Preventing blindness in premature babies

Fundraising case for support

The UK’s first ROP telemedicine pilot offers vision for the future

October 2014
Executive summary

Can you imagine how you would feel growing up in a world where you have never seen a sunset or looked into the eyes of a loved one? Unfortunately, for a growing number of premature babies, the risk of blindness is very real. Retinopathy of Prematurity (ROP) is a retinal condition that affects around 70% of very premature, low birth weight babies and, in severe cases, can cause blindness. With timely screening and detection, blindness is preventable, but limited expertise to do this means transporting tiny babies across the East of England to be tested in Cambridge, causing unnecessary risk and stress to them and their families. However, these problems could be overcome by establishing a regional ROP telemedicine service, which could then form a template for a new national service.

In the past decade the number of babies born with eyesight problems due to premature births has risen by 22%. Each day four children in the UK are registered blind or partially sighted which will have a profound impact on their lives, and that of their families.

Of the 70% of very premature babies affected by ROP, 15% will develop a form of the disease so severe that it threatens their sight. And although it can be treated, it is sadly still responsible for 5% of all UK childhood blindness registrations, primarily due to delayed detection and treatment. Effective management of severe ROP relies on timely screening, detection and laser treatment in a regional centre like Addenbrooke’s, the treatment centre for the East of England neonatal network.

Recognising the point when ROP threatens sight requires years of clinical experience – expertise that isn’t available in many district general hospitals. Consequently, babies have to be transferred by ambulance to Addenbrooke’s for a second opinion on ROP severity to assess if treatment is needed. With treatment at the right time, blindness is preventable. In about a third of these cases, ROP has not reached a sight-threatening stage and the baby returns to the referring hospital without treatment. For these tiniest of babies, ambulance transfer causes needless risk and, for their parents, a great deal of stress. Fortunately, recent advances in digital retinal imaging offers a solution by making it easy to transfer the retinal images electronically and enable reliable remote diagnosis (telemedicine) without baby having to leave their local hospital.

Equipment

The gold standard in digital retinal imaging equipment for ROP telemedicine is the Retcam digital camera. It is used very successfully in many countries, including the US. But here in the UK the £55,000 cost of a Retcam means that it is only available in specialist centres like Addenbrooke’s. Ophthalmologists at Addenbrooke’s have discovered that there is a more cost effective yet highly reliable way to set up a telemedicine service. The recent launch of digital ophthalmoscope (DIO) equipment at around £7,000 makes it easier for ophthalmologists at district general hospitals to capture a good quality retinal image file suitable for secure electronic transfer to Addenbrooke’s to enable expert remote diagnosis. Ophthalmoscopy is a core skill for all ophthalmologists, so they could be trained to acquire a good quality retinal image file. Indeed, this is already happening between the hospitals in the region that have a DIO.
Regional support for the project

A recent survey of screening ophthalmologists in hospitals across the region confirmed that most felt that an ROP telemedicine service would greatly benefit their patients and empower them to make a diagnosis without requiring a transfer. Furthermore, many of the consultants who trialled the DIO found it easy to use. Screening ophthalmologists from ten hospitals agreed to participate in the pilot telemedicine study and two have already purchased the system. The participants are:

1. Broomfield (Chelmsford)
2. Colchester Hospital
3. East and North Hants Hospital (Lister)
4. Ipswich Hospital
5. James Paget Hospital (Great Yarmouth)
6. Norfolk and Norwich Hospital*
7. Peterborough City Hospital*
8. Princess Alexandra Hospital (Harlow)*
9. Queen Elizabeth Hospital (Kings Lynn)
10. West Suffolk Hospital (Bury St Edmunds)

*Have already purchased the DIO system

How this pilot could improve patient care and clinical outcomes

Once successfully established this innovative service would create multiple benefits:

- Reduce risk and disruption to infants who are likely to be premature, have an extremely low birthweight and suffer from chronic respiratory disease.
- Eliminate unnecessary stress, inconvenience and cost for parents whose premature babies are already battling to stay alive.
- Reduce unnecessary use of the highest-level NICU cots for babies with pre-treatment threshold ROP, leaving the cots free for the most poorly babies. In the year to March 2014 NICU had to turn away an average of 35 intensive care babies per month, including some that had to be transferred out of the region, causing great disruption to families.
- Eliminate unnecessary journeys via the Acute Neonatal Transport Service (ANTS), an extremely busy service that often requires a specialist registrar and neonatal nurse to travel with the baby.
- Reduce the number of babies with threshold ROP who are monitored on a wait-and-see basis in their local hospital and miss laser therapy at the optimal time.
- Enable savings and free up valuable NHS resources to improve patient care in other areas where there is urgent need.
- Improve skills for ophthalmic trainees in neonatal retinal examination and ophthalmoscopy.
- Establish a proven template for a national ROP telemedicine screening service.
Launching the regional pilot will benefit these audiences:

- 40 babies in the region will be at risk from ROP.
- Half of these or 20-25 babies will need to be transferred by ambulance for a second opinion.
- Half of these babies will not need laser eye surgery i.e. 13 babies who have been transferred unnecessarily, so the trip was wasted.
- Every year 1-2 babies are treated later than they should be because there are delays in them reaching CUH for a second opinion. These babies often develop some visual impairment due to late treatment.
- 10 Screening Ophthalmologists will be supported by the pilot in the neonatal network – two of these units are currently without experienced Screening Ophthalmologists.

A successful regional pilot would create an impressive multiplier effect if this new method of screening is implemented nationally

- 400 babies are treated nationwide each year for ROP, so there will be double this number - 800 - who reach Stage 2/3 ROP and would benefit from an expert opinion.
- Of these about half would be babies already within the level 3 centre and half would be babies from other units.
- Therefore we estimate that 400 babies per year are transferred to a regional centre for an opinion and in about half treatment would prove unnecessary.
- Rolled out nationally, this programme could prevent 200 babies from being transferred unnecessarily between hospitals.
- Average transfer costs are £3,000 per return trip, so nationwide this would be £600,000 per year not including the waste of this resource for other babies and the stress for the babies themselves.
- A national programme would give 150 Screening Ophthalmologists in level 1 and 2 units direct access to a second opinion. Their annual leave could also be safely covered by a less experienced colleague.
- ROP is still responsible for 3% of blindness registrations in the UK. Improved diagnostic support should enable optimal recognition and treatment of sight threatening ROP and we would hope to see this number decrease with time.

Rolling out a successful pilot nationally

Once this pilot has been funded and completed, the ultimate ambition of the Cambridge team is to roll this model out nationally to save all babies requiring a sight-saving diagnosis a long and stressful ambulance transfer for screening. There are 20 neonatal networks in England. Treatment for ROP generally only takes place in level 3 centres (neonatal intensive care units) and babies are transferred from other units within the network to the level 3 centre for ROP diagnosis and treatment. Not all level 3 centres have Ophthalmologists who are able to treat e.g. Norwich.

The same problems apply nationally that apply to our region:

- This is a highly specialised clinical field and there is a paucity of treatment centres with Ophthalmologists who have sufficient experience in ROP screening
- Geographical distances within the networks requiring long transfers
- Increasing incidence of prematurity due to maternal age and an increase in multiple baby pregnancies. There are currently 54,000 premature births in the UK per year. Approximately 5% of these i.e. 2,700 per year are the ones who are born
weighing less than 2lbs and are at the highest risk of ROP. All 2700 would require ROP screening and approximately 15% of this number i.e. 400 babies would be expected to be diagnosed and require laser surgery.

- Increasing survival of extremely premature babies due to improvement in neonatal care means more babies are likely to develop ROP.
- There have been recent problems in replacing retiring Screening Ophthalmologists in District General Hospitals meaning that demand for a service like this will continue to increase.

Map showing the UK’s neonatal networks which could implement a similar telemedicine screening programme on the basis of Cambridge’s pilot.

If approximately 400 babies are treated nationwide each year for ROP, there are likely to be about double this number – 800 who reach Stage 2/3 ROP and would benefit from an expert opinion. Of these about half would be babies already within the level 3 centre and half would be babies from other units. Therefore we would estimate that about 400 babies per year are transferred to a regional centre for an opinion and in about half treatment would prove unnecessary i.e. rolled out nationally, this programme could prevent 200 babies from being transferred unnecessarily between hospitals. Average transfer costs are £3,000 per return trip, so nationwide this would be £600,000 per year not including the waste of this resource for other babies and the stress for the babies themselves. A national programme would give 150 Screening Ophthalmologists in level 1 and 2 units direct access to a second opinion. Their annual leave could also be safely covered by a less experienced colleague.
ROP is still responsible for 3% of blindness registrations in the UK. Improved diagnostic support should enable optimal recognition and treatment of sight threatening ROP and we would hope to see this number decrease with time.

Case study

Born in Colchester Hospital at only 24 weeks, Baby Ella was an extremely low birthweight baby (660g), with a high risk of developing ROP. Ten weeks after her birth the local consultant ophthalmologist thought she was developing severe ROP and wanted a second opinion about the need for treatment.

Since the Rosie NICU was full, another baby was transferred to a different hospital to free up a cot for Ella. She was transferred by ANTS ambulance but her parents had to drive, leaving their two other children at home in Colchester. Baby Ella’s dad subsequently had to go home early to look after them, leaving mum and Ella in Cambridge.

Retinal images taken with the Retcam and DIO confirmed that ROP treatment wasn’t necessary. However, because she couldn’t travel in the ambulance within eight hours of pupillary dilation, Ella had to stay in a NICU cot overnight and her mother had to find transport back to Colchester. Had the ROP Telemedicine service been available, two transfers, a blocked NICU cot and great deal of stress to Ella, her parents and their other children could easily have been prevented.

Miss Louise Allen, Consultant Paediatric Ophthalmologist and Clinical Director of Ophthalmology

Louise graduated from St Thomas's Hospital Medical School in London in 1989 and then completed ten years of general training in ophthalmology at major teaching centres in Southampton, Birmingham, Norwich and Cambridge. With an interest in the genetics of eye disease, Louise took two years out before her medical training to undertake a university research project, funded by the Guide Dogs for the Blind Association and based at the Cambridge Institute for Medical Research. After completing her medical training, she spent a year as a Clinical Fellow at Great Ormond Street Children’s Hospital in London, gaining further specialist experience in all aspects of paediatric and inherited eye disease, in the company of renowned experts in the field. Louise was appointed to a consultant post at CUH in 2001.
Timescales & budget

This project could start within a month of approval and would be audited at the end of the first and second year then every 5 years subsequently.

<table>
<thead>
<tr>
<th>Item</th>
<th>Year 1</th>
<th>Year 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Equipment</strong></td>
<td>Approx.</td>
<td></td>
</tr>
<tr>
<td>7 digital ophthalmoscopes and laptops</td>
<td>£49,070</td>
<td>£230</td>
</tr>
<tr>
<td>7 password protected memory sticks</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2. Training Screening Ophthalmologists in referring hospitals</strong></td>
<td>£1,470</td>
<td>£300</td>
</tr>
<tr>
<td>Training of 7 Screening Ophthalmologists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travelling costs for training purposes between referral centres</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4. Consultant’s time in preparing and transferring images</strong></td>
<td>£1,000</td>
<td>£1,000</td>
</tr>
<tr>
<td>@ £20 per patient (for first two years of scheme only)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5. Statistical support</strong></td>
<td>£500</td>
<td>£500</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>£52,570</td>
<td>£1,500</td>
</tr>
</tbody>
</table>

Please get in touch

We hope that you find this case for support compelling and that you will consider supporting this important project.

To donate, please visit www.act4addenbrookes.org.uk/donate, then tick the ‘Retinopathy telemedicine project’ option.

Alternatively, please send a cheque made out to: ‘ACT – fund 9852 (Retinopathy telemedicine project)’

If funds are raised in excess of the cost of project, we will endeavour to ensure that funds go towards projects of most need.

If you would like to discuss this in more detail please contact Gemma Downham, Fundraising Manager at ACT on 01223 596434 or by email at gemma.downham@addenbrookes.nhs.uk

Addenbrooke's Charitable Trust
Box 126
Addenbrooke's Hospital
Hills Road
Cambridge CB2 0QQ

Registered charity number 1048868

Thank you