

Newborn Hearing Screening in Northern Ireland

Annual Report 2016 - 17





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# **Executive Summary**

#### **Background**

One to two babies in every 1,000 is born with a hearing loss in one or both ears<sup>1</sup>. Research studies have demonstrated the importance of detecting a hearing loss as early as possible. The Newborn Hearing Screening Programme (NHSP) is offered to all babies, who are born or resident in Northern Ireland, up to 6 months of age. The aim of the screening programme is to identify babies with who have a significant permanent childhood hearing loss<sup>2</sup> to allow early referral, diagnosis and intervention. Early detection and effective interventions result in improved outcomes for children. This is the first annual report of the Northern Ireland NHSP and summarises the performance of the programme from 1<sup>st</sup> April 2016- 31<sup>st</sup> March 2017.

#### Programme Delivery

The NHSP is commissioned and quality assured by the Public Health Agency (PHA) in collaboration with the five Health and Social Care Trusts (HSCTs) in Northern Ireland, who manage and deliver the programme. It is a complex programme involving a wide range of professional staff including local newborn hearing screening co-ordinators, hearing test screeners, child health system staff, midwives, paediatric staff, neonatal and special care baby unit staff, health visitors, community and hospital audiology and ear, nose and throat (ENT) specialist staff.

<sup>&</sup>lt;sup>1</sup>PHA Your baby's hearing screen NINHSP Information for parents accessed via:

https://www.publichealth.hscni.net/sites/default/files/ENGLISH%20%20L1%20%20Your%20Baby%27s%20Hearing%20Scr een%20%28Well%20Baby%29.pdf

<sup>&</sup>lt;sup>2</sup> 'NHSP defines this as a bilateral permanent hearing loss averaging  $\geq$  40dBnHL across 0.5 to 4kHz". Sutton et al Guidelines for surveillance and audiological referral of infants & children following the newborn hearing screen, July 2012.

#### Screening tests

The programme follows two separate screening protocols (outlined in detail in appendices 1 and 2) depending on whether a baby has been in a neonatal/special care baby unit for more than 48 hours prior to screening.

There are also two types of hearing screening tests provided. The type of test that a baby requires and is offered will depend on (a) which screening protocol is applicable (see appendix 1 and 2) and (b) the results of their initial test if they have been following a well baby/early discharge protocol.

## Key developments

During 2016-17 there were a number of developments within the NHSP, most notably scoping the potential to procure a regional managed IT service to support the programme and enhance current data processing and quality assurance practice.

#### Headline results

The key highlights of the NHSP during 1<sup>st</sup> April 2016 – 31<sup>st</sup> March 2017 include that:

- There were 23,936 'current residents' (i.e. babies) eligible for screening. Of these:
  - o 99.6% (23,830) were offered screening
  - 96.8% (23,167) completed screening by the age of 4 weeks; this increased to 98.9% (23,675) by 3 months
  - 2% (467) were referred by the age of 3 months to audiology services for diagnostic assessment.

In relation to 'live births' in hospitals in Northern Ireland during the same period:

72.9% (17,577/24,127) of babies had their hearing screening test completed before discharge from hospital.

# BACKGROUND

Screening is defined as 'the process of identifying healthy people who may have an increased chance of a disease or condition and offering them information, screening tests and, if required, further confirmatory (diagnostic) tests and treatment'<sup>3</sup>. The aim of screening is to reduce the problems and complications associated with the underlying disease / condition.

Following the recommendation from the UK National Screening Committee (UKNSC) that a national neonatal hearing screening programme should be established, the Northern Ireland Newborn Hearing Screening Programme (NHSP) was launched in October 2005.

Hearing screening is offered to all babies, who are born or resident in Northern Ireland, up to 6 months of age (i.e. from birth (day 0) until day 182 of life inclusive). This is the first annual report of the Northern Ireland NHSP and summarises the performance of the programme from 1<sup>st</sup> April 2016- 31<sup>st</sup> March 2017.

# Aim of newborn hearing screening

One to two babies in every 1,000 is born with a hearing loss in one or both ears. Research studies have demonstrated the importance of detecting a hearing loss as early as possible. The aim of the NHSP is to identify babies who have a significant permanent childhood hearing loss<sup>4</sup>, i.e. a bilateral hearing loss of 40

<sup>&</sup>lt;sup>3</sup> PHE Screening explained https://www.gov.uk/guidance/nhs-population-screening-explained

<sup>&</sup>lt;sup>4</sup> 'NHSP defines this as a bilateral permanent hearing loss averaging  $\geq$  40dBnHL across 0.5 to 4kHz" Sutton et al *Guidelines* for surveillance and audiological referral of infants & children following the newborn hearing screen, July 2012.

dBnHL or more<sup>5</sup>, in order to detect permanent childhood hearing impairment (PCHI) at the earliest stage, ideally within 4 weeks of birth. This allows timely referral, diagnosis and intervention. Early detection and effective interventions result in improved outcomes for children, in particular, normal speech and language development.

### Programme delivery

In Northern Ireland the NHSP is commissioned and quality assured by the Public Health Agency (PHA) in collaboration with the five Health and Social Care Trusts (HSCTs), who manage and deliver the programme. It is a complex programme involving a wide range of professional staff including local newborn hearing screening co-ordinators, screeners, Child Health System staff, midwives, paediatric staff, neonatal and special care baby unit staff, health visitors, community and hospital audiology and ear, nose and throat (ENT) specialist staff.

#### Screening pathway

#### Offer of screening

All babies resident in Northern Ireland (including those born in or who have moved in to NI) are offered screening from over 34 weeks gestational age up until the age of 6 months<sup>6</sup>.

#### **Exclusions**

For some babies hearing screening can be inappropriate if the infant has a condition, including atresia, bacterial meningitis or temporal bone fracture, which requires direct referral for diagnostic testing, or if the infant is receiving palliative care and screening is not therefore indicated.

<sup>&</sup>lt;sup>5</sup> Davis A, Bamford J, Wilson I, Ramkalawan T, Forshaw M - A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. Health Technol Assess 1997;1(10)

<sup>&</sup>lt;sup>6</sup> 6 months is defined as day 182 of life, with birth being day 0

#### Screening protocols and tests

The programme follows two separate screening protocols (outlined in detail in appendices 1 and 2) depending on whether a baby has been in a neonatal/special care baby unit for more than 48 hours prior to screening. This is because babies who have spent at least 48 hours in a special care unit have a slightly increased risk of hearing loss. Whilst About 1 in every 900 babies has hearing loss in one or both ears, this increases to about 1 in every 100 babies who have spent at least 48 hours in a special care unit<sup>7</sup>.

There are also two types of hearing screening tests provided. The type of test that a baby requires and is offered will depend on (a) which screening protocol is applicable (see appendix 1 and 2) and (b) the results of their initial test if they have been following a well baby/early discharge protocol.

A baby's newborn hearing screening test is often conducted prior to discharge from hospital, but can also be performed following discharge at an outpatient clinic. The screening tests are described below.

Automated Otoacoustic Emission (AOAE)

An **AOAE** test involves placing a small soft tipped earpiece in the outer part of a baby's ear to send clicking sounds to the inner ear. Using a computer, the screener carrying out the test can detect how the baby's inner ear responds to sound. The test causes no discomfort to the baby and is often conducted while they are asleep. This test measures the mechanical function of the inner ear. In the cochlea, when a noise is heard, acoustic energy is generated which will cause vibration of hair cells in the inner ear (these are known as otoacoustic

<sup>&</sup>lt;sup>7</sup> PHE *Babies in special care units: screening tests for you and* your babies (Information leaflet) accessed at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/712824/NICU1\_Babi es\_in\_special\_care\_units\_Screening\_tests\_for\_you\_and\_your\_baby.pdf

emissions). The AOAE test screens for these otoacoustic emissions. All babies are offered this test.

• Automated Auditory Brainstem Response (AABR)

An **AABR** is a different type of test. Rather than measure acoustic energy within the inner ear, it measures electrical brain activity. This screening test involves placing small sensors on a baby's head, shoulder and nape of the neck. Soft headphones are placed over baby's ears and a series of clicking sounds are played. A computer measures how baby's ears respond to these sounds. This test is usually not required for all babies.

#### <u>Referral</u>

Depending on the results of these screening tests, a child may require referral for further specialist assessment by audiology services. This is to confirm a diagnosis and allow timely follow up and treatment if required.

### Hearing loss

It is, however, important to remember that no screening test is 100% accurate and also that hearing loss can occur at any stage of life. It is therefore important that parents remain vigilant for any changes or concerns regarding their child's hearing.

A developmental checklist (see appendix 3) is shared with parents via the Personal Childhood Health Record (PCHR), to encourage monitoring of their baby's hearing throughout the early stages of life. Should a parent/guardian have any concern about hearing, this can be discussed with the health visitor or GP

# Risk factors and 'targeted' follow up

As outlined above, hearing loss can occur at any time in childhood, even in the absence of specific risk factors. The prevalence of hearing loss is higher among infants who have one or more of the following known risk factors:

- **Congenital Infection** Proven or possible congenital infection due to toxoplasmosis, rubella, cytomegalovirus (CMV) or herpes as determined by TORCH<sup>8</sup> screen, and notified at any age.
- Craniofacial Anomalies A (noticeable) craniofacial anomaly (excluding minor pits and ear tags) at any age, e.g. cleft palate.
- Syndrome Confirmed syndrome related to hearing loss, e.g. Down's syndrome.
- **NNU<sup>9</sup> protocol results** Bilateral clear response at AABR and the infant has not acquired a clear response in at least one ear at AOAE.

At the time of newborn hearing screening, a child identified as having one or more of these known, nationally agreed, risk factors for hearing loss, is referred for a further hearing assessment at the age of 8 months, regardless of their hearing screening result.

<sup>&</sup>lt;sup>8</sup> a TORCH screen is a blood test used to screen for a number of infectious diseases that are known by the acronym TORCH

<sup>-</sup> Toxoplasmosis, Other agents (including syphilis and HIV), Rubella, Cytomegalovirus and Herpes simplex

<sup>&</sup>lt;sup>9</sup> NNU = neonatal unit

# Failsafe

A failsafe is a back-up mechanism which, in addition to usual care, ensures that if something does not go to plan in the screening pathway, the back-up process identifies what has happened and initiates appropriate action.

The NHSP includes a robust mechanism to capture babies who have not been offered, or taken part, in screening. This failsafe 'mop up' report identifies all babies from age 14 days until age 182 days (i.e. for the duration of the programme) with a nil or inconclusive result. The report is run each week by the NHSP Coordinator in each Trust, using the Child Health Information System. Once a baby has been identified on this list, their parent/guardian will be contacted to offer a screening hearing test.

### Key developments 2016-17

During 2016-17 there were a number of developments within the NHSP, most notably scoping out the potential to procure a managed regional IT service to support the programme and enhance current data processing and quality assurance practice. Currently, results from screening tests are recorded on handwritten daily worklists which are input into the Child Health System.

The screening programme has identified the considerable advantages associated with a bespoke IT infrastructure that would reduce the need for manual entry of data. An electronic mechanism would facilitate an automated capture and retention of NHSP screening results. This would support patient management and allow data reporting against national standards, which is limited at present. Significant business processes to procure this system occurred during 2016-17, including engagement with regional stakeholders and service providers in order to shape the implementation of this complex system.

The programme also continues to utilise published information from the 'Northern Ireland Health and Social Care Interpreting Service' as a guide to

ensure that the most up-to-date translated leaflets are provided to service users. Translated leaflets are currently available in multiple languages.

# Programme performance 2016-17

The NHSP routinely collects and collates data to measure and monitor programme performance. The procurement of a managed IT service will improve the data reports that can be produced, including in relation to timeliness of diagnostic assessment and outcomes in line with national standards.<sup>10</sup>

# Programme data

- Cohort: data is produced on the offer, uptake and outcome of newborn hearing screening of:
  - 'Livebirths' before discharge from hospital and
  - 'Current residents'
- Key definitions:
  - 'Livebirths' this includes all babies who were born alive in hospitals in Northern Ireland from 1<sup>st</sup> April 2016 to 31<sup>st</sup> March 2017.
  - 'Current residents' this includes all babies who were:
    - born between 1<sup>st</sup> April 2016 and 31<sup>st</sup> March 2017 and
    - were resident in Northern Ireland, at some point, between 1<sup>st</sup> April 2016 and 31<sup>st</sup> March 2017.
  - The current resident cohort may include babies who were not born in hospital, or who were born outside

<sup>&</sup>lt;sup>10</sup> PHE NHS Newborn Hearing Screening Programme Standards 2016 to 2017 available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/685452/NHSP\_Stand ards\_2016\_-\_17.pdf

Northern Ireland and moved into Northern Ireland within the first six months of life. It may also vary from the total number of 'live births' as children may have been born in Northern Ireland hospitals but moved out of Northern Ireland.

- <u>Source</u>: Data on the performance of the programme is provided by the Child Health System (CHS). There are four CHS areas in Northern Ireland and these collectively cover the five health and social care trust geographies, i.e. Eastern (Belfast Health and Social Care Trust and South Eastern Health and Social Care Trust), Northern (Northern Health and Social Care Trust), Southern (Southern Health and Social Care Trust) and Western (Western Health and Social Care Trust).
- <u>Frequency of reporting</u>: data is produced quarterly to cover the periods April to June, July to September, October to December and January to March. The reports that produce the data for a given quarter are run four months after the end of a quarter.
- <u>Methodology</u>: the annual figures included in this report have been calculated by summing the figures in each quarter.

### Headline results

Regional data relating to the NI Newborn Hearing Screening Programme highlights that from 1<sup>st</sup> April 2016 – 31<sup>st</sup> March 2017:

- There were 23,936 'current residents' eligible for screening. Of these:
  - o 99.6% (23,830) were offered screening
  - 96.8% (23,167) completed screening by the age of 4 weeks; this increased to 98.9% (23,675) by 3 months

 2% (467) were referred by the age of 3 months to audiology services for diagnostic assessment.

In relation to 'live births' in hospitals in Northern Ireland during the same period:

• 72.9% (17,577/24,127) of babies had hearing screening completed before discharge from hospital.

# Trends in data

Figure 1 shows that in 2016-17, as in 2014-15 and 2015-16, over 99% of current residents were offered hearing screening and 98.9% had completed screening by 3 months of age. As outlined above, babies may decline screening, or in some instances screening may not be appropriate.

Figure 1: Proportion of 'current residents' in NI offered newborn hearing screening and completion rates by 4 weeks and 3 months of age 2014-17

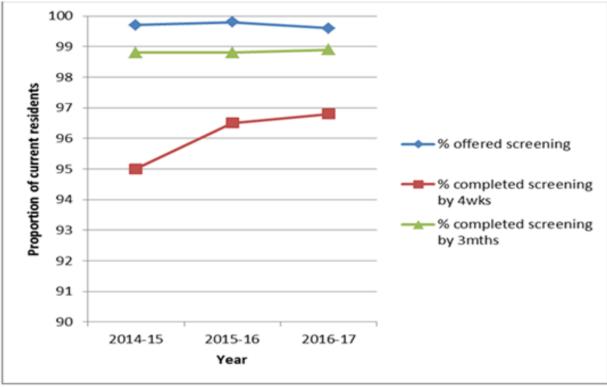


 Table 1: Proportion of 'current residents' in NI offered newborn hearing screening and completion rates by 4 weeks and 3 months of age 2014-17

Year	Number of No. current offered residents screen	No.	% offered	No. completed by		% completed by	
				4 wks	3mths	4wks	3mths
2014-15	24149	24073	99.7	22944	23859	95.0%	98.8%
2015-16	24190	24130	99.8	23340	23901	96.5%	98.8%
2016-17	23936	23830	99.6	23167	23675	96.8%	98.9%

Table 2 shows that from 2014-2017 there has also been a consistently high proportion of current residents (>98%) who have completed screening by 3 months of age. Of these, approximately 2% per year require referral to audiology services for further testing following the result of their screening test.

Table 2: Proportion of 'current residents' in NI with screening outcome (bilateral clear response or referral for ABR) by 4 weeks and 3 months of age 2014-17

	Number	by 4 weeks			by 3 months		
Year	of current residents	% completed	% with BCR	% referred	% completed	% with BCR	% referred
2014-15	24149	95.0% (22944)	93.1% (22482)	1.9% (462)	98.8% (23859)	96.7% (23351)	2.1% (508)
2015-16	24190	96.5% (23340)	94.5% (22856)	2.0% (484)	98.8% (23901)	96.7% (23390)	2.1% (511)
2016-17	23936	96.8% (23167)	95.0% (22730)	1.8% (437)	98.9% (23675)	97.0% (23208)	2.0% (467)

Data from 2014-17 (table 3) also indicates that >70% of babies born alive in hospitals in Northern Ireland per year completed hearing screening before discharge from hospital.

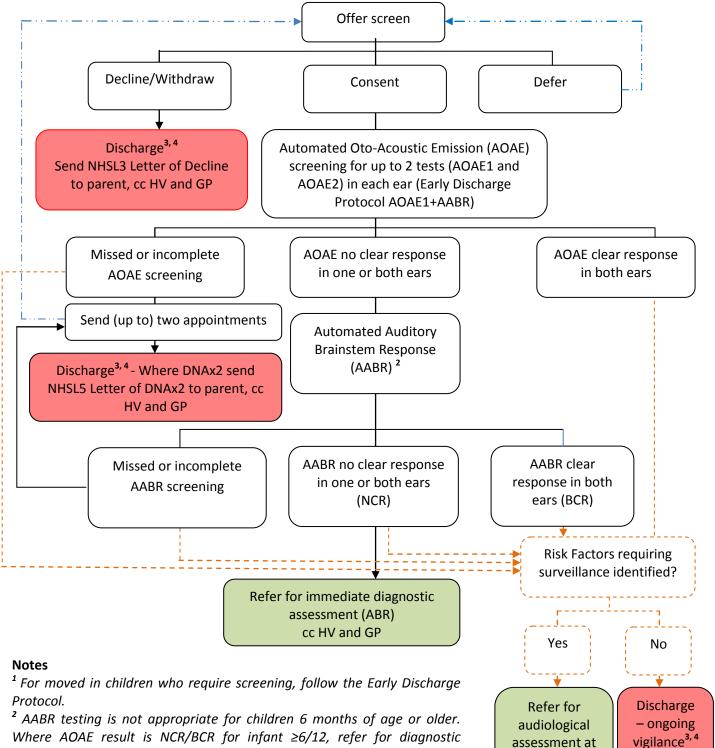
Table 3: Proportion of 'livebirths' in NI offered and completed hearing screening beforedischarge from hospital 2014-17

Year	Number of livebirths	No. completed screen before discharge	% completed screen before discharge
2014-15	24438	17574	71.9%
2015-16	24480	17786	72.7%
2016-17	24127	17577	72.9%

#### Appendix 1: Northern Ireland Newborn Hearing Screening Programme

#### Well Baby / Early Discharge Protocol - Patient Journey

Residents (including moved in children) up to 6 months of Age<sup>1</sup>



assessment. <sup>3</sup> Paediatricians / neonatologists are responsible for ensuring that any child in receipt of ototoxic therapy; diagnosed with bacterial meningitis or any

syndrome associated with hearing loss; or, any child with a temporal bone fracture is referred immediately for diagnostic assessment (irrespective of whether newborn hearing screening has taken place or the results of newborn hearing screening).

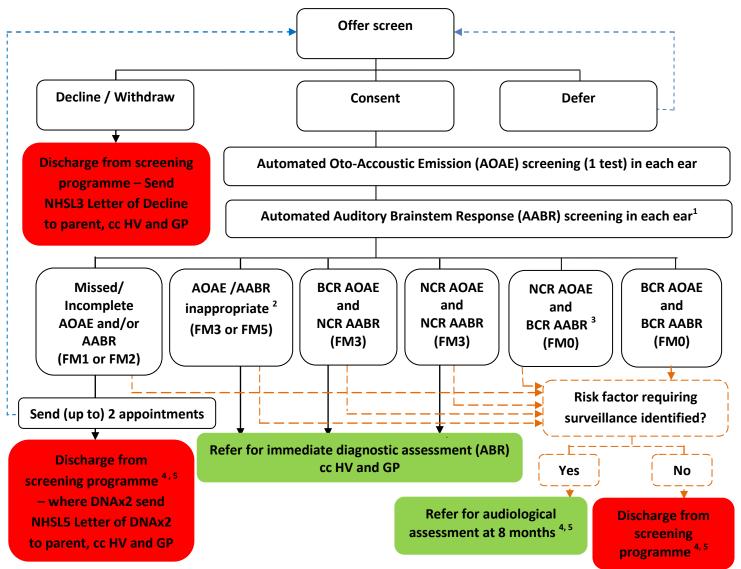
<sup>4</sup> Children should be referred for appropriate audiological assessment where there is any parental or professional concern.

8 months<sup>3, 4</sup>

#### Appendix 2: Northern Ireland Newborn Hearing Screening Programme

#### NICU/SCBU (> 48hrs) Protocol – Patient Journey

#### Residents (including moved in infants) up to 6 months of age



#### Notes

<sup>1</sup> AABR testing is not appropriate for children who are 6 months of age or older. Where an AOAE result is NCR and the child has reached 6 months of age or older, refer for diagnostic assessment.

<sup>2</sup> Screening can be inappropriate because an infant has a condition, e.g. atresia, and requires direct referral for neurological ABR testing (FM3), or where an infant is receiving palliative care and screening is not indicated and referral for ABR is not required (FM5). Where (FM3) infants are seen by screeners before referral, risk assessment should be carried out, but risk factors should not be assessed where an infant is receiving palliative care (FM5).

<sup>3</sup> This outcome is Risk Factor 10 and infants are automatically referred for audiological assessment at 8 months.

<sup>4</sup> Paediatricians / neonatologists are responsible for ensuring that any child in receipt of ototoxic therapy; diagnosed with bacterial meningitis or any syndrome associated with hearing loss; or, any child with a temporal bone fracture is referred immediately for diagnostic assessment (irrespective of whether newborn hearing screening has taken place or the results of newborn hearing screening).

<sup>5</sup> Children should be referred for appropriate audiological assessment where there is any parental or professional concern.

Screening Outcomes:	BCR – clear response achieved in both ears; or	
	NCR – no clear response in one or both ears	
Further Management Codes:	FM0 – no further action;	16
	FM1 – for first screen;	10
	FM2 - for further screen;	
	FM3 – refer for ABR test (to diagnostic audiology); and,	
	FM5 – not indicated	

# Appendix 3 YOUR BABY'S DEVELOPMENT (HEARING, SPEECH AND LANGUAGE)

Extracted from the Northern Ireland Personal Child Health Record (PCHR – 'red book') for translation of newborn hearing screening programme information. The full version of 'Your Baby's Development' is available within the PCHR, pages 10-14 (revised 2014).

#### Birth to 8 weeks

- Is startled by sudden loud noises, e.g. a hand clap or a door slamming.
- Blinks or opens eyes widely, stops sucking or starts to cry at loud noises.
- Pauses, appears to listen and may turn towards sudden ongoing sounds when they begin, e.g. a vacuum cleaner.

#### 9-16 weeks

- Quietens or smiles to familiar voices even when unable to see speaker. Turns eyes or head towards voice. Shows excitement at sounds, e.g. voices, footsteps.
- Makes soft sounds when awake. Gurgles and coos.

### 5-9 months

- Makes laughter-like and sing-song sounds. e.g. 'a-a', 'muh', 'goo', 'der', 'aroo', 'adagh'.
- Turns immediately to familiar voices across the room or to very quiet noises on each side (if not too occupied with other things).
- Listens closely to familiar everyday sounds and looks for very quiet sounds made out of sight. Makes sounds to show friendliness or annoyance.
- Babbles, e.g. 'da da da', 'ma ma ma', 'ba ba ba'. Shows pleasure in babbling loudly and tunefully in response to others. Starts to copy other sounds like coughing or smacking lips.

### 9-12 months

• Shows some response to own name.

- Babbles loudly, often making sounds with rhythm that sound like a simple conversation.
- Responds to words like 'no' and 'bye bye' even when the speakers gestures cannot be seen.
- Waves 'bye bye' and claps hands.
- Around 12 months, may use 1 or 2 words.

#### 1-2 years

- Around 15 months, makes lots of speech like sounds. Uses 2-6 words correctly that you understand, e.g. 'teddy' when seeing or wanting a teddy bear.
- Around 18 months, when playing, makes speech-like sounds with rhythm that sound like a simple conversation. Uses 6-20 words that you understand. Follows simple instructions, e.g. 'show me your shoes'.
- Finds and points to pictures in books by using words 'look' and 'see'. Turns pages one at a time.
- Around 24 months, uses 50 or more words correctly that you understand. Puts 2 or more words together to make simple sentences, e.g. 'more milk'. Joins in nursery rhymes and songs. Talks to self during play – speech may be unclear to others.

#### 2-3 years

- Around 30 months, uses 200 or more words that you understand. Uses pronouns, e.g. 'l', 'me' and 'you'. Uses sentences but many will lack adult structure. Talks to self during play. Asks questions. Says a few nursery rhymes.
- Around 36 months, uses a large number of words speech is clear to familiar listeners.

#### 3-5 years

• Speech is clear to unfamiliar listeners. Around 4-5 years, talks in sentences, where words and grammar are mostly in the correct order.

References: B. McCormick, Children's Hearing Assessment Centre, Nottingham, UK – 'Can Your Baby Hear You?' (1982) Mary D. Sheridan – 'Birth to Five Years' (1997)

Other translations of this leaflet are available to view/download at:

https://www.publichealth.hscni.net/publications/newborn-hearing-screeningenglish-and-translations

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