Delivering better care for infants with brain injury: learning from the project

Key findings

- Significant improvements were made on all key performance indicators for neuroprotection:
- Age in minutes of baby at referral: there has been an overall reduction in the time taken for professionals to refer babies for transfer to cooling centres, 122 mins at baseline in 2009 compared to 85 mins in 2012.
- Age in minutes cooling started: reduced from 141 mins at baseline in 2009 to 30 mins in 2012.
- Age in minutes at target temperature, the key measure to judge whether babies are being cooled within the target time and therefore have the most effect long term outcome, shows a statistically significant reduction from 370 mins at baseline to 230 mins in 2012.
- Proportion of infants cooled within target of six hours rose from 36% at baseline to 91% in 2012.
- Proportion of infants with core temperature monitoring commenced at birth was zero at baseline and 100% in 2012.
- Instances of overcooling were 45% at baseline and zero in 2012.

41 babies were cooled within 6 hours that would otherwise have missed the therapeutic window. This means that at least five babies have been protected against long-term neurodisability (based on a trial showing 1 in 8 babies cooled within 6 hours will have a positive outcome).

This will result in societal cost savings of £26-£35m (based on the cost of looking after a severely disabled child as a result of HIE being estimated at £5-7m).

Successes

The team succeeded in establishing a regional neuroprotection care pathway for babies with HIE. They made good use of existing infrastructure by working with the regional Acute Neonatal Transfer Service, the national cooling database and radiologists.

The team negotiated the inclusion of cooled babies in the existing Commissioning for Quality and Innovation (CQUIN) payment for two year follow up on premature babies.

They also provided training to the clinical community in all 19 secondary care organisations in the region. Contrary to received opinion, that doctors need to be trained by doctors and nurses by nurses, they found in practice that clinical nurse specialists could successfully train both professional groups.

The team succeeded in bringing together the neonatal and radiology communities to agree a standard protocol.

They established family coffee mornings where parents of children with HIE could share experiences and produced a family booklet and a website where parents could obtain reliable information.

They developed a business case and succeeded in securing funding for one clinical nurse specialist post (plus administrative support) to sustain the work long term.

Strong support from consultants at all three tertiary centres was critical for the success of this project.

Challenges

The fact that HIE occurs infrequently (1-2 per 1,000 live births) made it difficult to employ some common quality improvement techniques, such as Plan-Do-Study-Act. It also meant there was little pre-knowledge among the units they were training.

It was difficult to make a cost benefit argument because no specific budget would feel the benefits.

Due to staff turnover in units (a regularly changing and rotating workforce of over 600 doctors and 700 nurses) it was necessary to be more repetitive in training (repeating key messages) than initially planned. It was important to recap the basics so that key knowledge was retained.

When talking about quality improvement techniques, they met resistance from colleagues more accustomed to traditional scientific research models and had to explain and ‘sell’ the purpose of the different methodology.

Engagement with families was delayed due to issues over ethical approval and they would have preferred to start that work earlier.

Advice to others doing similar projects

- Engagement with families needs to happen at an earlier stage.
- Factor in and plan for the need to do repetitive training due to shift patterns and changing workforce.
- A key, early decision that the team made was to shift their focus from the provision and coordination of care to one of providing supervision, guidance, planning and infrastructure. This would ensure a service would be established that would be sustainable after the end of the project.

More information about this project

For more information, visit the project website: www.BeBoP.nhs.uk