



Report of the Associate Director
2008

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1.0 Summary

This fourth report from Newborn Hearing Screening Wales shows that the screening programme continues to perform to the highest standards.

The screening results and results of assessment are reported for babies born in the financial year 2007 – 2008.

Results of the all Wales audit of permanent hearing loss are presented. The hearing status of babies diagnosed from the screen and achieved standards of habilitation for the period 1st April 2007 to 31st March 2008 and from the start of screening to 31st March 2008 are discussed.

Screening

The coverage rates are excellent with screening being offered to 99.9% of eligible babies and 99.3% tested, with very few parents declining the screen. The majority of sites located in the NHS Trusts throughout Wales perform the initial test within 7 days of birth, 77.4% of babies being screened within this time period, exceeding the target of 75%.

100% of high risk babies are completing the screening programme and 97.7% of well babies are completing screening within 4 weeks.

Assessment

An expected number of babies are being referred for assessment (1.5%) and the percentage of babies referred for assessment who are found to have normal hearing as a proportion of all babies screened is 0.7%, well within the 3% target. 87.4% of babies referred for assessment are completing the assessment process by three months of age.

The time taken to start the assessment process is within the allocated time for 90.3% of well babies and 96.2% of high risk babies. 92% of babies referred receive an assessment.

All Wales audit of permanent hearing loss

For the period 1st April 2007 until 31st March 2008, 1.2 per 1000 babies, eligible and suitable for screening, has been diagnosed as having permanent significant bilateral hearing loss (defined as greater than 40 dBnHL). The mean age of hearing aid fitting where appropriate was 19 weeks (allowing for prematurity) with 94% of babies fitted with hearing aids within 4 weeks of confirmation of the hearing loss. This figure has improved from 66% in the last report. 90% of babies had audiological confirmation by the age of 6 months.

Since the introduction of universal newborn hearing screening, the prevalence of permanent significant bilateral hearing loss (defined as greater than 40 dBnHL) has been found to be 1.4 per 1000 babies. The actual numbers are 182 diagnosed from the screening programme, 7 acquired hearing loss and 13 false negative screens. The mean age of hearing aid fitting to appropriate cases diagnosed from the screening programme was 34 weeks (median 19 weeks). This figure includes babies where the original decision not to fit hearing aids was altered after further information was gained about the hearing loss or parents reviewed their initial decision. Hearing aids were fitted within 4 weeks of confirmation of hearing loss in 67% of cases. Audiological confirmation by 6 months of age was achieved in 80%. The mean age of hearing aid fitting to those babies not identified by the screen was 120 weeks (30 months).

Yield, Sensitivity, Specificity and Predictive Value

Provisional figures regarding the yield from the programme indicate that the number of cases detected related to the total number of babies screened is 1:777. The sensitivity of the programme is 93.3% with a specificity of 98.7%. The predictive value of the screen is 9.3%.

2.0 Introduction

This report produced in January 2009 provides information on the performance of the newborn hearing screening programme over the financial year 2007 – 2008 and therefore reports on babies born between 1st April 2007 and 31st March 2008. The activity reported refers to trusts which were in place at that time and does not refer to more recent trust mergers. It is only available electronically from the screening programme and will be available on the website www.screeningservices.org/nbhs.

3.0 Results of screening

3.1 Standards

The table below outlines the standards set by the screening programme to monitor performance. As in previous years most of the standards have been met, some with slight improvement in the values achieved. Appendix 1 reports on results by NHS Trust and Appendix 2 on results by Local Health Board.

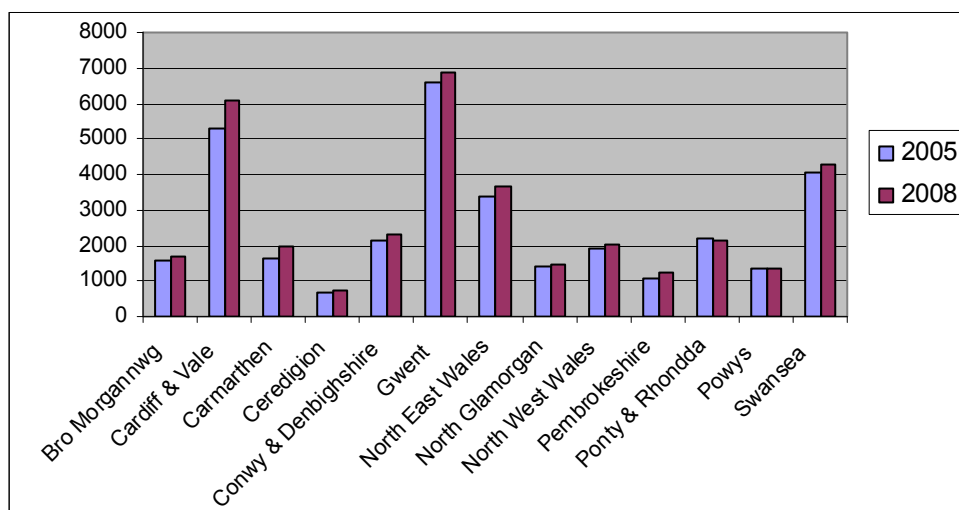
NBHSW Standards – Screening Programme						
Number	Objective	Criteria	Minimum Standard	Actual Value	Met	Variance From Previous Reporting Period
1	To maximise the number of babies who are offered screening	The percentage of eligible babies who are offered screening	>= 99% of all babies	99.9%	Yes	=
2	To maximise the number of babies who enter the screening programme	The percentage of eligible babies who enter the screening programme	>=95% of all babies tested	99.3%	Yes	=
3	To screen most babies within the first week of life.	The percentage of babies receiving the first screening test within the first week of life	>75% of those well babies screened	77.4%	Yes	-1.7%
4	To maximise the number of babies who complete the screening programme within the allocated time periods	Well babies - the percentage of babies who complete the screening programme within 4 weeks	>=90% of all babies entering the screening programme	97.7%	Yes	+0.8%
		High Risk babies in SCBU > 48 hours - the percentage of babies who complete the screening programme	>=95% of all High Risk babies entering the screening programme	100%	Yes	=
		All babies - the percentage of babies who complete the screening programme	>=95% of all babies entering the screening programme	100%	Yes	=

Number	Objective	Criteria	Minimum Standard	Actual Value	Met	Variance From Previous Reporting Period
5	To minimise the number of babies requiring a diagnostic ABR who have normal hearing	Those babies who are referred for diagnostic ABR with normal hearing	<3% of all those who complete assessment and are found to have normal hearing as a proportion of all babies screened	0.7%	Yes	+0.1%
6	To start the assessment procedure (diagnostic ABR) in appropriate cases within the allocated time	Well babies: Those babies that start assessment procedure within 4 weeks of the second screening episode	>=90% of those requiring assessment	90.3%	Yes	+7.9%
		High risk babies: Those babies that start assessment procedure within 8 weeks of AABR		96.2%	Yes	+2.3%
7	To complete the assessment procedure within the allocated time	Those babies that complete the assessment procedure by 3 months of age (in appropriate cases)	>=80% of those requiring assessment	87.4%	Yes	+0.9%
8	To minimise the number of babies who do not receive screening	The percentage of offered screening appointments which are not attended (well babies)	<=4% (<u>includes all DNA and cancelled appointments</u>)	5.8%	No	+0.6%
9	To minimise the number of babies who do not receive screening	The percentage of offered screening appointments which are declined (well babies)	< 1% of well babies	0.1%	Yes	-0.1%
10	To refer an appropriate number of babies for assessment	The percentage of screened babies referred for assessment	Between 1-2%	1.5%	Yes	+0.2%
11	To minimise the number of babies who do not receive an assessment	The percentage of offered assessment appointments which are not attended	< 10% (DNA appointments only)	14.8%	No	-3.2%
12	To minimise the number of babies who do not receive an assessment	The percentage of babies who are referred for assessment and not seen	< 5%	8.4%	No	=

Number	Objective	Criteria	Minimum Standard	Actual Value	Met	Variance From Previous Reporting Period
13	To refer an appropriate number of babies for a repeat screen from audiology (one ear clear response, well babies)	The percentage of babies referred	< 1%	1.6%	No	+0.2%
14	To refer an appropriate number of babies for targeted behavioural test	The percentage of babies referred	< 1%	0.5%	Yes	=

3.2 Birth rate

It is worth noting that the birth rate has increased by 4,000 since screening started in 2003. It had been predicted that birth rate in Wales was likely to fall but there has been a steady increase with approximately 1000 more births in the last year alone. The graph below shows the spread of the increase recorded by NBHSW.



3.3 Meeting the standards

Overall, the screening programme meets and exceeds the standards set. However the attendance rate for screening continues to fall short of the standard but very few eligible babies are not screened. Although the aim is to perform community screens in the home where possible, in some areas it has been necessary to implement clinics for this purpose which also impacts on attendance rates. The number of appointments not attended has increased with a cost impact on the programme. This will continue to be monitored. Whenever possible, screening should be completed in hospital.

The standards associated with attendance for assessments have not been met. Although the attendance rate has improved, it still falls short of the target of less than 10% of appointments not attended. The number of babies being seen for assessment remains at 92% of those referred despite the implementation of improvements to information given to

parents, flexible appointment booking and phone contact with parents and Health Visitors. Sites need to review their own non-attendance figures in the table "Time taken to complete assessment" in Appendix A. Further work needs to be undertaken by NBHSW to identify reasons for non-attendance at appointments. There are sites which have achieved good rates of attendance over the last two years and it will be useful to identify and develop areas of good practice. However, there has been improvement in the number of well babies that start the assessment within 4 weeks of referral. This standard has been met for the first time since screening started. Surveys of parents have shown that receiving an early appointment reduces anxiety. In general, Powys, whose babies are assessed in Wrexham and Gwent, shows the most improvement in a number of standards.

Audiology staff also undertake a further screen, on parental request, for those babies who have a clear response in only one ear. Although we wish to respond to parental anxiety, the screening programme aims to provide appropriate information to keep the number of referrals to a minimum. Gwent still receives the highest number of referrals but the reason for this is unclear. This will be discussed further at a local team meeting.

Babies who are not screened by the programme or who move into the area are referred by the programme for a targeted behavioural test (testing at 7 to 8 months). Cardiff has the highest referral rate again this year, leading to a significant workload for the community audiology department. This reflects the number of babies discharged early from hospital in Cardiff requiring community visits, which increases the non-attendance rate and consequently, the number of babies not receiving screening.

The standards can be judged as being appropriate monitoring tools, however activity figures may not be an effective judge of quality. NBHSW reviews quality within the programme with the Quality Advisory Board. Site visits have been undertaken between May and December 2008. This Quality Assurance will be reported in a separate report in 2009.

4.0 Screening report

4.1 Screening equipment

The Echoport replacement programme commenced in November 2008 and will be rolled out across the service during the early part of 2009. The Echoports are being replaced with Otoport, a handheld device which no longer relies on a laptop to record the information. This will remove the frequent problem of loss of connection between the laptop and Echoport experienced by screeners when using the Echoport. The data from the Otoport is uploaded at the end of each screening session to the Trust server and results imported into the NBHSW module of the Child Health System. The data is then deleted from the Otoport which enables a higher level of data security for the programme. The Otoports, being significantly more portable, also address some of the Health and Safety issues relating to transporting the equipment into the community.

4.2 Information Technology

The NBHSW information system is currently being developed to allow automatic loading of results from the Automated Auditory Brainstem Response (AABR) test equipment and it is hoped that this will be implemented in the early part of 2009.

Programme Managers and Administration staff continue to access the English Information System and to liaise with their colleagues in England for babies screened across the border which is crucial where further follow up is required.

The NBHSW model is also now available for professionals to view on the Map of Medicine in Wales.

4.3 Staffing

Screeners continue to undertake flexible working within Divisions in order to ensure continuity of a quality service in times of staffing shortage, as sickness and maternity leave continues to be a source of pressure for the service.

The provision of screening in Powys is to change during 2009. Currently screening is provided by Community Midwives who have been trained in newborn hearing screening. In order to ensure provision of a more easily managed service in Powys and ensure a uniform service throughout Wales, a decision was taken to split Powys service provision between the three NBHSW Divisions. This will mean that North East Powys will be served by North Wales Division and screening in South and West Powys will be delivered by screeners from Mid and West and South East Divisions. Additional screening hours will be allocated to allow for this and the recruitment process has commenced where appropriate, to enable the change to be implemented on 1st March 2009.

4.4 Training

In conjunction with the MRC Hearing and Communication Group, work has been undertaken this year to adapt the English e-learning system for use in Wales. It is hoped that once fully implemented this will reduce the heavy resource implications for management currently involved in training new screeners.

An accredited learning package was developed for the screeners in an effort to provide a structured career path and motivation following the disappointing results of Agenda for Change pay review. Existing screeners were able to apply to undertake an accelerated programme to complete the qualification in six months and the first cohort will complete their final assessment in December 2008. It is envisaged a second accelerated cohort will commence study in March 2009. Screeners who successfully complete the package will be eligible to apply for a Screener I post which will include additional responsibilities and is therefore a higher pay band, thus providing career progression and hopefully aiding screener retention.

Development and implementation of the package has taken up a significant amount of management time as Divisional Coordinators and Programme Managers are required to mentor students and mark assessments. This work has been intensive and the benefits will be reviewed following completion of the first cohort.

5.0 All Wales audit of permanent hearing loss

5.1 Habilitation: 1st April 2007 to 31st March 2008

NBHSW Standards – Habilitation Babies born between 1st April 2007 and 31st March 2008					
No	Objective	Criteria	Minimum Standard	Actual	Met
1	To confirm hearing loss within the allocated time	The percentage of babies who have audiological confirmation by the age of 6 months (not allowing for prematurity)	80% of those babies diagnosed by the screening programme as significantly hearing impaired.	90 %	YES
2	To offer hearing aids to appropriate cases within the allocated time	The percentage of those babies diagnosed as significantly hearing impaired who have hearing aids offered by the age of six months (allowing for prematurity).	90% of those offered hearing aids diagnosed from the screening programme.	81%	NO
3	To fit hearing aids to appropriate cases within the allocated time	The percentage of appropriate cases fitted with hearing aids within 4 weeks of decision to aid The percentage of those babies diagnosed as significantly hearing impaired who have hearing aids fitted by the age of six months (allowing for prematurity)	>=99% of those appropriate cases diagnosed from the screening programme.	94%	NO
			75% of those fitted with hearing aids diagnosed from the screening programme.	71%	NO
4	To ensure that appropriate habilitation services and facilities for audit are in place	The establishment and regular meetings of a multidisciplinary group monitoring services in each area. (Children's Hearing Services Working Group)	100%	100%	YES

The standards reported above have been revised since the last annual report to ensure that the description of the criteria is entirely accurate. There is a slight fall in the number of babies achieving confirmation of hearing loss by 6 months but the mean age of confirmation only increased from 10 weeks to 12 weeks. The target for fitting hearing aids within 4 weeks of decision to aid is hard to achieve but there has been a significant increase from 66% to 94%. A new standard reported is the percentage of those offered hearing aids by the age of 6 months, as audiologists felt that would allow parental choice to be reflected in the activity figures. 81% were offered hearing aids by 6 months, 71% were fitted by 6 months. In the last annual report the target for fitting hearing aids by 6 months was met, with 88% achieving this target.

Division	Average age of confirmation of hearing loss	Average age of hearing aid fitting (allowing for prematurity)
North Wales	12.3 weeks	13.7 weeks
Mid and West Wales	9.1 weeks	17.5 weeks
South Wales	13.8 weeks	22.4 weeks
Wales	12.2 weeks	19.1 weeks

5.2 Habilitation since the start of screening

NBHSW Standards – Habilitation over 4 years				
No	Objective	Criteria	Minimum Standard	Actual
1	To confirm hearing loss within the allocated time	The percentage of babies who have audiological confirmation by the age of 6 months (not allowing for prematurity)	80% of those babies diagnosed by the screening programme as significantly hearing impaired.	80%
2	To offer hearing aids to appropriate cases within the allocated time	The percentage of those babies diagnosed as significantly hearing impaired who have hearing aids offered by the age of six months (allowing for prematurity).	90% of those offered hearing aids diagnosed from the screening programme.	67%
3	To fit hearing aids to appropriate cases within the allocated time	The percentage of appropriate cases fitted with hearing aids within 4 weeks of decision to aid	>=99% of those appropriate cases diagnosed from the screening programme.	66%
		The percentage of those babies diagnosed as significantly hearing impaired who have hearing aids fitted by the age of six months (allowing for prematurity)	75% of those fitted with hearing aids diagnosed from the screening programme.	60%

Since the start of screening, 1.3 per 1000 babies screened (numbering 182) have been identified as having permanent significant bilateral hearing loss (defined as greater than 40 dBnHL). The mean age of identification of hearing loss was 22 weeks. Prior to the introduction of screening, the mean age of identification was 22 months in Trusts where figures were recorded.

The mean age of hearing aid fitting to appropriate cases was 34 weeks (median 19 weeks). This figure includes babies where the original decision not to fit hearing aids was altered after further information was gained about the hearing loss, or parents reviewed their initial decision. Audiological confirmation was achieved by 6 months in 80%, and 60% had hearing aids fitted by 6 months. 67% had hearing aids fitted within 4 weeks of audiological certainty.

These figures are similar to those achieved in the previous report but with a slightly lower percentage recorded in all reported activity with the exception of time taken to fit hearing aids. This reflects the reported activity of 2007 – 2008 being included in the amalgamated total over 4 years. Year to year variation is expected but it is hoped that the next report will demonstrate a positive trend. It should be noted that the targets are set to a very high standard.

5.3 Divisional Incremental Yield Plots

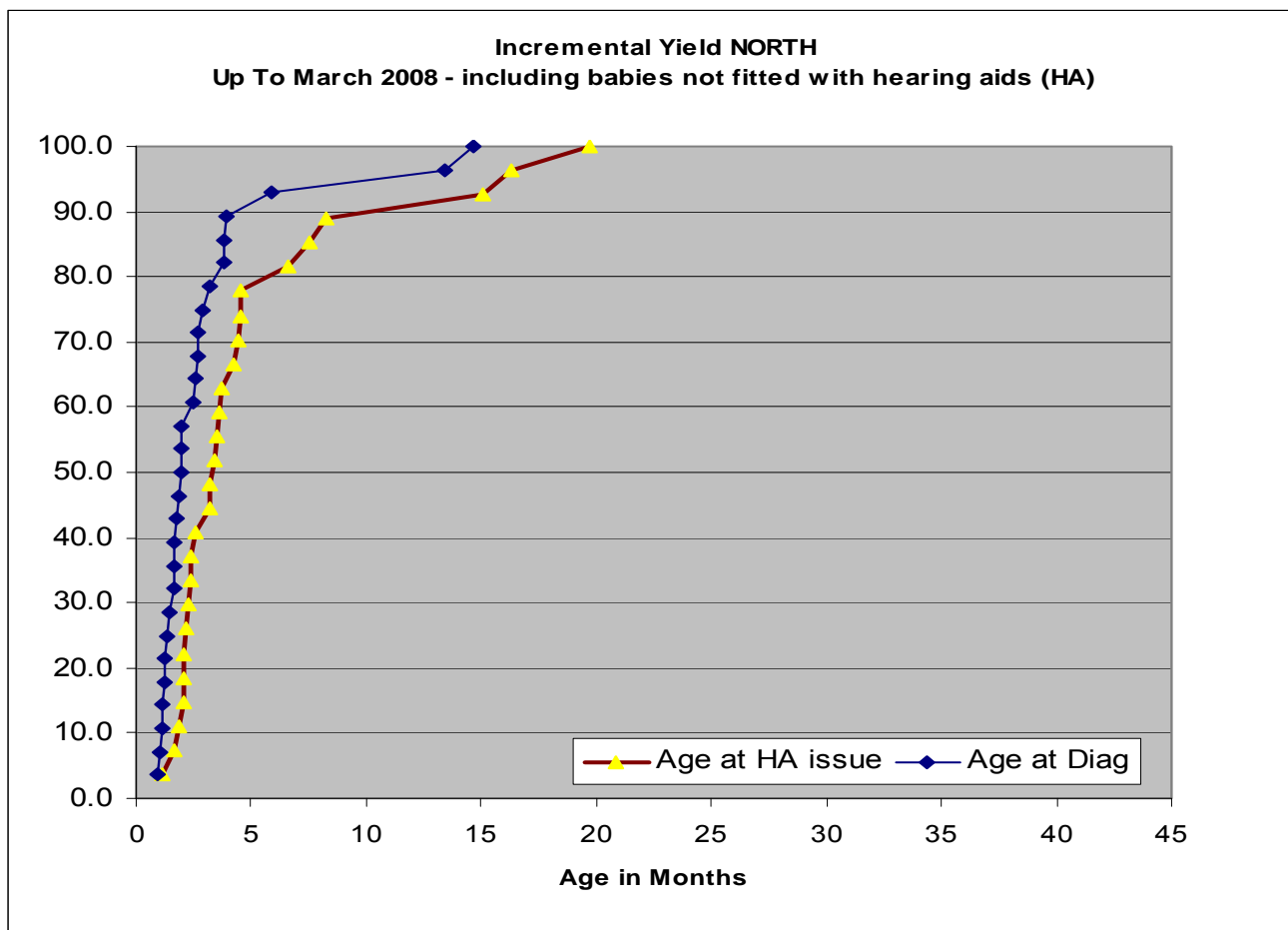
Incremental yield plots have been used to illustrate the age of diagnosis and the age of hearing aid fitting. The graphs below show the performance of each division. The 50th centile on the vertical axis marks the median age of hearing aid fitting which can be read off the horizontal axis in months. The graphs demonstrate the spread of age of diagnosis and hearing aid fitting, allowance having been made for prematurity.

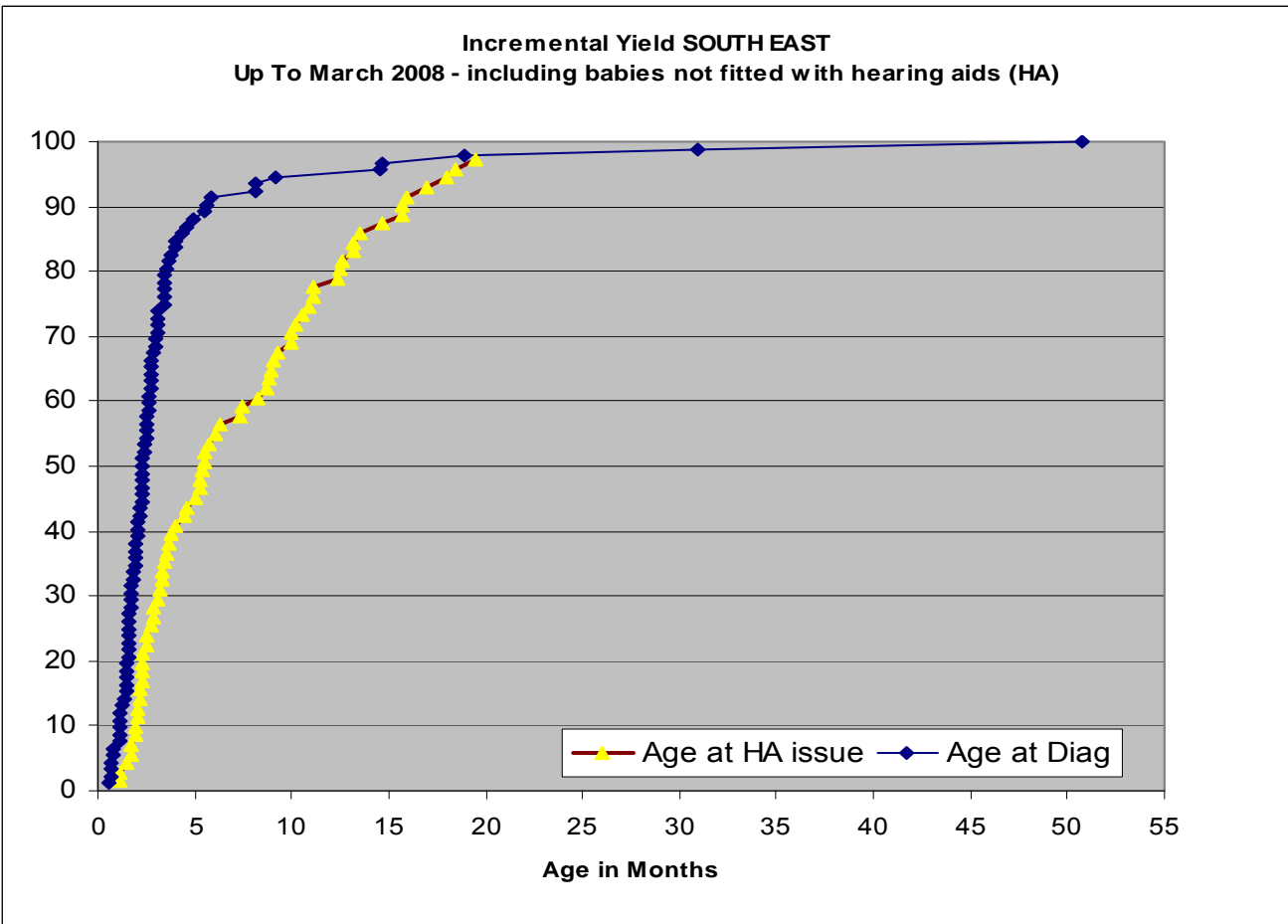
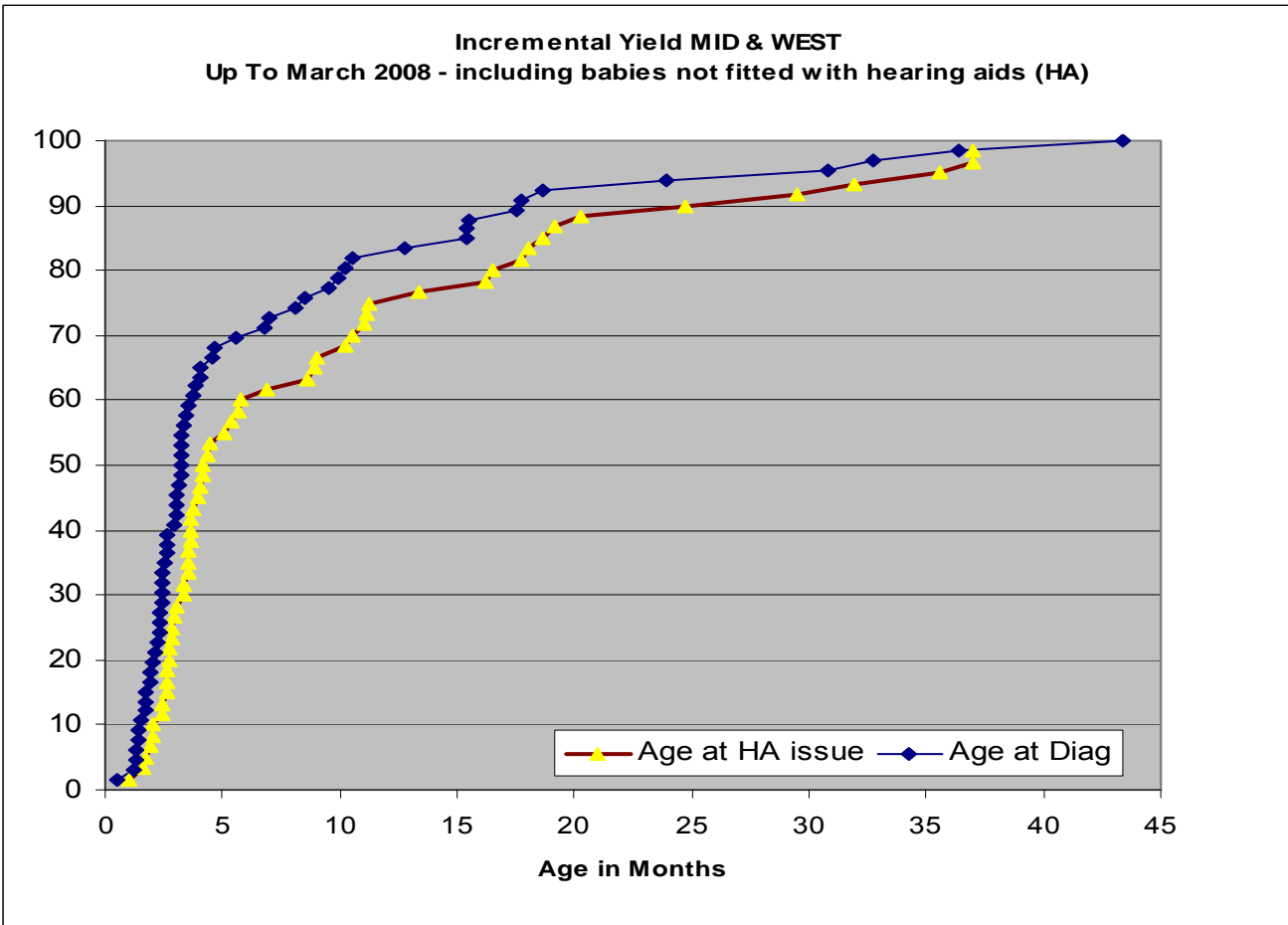
In NBHSW babies are deemed to have been diagnosed by the screening programme if they have been followed up by the audiological department since diagnostic testing. Hearing aid fitting may be shortly after birth or months later as further audiological information is obtained or parents change their minds about hearing aid fitting. The plot of age of diagnosis includes all babies whether or not hearing aids are fitted.

In South East Wales, the two plots separate as proportionally more babies in this division are diagnosed early and do not have hearing aids fitted and the median age of hearing aid fitting is later. In Mid and West and South East Divisions there are a few babies with later confirmation of significant hearing loss. These exceptional cases are due to reasons such as progressive hearing loss or very ill baby. Case reviews have been undertaken to identify any improvements that could be made to procedures.

Division	Average age of hearing aid fitting	Median age of hearing aid fitting
North Wales	21.3 weeks	14.6 weeks
Mid and West	41.9 weeks	18.4 weeks
South East Wales	32.7 weeks	23.6 weeks
Wales	34.3 weeks	18.9 weeks

Incremental Yield plots showing age at diagnosis and age of hearing aid (HA) issue.



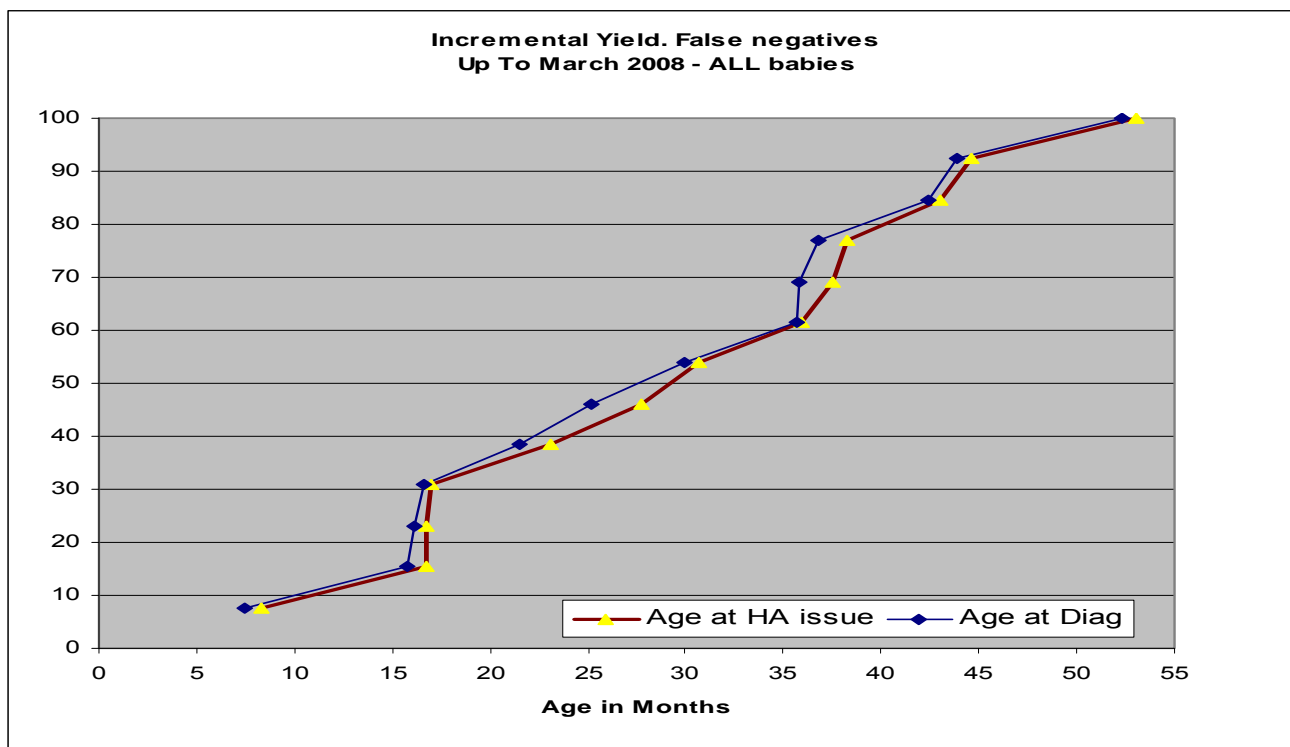


5.4 Prevalence of hearing loss in Wales

Since the start of screening, records have been kept on all babies diagnosed as hearing impaired under the age of 5 years. Those children diagnosed out with the screening programme include false negatives, acquired hearing loss (mainly meningitis) and movement into Wales of children diagnosed elsewhere. As we can assume that some of our hearing impaired children will leave Wales, we at present do not include these “movement in” in the population figures. Using this information, the prevalence of permanent bilateral hearing loss in children under 5 years appears to be 1.4 per 1000.

5.5 False negatives

The following incremental yield plot illustrates the delay that takes place in diagnosis if the babies are not identified by the screen. Further children may be identified in the future.



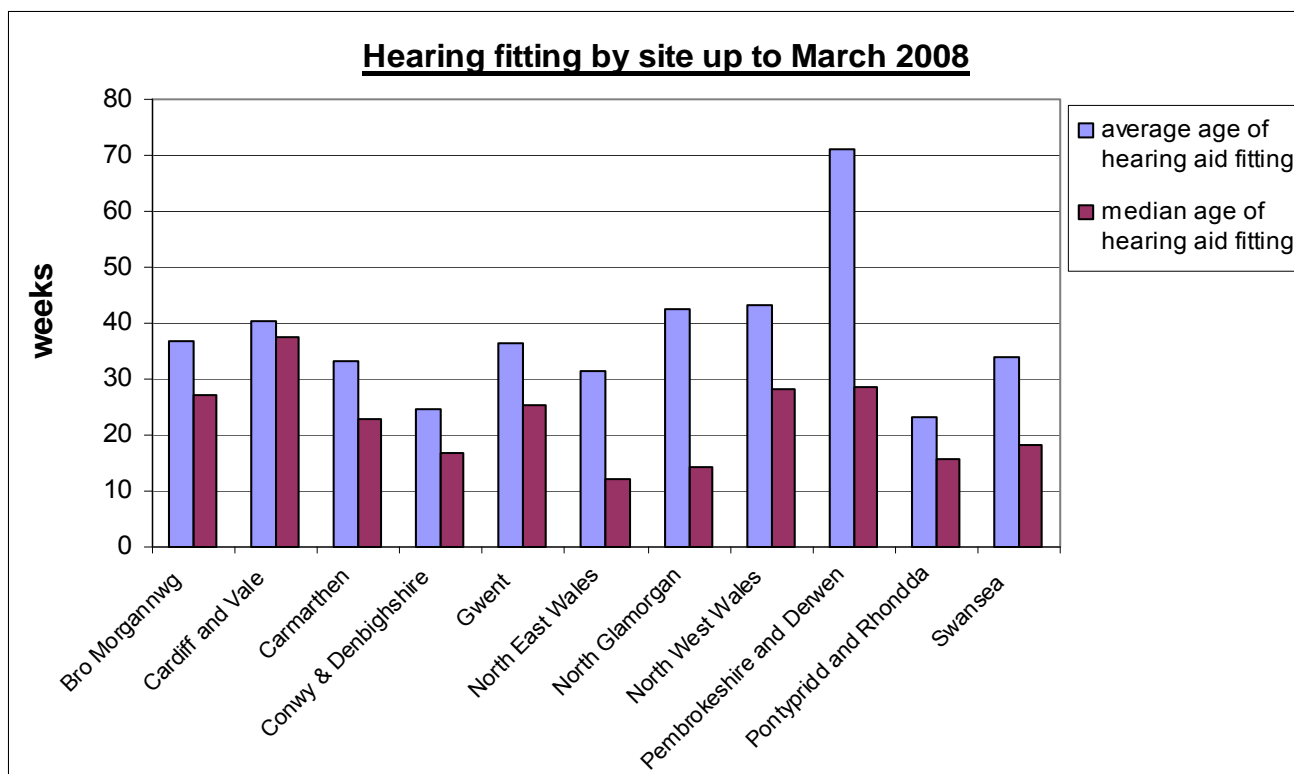
The programme has reviewed the cases of those babies missed by the screen and the reasons for are in the following table.

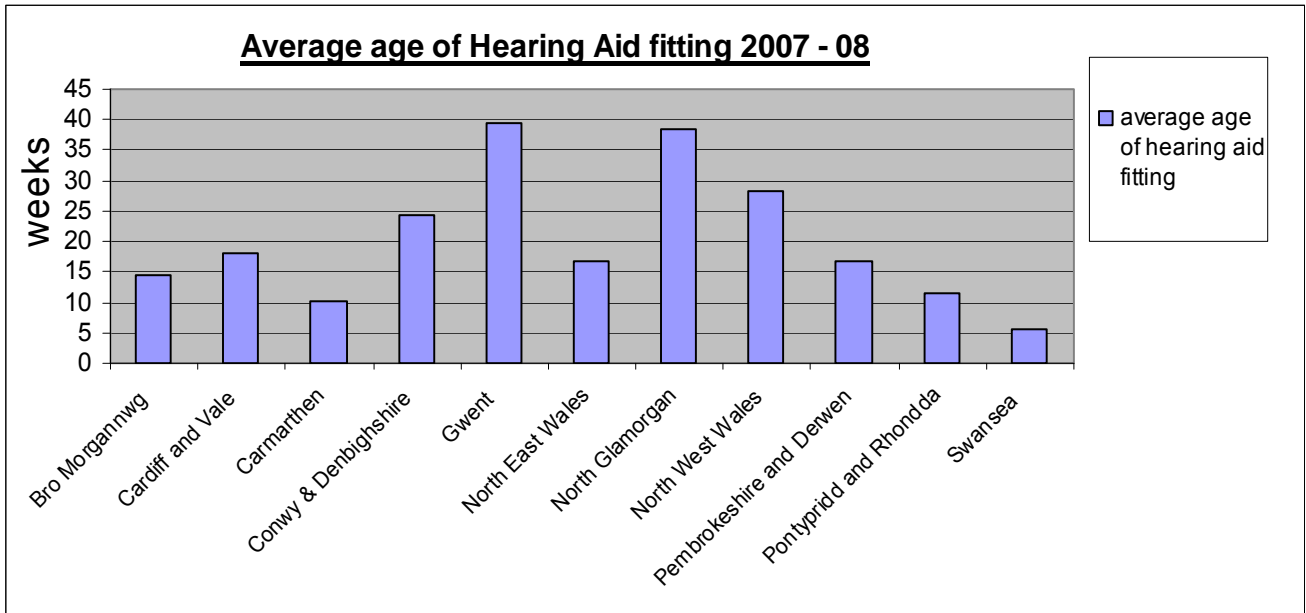
Number of children	Reason for failure to identify to identify hearing loss
6	High risk babies screened in SCBU. Passed AABR screen using equipment which has since been replaced due to concern about performance
3	Well babies passed screen in one ear using AOAE
1	Well baby passed screen in both ears
1	Well baby passed screen in both ears since diagnosed as auditory neuropathy spectrum disorder
1	Screeener error in recording results
1	Communication failure, not reappointed for repeat screen following meningitis under 6 weeks

As mentioned in the table above, one of the missed babies has been diagnosed with auditory neuropathy spectrum disorder. Section 7 outlines some of the issues related to this condition.

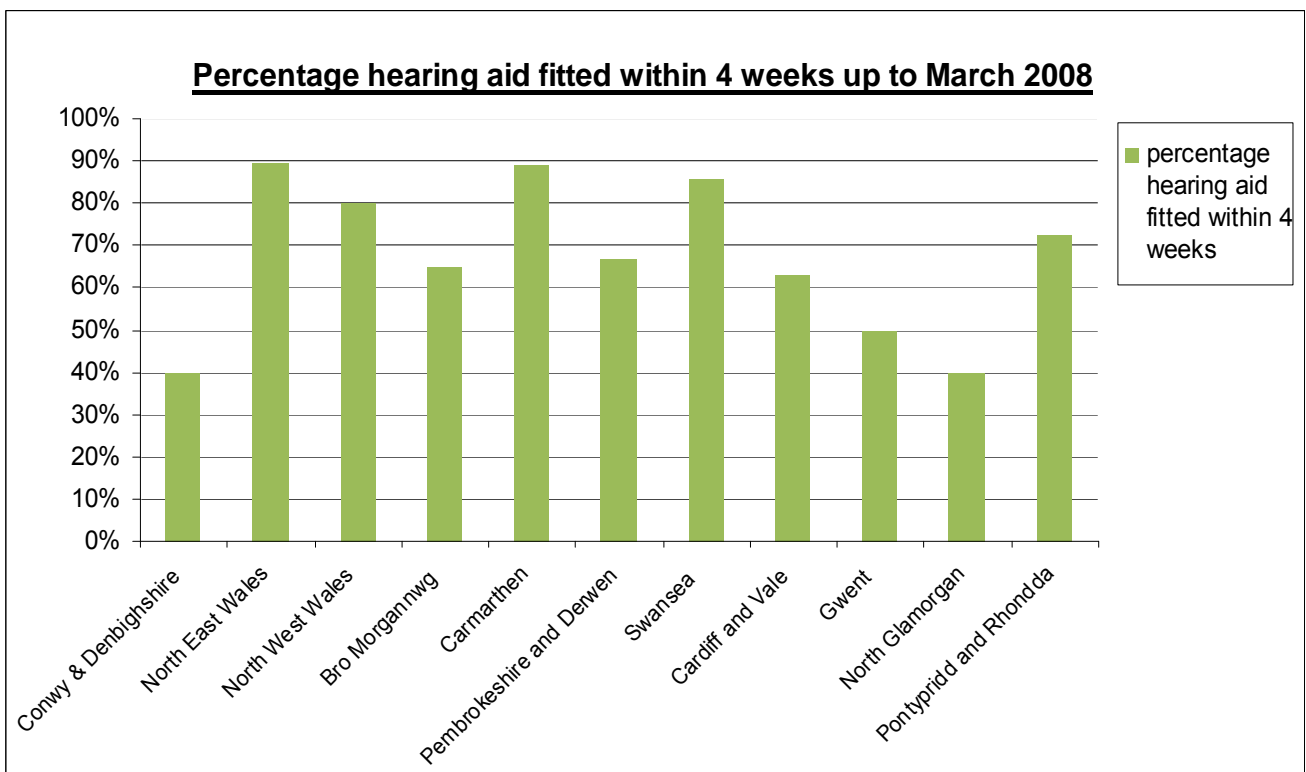
6.0 Age of identification and hearing aid fitting by site

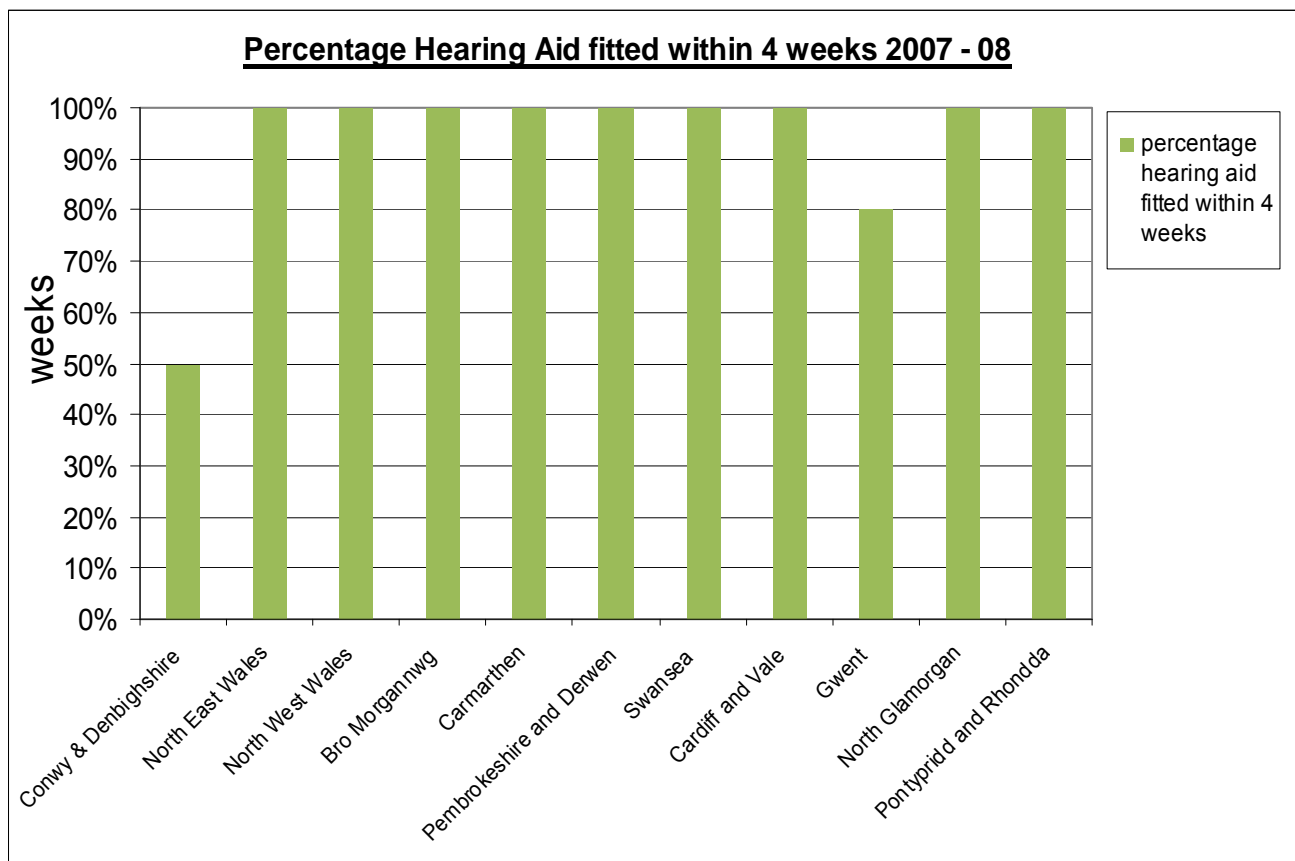
The graphs below show site activity. Trends are beginning to emerge which have formed the basis of quality assurance discussions during site visits. North Glamorgan babies receive final assessment and hearing aid fitting in Cardiff. The number of babies fitted with hearing aids in most sites in one year is too small to provide meaningful data but is of interest to sites.





The graphs below show the percentage of hearing aids fitted within 4 weeks of decision to aid. The second graph demonstrates the improvement in most sites over the last year. Again, small numbers in some sites need to be considered.





7.0 Auditory Neuropathy Spectrum Disorder

Auditory Neuropathy Spectrum Disorder (ANSD) is an uncommon hearing disorder in which the cochlea or inner ear receives sound normally but the transmission of signals between the cochlea and the auditory nerve or along the nerve is disorganised. This usually results in some degree of hearing loss, ranging from mild to profound. Other features include a fluctuation in hearing levels over time, poor speech perception, particularly in noise and worse speech perception than may be predicted from the degree of hearing loss. The prevalence of ANSD in the paediatric population is unknown; it occurs rarely in the well-baby population, but is identified more commonly in the high risk population, being thought to affect about 1 in 10 of those identified with a hearing loss in this group. 10% of the babies identified as having hearing loss in Wales have been diagnosed as ANSD. The condition presents a challenge for the newborn hearing screening programme at both the screening and the assessment stages, and for local services with regard to subsequent management of babies with the condition.

7.1 Implications for hearing screening

The aim of the newborn hearing screen is to identify babies with a permanent hearing loss. Both tests used to screen babies' hearing should identify a baby with permanent hearing loss in over 95 out of 100 cases.

The AOA (automated oto-acoustic emissions) test detects an acoustic signal from the cochlea which is evoked in response to a click stimulus delivered into the ear. The presence of an OAE suggests normal cochlear (outer hair cell) function.

The AABR (automated auditory brainstem response) detects electrical activity in the auditory pathway in the brainstem, also in response to a click stimulus.

In ANSD, while OAE's are usually present, the ABR is either absent or grossly abnormal at high stimulus levels. AABR is the screening test of choice for the high risk baby population because ANSD is more common in this group, so those with the condition would, by default, be referred for assessment even though ANSD is not a target condition for the programme. However, as AAOE is the primary test used to screen the well-baby population, a well baby who had ANSD would be likely to pass the screen (a screen false negative) and remain unidentified at an early age.

7.2 Implications for hearing assessment

Hearing assessment in very young babies is a skilled and, at times, complex procedure. A baby with either an absent or grossly abnormal ABR at high stimulus levels may have ANSD, and investigations to differentiate between this and sensorineural (cochlear) hearing loss need to be performed. Audiologists have had to develop new skills and become familiar with new test techniques to allow them to carry out comprehensive assessments, enabling them to identify babies with this uncommon condition.

7.3 Implications for management

When a baby has been identified with ANSD, the subsequent management can prove to be the most challenging aspect of care. Enabling parents to understand the nature of ANSD is difficult, so NBHSW have developed an information leaflet for parents to help this process. There is no consensus among professionals with regard to which children will benefit from amplification in the form of hearing aids or which may benefit from cochlear implantation. Multi-disciplinary working with a focus on communication development will certainly be an important factor. As more is understood about the condition and Early Years teams look after more children with ANSD, hopefully the most appropriate approaches to management will be agreed. The condition was discussed by delegates and a panel of experts at the recent international newborn hearing screening conference in Italy and a consensus document is awaited which should provide further guidance.

8.0 Quality Assurance

Over the last 6 months NBHSW has completed site visits to the 11 sites undertaking newborn hearing assessments. The visits reviewed quantitative and qualitative data and benchmarked each site with the other sites in Wales. The aim of the visit was to identify best practice in completing Newborn Hearing Screening Wales assessments and quality assure Paediatric Audiology services provided to children under 2 years of age.

The outcome of the meeting was a short report and action plan as agreed at the meeting which was sent to the Chief Executive of the trust. Standards and targets for Newborn Hearing Screening Wales assessments and service provision for early years have been revised and can be viewed in Appendix 3. A full report on the site visits will be available in 2009. This will include action plans and report on progress since the site visits.

The proposed trust mergers will no doubt change the location of assessments in some areas of Wales as well as responsibilities and roles within departments. NBHSW would wish to participate in discussions where outcomes will affect services for young children.

Quality management is integral within the management structure of the programme. The Quality Advisory Group gives direction and advice to the screening programme regarding matters of quality. Over the last year the advisory group has requested:

- A review of audiology services provided to NBHSW throughout Wales. A summary to be presented to the group in January 2009.

- A review of standards used to quality assure newborn hearing screening.
- Discussion with Heads of Audiology to ensure the quality of Paediatric services following trust mergers and to encourage the development of guidelines regarding hearing aid fitting to young babies.
- A review of babies diagnosed with auditory neuropathy spectrum disorder.
- Continued efforts to flag up concerns around services in South Powys.
- Continued development of screener training with the introduction of a BTEC qualification.
- Further development of user surveys to increase knowledge about non-attendance at assessment appointments, views of families attending assessments and the views of ethnic minorities.
- Review of information provision following assessment.
- A report from the Task and Finish Group looking at outcome measures for the programme to be considered by the All Wales Management Group (January 2009).
- Continued promotion of provision of information about hearing screening antenatally.
- The programme to work closely with the project developing bloodspot screening.
- Further information on the development of paediatric standards.

9.0 Professional training

NBHSW arranges two training days each year which are attended by Audiologists or Professional Leads with some professionals attending both. The audiology training day focussed on the assessment pathway, application of estimated hearing level in the management plan and the use of clicks versus tone pips for the initial assessment test. A session was also led by Christine Cameron from the MRC on hearing aid fitting in young babies.

The professional lead day reviewed the audits which had been completed on Children's Hearing Services Working Groups and aetiological investigations. Discussions took place around outcome measures and the hearing impaired database. Training was also provided for technical supports on the Otoport which replaced the Echoport in a phased roll out starting in November 2008.

10. Audit, presentations and publications

The audiologists undertake peer review on each NBHSW assessment and an audit is to be undertaken on the effectiveness of the process by Rhys Meredith from Singleton Hospital.

Representatives of NBHSW attended an international conference in June 2008 and presented 4 posters:

- Accuracy of information underpins Quality Management. Report from Newborn Hearing Screening Wales.
- Language and communication outcomes for early – identified children: supporting a standardised approach
- Report from Newborn Hearing Screening Wales
- Parental Experiences of the Newborn Hearing Screening Programme in Wales: a Postal Questionnaire Survey.

These can be seen on the website.

Two presentations were also given at this conference, one on the results of the screening programme by Sally Minchom and another on “Ensuring quality of audiological assessment” by Michelle Dodd from Glan Clwyd Hospital.

Presentations were also given at the annual screening conference in London and at Audiology Cymru. Newborn hearing screening featured in the CARIS annual report 2008.

A paper entitled “Parental experiences of the newborn hearing screening programme in Wales; a postal questionnaire survey” by Rosemary Fox and Sally Minchom has been published in Health Expectations, Vol 11, pp 376 – 383.

Appendix 1 NBHSW All Wales Results by NHS Trust

Total live births, eligible and suitable, consenting and tested by Trust & risk status

Standards:

>=95% of eligible babies who enter the screening programme (ie consenting and tested)

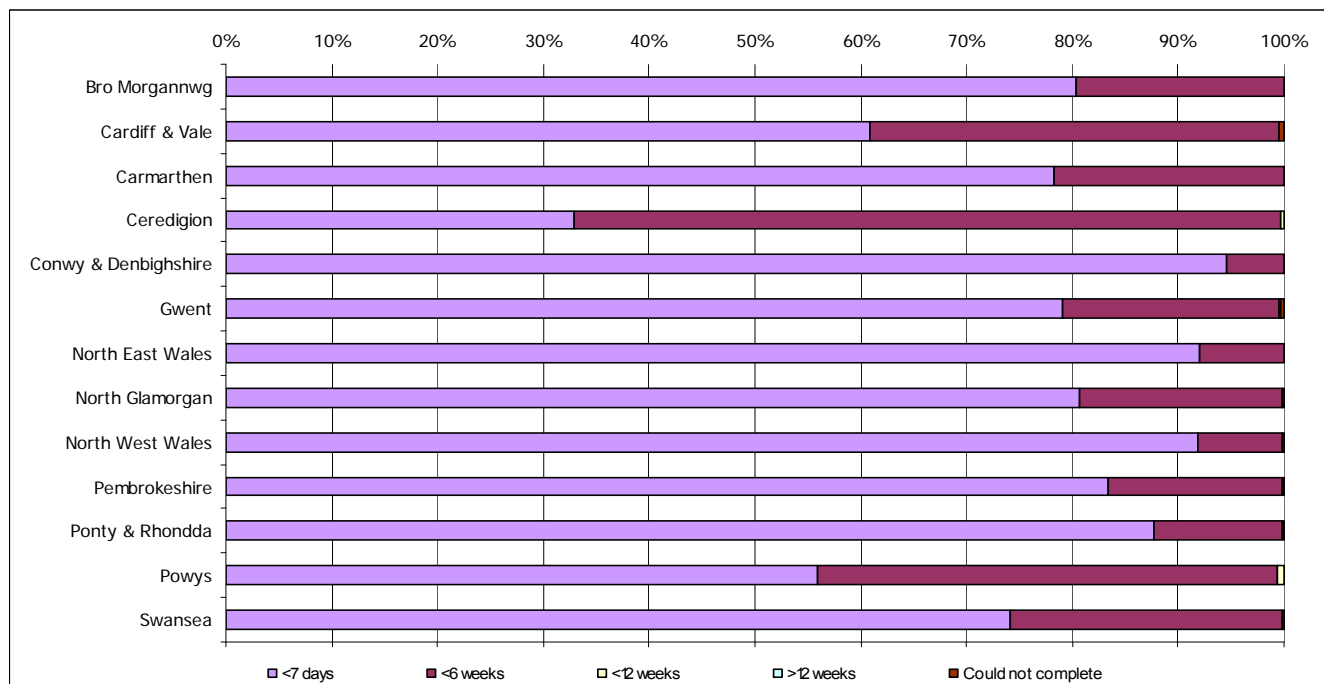
>=99% of eligible babies to be offered screening

NHS Trust	Births	Eligible and Suitable	Consenting & Tested	% Tested of eligible and suitable	Total Offered Screening	% Offered of eligible and suitable
Bro Morgannwg	1674	1645	1632	99.2%	1641	99.8%
Cardiff & Vale	6111	5874	5756	98.0%	5872	100.0%
Carmarthen	1944	1922	1914	99.6%	1921	99.9%
Ceredigion	752	738	729	98.8%	738	100.0%
Conwy & Denbighshire	2286	2235	2233	99.9%	2235	100.0%
Gwent	6876	6697	6647	99.3%	6694	100.0%
North East Wales	3688	3608	3604	99.9%	3608	100.0%
North Glamorgan	1476	1459	1451	99.5%	1458	99.9%
North West Wales	2048	2000	1996	99.8%	2000	100.0%
Pembrokeshire	1236	1213	1201	99.0%	1210	99.8%
Ponty & Rhondda	2161	2115	2112	99.9%	2114	100.0%
Powys	1364	1340	1330	99.3%	1336	99.7%
Swansea	4302	4201	4180	99.5%	4199	100.0%
All Wales Total	35918	35047	34785	99.3%	35026	99.9%

Well babies receiving first test within seven days of birth

Standard:

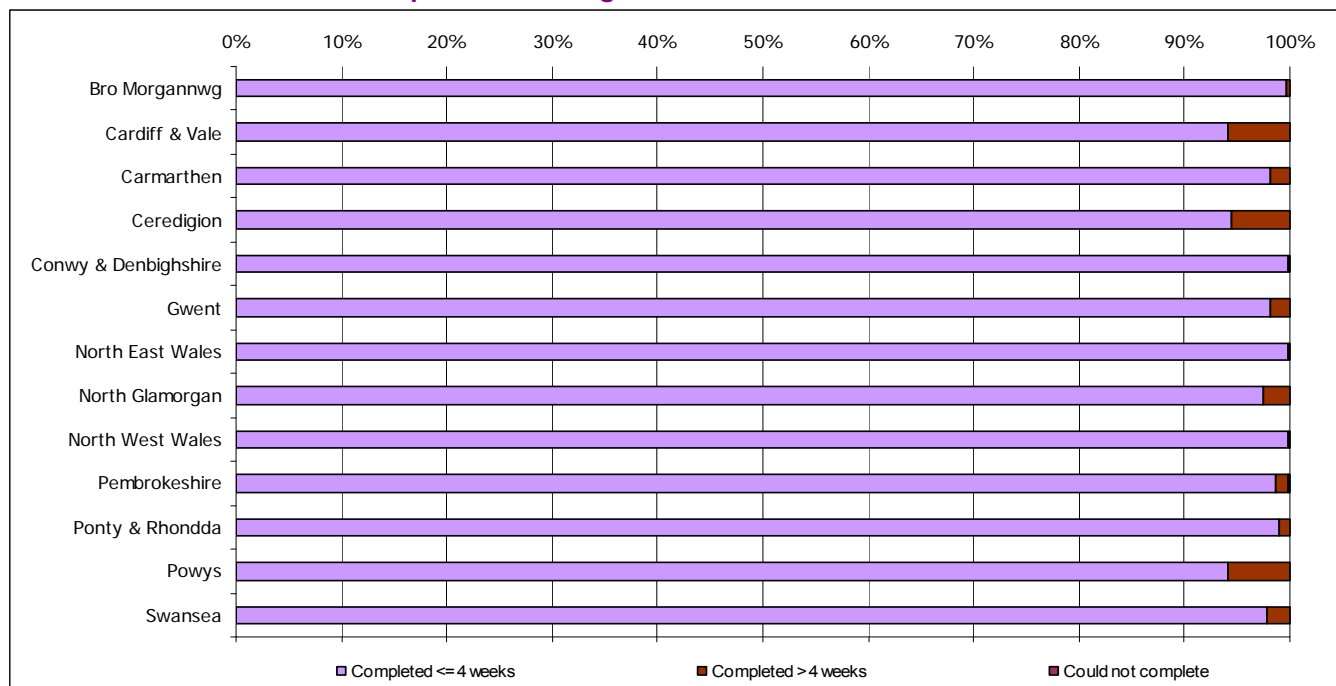
To screen > 75% of well babies within the first seven days



Well babies completing screening within 4 weeks

Standard:

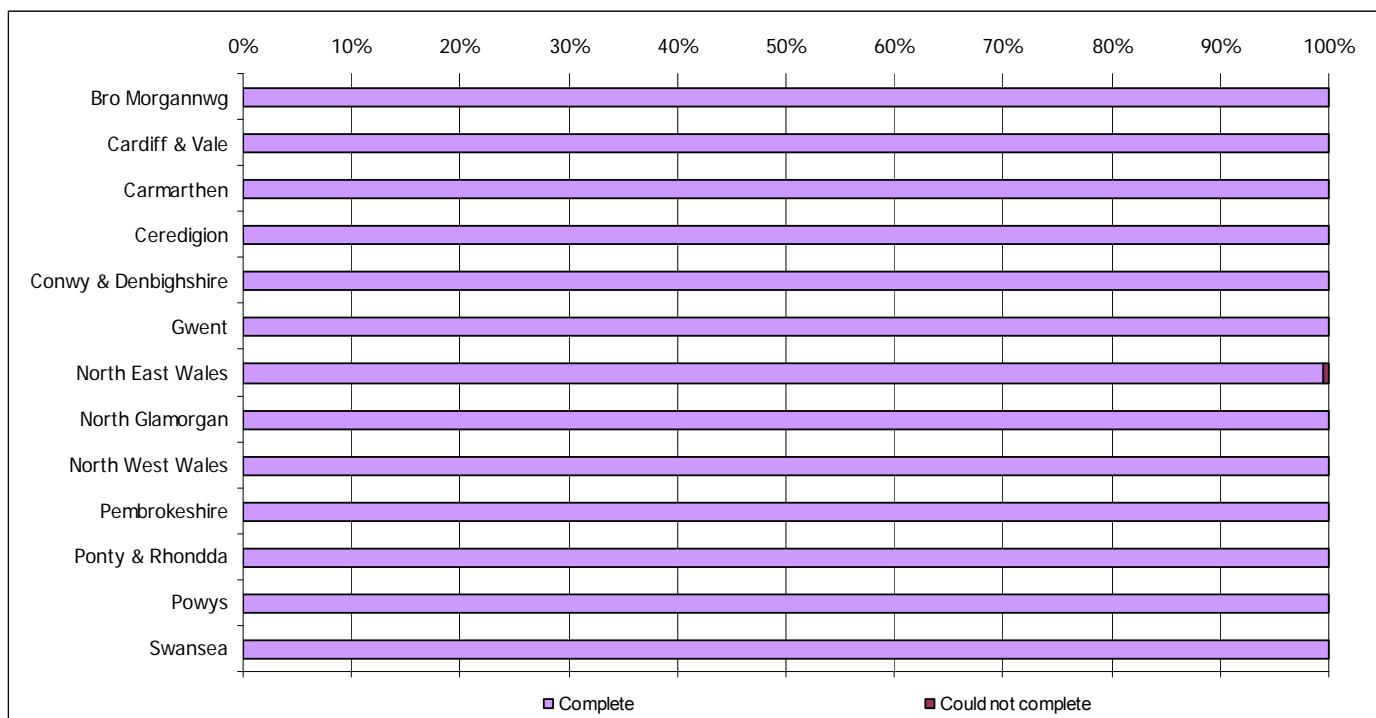
>= 90% of well babies to complete screening within 4 weeks



High risk babies completing screening

Standard:

>= 95% high risk babies (in SCBU > 48 hours) to complete screening



Attendance rates for screening appointments

Standard:

<=4% not attended (includes all DNA and Cancelled appointments)

<1% of offered screening appointments which are declined

	NUMBERS				PERCENTAGES		
	Attended	DNA or Cancelled	Parent Declined	Total	Attended	DNA or Cancelled	Parent Declined
NHS Trust							
Bro Morgannwg	1828	58	0	1886	96.9%	3.1%	0.0%
Cardiff & Vale	6720	842	5	7567	88.8%	11.1%	0.1%
Carmarthen	2152	69	6	2227	96.6%	3.1%	0.3%
Ceredigion	772	107	7	886	87.1%	12.1%	0.8%
Conwy & Denbighshire	2465	59	2	2526	97.6%	2.3%	0.1%
Gwent	7828	550	4	8382	93.4%	6.6%	0.0%
North East Wales	4159	82	2	4243	98.0%	1.9%	0.0%
North Glamorgan	1614	103	1	1718	93.9%	6.0%	0.1%
North West Wales	2202	65	3	2270	97.0%	2.9%	0.1%
Pembrokeshire	1364	32	9	1405	97.1%	2.3%	0.6%
Ponty & Rhondda	2480	56	0	2536	97.8%	2.2%	0.0%
Powys	1471	28	4	1503	97.9%	1.9%	0.3%
Swansea	4782	274	4	5060	94.5%	5.4%	0.1%
All Wales Total	39837	2325	47	42209	94.4%	5.5%	0.1%

Referrals for assessment

Standards:

Between 1-2% of screened babies referred for assessment

< 3% of babies complete assessment with normal hearing as proportion of all babies screened

	Total Babies Screened	Referred for Assessment	% of Screened Babies Referred for Assessment	Discharged from Assessment Normal Hearing	% Discharged from Assessment as Proportion of Babies Screened
NHS Trust					
Bro Morgannwg	1632	25	1.5%	9	0.6%
Cardiff & Vale	5756	116	2.0%	47	0.8%
Carmarthen	1914	29	1.5%	9	0.5%
Ceredigion	729	8	1.1%	4	0.5%
Conwy & Denbighshire	2233	19	0.9%	4	0.2%
Gwent	6647	125	1.9%	72	1.1%
North East Wales	3604	31	0.9%	11	0.3%
North Glamorgan	1451	29	2.0%	12	0.8%
North West Wales	1996	15	0.8%	5	0.3%
Pembrokeshire	1201	11	0.9%	6	0.5%
Ponty & Rhondda	2112	39	1.8%	15	0.7%
Powys	1330	21	1.6%	9	0.7%
Swansea	4180	57	1.4%	31	0.7%
All Wales Total	34785	525	1.5%	234	0.7%

Time taken to start assessment

Standard

>= 95% of those requiring assessment start procedure in appropriate timescales i.e.

well babies = within 4 weeks of second screening test

high risk babies = within 8 weeks of AABR

NHS Trust	Within timescales		Outside Timescales		% Starting within Set Timescales	
	Well	High Risk	Well	High Risk	Well	High Risk
Bro Morgannwg	15	9	1	0	93.8%	100.0%
Cardiff & Vale	79	34	2	1	97.5%	97.1%
Carmarthen	16	11	1	1	94.1%	91.7%
Ceredigion	5	2	1	0	83.3%	100.0%
Conwy & Denbighshire	9	8	1	0	90.0%	100.0%
Gwent	61	51	11	2	84.7%	96.2%
North East Wales	15	14	2	0	88.2%	100.0%
North Glamorgan	18	9	2	0	90.0%	100.0%
North West Wales	9	5	1	0	90.0%	100.0%
Pembrokeshire	5	2	3	1	62.5%	66.7%
Ponty & Rhondda	24	10	4	0	85.7%	100.0%
Powys	14	6	1	0	93.3%	100.0%
Swansea	36	18	3	0	92.3%	100.0%
All Wales Total	306	179	33	5		
%	90.3%	96.2%	9.7%	2.7%		

Time taken to complete assessment

Standards:

Of those requiring assessment

>= 80% complete procedure by 3 months of age

< 5% referred for assessment and not seen

NHS Trust	Never Attended	Attended then DNA'd final test	Not yet complete	Completed < 3 Months	Completed 3+ Months
Bro Morgannwg	0.0%	4.0%	0.0%	96.0%	0.0%
Cardiff & Vale	10.3%	1.7%	0.0%	87.1%	0.9%
Carmarthen	10.3%	0.0%	0.0%	86.2%	3.4%
Ceredigion	12.5%	0.0%	0.0%	87.5%	0.0%
Conwy & Denbighshire	5.3%	10.5%	5.3%	73.6%	5.3%
Gwent	12.8%	1.6%	0.0%	84.8%	0.8%
North East Wales	6.5%	3.2%	0.0%	90.3%	0.0%
North Glamorgan	6.9%	3.4%	0.0%	89.7%	0.0%
North West Wales	13.3%	6.7%	0.0%	73.3%	6.7%
Pembrokeshire	0.0%	9.1%	0.0%	81.8%	9.1%
Ponty & Rhondda	5.1%	5.1%	0.0%	89.7%	0.0%
Powys	0.0%	4.8%	0.0%	95.2%	0.0%
Swansea	5.3%	0.0%	0.0%	93.0%	1.7%
All Wales Total	8.4%	2.7%	0.2%	87.4%	1.3%

Attendance rates for assessment appointments

Standards:

<10 % of offered assessment appointments not attended (DNA appointments only)

NHS Trusts	Attended	Cancelled	Parent Declined	DNA	Total	% DNA
Bro Morgannwg	37	3	0	3	43	7.0%
Cardiff & Vale	131	30	0	37	198	18.7%
Carmarthen	28	1	1	6	36	16.7%
Ceredigion	9	3	0	2	14	14.3%
Conwy & Denbighshire	27	14	0	8	49	16.3%
Gwent	141	30	3	32	206	15.5%
North East Wales	38	8	1	6	53	11.3%
North Glamorgan	34	5	0	10	49	20.4%
North West Wales	17	4	2	2	25	8.0%
Pembrokeshire	14	3	1	2	20	10.0%
Ponty & Rhondda	44	4	0	10	58	17.2%
Powys	28	5	0	0	33	0.0%
Swansea	60	4	0	9	73	12.3%
All Wales Total	608	114	8	127	857	
%	70.9%	13.3%	0.9%	14.8%	100.0%	

Referrals to Audiology

Standard:

<1% of well babies referred to Audiology at parental request following one ear clear response

<1% of babies referred to targeted distraction test

NHS Trust	Discharged	Repeat Test Needed	Referred for Assessment	Referred to Audiology	Referred for Distraction Test
Bro Morgannwg	97.9%	0.0%	1.5%	0.3%	0.3%
Cardiff & Vale	95.4%	0.0%	2.0%	1.6%	1.0%
Carmarthen	96.0%	0.0%	1.5%	2.0%	0.5%
Ceredigion	97.4%	0.0%	1.1%	0.7%	0.8%
Conwy & Denbighshire	98.1%	0.0%	0.9%	0.9%	0.2%
Gwent	94.6%	0.0%	1.9%	2.8%	0.8%
North East Wales	97.9%	0.0%	0.9%	0.9%	0.3%
North Glamorgan	95.7%	0.0%	2.0%	1.7%	0.6%
North West Wales	98.2%	0.0%	0.8%	0.7%	0.4%
Pembrokeshire	96.4%	0.1%	0.9%	2.2%	0.4%
Ponty & Rhondda	96.7%	0.0%	1.8%	1.0%	0.4%
Powys	97.9%	0.0%	1.6%	0.5%	0.0%
Swansea	97.2%	0.0%	1.4%	1.2%	0.3%
All Wales Total	96.5%	0.0%	1.5%	1.5%	0.5%

Appendix 2. NBHSW All Wales results by Local Health Board

Total live births, eligible and suitable, consenting and tested by Local Health Board

Standards:

>=95% of eligible babies who enter the screening programme (i.e. consenting & tested)

>=99% of eligible babies to be offered screening

Between 1-2% of screened babies referred for assessment

Local Health Board	Births	Eligible & Suitable	Consenting & Tested	% Tested of Eligible & Suitable	Total Offered Screening	% Offered of Eligible and Suitable	Referred for Assessment	% Referred for Assessment
Blaenau Gwent	783	776	769	99.1%	776	100.0%	11	1.4%
Bridgend	1545	1526	1514	99.2%	1522	99.7%	24	1.6%
Caerphilly	2039	1985	1960	98.7%	1985	100.0%	40	2.0%
Cardiff	4253	4139	4048	97.8%	4138	100.0%	82	2.0%
Carmarthenshire	1958	1934	1925	99.5%	1933	99.9%	32	1.7%
Ceredigion	630	620	612	98.7%	620	100.0%	4	0.7%
Conwy	1088	1068	1067	99.9%	1068	100.0%	4	0.4%
Denbighshire	1059	1039	1039	100.0%	1039	100.0%	13	1.3%
Flintshire	1829	1798	1795	99.8%	1798	100.0%	20	1.1%
Gwynedd	1186	1166	1163	99.7%	1166	100.0%	11	0.9%
Merthyr Tydfil	703	691	689	99.7%	690	99.9%	15	2.2%
Monmouthshire	838	807	805	99.8%	806	99.9%	11	1.4%
Neath Port Talbot	1557	1537	1532	99.7%	1537	100.0%	14	0.9%
Newport	1847	1814	1807	99.6%	1812	99.9%	36	2.0%
Pembrokeshire	1240	1220	1206	98.9%	1217	99.8%	14	1.2%
Powys	1208	1187	1183	99.7%	1186	99.9%	19	1.6%
Rhondda Cynon Taff	2817	2770	2761	99.7%	2769	100.0%	52	1.9%
Swansea	2647	2591	2581	99.6%	2591	100.0%	42	1.6%
Torfaen	1033	1017	1011	99.4%	1017	100.0%	22	2.2%
Vale of Glamorgan	1496	1446	1428	98.8%	1446	100.0%	31	2.2%
Wrexham	1642	1621	1619	99.9%	1621	100.0%	11	0.7%
Ynys Mon	707	698	698	100.0%	698	100.0%	5	0.7%
Cheshire West PCT	1	0	0		0		0	
Herefordshire PCT	53	43	42	97.7%	43	100.0%	0	0.0%
Shropshire PCT	183	154	154	100.0%	154	100.0%	0	0.0%
Unknown	1576	1400	1377	98.4%	1394	99.6%	12	0.9%
All Wales Total	35918	35047	34785	99.3%	35026	99.9%	525	1.5%

Appendix 3 NBHSW Standards - Screening Programme

Revised standards

Objective	Criteria	Minimum Standard	Responsibility for recording
1. To maximise the number of babies who are offered screening	The percentage of eligible babies who are offered screening	≥ 99% of all babies	Screeners Clerical staff Programme Manager
2. To maximise the number of babies who enter the screening programme	The percentage of eligible babies who enter the screening programme	≥ 95% of all babies fit to test	Screeners Clerical staff
3. To screen most well babies within the first week of life	The percentage of babies receiving the first screening test within the first week of life	> 75% of those screened	Screeners Clerical staff
4. To maximise the number of babies who complete the screening programme with in the allocated time periods.	Well babies – the percentage of babies who complete the screening programme within 4 weeks High risk babies in SCBU > 48 hours – the percentage of babies who complete the screening programme All babies – the percentage of babies who complete the screening programme	≥ 90% of all babies entering the screening programme ≥ 95% of all babies entering the screening programme ≥ 95% of all babies entering the screening programme	Screeners Clerical staff
5. To minimise the number of babies requiring a diagnostic ABR who have normal hearing	Those babies who are referred for diagnostic ABR with normal hearing	< 3% of all those who complete assessment and are found to have normal hearing as a proportion of all babies screened	Screeners Clerical staff
6. To start the assessment procedure (diagnostic ABR) in appropriate cases within the allocated time	Well babies: Those babies who start the assessment procedure within 4 weeks of the second screening episode High risk babies: Those babies which start the assessment procedure within 8 weeks of AABR	≥ 90% of those requiring assessment	Audiologist completing assessment procedure Clerical staff
7. To complete the assessment procedure within the allocated time	Those babies that complete the assessment procedure by 3 months of age (in appropriate cases)	≥ 80% of those requiring assessment	Audiologist completing assessment procedure Clerical staff
8. To minimise the number of babies who do not receive screening	The percentage of offered screening appointments which are not attended (well babies)	≥ 4% (includes all DNA and cancelled appointments)	Screeners Clerical staff
9. To minimise the number of babies who do not receive screening	The percentage of offered screening appointments which are declined (well babies)	< 1% of babies	Screeners Clerical staff
10. To refer an appropriate number of babies for assessment	The percentage of screened babies referred for assessment	Between 1-2%	Screeners Clerical staff

11. To minimise the number of babies who do not receive assessment	The percentage of offered assessment appointments which are not attended	< 10% (DNA appointments only)	Audiologists Clerical staff
12. To minimise the number of babies who do not receive assessment	The percentage of babies who are referred for assessment and not seen	< 5%	Audiologists Clerical staff
13. To refer an appropriate number of babies for a repeat screen from audiology (one ear clear response, well babies)	The percentage of babies referred	< 1%	Screeners Clerical staff
14. To refer an appropriate number of babies for targeted behavioural test	The percentage of babies referred	< 1%	Screeners Clerical staff
15. To provide a written report following the assessment procedure within the allocated time	Those babies that complete the assessment procedure or reach 3 months of age that have a written report provided to primary care within 14 days of completing the assessment. This is measured from the date of final assessment plan to date on report/letter sent to Primary Care.	≥ 95% of cases requiring assessment	Sample provided by Audiologist/ Professional Lead on request
16. To provide information to promote informed choice	The percentage of mothers who report receiving written information in the antenatal period. The criteria for inclusion in the survey may be selected to compare the experiences of mothers. The percentage of mothers who provide positive responses on the information subscale of a user survey. The criteria for inclusion in the survey may be selected to compare the experiences of families.	100% of mothers > 90% positive responses from mothers completing the user survey	A survey to be conducted using a standardised/ validated tool at least every two years. Sample of mothers to be randomly selected from the database.
17. To evaluate mothers satisfaction with the screening programme	The percentage of mothers who provide positive responses on a general satisfaction subscale of a user survey. The criteria for inclusion in the survey may be selected to compare the experiences of families.	> 95% positive responses from mothers completing the user survey	A survey to be conducted using a standardised/ validated tool at least every two years. Sample of mothers to be randomly selected from the database.

2.6. NBHSW Standards – Habilitation

(Data to be recorded on Screening Module, Child Health System and/or Auditbase)

Objective	Criteria	Minimum Standard	Responsibility for recording
1. To confirm hearing loss within the allocated time	The percentage of babies who have audiological confirmation by the age of 6 months	80% of those babies diagnosed by the screening programme as significantly hearing impaired 80% of those babies who are diagnosed as significantly hearing impaired in the first 5 years of life	Audiologist completing assessment procedure
2. To offer hearing aids to appropriate cases within the allocated time	The percentage of those babies diagnosed as significantly hearing impaired who have hearing aids offered by the age of six months (allowing for prematurity). The audiologist must inform the Divisional Coordinator that the decision not to aid was parental choice.	90% of those offered hearing aids diagnosed from the screening programme 60% of those diagnosed as significantly hearing impaired in the first 5 years of life	Audiologist completing assessment procedure
3. To fit hearing aids to appropriate cases within the allocated time	The percentage of appropriate cases fitted with hearing aids within 4 weeks of audiological certainty (diagnosis) The percentage of those babies diagnosed as significantly hearing impaired who have hearing aids fitted by the age of six months (allowing for prematurity).	>=99% of those appropriate, diagnosed from the screening programme >=99% of babies diagnosed as significantly hearing impaired in the first 5 years of life 75% of those fitted with hearing aids diagnosed from the screening programme 60% of those diagnosed as significantly hearing impaired in the first 5 years of life	Audiologist completing hearing aid fitting
4. To ensure families have information of the full range of support available both locally and on a national basis	The percentage of cases referred to a Teacher of the Deaf/professional knowledgeable about early support within 24 hours of diagnosis of hearing loss. This is measured from the date of final assessment plan to a documented date recorded by local service.	100% of those appropriate	Sample provided by audiologist/professional lead on request

<p>5. To ensure that appropriate habilitation services are in place</p>	<p>The establishment and regular meetings of a multidisciplinary group monitoring services in each area. (Children's Hearing Services Working Group). This group should regularly review the services provided to hearing impaired children and their families to ensure a coordinated and appropriate provision.</p> <p>Self assessment rating of services verified at NBHSW quality assurance site visits should achieve a scale of 4 or 5 thereby meeting most or all of the standards outlined in the NBHSW site document. Where there are different community and hospital services these need to be identified and scored separately.</p> <p>The Paediatric audiology and early support services for families should undertake audit of all services using self assessment audit tools where available. Parent satisfaction surveys with early years services should also be undertaken.</p>	<p>100%</p> <p>70%</p> <p>100%</p>	<p>CHSWG</p> <p>To ensure that appropriate habilitation services are in place</p> <p>CHSWG/ individual services</p>
<p>6. To arrange audiological follow up of those babies requiring further hearing tests referred from the screening programme</p>	<p>The percentage of babies who are sent an appointment for a targeted behavioural test at a developmentally appropriate time</p>	<p>100%</p>	<p>Sample by Professional Lead on request.</p>
<p>7. To complete audiological follow up of those babies requiring further hearing tests referred from the screening programme</p>	<p>The percentage of babies who complete targeted behavioural test as per protocol or whose Primary Health Care Team are notified of their non attendance</p>	<p>100%</p>	<p>Sample by Professional Lead on request</p>
<p>8. To complete audiological follow up of those babies requiring further hearing tests from assessment.</p>	<p>The percentage of babies who complete hearing tests to audiological certainty (excluding those who fit the criteria of screen positive). Management plans are agreed by peer review.</p>	<p>> 90%</p>	<p>Sample by audiologists on request</p>