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1) PROGRESS AND NEWS

Happy New Year to all our readers.

As you may know, 2009 will be a big year for New Zealand's newborn hearing screening and early intervention programme, with a number of district health boards beginning implementation.

With that in mind, this update focuses on information from the UK Programme, which is well respected internationally and uses similar screening protocols to our own, and on new literature.

The previous update contained links to conferences which may interest our readers. If you have information about an upcoming relevant conference, please don't hesitate to get in touch and I can include information about your conference within future updates.

2) INFORMATION FROM THE UK PROGRAMME

QUALITY ASSURANCE REPORT DEMONSTRATES ISSUES IN SOME KEY AREAS

[The National Health Service Newborn Hearing Screening Programme's Quality Assurance report for 06-08](#) and the [London SHA area report](#) have been released and these reports identify a number of issues with the screening programme that need to be addressed.

For those who are interested, there is a large amount of information on the NHSP website about the way their Quality Assurance programme works. The QA support programme began in November 2006. It is overseen by an external Quality Assurance Board. Each service and its associated Audiology, Medical, Education and Social Care service is visited at least once every 18 months and provision will be reviewed against the NHSP Quality Standards. The visit will be carried out by a QA team of professionals in Screening, Audiology, Paediatrics and Education.

The release of the reports has prompted National Deaf Children's Society to begin a campaign aiming to get authorities to improve the programme's effectiveness.

Overview of the programme:

It is thought that approximately 700 children in England are thought to be born each year with bilateral and 400 with unilateral hearing impairment. Implementation of the English programme finished in March 2006 and the focus since that time has been the ongoing maintenance of the programme and its continuous improvement. The programme uses the eSP data collection system.

Most babies receive an aOAE screen only, those referring or with risk factors get screened using aABR in addition.

They have a Quality Assurance Team, which is made up of current practitioners from various areas (e.g. screening, audiology) who are commissioned by the programme centre to carry out peer review visits. Programme Centre staff also form part of the visiting teams. These visits are for QA purposes and the group identify strengths and weaknesses in services related to the care pathway and Quality Standards. Sometimes if they have significant concerns, they revisit particular areas.

Concerns

The reports show significant improvement is still needed in screen coverage, time to and for diagnostic assessment and completeness of data reported. I have attempted to summarise the findings of the report below:

- 11 of 32 Primary Care Trusts (PCTs) met the government target to screen 98% of newborns within a month of their birth.
- London area has the poorest performance overall, and they are thought to be ***missing around half the cases*** of PCHI due to poor coverage and administrative issues. These issues exist despite London having high population density and highest number of new births nationwide
- It seems that in some areas, the value of the screening programme is unknown due to the lack of diagnostic data reported.
- The report recommends an external peer review of diagnostic testing results (particularly interpretation of diagnostic ABR) and are concerned at the length of time it is taking to assess babies, despite the fact that some areas have been operating since 2001.
- Programme governance was the most common category of recommendations – providers in some areas were found to be operating in isolation, the role of team leader (an overview role) was often dis-established or vacant post implementation period, role of local coordinator devalued,
- Only around half the babies were seen for first diagnostic assessment within 4 weeks of screen.

Other comments

- The QA team note that each 'standard' was given equal weighting in their analysis of how that particular area was performing. As such, they note the importance of conducting the analysis in such a way that individual areas of weakness are visible.
- Yield rates were higher for the highest performing sites.
- Most of the areas reported they had made changes as a result of the QA visits.

Media Coverage

There has been quite a bit of media coverage regarding the reports, and NDCS have begun a campaign to see the effectiveness of the programme improved.

Links to some of the recent media are found below:

Evening Standard 24.11.08

[View the story here...](#)

London Tonight 24.11.08

[View the story here...](#) or view the [transcript](#).

BBC Online News 20.11.08

[View the story here...](#)

COMO CONFERENCE PRESENTATIONS from the UK team

Following the 2008 Como conference, held in Cernobbio, Italy, the UK Newborn Hearing Screening Programme team have made their [presentations available on the Programme website](#).

I realise we include a links to this site quite regularly in these updates, but I can't recommend it enough in terms of the range and quality of information included. For me, the UK presentations were the highlight of the Como conference, and to have them all included here, particularly for those unable to attend, is hugely valuable.

[Improving performance through QA and Training: the experience of the English Programme](#)

1071KB - Posted by: Elizabeth Orton - 24/06/08 Presentation given by Liz Orton, Gwen Carr, Christine Cameron, Siobhan Ryan and Lindsay Kimm

[Considerations when starting up a Newborn Hearing Screening Programme](#)

147KB - Posted by: Sonya Clark - 24/06/08

Poster by Sonya Clark, Anne Stevenson, Gail Allan and Adrian Davis

[QA –Is it worth it? Quality Assurance as a catalyst to strategic partnership working](#)

199KB - Posted by: Siobhan Ryan - 24/06/08

Poster by Siobhan Ryan and Clare Jones

[How safe is your hearing screening programme?](#)

1868KB - Posted by: Nick Waddell - 24/06/08

Poster by Nick Waddell and Siobhan Ryan

[Parental perceptions of the experience and impact of the early identification and management of unilateral hearing loss](#)

193KB - Posted by: Gwen Carr - 25/06/08

Poster by Emily Pattison, Gwen Carr, Graham Sutton, Mary Kean and Adrian Davis.

[Newborn Hearing Screening Programme Site Support Helpdesk](#)

82KB - Posted by: Gillian Atty - 24/06/08

Poster by Gill Atty, Aileen Masson and Anne Stevenson

[Linking parents of deaf children in an internet-based network as an alternative to meeting in structured groups](#)

301KB - Posted by: Declan O'Brien - 24/06/08

Poster by Declan O'Brien, Gwen Carr and Anne Stevenson

[Current Performance of the English Newborn Hearing Screening Programme](#)

242KB - Posted by: Sally Wood - 24/06/08

Poster by Sally Wood, Adrian Davis, Sonya Clark, Graham Sutton, Nick Waddell, Adam Bruderer, Anne Stevenson, Heather Kelly, Liz Orton and Lindsay Kimm

[Clinicians' views of management of unilateral and mild hearing loss in young children](#)

204KB - Posted by: Graham Sutton - 24/06/08

Poster by Graham Sutton, Emily Pattison and Gwen Carr

[Acoustic reflex measures in neonates and young infants](#)

179KB - Posted by: Graham Sutton - 24/06/08

Poster by Graham Sutton and Mariana Mejia-Turnbull

[Quality Data: Using Data to Improve Quality of Service](#)

232KB - Posted by: Adam Bruderer - 24/06/08

Poster by Adam Bruderer and Nick Waddell

3) NEW LITERATURE

Newborn Hearing Screening Follow-up: Factors Affecting Hearing Aid Fitting by Six Months of Age.

Authors: Spivak L, Sokol H, Auerbach C, Gershkovich S.

Source: Am J Audiol. 2008 Nov 24.

PURPOSE: To determine the extent to which the goal of hearing aid fitting by six months of age is being achieved and to identify barriers to achieving that goal.

METHOD: Screening and follow-up records from 114,121 infants born at six hospitals were collected over a six year period. Infants diagnosed with permanent hearing loss requiring amplification were categorized as fit on time, fit late, or lost to follow-up. Seven factors were empirically identified as potential barriers to timely intervention.

RESULTS: Ninety-one percent of referred infants returned for follow-up evaluation. Hearing aids were fit on 107 of the 192 infants requiring amplification. Thirty-nine percent were fit on time and 61% were fit late or lost to follow-up. Unilateral hearing loss and late diagnosis were statistically significant ($p < .0001$) predictors for late fitting and loss to follow-up. Conductive hearing loss and coverage by Medicaid were also statistically significant ($p < .0001$) predictors for loss to follow-up.

CONCLUSION: High return rate for follow-up does not ensure hearing aid fitting by six months of age. Infants with unilateral hearing loss are at particular risk of being lost to follow-up.

Hearing screening for newborns: the midwife's role in Early Hearing Detection and Intervention.

Authors: Biernath K, Holstrum WJ, Eichwald J.

Source: J Midwifery Womens Health. 2009 Jan-Feb;54(1):18-26.

Universal newborn hearing screening is becoming the standard of care in the United States. However, there has been some controversy around this pediatric preventive health care practice. In 2001, the US Preventative Services Task Force (USPSTF), the leading independent panel of experts on prevention and primary care in the United States, reviewed the scientific literature and found inconclusive evidence to recommend for or against universal newborn hearing screening. As a result of this lack of recommendation, some pediatric providers were not screening the hearing of all newborn infants. The USPSTF released an update in July 2008 concluding there is scientific evidence to recommend newborn hearing screening for all infants. Universal newborn hearing screening is the first step in the national Early Hearing Detection and Intervention (EHDI) program. EHDI includes not only universal newborn hearing screening but also diagnostic evaluation for any infant failing the initial hearing screen and intervention services for any infant diagnosed with hearing loss. During the prenatal and postnatal periods, obstetric care providers can play a vital role in the EHDI process through education, screening, referral, and assistance with follow-up. Through these services, clinicians can work with parents and pediatric care providers to help newborns and infants develop communication and language skills that will last a lifetime.

Parental experiences of the newborn hearing screening programme in Wales: a postal questionnaire survey.

Authors: Fox R, Minchom S.

Source: Health Expect. 2008 Dec;11(4):376-83.

OBJECTIVES: To evaluate parental experiences and satisfaction with Newborn Hearing Screening Wales, which was set up over 18 months in 2003-04 to provide an all-Wales neonatal hearing screening programme.

METHODS: A postal questionnaire was developed and piloted, then distributed to mothers of babies who had recently been screened.

RESULTS: General satisfaction levels were high. Women were less satisfied with the information provided than with staff or the test itself. Women whose babies had had no clear responses on initial screening were significantly more likely to feel that the test upset their baby ($P<0.05$) and that there were things they were unhappy with about the screening programme ($P<0.01$). These women also reported significantly more anxiety after screening than women whose babies had clear initial responses ($P<0.01$).

CONCLUSIONS: The survey results provide a baseline against which future user satisfaction surveys of neonatal hearing screening programmes can be evaluated. They highlight significant differences in user satisfaction between those whose babies had clear responses on initial screening and those who did not, and point to areas where improvement may be possible.

Reading and communication skills after universal newborn screening for permanent childhood hearing impairment.

Authors: McCann DC, Worsfold S, Law CM, Mullee M, Petrou S, Stevenson J, Yuen HM, Kennedy CR.

Source: Arch Dis Child. 2008 Nov 17.

BACKGROUND: Birth in periods with universal newborn screening (UNS) for PCHI and early confirmation of PCHI have been associated with superior subsequent language ability in children with permanent childhood hearing impairment (PCHI). However their effects on reading and communication skills have not been addressed in a population-based study.

METHODS: In a follow-up study of a large birth cohort in southern England, we measured reading by direct assessment and communication skills by parent report in 120 children with bilateral moderate, severe or profound PCHI aged 5.4 to 11.7 years, of whom 61 had been born in periods with UNS, and in a comparison group of 63 children with normal hearing.

RESULTS: Compared to birth during periods without UNS, birth during periods with UNS was associated with better reading scores (inter-group difference 0.39 SDs, 95% CI 0.02 to 0.76, $p=0.042$) and communication skills scores (difference 0.51 SDs, 95% CI: 0.06 to 0.95, $p=0.026$). Compared with later confirmation, confirmation of PCHI by age nine months was also associated with better reading (difference 0.51 SDs, 95% CI: 0.15 to 0.87, $p=0.006$) and communication skills, (difference 0.56 SDs, 95% CI 0.12 to 1.00, $p=0.013$). In the children with PCHI, reading, communication and language ability were highly correlated ($r=0.62$ to 0.84 , $p<0.001$).

CONCLUSION: Birth during periods with UNS and early confirmation of PCHI predict better reading and communication abilities at primary school age. These benefits represent functional gains of sufficient magnitude to be important in children with PCHI.

Newborn hearing screening: An outpatient model.

Authors: Griz S, Mercês G, Menezes D, Lima ML.

Source: Int J Pediatr Otorhinolaryngol. 2008 Dec 4.

OBJECTIVE: The purpose of this study was to assess the feasibility of implementing an outpatient model of a newborn hearing screening program with a particular focus on determining how compliance with the follow-up appointment related to specific socio-economic and demographic factors associated with the mother.

METHOD: Mothers who delivered their babies in public hospitals in Recife, northeast Brazil, were invited to participate in a two-step program. In Step 1 they were interviewed with regard to specific socio-economic and demographic factors, and then scheduled for a hearing screening test for their baby 1 month after discharge. In Step 2, the baby's hearing was screened using transient otoacoustic emissions.

RESULTS: A total of 1035 mothers consented to participate in Step 1, but only 149 returned to participate in Step 2 (14.3%). Analysis of the socio-economic and demographic factors indicated that mothers who did not comply with the scheduled newborn hearing screening (NHS) test generally had less than a high school education and came from primarily lower income families who lived in rural areas outside of Recife.

CONCLUSION: The results of this study highlight some socio-economic and demographic factors of the population of northeast Brazil that contribute to a low compliance rate for an outpatient model of a newborn hearing screening program. Possible solutions to the low compliance rate are considered.

PROJECT HIEDI

Project HIEDI is run by an independent group established in 2002 to see the introduction of a national newborn hearing screening and early intervention programme in New Zealand.

It has a Steering Team of volunteers, and a part-time Project Manager. The Steering Team is: Professor Peter Thorne (Project Leader), Dr Bill Keith, Dr Dianne Webster, Oriole Wilson, Margaret Cooper and Janet Digby (Project Manager).

For further information about Project HIEDI you can contact the Project Manager for HIEDI and author of these updates, Janet Digby by phoning (09) 445 6006 or e-mailing janet@levare.co.nz. You can also visit the Project HIEDI webpage on the [National Foundation for the Deaf website](#).

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