



## Closing the Gap through Clinical Communities

### **Final Report – Guidance for Award holders**

This report is your opportunity to report back on the outcomes and the story of your project. It will form a vital part of the learning that The Health Foundation aims to capture and share through this programme.

In order to capture the information needed in the report we have put together this template. It will help you formulate all of the reports and achieve consistency.

The final deadline for submission of completed reports 10 January 2012. .Please send your completed reports to Nicola Griffiths [nicola.griffiths@berkshire.co.uk](mailto:nicola.griffiths@berkshire.co.uk)

The style of your report should be clear, concise and written in plain English. A useful guide to writing reports in plain English is available here:

<http://www.plainenglish.co.uk/files/reportsguide.pdf>

You should assume that you are writing for the person with no prior knowledge of your project. Please explain any technical terminology and acronyms.

The Health Foundation is very interested in award holders using narrative to describe the experiences of the projects, particularly highlighting the successes and challenges. It is perfectly acceptable to provide this narrative in the first person (using “I” or “we”).

Please use graphs, run charts, pictures and other media we believe this really helps in to tell your story. Where you use tables, graphs or charts, please also include an explanation of their content and relevance.

As you suggested we have included guidance on the number of words. This is guidance – you can write more or less!

## **Final Report for Closing the Gap through Clinical Communities (award holders)**

### **Project Title:**

Neuroprotection in the newborn infant: Improving the quality of care of infants suffering from hypoxic-ischaemic brain injury in the East of England.

### **Lead Organisation**

Cambridge University Hospitals NHS Foundation Trust

### **Partner organisations**

East of England Perinatal Network.

### **Lead Clinician**

Dr Topun Austin

### **Abstract:**

Hypoxic-ischaemic encephalopathy (HIE) occurs in infants born at term that have had a critical shortage of blood flow and oxygen to the brain. It is a devastating condition associated with a high mortality rate; survivors have a high risk of developing lifelong neurodevelopmental problems resulting in an enormous physical, psychological and financial burden for the patient, their families and wider society.

Until recently there was no specific treatment for babies born with HIE, however it has now been shown that cooling the baby by a few degrees for 72 hours after birth can prevent associated brain injury in a significant number of infants. As this treatment has moved from research to clinical practice we needed to ensure that all eligible infants receive the treatment in a timely manner, as failure to do so could result in infants not getting the optimal treatment, with potential lifelong consequences.

The East of England Neuroprotection Team set out in January 2010 to improve the quality of care delivered to these very vulnerable babies through developing a coordinated and family centred approach to neonatal Neuroprotection within the region. The principal approaches that we have used to meet this goal are:

- To engage with families around the region and learn from their experiences by collecting stories and taking improvement ideas to them for discussion
- To select key measures and collect data that would be indicative of progress
- To engage with clinical staff throughout the region to find out about their practice and understanding of HIE prior to the project, and to work with them in the development of new pathways and training materials
- To deliver a varied and tailored training programme throughout the region, aimed at all levels of clinical staff.

- To embark on a rigorous communication exercise with clinical staff, commissioners and managers outlining the needs of the patient group and their families.

## 1.1 The Quality Challenge Background Knowledge

Despite improvements in obstetric and neonatal care over the past 30 years, neonatal encephalopathy is a significant cause of long term neurodisability. The incidence of HIE is around 2/1000 live births (*Evans et al., J Obstet Gynecol 2001;21:114-20*). Between 10-15% of encephalopathic infants die in the neonatal period and of those who survive, between 10-15% will go onto develop cerebral palsy. Surviving infants are also at high risk of developing other neurodevelopmental problems, including learning difficulties, behavioral problems and autism (*van Handel et al., Eur J Pediatr 2007;166:645-54*).

Until recently the acute management of these infants has been largely supportive, with the aim of optimizing organ function to minimize further damage. Evidence has emerged in recent years of the therapeutic benefit of mild whole body hypothermia in preventing long term neurodevelopmental problems (*Gunn et al., Pediatrics 1998;102:885-92*). This involves actively cooling the infant, using specialized mattresses or wraps, from 37 to 33°C as soon as possible after birth for 72 hours before slowly rewarming back to normal temperature. The earlier the treatment is initiated the more likely it is to be beneficial: all the main clinical trials enrolled infants within 6 hours of life and evidence from the largest trial, the TOBY study, suggested that treatment may be more beneficial the earlier it is commenced (non-significant trend) (*Azzopardi, NEJM, 2009*)

Appropriate identification of a baby eligible for cooling requires staff to be aware of a range of different factors or symptoms, which can present in a number of different combinations. There is a basic minimum of factors that must be in place for a baby to be appropriately cooled, which are outlined in the 'do you need to cool' decision pathway on the front cover of the Neuroprotection Care Pathway 1 (Appendix 5)

In the early stages of the project we undertook a study of all 19 units within the East of England, in an attempt to understand the incidence and current variation in practice relating to neuroprotection and preparedness across the region for providing therapeutic hypothermia treatment. The full summary of the survey can be seen in Appendix 1, however some of the most important findings were as follows:

- Only four of the 19 units were able to monitor core (rectal) temperature; the most reliable method for monitoring temperature whilst cooling as recommended by the British Association of Perinatal Medicine (BAPM) and NICE.
- There was wide variation across the region in uptake or availability of cooling protocols.
- Not one unit across the region was able to provide any written information to parents relating specifically to HIE.
- Varying use of hospice support.
- Wide variation in MRI scanning practice across the region, as well as reporting capabilities.

We undertook a similar but much less formal exercise with families to gauge their feelings about the way they were dealt with whilst their baby was receiving treatment for HIE and after discharge. Feedback has been varied, however one theme came up time and time again: communication. Parents frequently felt that information wasn't available to them in a way that they found easy to understand.

Other themes that arose from speaking to families about their experience were as follows:

- Not feeling prepared for discharge, and having little understanding of what would happen next.
- Frustration at the lack of information on the long term picture for their child.
- Where a baby had to be transferred for care at another hospital, some mothers were not getting their post-natal care transferred effectively.
- A residual fear each day that something might go wrong, with parents feeling the need to be continuously on the lookout for symptoms of deterioration. This resulted in some families feeling that they had lost out on the enjoyment of their child's early stages.
- Families felt that at times they were not given enough hope, and only had the worst case scenario painted for them.

Unfortunately, some of the issues families really struggled with cannot be changed. It is simply not possible for example to give families the long term picture that they so desperately want early on. Nevertheless, we still felt that it was important to collect parent's views on these issues, as at the very least we can help to make clinical staff more sensitive to their insecurities or needs.

## **1.2 Local Problem and context**

### **Regional setting:**

The project covers infants born with HIE across the whole of the East of England. Within the region there are 19 secondary care organisations (18 NHS acute hospitals and 1 military hospital attached to Lakenheath US Air Force Base.) Three of the hospitals within the region are specialist tertiary centres where these babies will ultimately need to be treated. The geographic size of the region is considerable, which in itself has presented unique challenges to this project.

We have been fortunate to be working within a region that has a very well established perinatal network in place. The network has a strong specialist commissioning presence, as well as good support from the clinical community. The Network has been supportive of the project throughout, and has helped us to achieve our aims through introducing CQUIN (Commissioning for Quality and Innovation) targets in line with our key performance indicators and in supporting us in the development and roll out of clinical pathways.

The region is also supported by ANTS (the Acute Neonatal Transfer Service), a specialist neonatal ambulance service that manages and executes transfers within the region. The project team established links with ANTS early on in the project, as they are integral to the development and implementation of regional pathways. They have also

been supportive in allowing us to access their activity data from around the region, thus negating the need for us to go to each Trust individually.



### **Time critical transfers:**

The treatment of HIE is time critical, with optimum treatment requiring the baby to be at target temperature within 6 hours of birth. The occurrence of HIE in the newborn is more often than not an unexpected event in the last moments of labour and so staff need to know how to respond quickly, effectively and above all safely.

As soon as a baby is delivered it must be assessed and, if outside of one of the tertiary centres, referred for emergency transfer. The region is covered by the Acute Neonatal Transfer Service (ANTS), who have specially equipped ambulances to transfer a baby to a tertiary centre. On average, a baby is eight hours and thirty two minutes of age by the time it arrives at a tertiary centre for cooling, and so the referring unit and transfer team must begin cooling prior to their arrival if the baby is to receive treatment within the optimum window of 6 hours.

### **1.3 Intended Improvement**

A high quality clinical service for neonatal neuroprotection can be summarised as a ‘seamless patient journey from birth to long term follow up’. The management of a baby with HIE is complex from the moment of birth through to discharge home and provision of specialist long-term support services if required. While the introduction of new treatments offers a real hope that the burden of disability could be reduced it also raised new challenges for successful implementation.

We sought to improve the clinical quality of service in the five areas outlined below, with the expectation that the interventions described would lead to quantifiable changes in clinical quality in terms of process, outcomes utilisation and structure:

- 1) Resuscitation, stabilisation and early identification of infants with HIE** - We aimed to provide comprehensive training to all relevant healthcare professionals across the East of England in advanced resuscitation and early identification of the

infant with HIE. Training was to be backed up by the development of clear guidelines for the early referral of these infants for neuroprotective management.

*Quality improvement:*

- all healthcare professionals competent at the resuscitation and early management of these infants including structured neurological and electrophysiological assessment.
- all eligible infants referred to specialist centres.
- appropriate structure in place for early and expedient referral of these infants.

**2) Neuroprotection** - We set out to provide comprehensive training and guidelines as to the early management of an infant with HIE, prior to transfer to a regional centre for cooling therapy. We also strove to facilitate the training of cooling and use of cooling equipment at the designated centres where appropriate.

*Quality improvement:*

- regional standards of cooling (maintenance of temperature, complications, management of outliers) in line or above national standards recorded by the TOBY register. The TOBY register is a national register of all cooled babies.
- ultimately improved outcome measures for babies receiving hypothermic neuroprotection.

**3) Neuroimaging:** By coordinating the assessment and follow up of these infants our aim was to ensure that they all receive consistent and thorough investigation, including appropriate neuroimaging, enlisting the support of specialists in neonatal neuroimaging to provide support and training where necessary.

*Quality improvement:*

- all eligible infants receive comprehensive and timely investigation.
- standardisation of neuroreporting across the region.

**4) Neurodevelopmental follow up** - The neurodevelopmental coordinator was to work closely with local hospitals, community services and families to ensure that they receive comprehensive neurodevelopmental assessment and follow up, including a structured neurodevelopmental assessment at 2 years of age.

*Quality improvement:*

- all infants to be followed up at appropriate ages.
- improved follow up and early access to specialist services.
- ultimately improve clinical outcomes for these children, although this will be difficult to demonstrate in the lifetime of the award.

**5) Family centred care:** The birth of a baby with HIE is always a devastating event for the whole family who up until this point were eagerly anticipating the arrival of a normal healthy baby. At the start of the project we aimed to evaluate the existing quality of care through engaging with parents who have had babies with HIE and evaluating their experience of immediate and longer term care.

*Quality improvement:*

- A support network to be established for families that have had babies with HIE.
- Improvements to be made in future family engagement through acting on the feedback from families that have already gone through it.

As the project has developed, the methods that we have used to achieve our aims have changed, as outlined in section 1.4.

## **1.4 Changes along the way**

Although the core aims of the project have remained constant, the means by which we have been able to deliver them and the role of the project team has undergone some change. The primary change was one of shifting focus between taking a role in the provision and coordination of care across the region, to one of providing supervision, guidance, planning and infrastructure. The reason for this change was for future sustainability- it would not have been appropriate for the project team to have taken a role in coordinating infants care when we knew that in April 2012 we would be drawing the project to a close. We realised that if we were to leave something behind that would be of long term benefit to patients and clinical staff we would need to think less about providing any level of care ourselves, and more about facilitating others to do so.

The main functions that were part of the original bid, which for the above reason we scaled back on, were:

- *The project team did not take a role in finding emergency cots for transfer throughout the region of cooling babies.* Instead we liaised with the Emergency Bed Service, a 24hour and sustained service, to ensure that they had the necessary information and protocols to allow them to perform this function.
- *The project team did not take a role in coordinating follow up appointments for infants.* Instead we negotiated with the network that they would expand their existing regional target (CQUIN) for two year follow up on premature babies to include all cooled babies. This will mean that if trusts fail to perform a two year neurodevelopment assessment on infants that have been cooled they will incur a financial penalty.

## **2. Methods**

### **2.1 The Intervention**

#### **Describe the intervention you used and its component parts.**

We have used the previously mentioned five strands of the project to break down interventions used:

##### **1) Resuscitation, stabilisation and early identification of infants with HIE**

- Training: In order for clinical staff to treat HIE babies appropriately, and identify them quickly, training has been crucial. Training packages were developed through working with early adopter units, and were continually reviewed through attendee feedback. Training was carried out mainly by the Clinical Nurse Specialists on the team through on site visits to each of the units. The aim was that each unit would be visited every 3-4 months, and so the message would be repeated regularly. With ever changing staff and relatively few cases being seen by staff, we found that we needed to repeat the key messages often for them to sink in.

- Posters & laminated reminders: A poster, entitled 'Do you need to cool?', was circulated throughout all units giving them a simple set of options to work through, guiding towards whether cooling is appropriate (appendix 2). We also developed laminated reminder pages for staff to access in an emergency (appendix 3). This intervention was started because we found it difficult to get face to face time with some staff, and that without the benefit of regular practice staff were finding that they could sometimes forget the basics. The laminates were a way of us getting across the most pertinent facts to all staff, enabling them to provide the bare essentials of care.
- Debriefs: The debriefs involved looking at cases that have occurred on the unit and assessing whether appropriate decisions were made and treatment given. We found it very powerful to go into a unit to discuss a case that had not gone very well. This often provided evidence to unit managers of the gaps in the staff's knowledge and experience. (appendix 4).

## **2) Neuroprotection**

- Training: As above in section 2.1.1 Resuscitation, stabilisation and early identification of infants with HIE.
- Care pathways: Neuroprotection Care Pathway (NCP) documents (appendices 5, 6 & 7) were designed and circulated across the region, helping clinical staff with process and treatment at different stages of the pathway. There was no standard pathway documentation prior to the project, and so this was an important outcome. We tested a number of different approaches to paperwork for babies with HIE, before settling on a hybrid between checklist and a clinical document.
- Debriefs: As above in section 2.1.1 Debriefs
- Guidelines: The production of guidelines has helped to underline standard practice throughout the region. Although these do not make processes work in themselves, they are an important aspect of working with so many units across a large region. They have helped to ensure that everyone is signed up to and providing the same clinical care to HIE babies across the East of England.

## **3) Neuroimaging**

- Neuroimaging working group: This group has neonatal and radiology representation from the three tertiary hospitals within the region, with the task of agreeing standard imaging protocol and guidelines for the region and establishing a process of training and development for radiologists.
- Quarterly neurology videoconferences: With representation from radiologists across the three centres this multidisciplinary group is an outcome from the neuroimaging working group. As a forum for discussing some of the less straightforward cases across the region, this is a really great way of sharing knowledge between sites. All aspects of the case are discussed from resuscitation and identification through to clinical management, investigations, test results, MRI scans and follow up outcomes. There is the ability to view scans across sites so that radiologists can point any anomalies or learning points out to their colleagues.

- Training: A course was arranged for radiologists from the tertiary centres, run by the UK's leading specialist in perinatal MRI, with a specific emphasis on the interpretation of MRIs for infants with HIE.
- Audit: A local audit was performed to assess the accuracy of reporting of MRI scans in neonates with HIE across the three tertiary centres. The results to this audit showed some discrepancy in reporting skill across the region, and highlighted the need to continue to double report in some areas until radiologists were experienced to a necessary level.

#### **4) Neurodevelopmental follow up:**

- CQUIN: As mentioned in section 1.4, we realised early on that the project could have little influence over follow up practice across the region; although we could advocate best practice, we were forced to acknowledge that if carrying out best practice would require hospital investment we could not mandate that this be done. Instead, we went down the route of working with the network to extend their already existing commissioning for quality and innovation in healthcare target (CQUIN) to cover two year follow up of all cooled babies.
- Audit of whether follow up is happening: We are only now getting to the point at which babies from the start of the project should be receiving their two year follow up appointments, and we have agreement from the Network that they will track performance on our behalf against this measure.
- Six week follow up audit: We have carried out an audit (Appendices 8&9) to see whether, for families transferred to cooling at a tertiary centre, it is of benefit for the parents to come back to the cooling centre for a 6 week follow up after discharge. Previously these families have been followed up solely at their local hospital however there was some concern that they were missing out on important information from their stay at the cooling centre. Results to the audit can be seen in appendix 25 and following presentation of these results it was decided by the network that the appointments were of benefit to patients and so the two other NICUs in the region were asked to roll out this practice.

#### **5) Family centred care:**

- Interviews with families: We met with a number of families to gain qualitative appreciation of the experiences that they had gone through and identify areas for improvements. Families were given help to write their stories if they wished to share them with others. We decided to go with this less formal method of interviewing families rather than a questionnaire, because we felt that the data we were able to collect was richer due to the fact that we were able to have discussions with families.
- Family coffee mornings: Families that have had their babies cooled have all been invited to coffee mornings, throughout the region, so that they can meet other families and have fun with their children. These coffee mornings were in response to families frequently telling us that on discharge from hospital they felt very alone, and that unlike some other children's conditions they had never seen anything that focused on HIE. When we got families together, most had never seen or met another

child that had been cooled before and so they were very eager to share their stories with one another.

- Family information booklet: Following feedback from families that they wished they had been given some written information to take away and share with their family about HIE we wrote a booklet which is now available nationally via the charity BLISS - appendix 10.
- Website: A website has been developed, with a distinct area for families, enabling them to access the booklet in electronic format as well as reading families stories and finding useful support networks available ([www.bebop.nhs.uk](http://www.bebop.nhs.uk)).

## 2.2 Measurement

### How did you measure the impact and outcomes of your project in terms of improved quality to care.

Our key performance indicators are as follows:

1. Age in minutes of baby at referral
2. Age in minutes cooling started
3. Age in minutes at target temperature
4. Proportion of infants cooled within target of 6 hours
5. Proportion of infants with core temperature monitoring commenced at birth
6. Instances of overcooling

This data was collected via ANTS, who are involved in the transfers of these babies and so in a position to collect this data on our behalf. The data was displayed in run-chart format where appropriate or tables and fed back to the region via the newsletter and regular training sessions.

In addition to this we also monitored, for each unit, the numbers of HIE cases referred for cooling against the baseline number of live births so that we could ensure that units were in line with the expected 1-2 per 1,000 births. It was recognised early on that the project team were in a unique position to be able to spot discrepancies in HIE rates throughout the region and feed these back to units as necessary. Unfortunately, it is impossible to say whether *all* cases of HIE have been identified and treated, as if they do not receive cooling treatment they may well stay within their birth hospital, and so will not be flagged up to the Acute Neonatal Transfer Service as a referral. We can however use the 1-2 cases per 1,000 births as a guide, and have noted that the performance against this measure has gone from 0.56 cases per 1,000 births (below what would be expected) in our benchmarking period to 1.2 per 1,000 in the last 6 month period. This figure sits within the expected rates, and is the best guide we have that a more appropriate number of cases are being identified.

More qualitative data was collected from families, and recorded as stories or quotes to share via the information booklet and website (appendix 11). We also used training sessions to give quotes and read stories from parents to clinical staff.

## Results

### 3.1 Outcomes

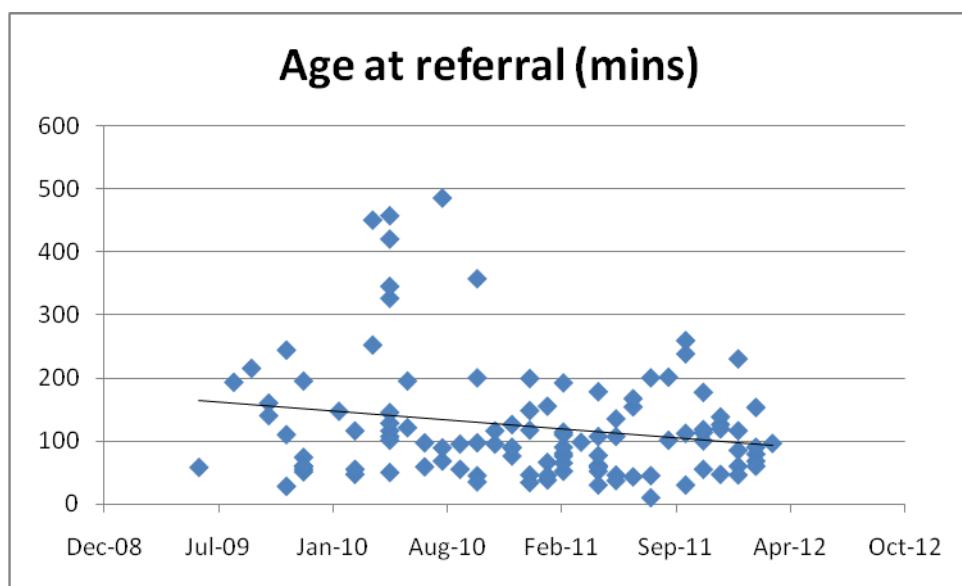
Our baselines data for our key performance indicators was as follows:

<b>Measure</b>	<b>Baseline</b>
Age at referral for cooling (mins)	122 (28-379)
Age cooling started (mins)	141 mins (4 – 379)
Age at target temperature (mins)	370 mins (225 - 520)
Cooled within optimum 6hrs	36% (4/12)
Appropriate temperature monitoring	0% (0/12)
Incidents of overcooling	45% (32, 32.6, 32.9, 33.2, 33.7)

Below, we have taken each of these measures in turn, explained its significance and outlined the improvement results throughout the project.

### 1. Age at referral for cooling:

As mentioned previously, the treatment of HIE requires fast identification and action. The clock starts ticking as soon as the baby is born, and so every minute that goes by without a baby being identified for cooling is a minute lost in their treatment. We selected the measure of the age of referral because it is the best indicator that we could access of the age at which a baby was identified for cooling. This is because as soon as possible once a unit is aware they have a baby for cooling, they need to refer them for transfer.



**Graph 1. Time to referral (mins)**

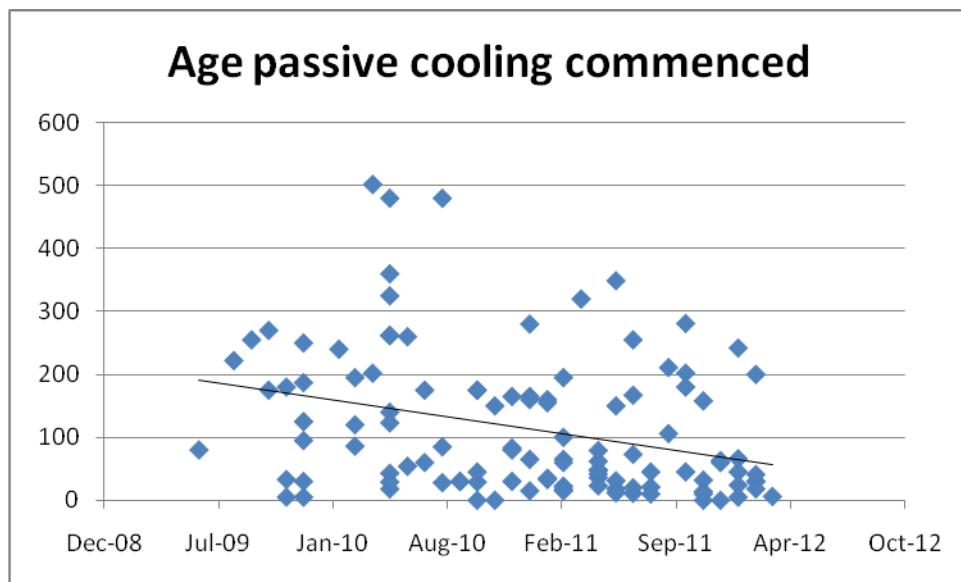
As you can see from Graph 1, there has been a trend towards quicker identification of HIE. In tabular form this can be seen as:

<b>Measure</b>	<b>Baseline (Oct – Dec 09)</b>	<b>Period 1 (Jan – Jun 10)</b>	<b>Period 2 (Jul – Dec 10)</b>	<b>Period 3 (Jan – Jun 11)</b>	<b>Period 4 (Jul – Dec 11)</b>	<b>Period 5 (Jan – Mar 12)</b>
Age at referral (mins)	122 (28-379)	136 (47 – 457)	95 (35 – 485)	71 (30 – 199)	112 (10 – 259)	85 (46 – 203)

We have been encouraged to see an overall reduction in the time that it is taking for professionals to refer babies for transfer to a cooling centre. We have seen a steeper decrease in the age that babies are having their cooling treatment started (see below) because more units seem to be starting to cooling at the resuscitation point and then referring afterwards.

## 2. Age cooling started (mins)

We decided to collect this measure as it is also indicative of how soon after birth babies are being identified as HIE.



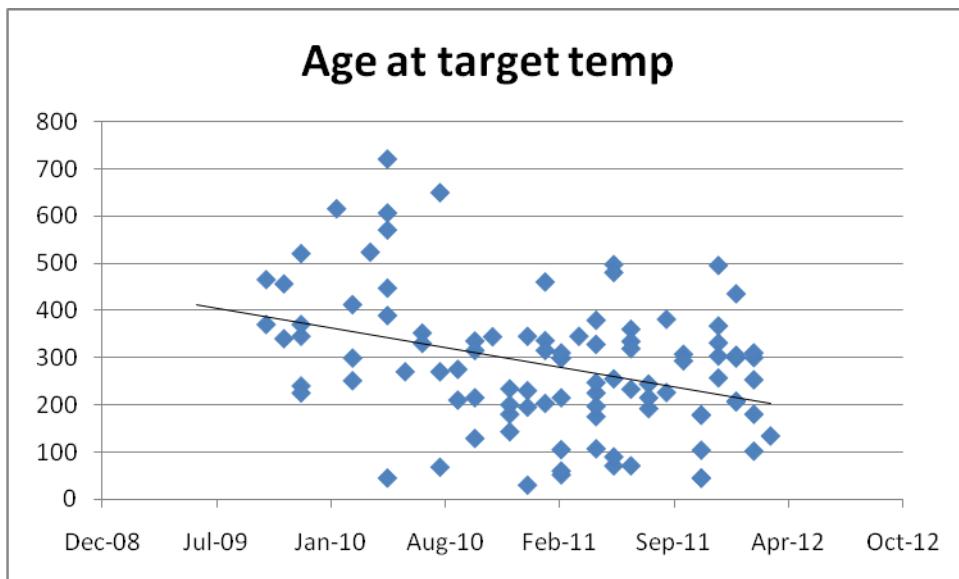
**Graph 2. Age cooling started (mins)**

Measure	Baseline (Oct – Dec 09)	Period 1 (Jan – Jun 10)	Period 2 (Jul – Dec 10)	Period 3 (Jan – Jun 11)	Period 4 (Jul – Dec 11)	Period 5 (Jan – Mar 12)
Age cooling started (mins)	141 (4 – 379)	221 (18 – 502)	52 (0 – 480)	48 (12 – 350)	48 (0 – 211)	30 (5 – 242)

We are seeing a larger proportion of babies starting to be cooled at birth- this is where one of the nurses or doctors turns the heat off whilst the baby is being resuscitated. This shows that cooling is very much at the forefront of people's minds, even in the height of a crisis. The original process across the region was to only start cooling after the referral had been made and a cot found at a tertiary centre, whereas now cooling is started before a cot has been found. Therefore we are now seeing more babies having their cooling started before the referral is made, which is a much more efficient process and is helping to have an impact on the time to target temperature measure.

## 3. Age at target temperature

This is probably one of the most vital of the measures that we collect, as it enables us to record how many of the babies within the region are being cooled within the target window of six hours. This is the factor that will have most effect on long term outcome.



**Graph 2. Time to target temperature (mins)**

Measure	Baseline (Oct – Dec 09)	Period 1 (Jan – Jun 10)	Period 2 (Jul – Dec 10)	Period 3 (Jan – Jun 11)	Period 4 (Jul – Dec 11)	Period 5 (Jan – Mar 12)
Age at target temp (mins)	370 (225 – 520)	429 (45 – 720)	270 (60 – 649)	215 (52 – 460)	219 (45 – 381)	230 (103 – 310)

We have seen a statistically significant reduction in the time it is taking for infants to reach target temperature.

#### 4. Cooled within 6 hours:

All the clinical trials started cooling within 6 hours of life and there is good experimental evidence that the earlier cooling is started the more effective it is. Therefore we decided to report on how many babies were falling into this bracket as well as the absolute age in minutes shown above.

Measure	Baseline (Oct – Dec 09)	Period 1 (Jan – Jun 10)	Period 2 (Jul – Dec 10)	Period 3 (Jan – Jun 11)	Period 4 (Jul – Dec 11)	Period 5 (Jan – Mar 12)
Target temp within 6 hours	36% (4/11)	24% (4/17)	88% (15/17)	76% (25/33)	100% (21/21)	91%* (10/11)

\* The baby that fell outside of the 6hr target was appropriate, because there were questions over its eligibility for cooling.

Evidence has shown that the number needed to treat effectively with cooling in order to prevent one case of long term disability is 8. Through improvements in performance

throughout periods 2, 3, 4 and 5, 41 babies were cooled within six hours that otherwise would have missed the therapeutic window and so it is reasonable to assume that at least 5 of these would have gone on to develop long term disability, which has now been avoided. As well as being a great improvement in terms of quality of life for the baby and family, this represents a lifetime cost saving of £5-7 million pounds per baby (the estimated cost of looking after a severely disabled child over their life).

## 5. Appropriate temperature monitoring

NICE and the British Association of Perinatal Medicining (BAPM) guidelines state that infants being cooled must have their core temperature monitored rectally. On beginning the project, none of the non-tertiary centres were using rectal temperature monitoring, and this change in practice presented great challenge. We embarked on training for nurses and doctors, and assisted units in the sourcing of suitable equipment. We chose to monitor how many babies were having rectal temperature monitoring initiated at the referring unit so that we could see whether this correlated with better temperature management.

Measure	Baseline (Oct – Dec 09)	Period 1 (Jan – Jun 10)	Period 2 (Jul – Dec 10)	Period 3 (Jan – Jun 11)	Period 4 (Jul – Dec 11)	Period 5 (Jan – Mar 12)
Rectal temp monitoring	0% (0/11)	6% (1/17)	17% (3/17)	56% (19/33)	81% (17/21)	100% (11/11)

We are delighted with the uptake of core temperature monitoring throughout the region, and the fact that you can see such a clear correlation between the increase in the proportion of babies having their temperature appropriately monitored, and better temperature management.

## 6. Incidents of overcooling

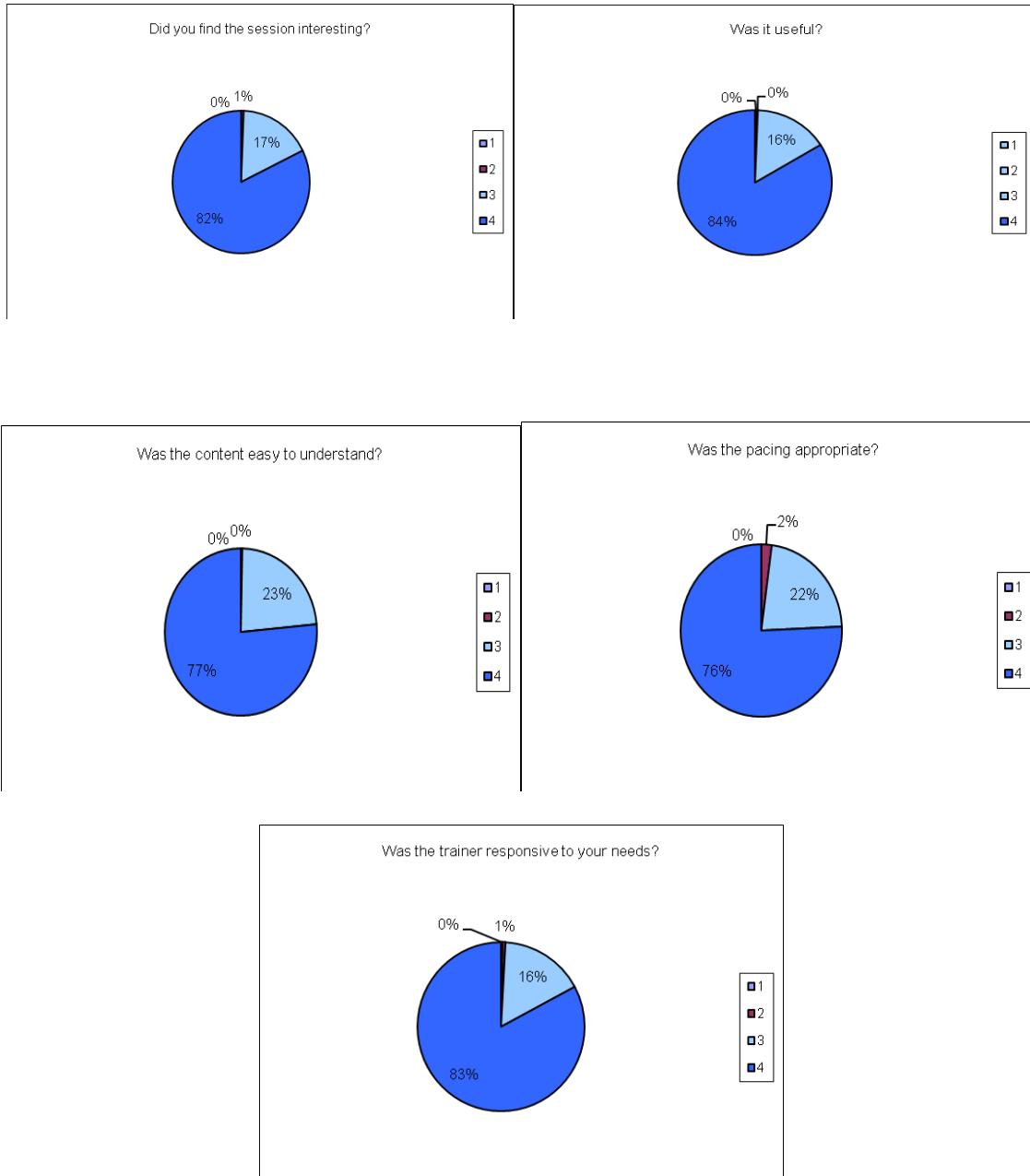
While cooling in the context of neonatal intensive care has been shown to be a relatively safe treatment, overcooling is associated with potentially life threatening complications. Therefore it was very important to ensure that babies who were being cooled were not overcooled and that this treatment was being undertaken in a safe manner. There is a relatively tight target window to hit of 33-34°C, and we wanted to make sure that through the emphasis we were putting on cooling there wasn't a rise in overcooling.

Measure	Baseline (Oct – Dec 09)	Period 1 (Jan – Jun 10)	Period 2 (Jul – Dec 10)	Period 3 (Jan – Jun 11)	Period 4 (Jul – Dec 11)	Period 5 (Jan – Mar 12)
Overcooling	45% (32, 32.6, 32.9, 33.2, 33.7)	33% (31.4, 31.5, 31.6, 31.8, 32.4, 32.9)	47% (31.4, 32.2, 32.4, 32.7, 32.8, 32.9)	27% (34.1, 32, 32.1, 32.2, 32.4, 32.5, 32.6, 32.9, 32.9)	31% (31.8, 32.1, 32.3, 32.3, 32.7)	0%

We have been pleased to see that incidents of overcooling have not risen as a result of the emphasis that there has been on cooling throughout the region. We are delighted with the results from Period 5 and will continue to monitor to ensure that incidents of overcooling remain at a low level.

### Training:

We also collect feedback from our training sessions, asking staff to mark each of the following statements on a scale of 1 – 4 (1 being not at all to 4, extremely.)



You can also see a collection of statements and feedback from our two registrar study days that we have run through the deanery in appendices 12 & 13.

**3.2 Please provide an assessment of the quality and robustness of the data that you have used, including comment on the validity and reliability of your measures, both qualitative and quantitative. This answer should cover:**

- **What were the barriers or difficulties you encountered in obtaining good quality data?**
- **What assumptions have been made?**
- **What limitations are there in your analysis?**

Much effort and discussion was had at the beginning of the project to identify key measures which would be indicative of improvement. The key performance measures were outlined in section 2.2 above.

We were fortunate to have engaged with ANTS early on in the project and were able to obtain robust datasets of the key performance measures. The data we collected forms a small part of a much larger set of data which ANTS routinely collect and regularly audit.

We are therefore happy that the data quality for these measures is satisfactory, and we have developed a very reliable, sustainable and simple way of collecting it through ANTS. This has been markedly preferable to the alternative resource heavy and ultimately impractical system of having to go to each unit individually.

Something that we have struggled with however, because of the sporadic nature of HIE, is the ability to test the impact different interventions may have on our performance measures. For example it has not been easy for us to adopt a PDSA model, applying rapid tests of change and then analysing the results, because if we were to test an intervention in a small scale in one unit we ran the risk of waiting for months until the next HIE case was born. In an effort to tackle this issue, we have come to view our debriefs as a sort of PDSA cycle, in that the unit have had their training and planned how they would deal with an HIE baby on the unit, they then have an HIE baby admitted and provide treatment. The debrief closes this loop and given them the opportunity to study how the treatment went, and to take any steps needed to improve it for the future (i.e. making sure the paperwork is more readily available or requesting another training sessions to build on staff knowledge.)

A secondary factor stemming from the relatively infrequent occurrence of the condition was that for each measure we did not have many data points. This meant that statistical analysis, or the teasing out of trends, was difficult.

Something that we have been disappointed about is that we have been unable to benchmark ourselves against other regions, because we have found that no other region is collecting data on cooling to the extent that we are. Although we have been told anecdotally by other regions when we have presented our data at national conferences that our performance is very impressive, it would be nice to be able to see how we are performing through concrete evidence.

### **3.3 What impact has this project had?**

We have summarised the impact of the project against specific groups:

#### **Team:**

Quality improvement was a new venture for the whole of the team, and we have had to undergo a steep learning curve in trying to adapt QI methodologies to our project. Individually and collectively, we all feel that the team has undergone a transformation throughout the life of the project. There have been a number of things that have contributed towards this development:

- The freedom and ability to spend time thinking about and planning things before implementing them.
- The attitude change that we went through from thinking that we had to deliver the perfect solution first time round, to seeing each intervention as a work in progress that could be developed and perfected *after* it had been introduced.
- There was some belief at the beginning of the project that doctors had to be trained by doctors, nurses by nurses. This was further underlined by a clinical Quality Improvement expert that had been advising us. For our team however it was not feasible, as the Clinical Nurse Specialists are responsible for all training on the units and so were required to train all of the doctors. Our experience has been that this has not been as much of a problem as some had expected and we think that this is for a number of reasons, primarily that: neonatal care as a speciality tends to have a more multidisciplinary approach than many other specialties, and as we were training staff in what was for many a new practice the nurses were the ones with the most experience and expertise. It has been very empowering to see how well this has been received by the medical profession. The following quotes are all from medical staff after attending one of the nurse-led training sessions:

*“Fantastic to have practical tips as well as theory/diagnosis”*

*“Ability to ask plenty of questions”*

*“Wish all our teaching sessions were like this. Usually people sprout statistics but we would prefer to be told what to do”*

- The whole team have developed skills that they have never had to draw on before for example through writing newsletters, developing a website, developing care pathways etc.
- The project has exposed the team to a wider network approach that they had not experienced previously.
- Clinical members of the team have developed a greater understanding and appreciation of the challenges faced by some of the other units around the region, which will go on to influence the way that they relate to these units in the future.
- We are now beginning to see just how valuable the right data is, and appreciate that if we had not been collecting performance data from the beginning we would not be able to prove what achievements we have made.

- We have all become more familiar with the process of change, and the challenges that you need to be prepared for. This will help when planning to embark on future improvements.
- Our interaction with families has had a profound effect on us all. Particularly for clinical staff, who often only meet with families during their initial inpatient stay after birth, this has been a very powerful and significant interaction. Often very rewarding, and at times sobering, it has helped us to appreciate the long term effect that the need for emergency care at birth and a stay on a neonatal intensive care unit can have on a family.

#### **Families:**

- It has been incredibly rewarding to be able to bring families together who have had similar experiences via our coffee mornings, and to be able to secure sustainable venues for the continuation of these events. There have been tears, and emotions have run high at times, but parents have been overwhelmingly grateful to have the opportunity to share their story with people who really understand where they're coming from. On the unit there can often be an emphasis on premature babies, and it is unlikely parents will come across anyone else with a baby being cooled. One mum commented about her experience on NICU:

*"We found [it] really useful to have stories that were similar to our own. Someone had sent their story to the ward, most of the stories were about preterm babies but someone had sent in their story about an HIE baby, we found that really helpful."*

For this reason, we have offered all parents that we have met the opportunity to have some help writing up their story to be shared with others through the booklet and the website.

- At several of the events the fathers seemed to bond particularly well and were able to talk about their experience of the situation with an understanding from one another of the types of emotions that they went through and the unique difficulties that fathers often go through of having to return to work, having to maintain a family life at home for other children, and being the link between the outside world of the extended family and friends and their newborn baby.
- We are really pleased to have been able to develop some resources for families that they can access whilst their baby is undergoing cooling and beyond. We had one mother tell us recently that whilst her baby was being cooled, she was relying on her brother to Google HIE and cooling at home and phone her to read out what he found. This really underlines why it was so vital for us to develop a booklet and a website for families- without this they either had no information at all, or ran the risk of accessing misleading information on the internet. The fact that these resources will be available for families across the UK and not just in the East of England is something that we are very proud of.

#### **Clinical community (East of England):**

- It has been wonderful for the region to have a 'good news story' that they could celebrate throughout the last two years. At times it can feel that there is little to celebrate out there, but we have been careful to underline to staff throughout the

region how much they have to be proud of in their performance in the area of neonatal neuroprotection.

- In a time where training budgets are being cut and staff are being told that they are not permitted time away to attend non-mandatory training, our ability to go onto the units to provide training has proved very popular. In many cases, our training sessions have been the first experience that clinical staff have had of Neuroprotection, and feedback has been extremely positive as outlined in section 3.1.
- It has been very powerful for the clinical staff around the region to have the opportunity to learn more about the families experiences of HIE and cooling. We always take the opportunity whilst delivering training to read out some excerpts from parents stories and quotes, which has been very well received.
- Overall, this project has highlighted how successful a network approach can be to improvement. This will help to drive and inspire others to follow in our footsteps.
- We have already seen the format that we developed for our Neuroprotection Care Pathways adopted for the one of the regions nutrition care pathways!

#### **National clinical community:**

- Developing and maintaining a database was one of the original objectives of the project. In the work done around this we have ended up collaborating with and helping develop the national cooling database known as the TOBY register (TOtal BodY cooling). The TOBY register was set up in 2006 following completion of the largest cooling trial (the TOBY study). The aim of the register was to record information on babies being cooled in the UK outside the confines of a clinical trial. The register records important information about the types of babies being cooled, any adverse effects of cooling and long term neurodevelopmental outcomes. This is recognised as an essential resource, as the relatively infrequent occurrence of HIE means that all babies need to be monitored centrally if we are to spot themes of adverse outcomes and research creep (where infants who did not fit the criteria set out in the clinical trials receive the treatment). In November 2010 it was announced that the funding to continue to run the register was to be cut, which was considered by the clinical community nationally to be an unacceptable risk. We facilitated a meeting between the TOBY register staff and BadgerNet (who are currently developing a new national neonatal database for all units to log their babies daily care) and have arranged for the information on the TOBY register to go into the BadgerNet database. This provides the UK with a fully sustainable and automated way of collecting essential information on all cooled babies. BadgerNet is currently being rolled out throughout the UK, and as this happens the paper register forms will cease and data will be collected electronically.
- The website that we have developed will be available for use by clinical staff throughout the UK and beyond. It is the first neonatal neuroprotection specific website of its kind, and contains many useful areas for health care professionals including interactive training tools, guidelines and resources they can point families towards.
- We have already presented, and are scheduled to continue to present, our outcomes and methods nationally and internationally. We have already received feedback from some other areas of the UK that they would like to know more about how we have achieved what we have.

### **Health economy / societal:**

- At a local and national level, we have been involved in a number of press campaigns and news stories about cooling. This has helped to raise the profile and awareness of what had previously been a fairly unknown condition and treatment. These have been 'good news' stories and have raised the profile of the region in this specialist area as well as the work done by the Health Foundation in funding the project.
- Across the East of England we have engaged with hospices and sure start centres to educate people about HIE, cooling, and families needs following treatment. We now have a number of surestart centres that are committed to providing support with coffee mornings for families beyond the close of the project. Our engagement with hospices has been an important step, because unfortunately a proportion of infants who are cooled will not survive their first few days of life, or may go on to develop severe neurodisability and so it is important that hospice staff understand the condition and how they can support families and babies with HIE through their childhood. The earlier they can engage with these families the better, and we have seen some wonderful examples of families of babies with HIE and hospices working together, such as Debbie, mum of Ava, who said of her relationship with her local hospice that they had become "like family".
- There are huge societal and economic benefits if you can protect a child from long term disability. It is difficult for us to calculate exactly how many infants have not gone on to develop long term neurodisability as a result of this project, however a rough idea can be developed using the following principle:

The numbers needed to treat with cooling therapy to have one infant, destined for long term neurodisability, go on to have a normal outcome is **eight**.



Treatment is proved effective if delivered within six hours



At the beginning of the project 36% of babies were cooled within six hours. Performance against this measure has steadily risen, and therefore you can calculate, for each time period, how many more infants have been treated within the six hour window than would have been if performance had remained the same. You can then apply the assumption that 1 in 8 of these infants will go on to have a positive outcome that they would not otherwise have had. Please see below:

Measure	Baseline (Oct–Dec 09)	Period 1 (Jan–Jun 10)	Period 2 (Jun–Dec 10)	Period 3 (Jan–Jun 11)	Period 4 (Jun–Dec 11)	Period 5 (Jan 12–Mar)	Total
Target temp within 6hours	36% (4/11)	24% (4/17)	88% (15/17)	76% (25/33)	100% (21/21)	91% (10/11)	N/A
Additional babies cooled	N/A	-2	9	14	14	6	<b>41</b>

within 6 hrs							
Babies avoiding long term disability as a result of performance improvement	N/A	-.25	1.12	1.75	1.75	0.75	<b>5.12</b>

Although the numbers are not large, the effect is immense. The cost alone of looking after a severely disabled child as a result of hypoxic-ischaemic brain injury is estimated at between £5 to £7m (£26.21 to £35.84m saved based on project numbers). The emotional burden on those individual families is also life changing and devastating.

#### 4. Discussion/ learning

##### 4.1 Summary

###### **Successes:**

- We have established a robust regional coordinated pathway for the management of babies with HIE, with supporting Neuroprotection Care Pathway (NCP) documentation. The NCPs are a vital means of both providing staff with a convenient way of recording vital clinical information and also prompting them at every step of the process to give appropriate care.
- Sustainable resources have been developed for the clinicians and families caring for these infants (quick help guides, training packages, information booklet, website).
- The success of the project has helped to demonstrate the effectiveness of a clinical network in providing integrated care.
- We have a clear method of collecting and analysing performance data beyond the life of the project.
- The profile of HIE has been raised across the region as well as nationally, and we have brought together families with shared experience.
- The need to follow up infants at two years has been underlined by the network, which have attached financial penalty to trusts failing to do this.
- Bringing together radiologists from across the region in order to agree a standard protocol is something that we are really pleased with, as we were advised early on that this would be difficult. Traditionally there has not been engagement between the neonatal and radiology clinical communities, however by using the carrot of some specialist training, and choosing a very discreet and specialist clinical condition, we have been able to break new ground in this area.
- Similarly, there has been little engagement and sharing of experience between the three tertiary centres in the East of England before, however it has been encouraging to see people being so open and honest about their experiences and practice in the quarterly videoconferences. We believe that this is in part because of the understanding that all units are in the same boat, and with so few cases relatively speaking there is real advantage for everyone in sharing knowledge.
- It has been of huge benefit to the project, in relation to engaging clinical staff, that we are dealing with a condition that people care deeply about. Staff feel an

intense personal and professional duty to do their best for these patients and their families, and are also aware that any shortcomings may be thoroughly investigated, as these cases can often be litigious. In addition to this, it has been to our advantage that the treatment necessary has not required large investment, and is essentially cost neutral to provide.

- It has been of significant value to the project team members and the wider network to be introduced to Quality Improvement science and methodology. All project team members, who will continue to work within the NHS beyond the project, feel confident in their abilities to continue to contribute towards improvements within their respective fields.
- Ongoing funding has been secured for training and administrative services for the neuroprotection service across the region.
- We are delighted to have been shortlisted by NICE to one of three finalists for a Shared Learning Award.

**Difficulties:**

- The nature of HIE has presented real difficulties in running the project in line with quality improvement methodologies. The fact that it occurs so infrequently (1-2/1,000 live births is equal to only 2-7 births per year for each individual hospital), and that it is generally an entirely unexpected complication needing urgent intervention, has made it difficult to perform rapid tests of change in the way that you might with a more common activity.
- There was little pre-existing knowledge around the area of HIE and cooling treatment (8 of the units in the region had never before identified a baby for cooling prior to the project starting in January 2010).
- We were working with a regularly changing and rotating workforce of over 600 doctors and 700 nurses.
- We did not manage to engage with families as quickly as we would have liked because we were given the steer that we had to seek ethical approval in order to carry out a questionnaire. In the end we decided to engage directly with families through our coffee mornings, which has been a real success for families and for the project, however in hindsight it would have been helpful if we had started this piece of work sooner in the project.
- At times, when presenting regional performance or when explaining interventions to staff, it has been hard to 'sell' quality improvement methodologies to an audience accustomed to the more rigorous and scientific research models. We have been aware of the need to prove to people at times that we are not carrying out 'sloppy research' but a different methodology altogether, which is less structured by design, not accident! It took us a while to understand QI ourselves and so be able to explain it to others; the Health Foundation away days helped with this. We also found that as we continued to collect data and prove that our interventions were having a positive impact, the message became much easier to sell.

**4.2 Please explain how you established the clinical community; how you think it impacted on the success of your project; what was the added value of approaching the problem through a clinical community? 400 words**

As a project, we have benefited greatly from the fact that in the East of England there is already an established network, with a clear structure of quarterly meetings that we have been able to align ourselves to. From a governance perspective we have had clear process to follow for the sign off and ratification of any new documentation or pathways. As such, we have been able to join an existing clinical community rather than create a new one.

Below this network structure we have formed a project steering group, made up of clinical staff of all levels from across the region. We have found that from an initial very large group, we have settled to a smaller but very interested group of people that regularly attend these meetings. It is likely that there is often some drop off to a group like this meeting quarterly across two years, as a result of people committing more than they are able to deliver or being more interested at the beginning but happy to take a back seat once they see that things are progressing. Happily, the core group that has remained is sufficiently representative of the interests of the whole region to be able to make decisions, and we have found that an added benefit of having a slightly smaller than intended group is that it is easier to progress things quickly outside of meetings via email agreement.

It is difficult to see how this project could ever have even got off the ground without being managed by a whole clinical community. We have been fortunate to have strong engagement from the beginning of the project from consultants in all three tertiary centres in the region. This has meant that we are able to come to consensus opinion easily, which has been vital. The fact that these babies are transferred throughout the region for care at different units made a regional and collaborative approach essential.

#### **4.3 Please tell us about your achievements, the challenges and the things that didn't work out quite as you planned. 800 words**

Our achievements can be seen summarised in section 4.1 above. Early on in the project, as mentioned previously, it became apparent that our initial aims had been too wide reaching and were not all realistic. Although we haven't abandoned any of our aims altogether, and have made significant progress in all of the five work streams that we set out with, we have scaled back on some to allow us time to focus in on others where we could have a much bigger impact. These were: early management and identification, family centred care, the engagement of radiology and data quality.

We have summarised achievements, challenges and things that didn't go as planned from the perspective of different stakeholder groups:

##### **The Families:**

Whilst developing our family resources (booklet and website) we have shared ideas and drafts with families to seek their opinion. Feedback has been very positive, and families have been really pleased to see that we are trying to fill the void of information that they felt they experienced whilst their child was being treated. Many families have fed back to us that they have really appreciated the opportunity to contribute, through sharing their stories and editing the booklet, to help parents of the future. They are also very

appreciative to know that their stories are being fed back to the people providing care in the region.

On a practical level, it has also been really rewarding to see the sharing of information that has taken place at some of the coffee mornings- where people with slightly older children with disabilities have been able to talk to families with younger ones and provide advice on anything from seeking respite care and sourcing equipment to what types of car they should think about getting for wheelchair use.

The family engagement was a project area that we struggled to get off the ground, and the ethics approval process stalled this area of the project considerably. Eventually we decided to take a different approach with families that didn't need ethical approval, but having seen the impact that it has made to families it would have been lovely to start this work sooner in the project. This would have enabled us to further test different interventions, and we would have had more time to work on making these interventions sustainable into the future.

Early on in the project we sought the engagement of BLISS to collaborate on our booklet. The reason for this was to ensure that someone would be there to continue to take responsibility for and print the booklet beyond the life of the project. Although we see the value of this relationship, and it is undoubtedly one of long-term benefit, it has been frustrating at times. We provided the content for the booklet, but it had to go through their design department to ensure consistency with their other publications. This has meant that we have been bound by their timescales, and we have experienced a disappointing delay in going to print as a result. Regardless of the fact that it would have gone into production sooner if managed solely by us however, we still feel that it is of greater use long term to be 'owned' by BLISS as there is the guarantee of sustainability and the ability to distribute nationally.

### **The clinical community:**

Training seems to be the one intervention that has had the biggest impact on the clinical community. Paperwork and governance have been important, but if the training aspect of the project hadn't existed then our engagement with the clinical community would have been severely limited.

Our ability to be out in the community, visiting units and seeing them on their 'home turf' as well as looking at their case notes and making the training meaningful to their working environment was key. This was expressed perfectly by one of the nurses in the region, working in a hospital that had recently had a debrief visit from Claire, one of the Clinical Nurse Specialists on the team after they had cooled a baby and encountered some difficulties. The week after Claire's visit they had another baby with HIE delivered, and their care was managed perfectly. The nurse in charge of that baby commented when she was congratulated by the team afterwards 'I just kept thinking, what would Claire do in this situation. What did Claire say?'. This was really rewarding for us, as it showed what impact training can have.

We have been through two main iterations of the Neuroprotection care pathway - the first was just a checklist, and the second is a much more extensive document that combined checklist and clinical data collection. The original paperwork was not very well

adopted, which we believe is partly because it didn't *have* to be filled out in order to hand important information over to the next clinical team looking after the baby. Our initial findings of the new care pathway are that it is being completed to a much higher standard. Because people are being asked to record clinical data, it seems that staff are taking it much more seriously and not seeing it as just a 'tick box' exercise. We're sure it also helps that we've gone from the first version being printed on normal paper in black and white to the new version being professionally printed in colour – this 'professional' approach seems to have more traction with clinical staff, and what may seem slightly peripheral (branding and presentation) has a major impact on compliance.

The clinical community has been very positive about the project in regional meetings. It has been of great benefit to the project that we have been creating a service to a standard that currently doesn't exist anywhere else in the UK, and have had national recognition at conferences for this which has allowed staff around the region to take real pride in what they have achieved.

We have found our approach of asking for link consultants and nurses from each trust has worked well on the whole, and where an individual unit has become a real shining star in terms of performance this is always related to how engaged their link staff are. It is a fact in our experience that the more engaged the link member on the unit, the better the whole unit's performance has been. We have been exceptionally lucky with some of our link nurses in particular, with many coming to training or even going into the units to oversee HIE babies care on their days off! As the project has worn on, we have started to use link nurses to present at study days on how they have introduced new initiatives into their department and have found that this works well- not only does it give them a boost to be asked but it also instils some healthy competition with the other link nurses.

#### **The team:**

The core team have all been new to the quality improvement methodologies of managing a project, and found it difficult at the start of the project to understand exactly what being involved in a 'QI' project meant. This was partly because it was a new concept, but also because the project and the condition that we were working with didn't sit very comfortably into a QI framework. It has already been mentioned in this report that the nature of HIE presented some real problems for us in running the project in the way that we were being asked to, and this probably meant that we stalled a bit early on. Momentum has build considerably throughout the project however, and it is certainly the case that if we were to be embarking on another QI project in the future we would be 'faster off the blocks' in the start up phase. It was also our experience that, earlier on in the project, some of the experts sourced to help us with our QI model also struggled to make our project fit with their tried and tested framework. As a result, there were times where we felt quite frustrated because we desperately wanted to fulfil the Health Foundation's brief but felt like we were trying to fit a square peg into a round hole.

We have also had some issues with staff recruitment slowing us down. The project manager was not able to start until July 2009, six months after the rest of the team, due to delays in getting the post out to advert. In hindsight, we would want to advertise this post much earlier in the future as it would have been beneficial to have a project manager in place during the start up phase. We also faced significant delays in recruiting to a nursing vacancy after one of the team left. Even though the post was funded, we had to go through the Trust vacancy review process which meant that we

had a four month gap in our establishment. This presented us with shortages in our capacity to go out and provide training, at a time when ideally we would really have been ramping up.

Otherwise, we have been very fortunate on the project to have a team of people who are passionate and very enthusiastic about what we are trying to do. Even though we can go for long stretches without all meeting, with many of the team out providing training or working remotely, we work closely and enjoy working with one another. With such a small team this collaborative approach to 'getting on' is essential!

It has also been a very refreshing and welcome experience to have complete control over our budget, and be outside of the strict NHS rules around procurement. In many cases, we have found that the flexibility afforded to us by being externally funded has meant that we have been able to save money by going with the cheapest supplier rather than having to go through standard approved contractors. We have also benefited from sitting slightly outside of the normal organisational structure as we have found that decision making has sped up, and we have been able to be more responsive to our environment.

#### **4.4 Interpretation**

**Explore possible reasons for differences between observed and expected outcomes paying particular attention to components of the intervention and contextual factors that helped determine the effectiveness (or lack thereof).**

We have found that we have had to be a lot more repetitive with our training than we had anticipated. In the original training plan we had drawn up a strategy of providing different 'layers' of training, becoming more detailed and complex, for each visit to the unit. What we hadn't accounted for was:

- a) The high staff turnover and varying shift patterns means that you are often delivering training to an audience that don't have any prior knowledge of cooling.
- b) Even though we aim to visit all units on a quarterly rotation, often the staff will not have had any contact with a cooling baby between visits and so the retention of knowledge is not very good. We are seeing now however that the messages seem to be sinking in more effectively, possibly thanks to our regular repetition.

The way that we have dealt with this is to offer different 'depths' of training depending on the needs of the audience that day. No matter how in depth we are going however we always take the time initially to cover the basics once more to make sure that no one has forgotten them.

An outcome that we had not expected to see is that in some cases we have felt that during the very early management of the baby the clinical team have been so focussed on getting the temperature of the baby down that they had forgotten some of the more basic, but essential, life support techniques. This was a worrying observation, and we have undertaken a communication exercise since reminding everyone that they still need to remember their neonatal life support practice. This message has also been incorporated more into our training.

Through our family coffee mornings, it has been interesting to see the number of families whose babies have had seemingly good outcomes, but who are still racked with

worry and fear for the future. Although their child doesn't fit into any societal bracket for needing additional help, as families they often have not recovered from the trauma of the birth and traumatic beginning.

## **5. Resources to share**

**Please attach any information or materials created as part of your work. These help The Health Foundation to really understand your approach and to promote it to the wider world, for example, government, patient organisations and professional bodies. Information could include:**

Much of our materials have been mentioned in this document already as appendices, as summarised below by theme, along with any other items of relevance:

### **Family engagement:**

Appendix 10- HIE Family Booklet  
Appendix 11- Family Stories

### **Communications/ training:**

Appendix 2- Do you need to cool poster  
Appendix 3- Ward laminates  
Appendix 4- anonymous systems analysis example  
Appendix 12- Drs study day feedback 2010  
Appendix 13- Drs study day feedback 2011  
Appendix 16- Sept 2010 Newsletter  
Appendix 17- Dec 2010 Newsletter  
Appendix 18- Mar 2011 Newsletter  
Appendix 19- July 2011 Newsletter  
Appendix 20- Oct 2011 Newsletter  
Appendix 21- Feb 2012 Newsletter  
Appendix 22- Poster Presentation at British Association of Perinatal Medicine (national conference)  
Appendix 23- Presentation at Reason meeting 2011 (national neonatal conference)  
Appendix 24- Presentation at national neonatal conference  
Appendix 26- Paris poster presentation  
Appendix 27- NICE award poster

### **Sustainability:**

Appendix 14- EoE Sustainability Proposal  
Appendix 15- EoE sustainability business case

### **Data collection:**

Appendix 1- HIE Survey Report  
Appendix 8- Follow up questionnaire (inborn)  
Appendix 9- Follow up questionnaire (outborn)  
Appendix 25- Follow up questionnaire summary

### **Pathways:**

Appendix 5- NCP1  
Appendix 6- NCP2  
Appendix 7- NCP3

## **6. Plans for Sustainability**

Beyond the life of this project, the East of England needs to ensure that:

- Performance against key performance indicators continues to be monitored and acted upon across the region.
- Training provision across the region continues.
- Guidelines and the Neuroprotection Care Pathway documentation are kept up to date.
- The three Neonatal Intensive Care Units (including radiology staff) within the region continue to share unusual cases and learning via the quarterly Neuroprotection Videoconference set up by the project team.
- Family groups established throughout the region continue to be supported with representation from the network to liaise and pick up important messages for the region from families.
- Liaison with radiology staff at the three NICUs continues, enabling further learning about the use of MRI to develop a prognosis for infants with HIE.

We developed a proposal for the staffing structure that we believe would support the above, and took it to the October 2011 round of regional board meetings (appendix 14). Our principal recommendation from this proposal was that the boards ask us to produce a business case for the recruitment of these posts to bring back for approval at the next round of meetings in early 2012. The boards followed this recommendation, and a case was developed for presentation in January (appendix 15). Our business case has been approved by the network boards, who have agreed to fund 1x Clinical Nurse Specialist role to continue training and one day a week administrative support to coordinate the service. We are delighted with this outcome, as in the current economic climate we had not expected at the beginning of the project to be in a position to have two permanent posts funded.

As part of the business case we outlined the risks of failing to provide some resource for the continuation of the service across the region, as summarised below:

- Training: Due to the infrequent occurrence there is a risk that, without dedicated regional resource for Neuroprotection training, the time will not be put aside locally for staff to deliver and attend in house training. We have also seen a lack of confidence in many units to provide training themselves, due to the acuity of these babies and the fact that they don't deal with them very often.
- Performance: The results achieved throughout the project's life have been the result of sustained communication and interaction with the units. The sporadic occurrence of HIE has meant that it can be difficult to truly embed learning and with such a narrow window of opportunity to affect the outcome of these babies (within 6 hours of birth), any drop in performance across the region will result in an unacceptable drop in the efficacy of the treatment, thereby threatening the long term neurodevelopment of this patient group.

- **Family engagement:** An important role of the clinical nurse specialist is to continue the dialogue established by the project team between the region and families. If this role were not to exist it is likely that the family coffee mornings may cease to operate, as families have fed back that the presence of a clinical person at these events is appreciated. It will also result in the region missing out on an opportunity to learn more about the long term effects on the family of having a baby with HIE, and to use this learning to better the experience of families in the future.
- **Governance:** The Neuroprotection team have released a number of tools to help healthcare professionals and families, and without continual review the risk exists that these may become out of date. This could result in them not being used any more or being mis-leading. The field of neuroprotection and the care of the HIE baby is constantly under review, and the East of England needs the mechanism in place to ensure that its practice remains safe and up to date.

We also have commitment of a core group from our steering group to continue meeting bi-annually so that performance can continue to be monitored, and governance of paperwork and guidelines can continue. It has been agreed that this group will report to the Clinical Development Groups, run by the network, on progress or necessary changes.

Our existing links with the network will be vital to the sustainability of the service, as they can take a role in policing performance. The transport service, ANTS, will also be key as they will be continuing to collect these babies for transfer, and so will be the first to know if performance seems to be slipping.

## 7. Plans for Spread

### 7.1 Explain your plans for spreading the learning and outputs of this project.

400 words

- We have already begun presenting the projects outcomes and learning at some national conferences, and have been accepted to present a poster at the International Forum for Quality and Safety in Healthcare in April 2012 and the Paediatric Academics Society Conference in Boston in May 2012.
- The project's website is an important tool for spreading learning and outputs, and we have put all of our locally developed paperwork on the site. We have got the contact details of all clinical leads in every neonatal unit in the UK, and plan to communicate with them once the website is launched and signpost them to the clinical areas.
- We are also in the process of writing a number of papers looking at: the role of the clinical nurse specialist in developing a Neuroprotection service, practical tips for developing a Neuroprotection service and the translation of Neuroprotection research into clinical practice. The aim is to submit these for publication in peer reviewed journals in 2012.

- Our collection of Neuroprotection Care Pathway documents provide us with a simple and straightforward package or ‘toolkit’ that could be shared with any region and adopted by them.
- We plan to collate all of our methods and results into a final report, which will be circulated to all networks nationally for their review.
- We have scheduled a mini-symposium for the 3<sup>rd</sup> July at which we will look at how to develop a regional neuroprotection service, as well as hosting a discussion on what our next focus should be on as a clinical community with regards to further neuroprotection issues. The target audience for this event is: neonatal and paediatric clinicians nationally, commissioners, transport leads from other networks, network managers and obstetricians.

## **7.2 How are you going to promote your innovation and convince others of its value?**

We have demonstrated that a regional approach to the management of infants with HIE can have a real positive impact on the quality of care these infants receive. The challenge now is to disseminate our work to as wide an audience as possible so that other regions can learn from our experience. As mentioned previously we plan to promote our work to the wider clinical community through use of our website, conference presentations and published papers as well as our closing mini-symposium in July. The main outcome that we would be looking for through doing this will be not only to inspire others to make similar improvements in performance but give them some resources and evidence to make the necessary changes.

We are fortunate in the UK that there is a coordinated network approach to the management of sick newborn infants, which means that our model can easily be adopted nationally. The experience of the TOBY register has demonstrated that there is a willingness nationally to collaborate and we hope to be able to tap into this interest and openness regarding the management of HIE.

## **7.3 What advice would you give to someone attempting to replicate your work in another organisation / setting? In your answer to this question please consider:**

Advice that we would give would focus on:

- *Ensure a solid evidence base:* it is important if change is to be adopted that the stakeholders understand the need for change and can see evidence from existing practice that change needs to happen. While there is unequivocal scientific evidence on the benefit of cooling, it may be harder to persuade clinicians and managers that there may be a need to improve the quality of the service. Obtaining baseline data is important in this aim.
- *Use a network approach:* Try to plug into an existing network that covers your patient group. By doing this you will not only have an existing group of interested people to engage with, but you also have a resource that can help with monitoring and sustaining your improvements once the project is completed.
- *Choose some pertinent measures, and monitor!:* Early on in the project it was our aim to collect a very large dataset on all babies being cooled in the region. We cut back on this severely (going from 26 data items per baby to 6), and opted instead to just collect a handful of data items, that were very strongly indicative of performance. This approach took courage, as it can be tempting to

record everything ‘just in case’. It was however, a good decision to cut back on data because it meant that what was left was easy to interpret. It wasn’t hidden by other less important data and it was easy to communicate to others outside of the project. Being able, at the end of the project, to show people what has been achieved in terms of data is incredibly powerful and unless you start collecting early on it is difficult to capture retrospectively.

- *Engage with your patient group early:* It can be tempting to spend time early on working on the clinical aspects that people are often much more confident with, but building up relationships with patients takes time and if you are to do anything meaningful with patient engagement, the sooner you can start the better.
- *Engage with your local transport team:* This only applies to those undertaking a project that involves transferring patients on for further treatment as ours does. The transport team are an essential resource in a project such as ours, as they not only see firsthand what staff are doing, but through delivering consistent messages with the project they are able to reinforce training and good practice.
- *Start your interventions small and build up:* It is tempting to work as a project group on developing an entire package of interventions, paperwork and pathways so that you can deliver a ‘complete and perfect product.’ This isn’t possible, and the more you can break your intervention down the easier it is to implement as a change and monitor whether it is successful. If you implement an entire package all at once, if something goes wrong in its practical application it can be difficult to pinpoint which bit needs changing.

#### **7.4 What do you see as the main challenges to the future spread of your work?**

300 words

We were fortunate in that we started just after cooling therapy was adopted as a treatment across the region, and so we weren’t trying to change processes that had been in place for years. As such, it was easier to develop paperwork and pathways because it was a brand new intervention and it wasn’t replacing anything. Anyone that tried to implement a coordinated Neuroprotection service across a whole region now would probably be faced with the fact that each individual hospital had developed its own processes and practice. This would make change harder.

As mentioned in section 3.2, other regions are not currently collecting performance data as we are and so there may not even be a perception of need within a region- if you’re not collecting data, how do you know that you have a gap.

The main challenge for any other region wishing to develop a coordinated service will be finding the resources to implement it. We have had to spend a lot of time delivering training, and even though they could adopt our paperwork ‘off the shelf’, they would need to provide extensive training to get staff to a point that they could actually deliver the service.

### **8. Return on investment**

#### **8.1 Can you estimate the cost of the intervention and the benefits accrued?**

The total cost of this project has been £454,741

This can be balanced against the analysis from section 3.3, which showed that throughout the life of the project 4.37 infants have been protected from long term neurodisability\*, resulting in a societal cost saving of £26.21 to £35.84m \*\*

\*It is of course impossible to prove what the outcome of infants would have been if they had not been cooled within the target of 6 hours or indeed if they had not been cooled at all. For this analysis we have used the findings of the TOBY trial that shows that 1 in 8 babies cooled within 6 hours will have a positive outcome when otherwise they would have gone on to develop long term neurodisability.

\*\*Based on the cost of looking after a severely disabled child as a result of hypoxic-ischaemic brain injury being estimated at between £5 to £7m.

## **8.2 What have been the cost implications to your work?**

Costs that will have been incurred by the region as a result of the project are:

- Every unit had to buy one adaptor to enable their monitors to have a rectal temperature probe attached to them, to the value of **£40**.
- Units have to buy rectal temperature probes at **£18** per probe (ave 5 per unit per yr.)
- It is estimated that each unit will have had to cover the costs of expenses for staff travel to study days to the value of between **£50 - £300** throughout the duration of the project (depending on distance from study day)

Total cost implication per unit: **£180 - £430**

## **8.3 What were the main difficulties you encountered in identifying cost and benefits of your work?**

*For those teams involved in the additional support from Springfield Consultancy please include the results of the work and explain how you have or intend to use the information.*

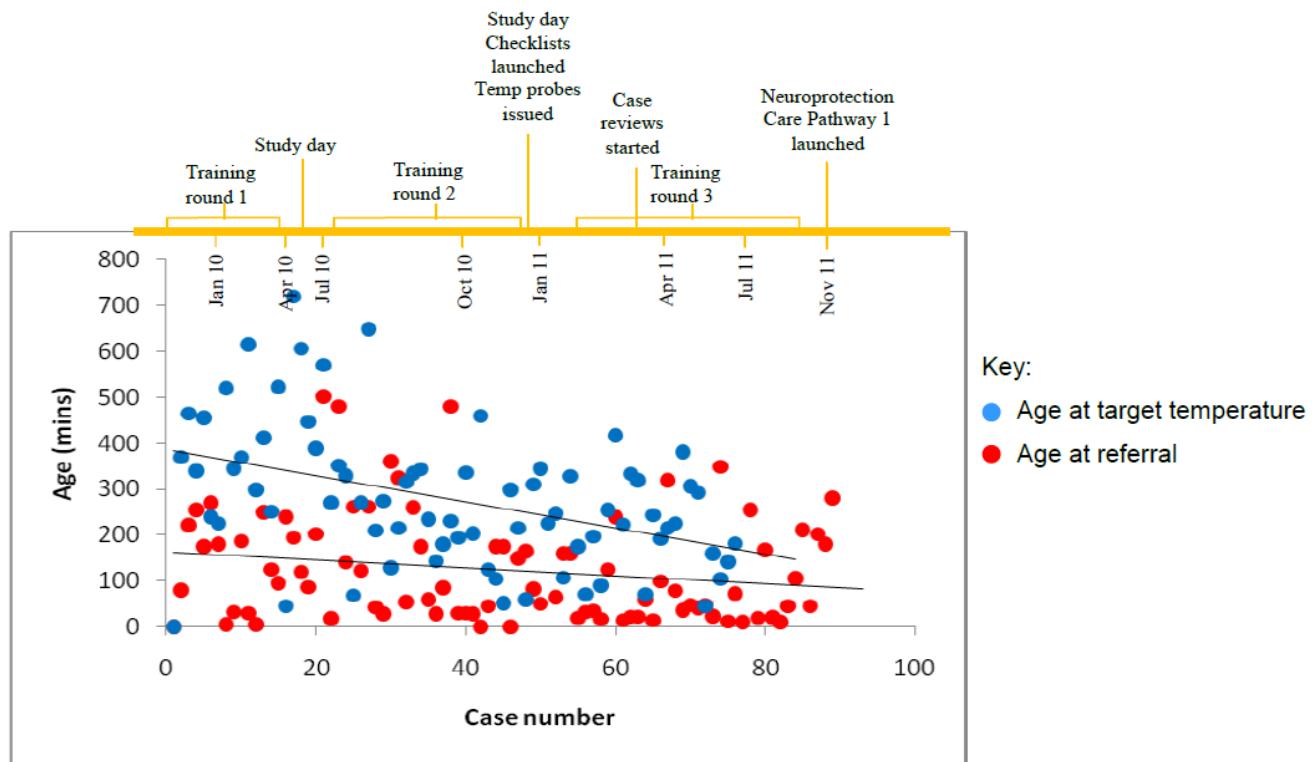
*600 words*

The cost benefit of an infant having a positive neurodevelopmental outcome is societal and therefore very difficult to quantify. It also makes the argument of cost benefits a difficult one to apply, because no one budget will feel the result. Thankfully, the cost of providing cooling treatment is very low, and as these infants would be being treated in intensive care units anyway due to their diagnosis of HIE, it does not represent any greater cost.

The other benefits of our work have been much easier to quantify- babies are treated more efficiently and more effectively without putting safety at risk. We are unable within the life of this project however to say for certain what effect this has had on longer term neurodevelopmental outcomes- this will not become apparent for years to come.

Instead we have to be content in the knowledge that trials have already proven the ideal circumstances of care that will give a baby the best possible chance of recovery, and babies within the East of England are receiving this standard of care more reliably now

than they were at the outset of the project. It is impossible for us to say whether this is as a result of our interventions or not, however the annotated graph below helps to show some of the effects that our interventions had.



Our work with Springfield was focussed less on health economics and more on the development on a business case for the sustainability of the service. We were provided with guidance from them on business case models that could be used and information to be included. We went on to use a business case model for our sustainability case.

## 9. Conclusions

The original aims of Closing the Gap through Clinical Communities were to

- build the knowledge and skills of clinical teams in how to make improvements in the quality of care
- contribute to the creation of a systematic body of knowledge concerning how best to engage clinicians in quality improvement activity
- stimulate learning about quality improvement amongst health professionals
- support clinical communities to make demonstrable improvements in quality by tackling known gaps between best practice
- support routine delivery of care

Reflecting on the previous sections of the report how well do you feel the project met these aims?

*600 words*

This project has posed some unique and interesting challenges to both the team and The Health Foundation in applying quality improvement methodologies to a rarely occurring condition. And it is for this reason that the project has been an extremely valuable experiment in developing an understanding of how quality improvement techniques can be adapted to address the specific needs of a project such as this.

As this report highlights we have been fortunate in having enthusiastic and constant engagement from clinicians at a senior level, and as a result clinical staff throughout the region have had the opportunity to develop an understanding of quality improvement as well as being motivated by its clear success. The motivation to adopt specific quality improvement techniques throughout the region is only now at its peak, as staff recognise the improvement that this project has made.

With the support of the Health Foundation we have been able to obtain both quantitative and qualitative evidence of how our improvements have come about, thus adding to the systemic body of knowledge on QI methodology.

We recognise that the regional interest in QI methodology has been delayed, due to the need to obtain tangible evidence of improvement, however we are now in a position to disseminate this knowledge. In our January steering group we were asked whether we would consider running a quality improvement symposium, using the project as a spearhead for the cause. We have taken much encouragement from this, as it is the most positive example that we have had so far of the regions thirst for an understanding of quality improvement as a standalone subject. Support of the project has always been good but it seems that now staff are making the association between the results that we are seeing as a region and the QI tools used.

We have also received a lot of encouragement and interest from the Perinatal Network in our methodologies, who we have already seen adopt some of our techniques or systems for improvements in other areas of neonatal care.

In 2009 the idea of cooling infants with HIE was emerging as a promising new therapy based on a large amount of robust research. Now, by 2012 we have been able not only to ensure that every infant in the region has a better chance of being identified and treated in a safe and expedient manner, but also that broader issues around neonatal neuroprotection and most importantly support for their families are understood. This is a fantastic example of translating best research into best practice in a short space of time.

Overall we are confident that the project has met the original aims of the Closing the Gap through Clinical Communities programme and we each feel on the team that our experiences have shown the importance of quality improvement in delivering the best care to our patients.