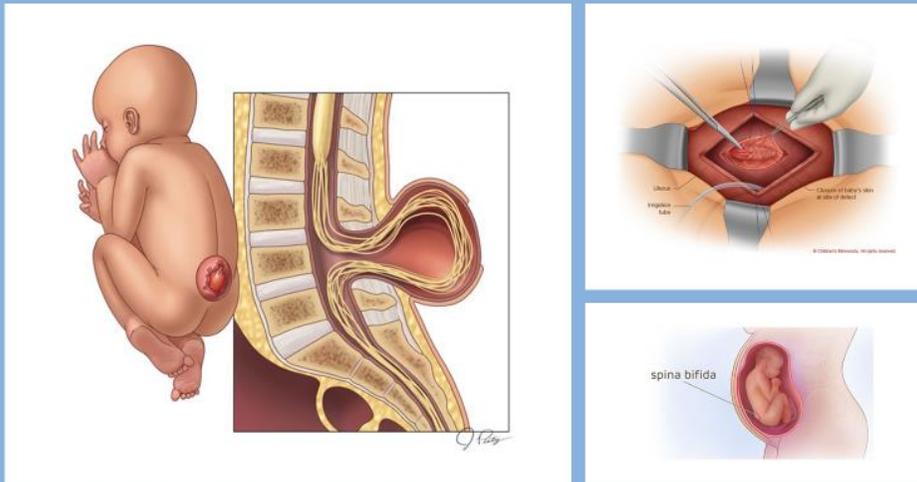


Appendix 1

Spina bifida and its wider impact

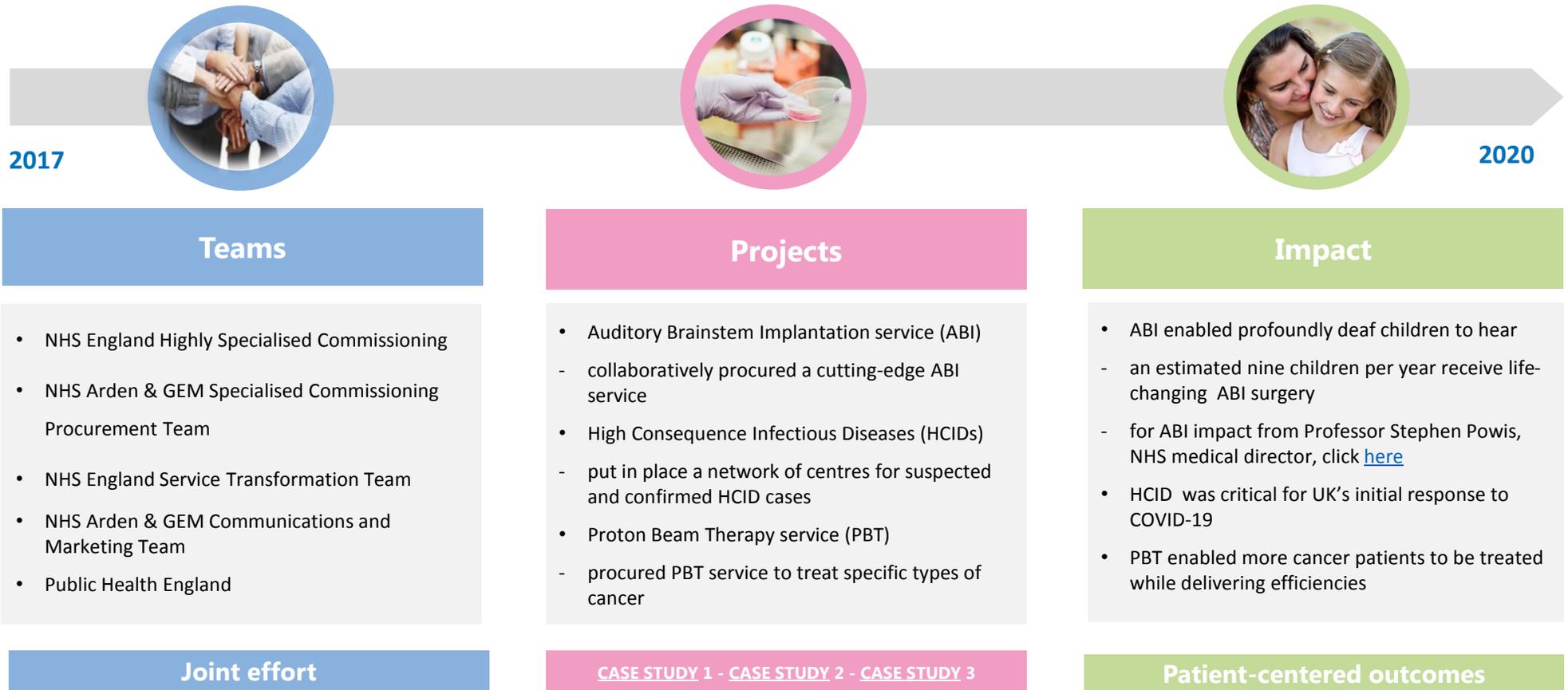
The surgery has a hugely positive impact on patients, families and the wider community



“The diagnosis of spina bifida has a serious and lifelong impact on a child and their family with physical, psychological and social implications. For a group of women, and their babies, open fetal surgery offers an effective and innovative treatment option.”

Dr Ayesha Ali, Public Health Medical Advisor for Highly Specialised Commissioning at NHS England

Sustained collaboration can unlock continuous improvement in the NHS



Underpinned by partnership working with internal and external experts, patients and patient representatives

Appendix 3

Carrie's story

"I had fetal surgery just over a year ago now at UCLH to repair the defect on my unborn babies spine. Max had L2-S5 myelomeningocele and we were told he had around a 20% chance of walking with aids, but would most likely have no movement or feeling from the waist down and be in a wheelchair full time. He would need a shunt and have bowel and bladder issues.

My local Fetal Medicine Unit (FMU) were extremely knowledgeable and offered a pioneering surgery at UCLH as one of the options for me and my baby. They did the amniocentesis to ensure there weren't other complications and referred me straight away. The hospital were in touch within 3 days and extremely helpful. They were able to reassure me, empathise with my concerns, point me in the direction of research and book me in for scans and a consultation the next week, where it was confirmed I was eligible for surgery and would be booked in for 25 weeks in London.

The FMU team at UCLH are outstanding and the high level of care I received from daily scans whilst admitted after the operation, to emails checking in, telephone calls if required and in depth follow up scans. I could not have wished to have been in better hands.

Max has absolutely thrived since surgery. His chiari II malformation reversed, the hydrocephalus levelled out and the fluid remained stable throughout my pregnancy. Max was born at 36 weeks at UCLH, only a few days away from my scheduled c-section. He came into the world kicking and screaming and hasn't stopped moving since. He has full feeling and movement all the way to his toes, the fluid on his brain has remained stable, so currently he hasn't gotten a shunt fitted and he has full control of his bladder and bowels. We don't know what Max's abilities would have been had we not had the surgery, but we know it absolutely gave him the best chance to thrive. He is now a 10 month old cheeky chappy, pulling himself up to standing, starting to take his first aided steps and crawling around the house faster than I can catch him.

We can not thank UCLH and their amazing team of specialist enough for the knowledge they gave us, the opportunities they have given Max and the support throughout what was an extremely difficult time."

Carrie – Parent of Max and surgery recipient



Appendix 4 Stakeholder feedback

“Congratulations on the successful completion of this important process. I enjoyed being part of this and think it was very well done.”

Clinical Lead

“The impact of this fetal surgery on the life of the patient cannot be overstated.”

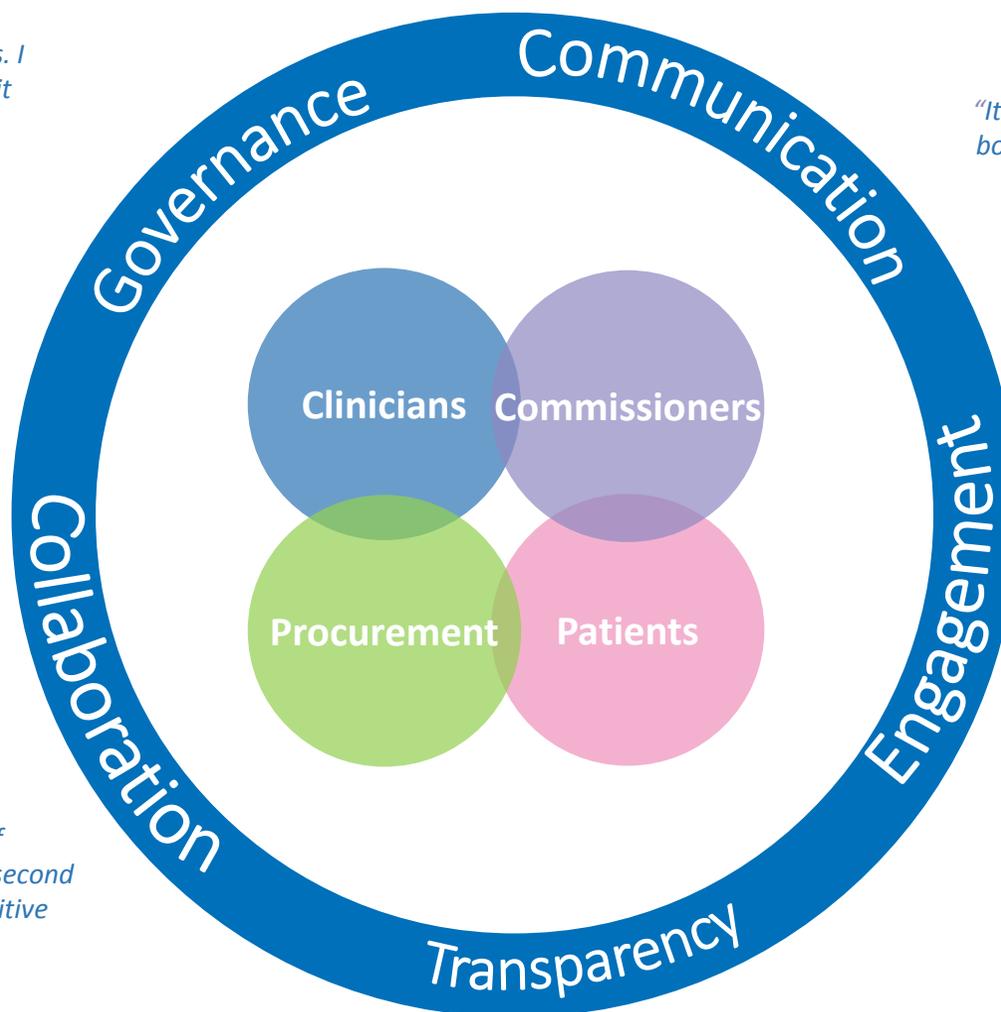
Clinical Lead

“Congratulations on a well steered piece of work. As this was my first procurement you have set the bar very high for your colleagues!”

Clinical Lead

“Really enjoyed being part of evaluation panel, it was my second for NHSE and was a very positive experience.”

Anonymous online survey



“It was an absolute pleasure to work with both Neli Garbuzanova and Bernie Stocks on this project. They were helpful and insightful throughout the process.”

Anonymous online survey

“More families will have greater information about fetal surgery, and more may have the option to undergo this procedure should they choose.”

Anonymous online survey

“Thank you for being very patient and supporting me through this procurement.”

Patient Representative

100% of survey respondents described the degree of collaboration between these stakeholder groups as ‘Good’ or ‘Excellent’.

“This was an important project for NHS England because it made available an evidence-based, ground-breaking intervention for women, improving the outcomes for their babies. It was a great collaborative effort from everyone involved in the project.”

Fiona Marley, Head of Highly Specialised Commissioning at NHS England

“The impact of this fetal surgery on the life of the patient cannot be overstated. The reduction in the rate of hydrocephalus, and the increase in the rate of independent ambulation are simply life changing.... in some cases, the difference between a life in a wheelchair and a life of independent movement.”

Dr Michael Belfort, Specialist in maternal-fetal medicine and fetal intervention

“Shine welcomes the NHS commissioning of the service as it provides an additional, quality assured pathway for families to explore as an option for treatment on diagnosis of an unborn baby with spina bifida, with the hope that health and life outcomes will be significantly improved for the baby after birth.”

Kate Steele, CEO at Shine Charity