

**Universal Newborn Hearing
Screening and Early Intervention
Programme
(UNHSEIP)**

**National Policy and Quality Standards
April 2009**

National Screening Unit

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1. Introduction

Universal newborn hearing screening is becoming the standard of care internationally. The early identification of hearing loss, and the application of appropriate medical and educational interventions, has been demonstrated to significantly improve long-term communication skills and cognitive ability.

New Zealand's Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) is in the early stages of national implementation, a process which began in 2007 and will be completed by 2010. The UNHSEIP is being jointly overseen and implemented by two Government agencies, the Ministries of Health and Education. The Ministry of Health has responsibility for screening, diagnosis of hearing loss and medical interventions, and the Ministry of Education has responsibility for Early Intervention services.

District Health Boards (DHBs) will be the main providers of newborn hearing screening, follow-up audiology services, and medical interventions, and Advisors on Deaf Children will provide Early Intervention services.

When the UNHSEIP is fully implemented, all 21 DHBs will be offering newborn hearing screening to every eligible baby born in their area, whether they are born in hospital or at home, within a framework of nationally consistent policies, standards and guidelines. Audiology services, for babies requiring follow-up from screening, may be locally or regionally provided. This is because paediatric audiology is a specialised field and some DHBs may choose to work together, rather than individually, to provide high quality services to their populations. Early Intervention services, for babies identified with hearing loss, are regionally based, and service providers travel to families and whānau as necessary.

These National Policy and Quality Standards (April 2009) form part of the contract between the Ministry of Health and DHBs, for the provision of newborn hearing screening services. It is acknowledged that the UNHSEIP is in the early stages of implementation and it is important to note that some aspects of the Programme are still under development. Throughout the Programme implementation period, the National Screening Unit will be working with DHBs to make sure that policies and standards are practical and achievable. Ongoing monitoring processes, feedback from providers and international best practice will inform the further development of this document, which will be reviewed once the Programme is fully implemented.

2. About Newborn Hearing Screening

Each year, it is estimated that between 135 and 170 babies are born in New Zealand with permanent congenital hearing loss. This represents a birth incidence of approximately three per one thousand births, which is consistent with international reports.

The first six months of a baby's life is a critical period for learning to hear and speak. Lack of exposure to language during this critical period, such as through a hearing loss, can affect a child's development, communication skills, educational and career achievement. The early detection of hearing loss, and the initiation of early medical and educational interventions, has been demonstrated to significantly improve long-term outcomes for children with hearing loss and their families and whānau.

With newborn hearing screening, the internationally recommended age for the diagnosis of hearing loss is three months, with interventions commencing by six months. While New Zealand's incidence of hearing loss is similar to international reports, the age of identification is poor, particularly when compared with countries that have introduced newborn hearing screening programmes. Data from the New Zealand Deafness Notification Database indicate that only a small minority of babies with hearing loss are identified by six months of age, and that the average age of detection is around three to four years of age.

The aim of the UNHSEIP is for early identification of newborns with hearing loss so that they can access timely and appropriate interventions, inequalities are reduced and the outcomes for these children, their families and whānau, communities and society are improved. The core goals of the UNHSEIP are described as '1-3-6' goals which are based on international programmes:

1. Babies to be screened by 1 month of age
3. Diagnostic audiological assessment completed by 3 months of age
6. Initiation of appropriate medical and audiological services, and Early Intervention education services, by 6 months of age.

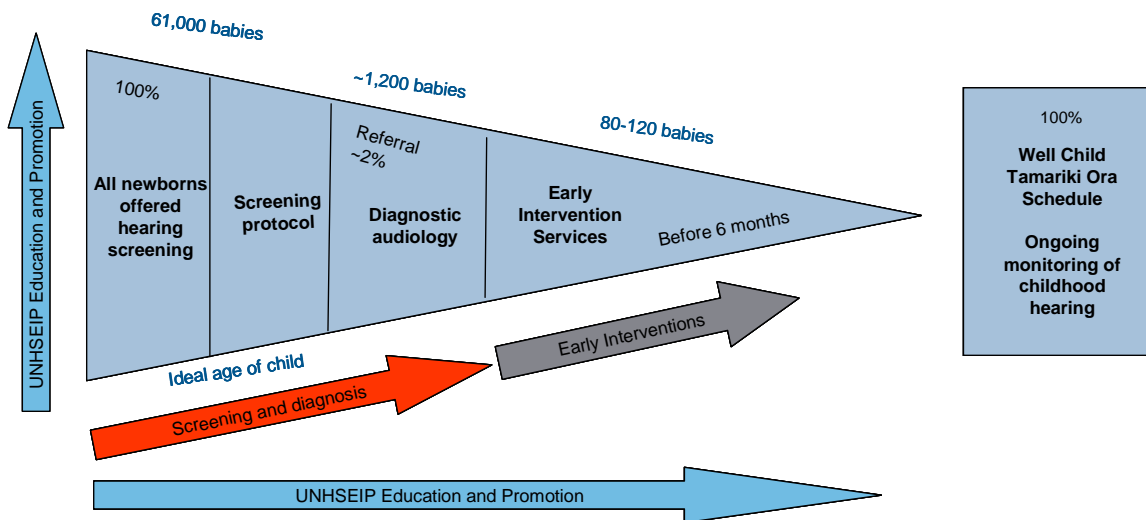


Figure 1: Overview of the UNHSEIP screening pathway

Based on international experience, less than 2% of babies will be referred from screening to diagnostic audiology. If a baby is diagnosed with hearing loss, then a multidisciplinary team will develop an action plan for the baby and family. This team will include an audiologist, an Adviser on Deaf Children (AoDC), and Ear, Nose and Throat Specialist (ENT), and depending on the degree of hearing loss and the needs of the family, other care providers such as Paediatricians and Speech and Language Therapists. For example, the fitting of hearing aids is generally managed by an audiologist, whereas fitting a cochlear implant requires specialised clinical and surgical care.

The UNHSEIP is not designed to identify babies with mild hearing losses. When the screening programme is fully implemented, it is estimated that between 80 and 120 babies each year will be identified with hearing losses of a sufficient degree to require Early Intervention Services funded by the Ministry of Education.

Babies with milder hearing losses generally do not require assistive hearing technologies or intensive intervention, though families may choose to access support services, such as resource materials and parent support networks. Special Education has an 0800 Information Line for families. Regular interaction and review with Well Child providers and family doctors will be important to detect progressive hearing losses.

3. Screening Programmes in New Zealand

3.1 The National Screening Unit

The National Screening Unit (NSU) of the Ministry of Health is responsible for the safety, effectiveness and quality of health and disability screening programmes. The NSU monitors the quality of screening programmes, and works with expert groups and consumers to make sure each screening programme is based on the latest evidence and meets high standards.

The NSU, in its leadership role, fosters a culture for screening programmes of:

- working together as one programme
- striving for excellence in a collaborative learning environment
- encouraging clarity of accountability for quality
- managing quality through a systems approach
- enhancing coordination of quality improvement activities.

3.2 An Organised Approach to Screening

Screening is more than just a test. It is a sequence of events which is often referred to as the 'screening pathway'. All steps in the screening pathway must be of a high standard to ensure that screening is safe, and that the benefits outweigh any harms.

The Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) is an organised screening programme. An organised screening programme is characterised by planning, co-ordination, monitoring and evaluation of all activities along the screening pathway in order to ensure quality in all parts of the programme. The nationally organised approach to the UNHSEIP will facilitate:

- clear lines of accountability
- high-quality service provision
- effective monitoring of defined policy and quality standards
- the timely availability and appropriate integration of screening services with diagnostic, support and intervention services
- monitoring and evaluation of the entire screening pathway.

For screening to be effective in meeting its aim of early identification of congenital hearing loss it is important that the Programme be well organised and focused. For this reason, an organised approach to screening on a national basis will be more successful than ad hoc or targeted screening.

Essential elements of the UNHSEIP are:

- co-ordination of all elements of the service
- tracking of coverage by ethnicity
- an organised invitation to the family and whānau for screening
- a multidisciplinary approach to screening, diagnosis and follow-up
- close linkages with treatment services
- specific operational policies, quality standards and on-going monitoring and quality assurance processes.

The difference between screening and diagnosis

There is an important distinction between screening and diagnosis. Screening divides people into two groups, those with an increased chance, or high risk, of a particular condition being present, and those with a decreased chance, or low risk. Further investigations and diagnostic tests are necessary for those with a high risk, to give a definite answer about whether or not the condition is present.

For example in newborn hearing screening, most babies pass the screening test, which means that at the time of screening they are unlikely to have a hearing loss. Babies who do not pass screening have a higher risk of having a hearing loss, and are referred for diagnostic audiology investigations. These investigations will provide definite answers about the hearing status of the baby.

As screening does not give a definite answer, it is vital that all recommended follow-up is achieved throughout the UNHSEIP.

4. General Policy Requirements

4.1 Policy and Quality Standards

The UNHSEIP National Policy and Quality Standards are intended to provide information about the Programme, to increase knowledge and understanding, and to assist all providers involved in the Programme to achieve minimum standards of good practice. It is also expected that all those involved in Programme provision will meet their professional and ethical standards as well as their legal obligations, including adherence to health legislation and any legislation related to the privacy of health information, such as the:

- New Zealand Public Health and Disability Act 2000
- Health Act 1956
- Privacy Act 1993
- Health Information Privacy Code 1994
- Health and Disability Commissioner's (Code of Health and Disability Services Consumer's Rights) Regulations 1996
- Health Practitioners Competence Assurance Act 2003
- Public Records Act 2005
- New Zealand Bill of Rights 1990
- Care of Children Act 2004.

4.2 Improving Māori Health

The New Zealand Health and Disability Strategies provide an overarching goal for the health and disability sector of improving health and disability outcomes for Māori. The New Zealand Health and Disability Act 2000 established statutory obligations for DHBs to reduce inequalities by improving the health status of Māori, and to increase Māori participation in the Health and Disability sector.

He Korowai Oranga – The Māori Health Strategy sets out a framework to improve the health status of Māori. Core factors for improving health services for Māori include:

- ensuring systems/processes are in place to facilitate the routine involvement of Māori in service development, planning and delivery
- addressing 'access' to health care barriers, such as financial and geographical barriers
- providing health care services in a culturally appropriate manner.

UNHSEIP providers have obligations to:

- develop and implement Māori health plans that identify the specific ways in which they will contribute to improving hearing outcomes for Māori
- reduce access barriers to UNHSEIP for Māori
- facilitate the involvement of Māori throughout service design, development and delivery
- develop relationships with Māori health providers
- develop staff competencies to meet the specific needs of Māori.

The NSU will evaluate UNHSEIP providers in accordance with these criteria, and monitor outcome data for Māori newborns.

4.3 Reducing Inequalities

Inequalities (in health) are differences in health status that are unnecessary, avoidable and unjust. Reducing inequalities is a health and disability sector goal and part of UNHSEIP's aim. Efforts to reduce inequalities are mandated by a number of instruments including the New Zealand Health Strategy, and in the case of DHBs, the New Zealand Public Health and Disability Act 2000.

New Zealand Deafness Notification data (Auckland District Health Board, 2007) indicates that there are currently ethnic inequalities in hearing loss. For example:

- hearing loss was identified later in Māori children and even more so in Pacific children compared to non-Māori, non-Pacific children
- hearing loss was disproportionately reported in Māori children compared to non-Māori children, accounting for nearly half of all deafness notifications.

Health and disability services play an important role in improving health and well-being. Consequently, it is important that in delivering the UNHSEIP, programme providers lead efforts to reduce hearing loss inequalities. This can be demonstrated through the targeted delivery of UNHSEIP services to Māori and Pacific newborns within each region, and by ensuring that all Māori and Pacific newborns are offered screening and where consent is given, that service is provided in a manner that will ensure continuity of care.

In addition, UNHSEIP programme providers specific obligations include:

- requirements to consult with Māori and Pacific populations
- requirements to develop relationships with organisations and providers that can assist with raising awareness of the UNHSEIP amongst Māori and Pacific populations.

The NSU will ensure that the UNHSEIP can be monitored by ethnicity and socioeconomic status to maintain a reducing inequalities focus.

4.4 Programme Monitoring

Programme monitoring is concerned with the routine, systematic collection and recording of information about aspects of a programme over time. The purpose is to assess whether progress is being made on achieving a programme's aims and objectives.

MINISTRY OF HEALTH		
Stage	Component	Indicator name
Screening	Coverage	Newborn hearing screening offered
		Newborn hearing screen declined
		Newborn hearing screening started
		Newborn hearing screening completed
	Referral to audiology	Referral rate to audiology
Audiology	Timeliness	Time from final screen completed to initial diagnostic audiology assessment completed
	Targeted follow-up	Targeted follow-up of babies at risk of developing delayed- onset or progressive hearing loss
	Diagnosis	Initial diagnostic audiological assessment completed
		Hearing loss detected by diagnostic audiology
		Age at identification of hearing loss
		Age at amplification
MINISTRY OF EDUCATION		
Stage	Component	Indicator Name
Early Intervention	Responsiveness	Responsiveness following referral to Early Intervention education services
	Engagement	Engagement in Early Intervention education services
	Retention	Retention of children in the Early Intervention education service through the early childhood years

OVERALL UNHSEIP OUTCOMES		
Stage	Component	Indicator Name
Across the UNHSEIP Screening Pathway	Progress against the key 1-3-6 goals of UNHSEIP	Age at key parts of screening, audiology and early intervention pathways
		<ul style="list-style-type: none"> • Aetiology of hearing loss. • Other disabilities in children with hearing loss. • Parental satisfaction surveys. • False-negative screens. • Workforce monitoring. • Measurement of the communication skills of individual children takes place at set ages during the early childhood years. • Strategies to improve programme performance.

4.5 Informed Consent

Information is valued by consumers and can help to increase levels of satisfaction with a health service. Consumers generally want more information about screening than they receive, especially on potential harms, and false positive test results, and they have a legal right to receive such information pursuant to the Code of Health and Disability Services Consumers' Rights Regulation 1996. Therefore, UNHSEIP providers must ensure that participation is voluntary and only undertaken with knowledge and informed consent in accordance with the Informed Consent Standard at 6.2.

4.6 Privacy

Under New Zealand law, when information is collected about an individual, the individual must be advised that their personal information is being collected and provide their authorisation to collection. The individual must also be informed about how the information that is collected will be stored and used and who will be able to access it. The specific legal requirements in relation to the collection, storage and use of health information are set out in the Health Information Privacy Code 1994. It is expected that UNHSEIP providers will comply with such requirements and the Information Privacy Notification Standard at 6.4.

4.7 Eligibility

The baby's eligibility for publicly funded health and disability services is dependent on their parent/s. If the parent is eligible, the baby is eligible and if the parent is not eligible, then the baby is not eligible. All babies born to New Zealand citizens or permanent residents are deemed eligible. All other babies will be deemed to hold the most favourable immigration status of either parent, for the purpose of assessing eligibility.

The 2003 Direction of the Minister of Health relating to Eligibility for Publicly Funded Personal and Disability Health Services in New Zealand (the Eligibility Direction) describes the groups of people who are eligible for publicly funded health and disability services in New Zealand (<http://www.moh.govt.nz/eligibility>).

The Crown Funding Agreement states that where DHBs provide services to ineligible people they should make "reasonable efforts" to recover costs, which essentially puts the responsibility for follow-up on DHBs. In general, acute services are provided to ineligible people regardless of their ability to pay, but the provision of non-acute services should only be provided where there is an agreement to pay.

4.8 Transferring Between Providers

Ensuring continuity of care for babies and their family and whānau who move between regions at any stage during their involvement with the UNHSEIP is a core responsibility of Programme providers.

If screening has commenced but is not complete, the transferring Programme provider must make sure that a copy of the baby's *Universal Newborn Hearing Screening Programme Patient Data Form* (Appendix A) is sent to the new provider. A further copy of the Form should also be given to the family and whānau, with relevant contact details of the new provider if possible.

If screening has not commenced, the transferring Programme provider should notify the new provider that the baby has not been screened. If the new provider is not yet providing the UNHSEIP, the family and whānau should be given the "Can your baby hear?" hearing checklist, on the understanding that if they are concerned about their baby's hearing at any time, they should talk to their doctor, Well Child provider or Early Childhood Teacher.

5. Programme Specific Policy Requirements

5.1 Family Centred Approach

The UNHSEIP is committed to working collaboratively with families and whānau to ensure that the Programme is family centred. The entire screening pathway, and all other activities provided within the UNHSEIP must be centred around babies and their families and whānau, and ensure that there is community acceptance and confidence in the Programme.

5.2 Team Approach

The success of the UNHSEIP depends on professionals working with families and whānau as a well-coordinated team. The team can be made up of a variety of health and education providers. A collaborative approach across traditional professional boundaries is required.

As many babies pass newborn hearing screening and do not require further follow-up, their families and whānau will probably only interact with newborn hearing screeners. These key team members are the most common contact point between families and whānau and the UNHSEIP.

For babies who do not pass screening, their families and whānau will interact with other UNHSEIP team members. For example, the audiologist will carry out the diagnostic assessment of the baby's hearing. If a hearing loss is found, then referral to an Ear, Nose and Throat specialist (ENT) and a paediatrician will normally be offered. Families and whānau may also choose to work with an Adviser on Deaf Children, other clinical, education and social support professionals and community groups.

5.3 Newborn Hearing Screeners

Newborn hearing screening must be carried out by trained and competent screeners, who are employed by DHBs. All screeners must complete the appropriate training as specified by the National Screening Unit. Newborn hearing screeners are responsible for offering screening, obtaining informed consent, carrying out the screening, and communicating the results to families and whānau.

Newborn hearing screening training is module based, and is nationally provided by an external agency contracted by the National Screening Unit. The training covers such topics as:

- programme information
- communication with parents

- how newborn hearing screening works
- screening processes and protocols
- patient management
- care of equipment.

In addition, it is the responsibility of each DHB to ensure that screeners complete local orientation requirements.

5.4 Newborn Hearing Screening Equipment

It is the responsibility of Programme providers to ensure that all newborn hearing screening equipment used within the Programme meets the necessary safety, quality and technical criteria.

There are four main manufactures/models of screening equipment available in New Zealand. These have been assessed and have all been found to meet necessary safety, quality and technical criteria.

- GNresound/Accuscreen
- Grason-Statler/Audioscreener
- Natus/Algo 3i
- Oticon/Beraphone.

The manufacturer's recommended equipment specific disposables, such as ear tips and ear cups, must be used. The disposables are single use only and must be discarded after use.

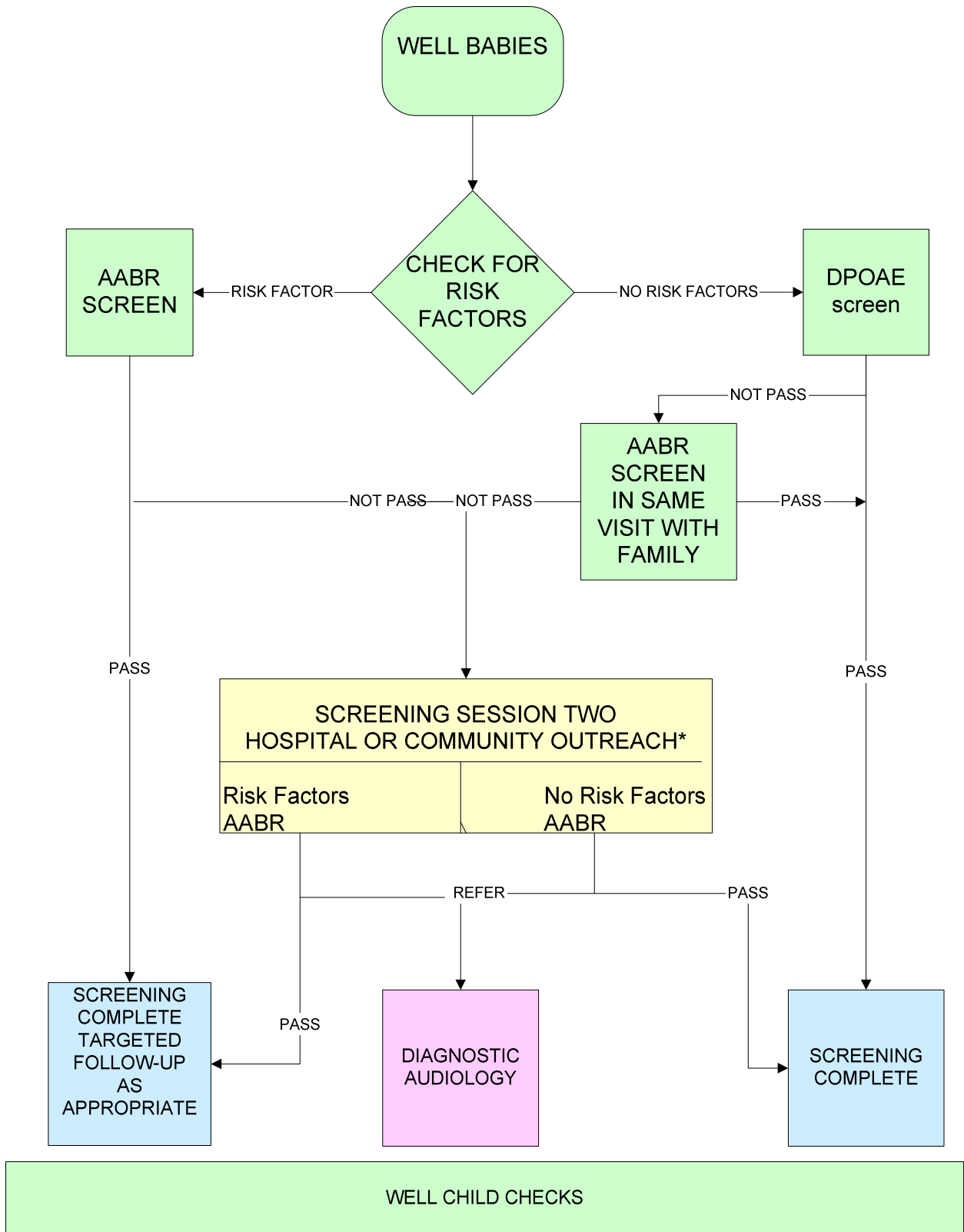
All screening equipment must be checked daily, as per the Programme's daily equipment checklists (Appendix B) and calibration must be maintained as per the manufacturer's instructions.

5.5 Newborn Hearing Screening Protocol for Well Babies

The UNHSEIP uses both automated otoacoustic emission (DPOAE) and automated auditory brainstem response (AABR) for screening. For well babies without risk factors for hearing loss, screening is carried out using DPOAE, followed immediately by AABR for those babies who do not pass the DPOAE.

For well babies identified with one or more risk factors for hearing loss, it is recommended that screening be carried out using AABR only. Risk factors are listed on the *Universal Newborn Hearing Screening Programme Patient Data Form* (Appendix A), and will be updated consistent with the latest evidence.

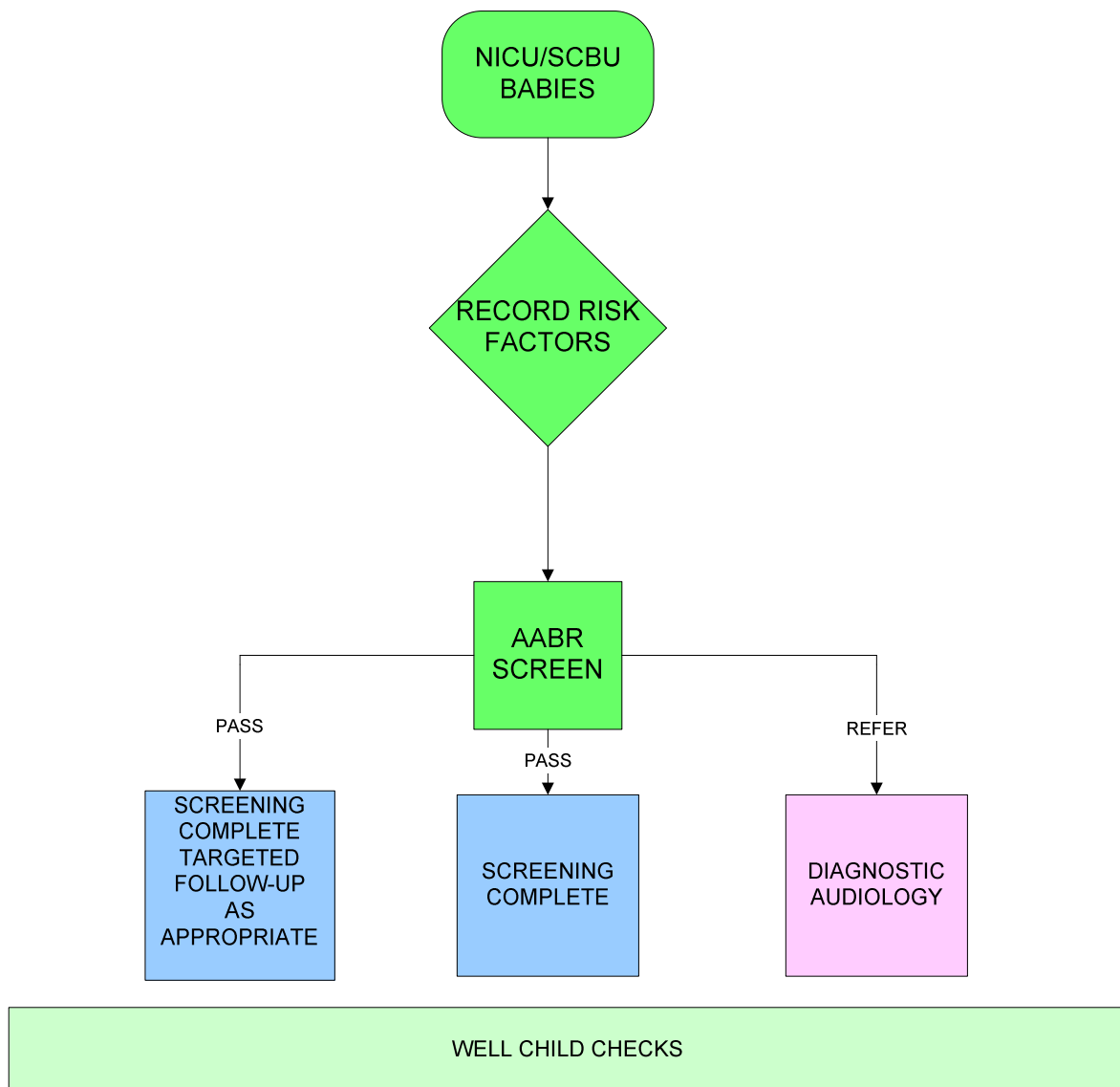
A full copy of the Newborn Hearing Screening Protocol for Well Babies is at Appendix C.



5.6 Newborn Hearing Screening Protocol for Neonatal Care Babies (NICU/SCBU)

Approximately 10% of babies born in New Zealand require special neonatal care. Babies who are resident in level three or level two neonatal care (NICU/SCBU), and have been there for more than 48 hours continuously must be screened using AABR only. Ideally, screening should be completed as close to discharge as possible, when the baby is deemed to be well. Neonatal care babies should be screened only once, and those who do not pass screening should be referred for a diagnostic audiology appointment.

A full copy of the Newborn Hearing Screening Protocol for Neonatal Care Babies is at Appendix D.



5.7 Risk Factors for Congenital and Delayed Onset/Progressive Hearing Loss

The Risk Factors for congenital and delayed onset/progressive hearing loss for the UNHSEIP include:

- Family History – an immediate family member, such as the baby’s parent, brother or sister, with a permanent hearing loss since birth or childhood
- Cranio-facial anomalies of the head neck and ears – unusual appearance of the head, face or ears including the pinna and ear canal, for example cleft lip and palate.
- Ventilation – ECMO (extracorporeal membrane oxygenation) or IPPV (intermittent positive-pressure ventilation) for any length of time; CPAP (continuous positive airway pressure) for more than 48 hours.
- Jaundice (hyperbilirubinemia) – transfusion level jaundice is a Risk Factor for sensorineural hearing loss which may be progressive or late onset*
- TORCH/s (in-utero infections) – serious infections including toxoplasmosis, rubella, cytomegalovirus, herpes and syphilis are known as TORCH/s
- Postnatal infections – postnatal infections associated with sensorineural hearing loss including bacterial/viral meningitis.
- Syndromes – there are a number of genetic syndromes that are associated with progressive hearing loss such as neurofibromatosis, Ushers, and Down syndrome. Hearing loss may be unilateral or bilateral, congenital or progressive.
- Neurodegenerative disorders – these include Hunter’s syndrome, or sensory motor neuropathies, such as Freidric’s ataxia and Charcot-Marie-Tooth syndrome. Hearing loss may be unilateral or bilateral, congenital or progressive
- Head trauma – including skull fracture, prematurely fused fontanelle and brain haemorrhage. Hearing loss may be unilateral or bilateral, congenital or progressive.
- NICU for more than 5 days – even if no other Risk Factors identified.

5.8 Targeted Follow-up

For babies that pass newborn hearing screening but have one or more of the Risk Factors listed in Section 5.7, it is recommended that they should have at least one audiology assessment between 24 to 30 months of age.

Early and more frequent assessment may be indicated for children with cytomegalovirus infection, syndromes associated with progressive hearing loss,

* Jaundice requiring phototherapy requires initial screening by AABR as this has been indicated to be a risk factor for auditory neuropathy. Only jaundice at transfusion level is a risk factor requiring targeted follow-up.

neurodegenerative disorders, trauma, or culture-positive postnatal infections associated with sensorineural hearing loss; for children who have received ECMO (extracorporeal membrane oxygenation); and when there is caregiver concern or a family history of hearing loss.

5.9 Audiologists

Audiologists are responsible for assessing the hearing status of all babies referred from screening, providing diagnostic and habilitation services for those with hearing loss, and working with families and whānau and with other professionals such as Advisers on Deaf Children to achieve the best outcomes for children with hearing loss.

Within the UNHSEIP, diagnostic audiology must be carried out by appropriately trained and competent audiologists. To provide services within the Programme, audiologists must complete the appropriate training as specified by the National Screening Unit.

As the UNHSEIP is implemented, audiology workforce development will be further clarified. The Workforce Working Group has already drafted recommendations for audiologists working within the Programme, and these recommendations will be further defined over time. The Workforce Working Group's draft recommendations are that audiologists should:

- have either a New Zealand Masters degree in audiology or its equivalent as assessed by the New Zealand Qualifications Authority (or other approved external organisation) or
- have an audiology postgraduate qualification (eg, one year Masters degree) and have passed an equivalency exam approved by the New Zealand Audiological Society
- have successfully completed an audiology upskilling programme for working with newborns and infants approved by the National Screening Unit
- have either completed or are in the process of completing a recognised New Zealand clinical competency programme that includes the diagnosis and habilitation of babies and children
- have their competency routinely monitored
- undertake continuing professional development, meet a professional code of ethics and ongoing competency requirements that are agreed to between the provider and the National Screening Unit
- provide consumer access to an appropriate complaints process.

5.10 Audiology Requirements for Diagnosis and Habilitation

A Technical Working Group, established to provide audiological advice and support to the UNHSEIP, developed detailed Diagnostic and Amplification Protocols which are Appendix F to these National Policy and Quality Standards. Audiologists should follow the UNHSEIP Diagnostic and Amplification Protocols when assessing and managing babies referred through the UNHSEIP. Outside of the UNHSEIP, the Protocols are also broadly applicable for the diagnosis and habilitation of babies and children up to 5 years of age.

If a Programme provider is unable to meet any Protocol requirements for babies referred to them through the UNHSEIP, this must be raised with the National Screening Unit as soon as possible. It is the responsibility of the Programme provider to document any deviations from the Protocols, find alternative solutions, and confirm that any alternatives will not be to the detriment of the baby and their family and whānau.

Audiology Room Requirements

The room should have an appropriate chair, such as upholstered recliner, so that the parent can hold the baby in comfort, and also have an alternate arrangement for the baby to sleep (such as a cot). In addition there should be access to a sink, either in the room or in close proximity.

Diagnostic ABRs and OAEs are typically carried out in a soundbooth. If this is not possible, the tests must be carried out in a quiet room with measured sound levels not exceeding:

- 22 dBSPL at 500 Hz
- 30 dBSPL at 1000Hz
- 35 dBSPL at 2000 Hz
- 43 dBSPL at 4000 Hz.

For ABR, electrical isolation is required.

For VRA/BOA assessment, the ambient noise in the test room must meet the current International Electrotechnical Commission (IEC)/International Organization for Standardization (ISO) standard. Calibration must be done when the audiometer is installed, or moved, and then as per the manufacturer's instructions.

Audiology Equipment Requirements

- 2 channel auditory evoked potential system with supra-aural, insert and bone conduction transducers
- diagnostic distortion product otoacoustic emissions (OAE) equipment
- diagnostic immittance equipment with high frequency tympanometry and acoustic reflexes

- diagnostic audiometer capable of presenting pure tone, narrow band noise, FM warbled-tone stimuli and monitored live voice through insert earphones, supra-aural earphones, sound field speakers and bone vibrator
- sound suite for VRA/BOA assessment with a minimum of 2 visual reinforcers (mechanical or video), talk back microphone, 1 sound field speaker, insert earphones, supra-aural earphones and bone conductor, diagnostic audiometer with capability of testing 250HZ through 8000Hz, to profound levels. VRA performed with hand puppets is not a suitable technique.
- real ear measurement system capable of measuring RECDs with an approved test stimulus
- computer with DSL v5 installed with NOAH or similar interface
- instruments should be calibrated as per the manufacturer's instructions.

5.11 After the Diagnosis of a Hearing Loss

The audiologist, Adviser on Deaf Children and Ear, Nose and Throat specialist are generally the key people that work with families and whānau when a baby is diagnosed with a hearing loss. Advisers are teachers of the deaf with additional training in working with families. If the family and whānau has agreed to talk to an Adviser, the Adviser will make contact within two working days of receiving a referral.

Advisers provide specialist ongoing support by visiting families and whānau at home. They monitor hearing and communication development, and are the main liaison point for the family centred intervention plan. The aim of the intervention plan is to facilitate the development of communication, through means such as hearing aids, cochlear implants and New Zealand Sign Language. Depending on the family's needs and choices, groups that may be involved in the intervention plan include:

- Parent Support Groups
- Cochlear Implant Specialists
- Deaf Education Specialists
- Paediatricians
- Speech Language Therapists
- Ophthalmologists
- Radiologists
- Genetic Services
- Private Habilitation providers.

6. Newborn Hearing Screening Standards

6.1 Offering Newborn Hearing Screening to Families/Whānau

Offering Newborn Hearing Screening Standard

The UNHSEIP has a principle of universality, with a goal that all families and whānau of eligible babies will be offered newborn hearing screening.

Criteria

To ensure that the population the DHB is responsible for is offered newborn hearing screening, Programme providers must ensure that:

- 1 mechanisms are in place for notification of births by DHB maternity services, local birthing units, private facilities and independent LMCs
2. good working relationships are maintained between key health providers, including LMCs, GPs and Well Child providers, to ensure all eligible babies are offered a hearing screening
3. effective partnerships are maintained with Māori and Pacific providers, particularly those working in maternity and child health areas
4. there is an established appointment making process for babies who are not screened before discharge, babies who are born at home, and babies who require further screening follow-up
5. good working relationships are established and maintained between all the departments involved in the provision of UNHSEIP services
6. effective partnerships are established and maintained between DHB Programme providers, particularly neighbouring DHBs, so that families and whānau who relocate will be offered screening.

6.2 Informed Consent for Newborn Hearing Screening

Informed Consent Standard

Each baby's parent or legal guardian must be provided with full and accurate information in order to provide informed consent for their baby having hearing screening, possible follow-up assessment and diagnostic services.

Each baby's parent or legal guardian must be sufficiently informed about the screening programme, how it operates and what it involves by being given accurate, sufficient and relevant information that is communicated clearly,

enabling an informed choice and informed consent to be made by the parent or legal guardian.¹

Criteria

1. Within the UNHSEIP, newborn hearing screening providers are required to ensure that:
 - the requirements of the Health and Disability Code of Consumers Rights 5 6 and 7 are fully met² so that the baby's parents or legal guardian are able to give informed consent to all aspects of the screening pathway³
 - the service clearly identifies and documents how and when verbal consent for the newborn hearing screen is obtained and how this is to be recorded ;⁴ and
 - the parent is asked for consent to the screening results being sent to other parties, namely the baby's doctor, Well Child provider and/or Lead Maternity Carer.

2. Newborn hearing screening providers must ensure that the baby's parent or legal guardian:
 - is provided with sufficient and relevant information in an appropriate manner that she/he understands, and that enables her/him to give informed consent in relation to the criteria set out in paragraph 3 below;
 - receives information that is appropriately conveyed in language, culture and manner;
 - is able to have his/her questions answered by an appropriately qualified and/or authorised person; and
 - is aware that she/he can decline hearing screening and/or follow up assessment and diagnostic services at any time and the consequences of that decision.

3. To ensure sufficient information has been provided, screeners must discuss all of the following:
 - the purpose of hearing screening

¹ A parent under sixteen may give informed consent for their newborn provided they are the lawful guardian and are competent to do so.

² Code of Rights 5, 6 and 7 include the right to effective communication, the right to be fully informed and the right to make an informed choice and give informed consent.

³ The Ministry of Education require separate written consent for referral to Early Intervention Education Services. This is not included in scope of this consent standard which applies to health services only

⁴ Consent may be gained over the telephone if necessary provided the person is identifiable as the parent or legal guardian and the full explanation is given.

- the difference between the hearing screening and the diagnostic services including an explanation that hearing screening is a screening test only and as such has inherent limitations
- the procedure, equipment and the anatomy involved in addition to other details that may be required by the parent
- how and when the screening results will be provided
- the objectives of and the benefits and limitations of participating in the UNHSEIP
- that the parent may decline the hearing screen, if she or he wishes to do so
- information about hearing loss prevention and how to check for hearing loss.

DHBs must also ensure that the national pamphlet (HE1921 *Your Baby's Hearing Screen: About Newborn Hearing Screening*) is given to all families/whānau, which provides the information described above.

6.3 Decline of Newborn Hearing Screening

Decline Standard

Each baby's parent or legal guardian must be provided with full and accurate information in order to provide informed consent about their baby having hearing screening, possible follow-up assessment and diagnostic services. Each baby's parent or legal guardian must be aware that she/he can decline hearing screening and/or follow up assessment and diagnostic services at any time.

Criteria

1. Programme providers must ensure that families and whānau who decline newborn hearing screening are:
 - provided with information as to how they can monitor their child's hearing, who can assist them and preventative measures
 - told that if they have any concerns about their child's hearing at any time they should talk to their Well Child provider or their doctor.
2. Programme providers must ensure, when families and whānau decline screening, that:
 - the data form box for no consent is ticked and the form signed by the screener – the form can be kept on file if this is agreed to by the family and whānau
 - it is noted in the baby's clinical notes that newborn hearing screening has been declined.

6.4 Information Privacy Notification

Under New Zealand law, when information is collected about an individual the individual must be advised of that collection and provide their authorisation. The individual must also be informed about how the information that is collected will be stored and used and who will be able to access it (*Privacy Act 1993*). Parents who are the lawful guardians of a newborn baby can provide their consent to the collection of information about that child.

The specific legal requirements in relation to the collection, storage and use of health information are set out in the *Health Information Privacy Code 1994*.

Use of Information (Privacy) Notification Standard

Individual clinical records are unique to each baby and that baby's parents or legal guardian and are protected from unauthorised access and unauthorised disclosure. All Programme provider's staff are required to ensure that they access and use health information appropriately and prevent the unauthorised use or unauthorised disclosure of health information.

Criteria

1. All contracted Programme providers and their subcontracted providers will ensure that:
 - the baby's personal information and data is collected, stored, accessed, and destroyed to a standard that complies with the Health Information Privacy Code 1994
 - the individual (or in this case the baby's parent or legal guardian) is fully informed (called Use of Information Notification) of the purpose, use and recipients of information that is collected about them and any consequences of not supplying such information
 - this notification must be provided at each point information is collected
 - parents are not required to sign the Use of Information (Privacy) Notification as this is not required by the Code
 - there are written protocols for the maintenance and privacy of each baby's personal health information
 - access to personal health records (both in use and in storage) is limited to those with authorisation
 - identifiable names, lists, files are not on display in public areas
 - copies of babies information are only forwarded to the General Practitioner / Primary Care Provider, Well Child Provider and Lead Maternity Carer with the parent's or legal guardian's consent.
2. Programme providers will ensure that staff involved in newborn hearing screening:

- sign a confidentiality declaration in relation to use of information at the commencement of their employment
 - know, understand and adhere to all legal and ethical professional obligations in relation to privacy and confidentiality of patient information and follow the written protocols for the maintenance of the privacy and confidentiality of each baby's information
 - know and understand that access to an individual baby's and parent's or guardian's personal health information is restricted under the law to the minimum number of persons and on a 'need to know' basis.
3. Programme providers will ensure the Use of Information (Privacy) Notification is printed on any form that is used to collect information in such a way it can be kept by parents to refer to later or given on a separate sheet or brochure at the time the information is collected. Recommended text for the Use of Information (Privacy) Notification is included at Appendix E.

6.5 Newborn Hearing Screening

Newborn Hearing Screening Standard

Newborn hearing screening must be carried out by appropriately trained screeners, according to the defined national protocols. The detailed screening protocols for well babies and neonatal care babies are at Appendices C and D.

Criteria

1. The timing of the offer of screening should be sensitive to mother and baby's bonding after birth and their recovery from the delivery process. For babies in special neonatal care the screening process should be sensitive to any other clinical needs.
2. Baby should be calm and the room should be quiet. If this is not the case, screening should not be initiated.
3. The Universal *Newborn Hearing Screening Programme Patient Data Form* must be used to document required information fields and to record the results of screening.
4. Screening data must be transferred to an appropriate electronic database/information system as specified by the National Screening Unit.
5. If appropriate, outpatient clinics and/or community based newborn hearing screening must be offered, as well as screening in hospitals/birthing facilities.
6. Screening should be completed by the time the baby is four weeks old (corrected age).

6.6 Results of Newborn Hearing Screening

Results of Newborn Hearing Screening Standard

The results of newborn hearing screening must be communicated to the family and whānau immediately, when the screening test has been completed.

Criteria for a pass result

The screening equipment recorded a “pass” or clear response for both ears.

1. The newborn hearing screener must follow the script on communicating results, as detailed in the Screener Training Manual.
2. Family and whānau must be provided with the national leaflet HE 1922 *Newborn Hearing Screening Results*.
3. If the baby has been identified as having one or more risk factors for delayed onset/progressive hearing loss, the newborn hearing screener must ensure that the family and whānau are aware of this.

Criteria for a refer result

The screening equipment recorded a “refer” or no clear response for one or both ears, and the screening protocol indicates that the baby should be screened again using AABR.

1. The newborn hearing screener must follow the script on communicating results, as detailed in the Screener Training Manual.
2. The screener must discuss with family and whānau what the next steps will be, including the likely timing and location of the repeat screen.
3. Family and whānau must be provided with the national leaflet HE1923 *Repeat Newborn Hearing Screen*.

Criteria for referral to diagnostic audiology

The screening equipment recorded a “refer” or no clear response for one or both ears, and the screening protocol indicates that the baby should be referred to diagnostic audiology.

1. The newborn hearing screener must follow the script on communicating results as detailed in the Screener Training Manual.
2. The screener must discuss with family and whānau what the next steps will be, including the likely timing and location of the audiology appointment.
3. Family and whānau must be provided with the national pamphlet HE 1924 *Your Baby’s Newborn Hearing Screen: Referral to Audiologist*.

7. Referral to Diagnostic Audiology

7.1 Diagnostic Audiology

Diagnostic Audiology Standard

All diagnostic audiology assessments should be carried out according to the UNHSEIP Diagnostic and Amplification Protocols which are Appendix F to these National Policy and Quality Standards.

Criteria

Programme providers must ensure that:

1. necessary equipment and resources, as described in the national documentation, are readily available to carry out diagnostic audiological assessments for babies referred from newborn hearing screening.
2. families and whānau are offered a diagnostic audiology appointment in a timely manner. The maximum waiting time for an appointment is four weeks after the completion of screening.
3. all diagnostic assessments are completed by the time the baby is three months old (corrected age). This takes into account the fact that full diagnosis may take more than one appointment.
4. all data on diagnostic assessments is collected, stored and reported as per the National Screening Unit requirements.

7.2 Results of Diagnostic Audiology

Results of Diagnostic Audiology Standard

The results of diagnostic audiology must be communicated to the family and whānau immediately, in a sensitive and culturally appropriate manner.

Criteria for giving results when no hearing loss is identified

The audiologist must:

1. explain to the family and whānau what the results of the diagnostic assessment mean, taking time to make sure they understand that their baby does not have a hearing loss.
2. provide the family and whānau with the hearing checklist, and confirm that, if they have concerns about their child's hearing at any time, they should talk to their doctor, Well Child provider or Early Childhood Teacher.

Criteria for giving results when a hearing loss is identified

The audiologist must:

1. explain to the family and whānau what the results of the diagnostic assessment mean, taking time to make sure they understand that their baby has been diagnosed with a hearing loss
2. provide the family and whānau with an opportunity to ask questions and to discuss next steps. If the family and whānau want to make another time to have further discussions, appropriate options should be discussed
3. provide the family and whānau with appropriate written resources, including the *The Family Book – Te Pukapuka O Nga Whanau* and *Getting Started*
4. explain the role of Advisers on Deaf Children and ask the family and whānau if they would like to talk to an Adviser. Agreement or decline of this offer should be recorded
5. if other referrals are required, explain the reasons for the referral and what role the practitioner has. Referral to Parent Support Groups should also be offered at this time.

8. District Health Board Responsibilities

8.1 Programme Management and Official Requirements

The UNHSEIP must be effectively and efficiently managed by each provider, ensuring that a high level of public confidence is maintained, in a manner that is consistent with relevant legislation, standards and Ministry of Health policy.

Programme Management Standard

The day-to-day operation of the Programme must be managed in an efficient and effective manner which ensures the provision of timely, appropriate and safe services to all families and whānau.

Criteria

Programme providers must ensure that:

1. Each provider has a clearly documented management structure which includes:
 - identification of the person/persons who has designated responsibility for the management of all aspects of the service, and clarification of roles, if accountability is shared across more than one person or department
 - responsibilities and accountabilities of specific individuals, groups and/or committees and the relationship between them
 - clear delineation of the relationships and responsibilities of clinical and non-clinical staff
 - representation of relevant consumer and professional groups on any advisory and/or management groups.
2. Legislation, regulatory and contractual requirements, that determine the provision of services, are clearly met.
3. All copies of the National Policy and Quality Standards and other UNHSEIP documentation is kept up-to-date using a version control process.
4. During the temporary absence of the manager/coordinator, a suitably qualified and experienced person will undertake the manager/coordinator's role. This may be achieved by, but is not limited to:
 - ensuring the availability of appropriately trained and designated replacements, for example, nominated delegates (temporary absence includes but is not limited to illness, leave and position vacancy)
 - the level of resources, expertise or equipment provided by the service to meet normal volumes/activities is appropriate.
5. Each provider facilitates communication with other UNHSEIP providers, sharing information and learnings as appropriate.

Legislative Requirements Standard

The day-to-day operation of the Programme must comply with the principles and detail of relevant legislation.

Criteria

UNHSEIP Providers must ensure that the requirements of the following legislation (and any other that is deemed relevant) are met:

- Building Act 1991
- Building Regulations 1992
- Health Act 1956
- Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996
- Health (Retention of Health Information) Regulations 1996
- Health Information Privacy Code 1994
- Health and Safety in Employment Act 1992
- Human Rights Act 1993
- Medical Practitioners Act 1995
- Health Practitioners Competency Assurance Act 2003
- Public Records Act 2005.

8.2 Quality Assurance and Risk Management

Quality Assurance and Risk Management Standard

An established quality and risk management system, that reflects continuous quality improvement principles, must be in place.

Criteria

1. Programme providers must maintain written policies, procedures, guidelines, systems or plans that ensure compliance with these National Policy and Quality Standards, and all other relevant standards that must be complied with, including:
 - updating or formulating procedures and processes whenever it is found that there is an absence of documentation that could potentially affect the safety and/or quality of service delivery
 - ensuring that staff are adequately informed and regularly updated of the content of these documents.
2. Programme providers must have a current documented quality management system that:
 - clearly identifies the personnel that are responsible for ensuring the quality management processes are documented and implemented

- clearly identifies in detail all quality improvement processes and includes an internal audit plan
- references the quality model or philosophy selected by the organisation, for example, PDCA Cycle (Plan, Do, Check, Act), Accreditation, ISO Certification, etc.
- is reviewed by the management at regular intervals to ensure compliance
- has the commitment and participation of management and staff, and enables consumer participation wherever appropriate.

3. Programme providers must:

- implement a system to regularly assess all practices including management systems, policies, procedures and guidelines
- ensure that any changes/advances in practice that are adopted are documented, are communicated to, and implemented by all staff involved in service delivery
- ensure that quality improvement information is collected, analysed and evaluated and the results communicated to service providers and, where appropriate, consumers as part of the quality improvement process
- ensure that quality improvement information is relevant to the organisation's needs and its analysis is both accurate and unbiased
- ensure written evidence of routine quality assurance is available for audits and site visits
- ensure information and experiences regarding quality assurance processes are shared within the provider organisation and where appropriate to other UNHSEIP Programme providers.

8.3 Communication with the Media

Communication with the Media Standard

All media communication will be consistent with the philosophy of the UNHSEIP.

Criteria

The Programme provider must:

1. inform the National Screening Unit Newborn Hearing Screening Programme Manager of any media inquiries relating to the Programme
2. direct all media inquiries to the National Screening Unit Newborn Hearing Screening Programme Manager for comment
3. seek prior written approval from the National Screening Unit Newborn Hearing Screening Programme Manager to communicate with the media about the Programme

4. forward media material relating to the Programme to the National Screening Unit Newborn Hearing Screening Programme Manager for review prior to any public release.

8.4 Data Management

Data Management Standard

All data collected must be relevant, accurate, reliable, reported in a consistent and timely manner, and used and stored in a manner that complies with relevant legislative requirements and Government policy on personal health information.

Criteria

Programme providers must:

1. ensure that data management conforms to relevant legislation and to the guiding principles of data collection and management as described in the Guide to NZHIS National Collections 2006
2. ensure that all staff involved in the Programme:
 - sign a confidentiality declaration in relation to use of information at the commencement of their employment, and
 - know, understand and adhere to all legal, ethical and professional obligations in relation to privacy and confidentiality of patient information, and follow the written protocols for the maintenance of the privacy and confidentiality of each baby's information
3. collect and store, in a manner consistent with privacy legislation and Programme data requirements as specified by the National Screening Unit.

8.5 Monitoring and Evaluation

Monitoring and Evaluation Standard

Accurate and reliable data must be collected to enable Programme providers and the National Screening Unit to undertake Programme monitoring and evaluation at both a regional and national level.

Criteria

Programme providers must:

1. ensure that high quality Programme data is collected to:
 - support effective business processes

- regionally and nationally monitor the Programme in accordance with the Monitoring Framework
 - inform future policy and Programme development decisions
2. develop and maintain systems and procedures to ensure that:
 - data is captured in a complete, timely and accurate manner
 - checks are undertaken to identify any errors that may arise during data entry
 3. provide regular reports to the National Screening Unit as per contract requirements.

8.6 Complaint Management

Complaint Management Standard

Each family and whānau has the right to complain if dissatisfied with the service. Programme providers must provide a procedure for making complaints, compliant with the Code of Health and Disability Services Consumers' Rights 1994.

Criteria

Programme providers must:

1. maintain clearly defined processes for identifying, managing and resolving complaints that:
 - are understood and implemented by all staff
 - have the underlying principle of being resolved at the lowest possible level
 - comply with legislative and contractual requirements
2. record all complaints, comments and suggestions in a specific service logbook/file/database
3. identify specific personnel with responsibility for ensuring that the complaint management process is effective and efficient
4. assure each person/family and whānau who access the complaint process of anonymity and confidentiality
5. immediately inform the National Screening Unit Newborn Hearing Screening Programme Manager of any serious issue or complaint relating to the Programme.

8.7 Adverse and Sentinel Event Management

A serious adverse event is one that may significantly compromise Programme activities, and/or an event for which a facility fails to take corrective actions in a timely manner. A sentinel event is an event that signals something serious has occurred and warrants in-depth investigation.

Adverse and Sentinel Event Standard

Programme providers must ensure that there are robust processes in place for managing adverse and sentinel events.

Criteria

Programme providers must:

1. systematically record all adverse and/or sentinel events. Such events include, but are not limited to:
 - poor screening quality
 - failure to give results in a timely manner
 - accidents, incidents, near misses and clinical events
 - complaints and suggestions
 - infections/notifiable diseases
 - other reportable events as indicated by legislation, regulation, professional practice standards and contracts
2. report adverse and/or sentinel events, in writing at the earliest opportunity, to the National Screening Unit Newborn Hearing Screening Programme Manager
3. if Programme quality is deemed to have been compromised, agree to review by a designated party.

8.8 New Technologies

New Technologies Standard

The approval and inclusion of new technologies must be managed in accordance with evidence-informed principles and the relevant policies and procedures and ethical review where required.

Criteria

Programme providers must:

1. identify to the National Screening Unit, at their earliest convenience, any new technologies relating to the Programme, for consideration and assessment

2. not introduce any new technologies into Programme service delivery without the prior approval of the National Screening Unit.

8.9 Research

The aim of New Zealand's UNHSEIP is for early identification of newborns with hearing loss so that they can access timely and appropriate interventions, inequalities are reduced and the outcomes for these children, their families and whānau, communities and society are improved.

Research Standard

All research applications and approved research projects must be in keeping with the aim of the Programme, and be managed in accordance with evidence-based principles, current legislation, policies and procedures.

Criteria

Programme providers must:

1. notify the National Screening Unit about any proposed research activity prior to its commencement
2. seek feedback on any proposed research activity, prior to commencement, from the relevant external Programme Advisory Group, as designated by the NSU
3. ensure processes are in place to resolve ethical issues in relation to research activities.

Universal Newborn Hearing Screening Programme

Patient Information				Ethnicity				
NHI No: _____		Date of Birth: / /		<small>(Please ask parent/guardian to complete)</small> Which ethnic group does your baby belong to? <small>Mark the space or spaces that apply to you.</small>				
Last Name: _____				<input type="checkbox"/> New Zealand European <input type="checkbox"/> Māori <input type="checkbox"/> Samoan <input type="checkbox"/> Cook Island Maori <input type="checkbox"/> Tongan <input type="checkbox"/> Niuean <input type="checkbox"/> Chinese <input type="checkbox"/> Indian <input type="checkbox"/> Other (please state): <small>(eg. Dutch, Japanese, Tokelauan)</small>				
First Name(s): _____				<input type="checkbox"/> _____ <input type="checkbox"/> _____				
Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female								
Gestational AGE _____ Wks		Weight _____ g		Time of Birth _____				
Multiple Birth: <input type="checkbox"/> YES <input type="checkbox"/> NO				Order: _____ of _____				
Protocol: <input type="checkbox"/> Well Baby <input type="checkbox"/> NICU / SCBU for more than 48 hours								
Delivery Site: _____				Home Birth: <input type="checkbox"/> YES <input type="checkbox"/> NO				
Consent Consent Given <input type="checkbox"/> YES <input type="checkbox"/> NO Privacy Notification Seen <input type="checkbox"/> YES <input type="checkbox"/> NO								
Risk Factors for Hearing Loss <input type="checkbox"/> Family History <input type="checkbox"/> Cranio-facial Anomalies <input type="checkbox"/> Head Trauma <input type="checkbox"/> Bacterial/Viral Meningitis <input type="checkbox"/> Syndrome <input type="checkbox"/> TORCH/S <input type="checkbox"/> Jaundice Any Level <input type="checkbox"/> Jaundice Transfusion Level <input type="checkbox"/> Ventilation <input type="checkbox"/> NICU more than 5 days <input type="checkbox"/> Other _____								
Contact Details								
Last Name: _____		Relationship to Baby: _____		Home Phone: _____				
First Name: _____				Mobile Phone: _____				
Home Address: _____				Text message: <input type="checkbox"/> OK				
_____				Alternative Contact: _____				
_____				Relationship to Baby: _____				
Discharged to Home Address: <input type="checkbox"/> YES <input type="checkbox"/> NO		Out of DHB Area: <input type="checkbox"/> YES <input type="checkbox"/> NO		Home Phone: _____				
Language _____		Translator required: <input type="checkbox"/> YES <input type="checkbox"/> NO		Mobile Phone: _____				
Care Providers' Contact Details								
LMC: _____		GP: _____		Well Child Provider: _____				
Screening Details								
Screen location	Date	Time	Method	Results		Screeener	Equipment	Comment
				Right	Incomplete	Pass	Refer	
				Left	Incomplete	Pass	Refer	
				Right	Incomplete	Pass	Refer	
				Left	Incomplete	Pass	Refer	
				Right	Incomplete	Pass	Refer	
				Left	Incomplete	Pass	Refer	
				Right	Incomplete	Pass	Refer	
				Left	Incomplete	Pass	Refer	
Appointment date and time _____				Appointment date and time _____				
Appointment date and time _____				Appointment date and time _____				
Recommended Follow-up								
Pass No follow-up required	Pass Targeted follow-up required	Refer Diagnostic Unilateral referral	Refer Diagnostic Bilateral referral	Incomplete	Missed	Lost Contact		
				Declined	DNA	Transferred out of screening coverage		
Audiologist Appointment date and time _____				Date input by: _____				
				Date: / /				

* does not require targeted follow up

Guide to Completion of the Universal Newborn Hearing Screening Programme Patient Data Form

A new data form is to be completed for each baby. This is used to track the baby's progress through the screening pathway.

Patient Information

The baby's patient sticker may be used if available.

Protocol

It is important that the Protocol used is indicated by the relevant tick box – 'Well Baby' or 'NICU/SCBU.'

Ethnicity

Must be asked, as it is listed on the on the data form.*

- Staff must not guess the baby's ethnicity.
- The parent or guardian should identify the ethnicity of their baby.
- A baby should not automatically be given the mother's or father's ethnicity.
- Do not transfer ethnicity from another form.
- Allow as many ethnicities as a parent or guardian chooses.
- A parent or guardian can choose not to answer the ethnicity question.
- If the parent or guardian does not wish to answer the ethnicity question, this should be indicated on the form.

If the screener is asking a parent or guardian for ethnicity details by telephone, then:

- Explain that you will be asking a number of questions for administrative purposes.
- Explain that you would like to collect the baby's ethnicity and read out the question as shown on the form.
- Explain that more than one ethnicity may be chosen.
- Read the categories in the order they appear on the form.
- Explain that the parent or guardian can choose not to answer the ethnicity question.
- Record all responses made.

Consent

Verbal consent is required before screening. Tick the appropriate box.

Confirm that the 'Use of Information (Privacy) Notification' has been seen by the parent or guardian prior to screening. Tick the appropriate box. In the case of a NICU or SCBU baby, consent can be sought by telephone if necessary, once the 'Use of Information (Privacy) Notification' has been seen by a parent or guardian.

* Ministry of Health, Ethnicity Data Protocols for the Health and Disability Sector, 2004. These protocols outline the standards for ethnicity data processes for DHBs and other health providers.

Known Risk Factors for Hearing Loss

For Well Babies, check all Risk Factors with parent or guardian and also check the baby's medical record. For NICU or SCBU babies, the 'Risk Factor Checklist' should be completed by ward staff.

If any Risk Factors are ticked, AABR is to be used.

Targeted follow-up is required for all babies with Risk Factors, with exception of jaundice requiring phototherapy.

Contact Details

Mother's patient sticker can be used, if available.

If the mother is not the contact person, "Relationship to baby" must be clearly indicated, e.g. guardian.

Care Providers' Contact Details

If information is available, please complete this section.

Screening Details

It is important that ALL screening attempts and ALL screening information fields are completed for each attempt.

The 'Appointment date and time' field is for missed babies or rescreen appointments.

Recommended Follow-up

This section must be completed.

Data Input by

Data Form details are to be entered into the newborn hearing screening patient information system spreadsheet. This information will be used for reporting to the National Screening Unit as required.

For programme reference, enter the initials of the person who enters the data on patient information system and include the date of the entry.

Data Form Distribution and Actions

Recommended Follow-up	Action to be taken
Pass: No follow-up required	Original to be kept on file
Pass: Targeted follow-up required	Original to be kept on file <ul style="list-style-type: none">• copy to audiology
Refer Diagnostic: Unilateral or Bilateral referral	Original to be kept on file <ul style="list-style-type: none">• copy to audiology
Incomplete, Missed, Declined, DNA or Lost Contact	Original to be kept on file
Transferred out of screening coverage	Original to be kept on file <ul style="list-style-type: none">• copy to the DHB that covers the region of transfer

Appendix C

NEWBORN HEARING SCREENING PROTOCOL FOR WELL BABIES

Scope of the Screening Protocol for Well Babies

This protocol describes screening for hearing loss in babies who are deemed 'Well Babies'. Babies who are currently resident in level two or level three neonatal care, and have been there for more than 48 hours continuously, should be screened using AABR only.

Overview of the Screening Protocol for Well Babies

The Screening Protocol for Well Babies provides the opportunity for two screening sessions before referral to diagnostic audiology (as per the protocol flow chart). Ideally, screening should be completed before discharge from the maternity facility. For babies who are not born in a maternity facility and for families and whānau who choose early discharge, screening may be carried out in a community setting.

The programme uses both automated otoacoustic emission (AOAE) and automated auditory brainstem response (AABR) for screening. For Well Babies without Risk Factors for hearing loss, screening will be carried out using AOAE, followed immediately by AABR for those babies who do not pass the AOAE.

For Well Babies identified with one or more Risk Factors for hearing loss, it is recommended that screening be carried out using AABR only. Risk Factors are listed on the Universal Newborn Hearing Screening Programme Patient Data Form, and will be updated consistent with the latest evidence.

Babies who do not pass screening session one should be screened again using AABR only. Well Babies who do not pass the first AABR should not be rescreened by AOAE because they are presumed to be at risk of having a subsequent diagnosis of auditory neuropathy.

Screening session two should take place while the baby is still in the maternity facility. If this is not possible or practical, then screening session two should take place in a community setting. For babies who are not born in a maternity facility, screening will be carried out in a community setting, and will follow the Universal Newborn Hearing Screening Protocol for Well Babies.

Babies who do not pass screening session two will be referred for a diagnostic audiology appointment[†].

Babies over three months of age should not be screened but require a direct referral to audiology.

* Joint Committee on Infant Hearing 2007. Year 2007 position statement: Principles and guidelines for early hearing detection and intervention. Available from www.asha.org/policy.

† If a baby has not passed two screening sessions, and was under 72 hours of age when screening was completed, the family and whānau can be given the option of a third screening session, rather than referral to audiology. Decisions regarding this option should be made on an individual case basis.

General principles

Screening

- The timing of the offer of screening should be sensitive to bonding of the mother and baby after birth and their recovery from the delivery process.
- Baby should be calm and the room should be quiet. If this is not the case, screening should not be initiated.
- A maximum of three attempts per session can be made to initiate screening, and each unsuccessful attempt must be recorded as an 'incomplete' result.
- The Universal Newborn Hearing Screening Programme Patient Data Form must be used to record the screening, and screening data must be transferred to an appropriate electronic database/information system.
- Screening should be completed by the time the baby is four weeks old.

Equipment

- Equipment checks are to be done daily.
- The same OAE ear tip can be used in both ears of the same baby.
- AABR must be done using ear cups.
- OAE ear tips and AABR ear cups and sensors are disposable and are for single use only.

Screening session one

- If a pass result is obtained on both ears using OAE, screening is complete for the baby.
- If one ear or both ears do not pass using OAE, then *both* ears will be screened using AABR.
- If both ears pass AABR, screening is complete for the baby.
- If one ear or both ears do not pass AABR, the baby will be screened again at screening session two.

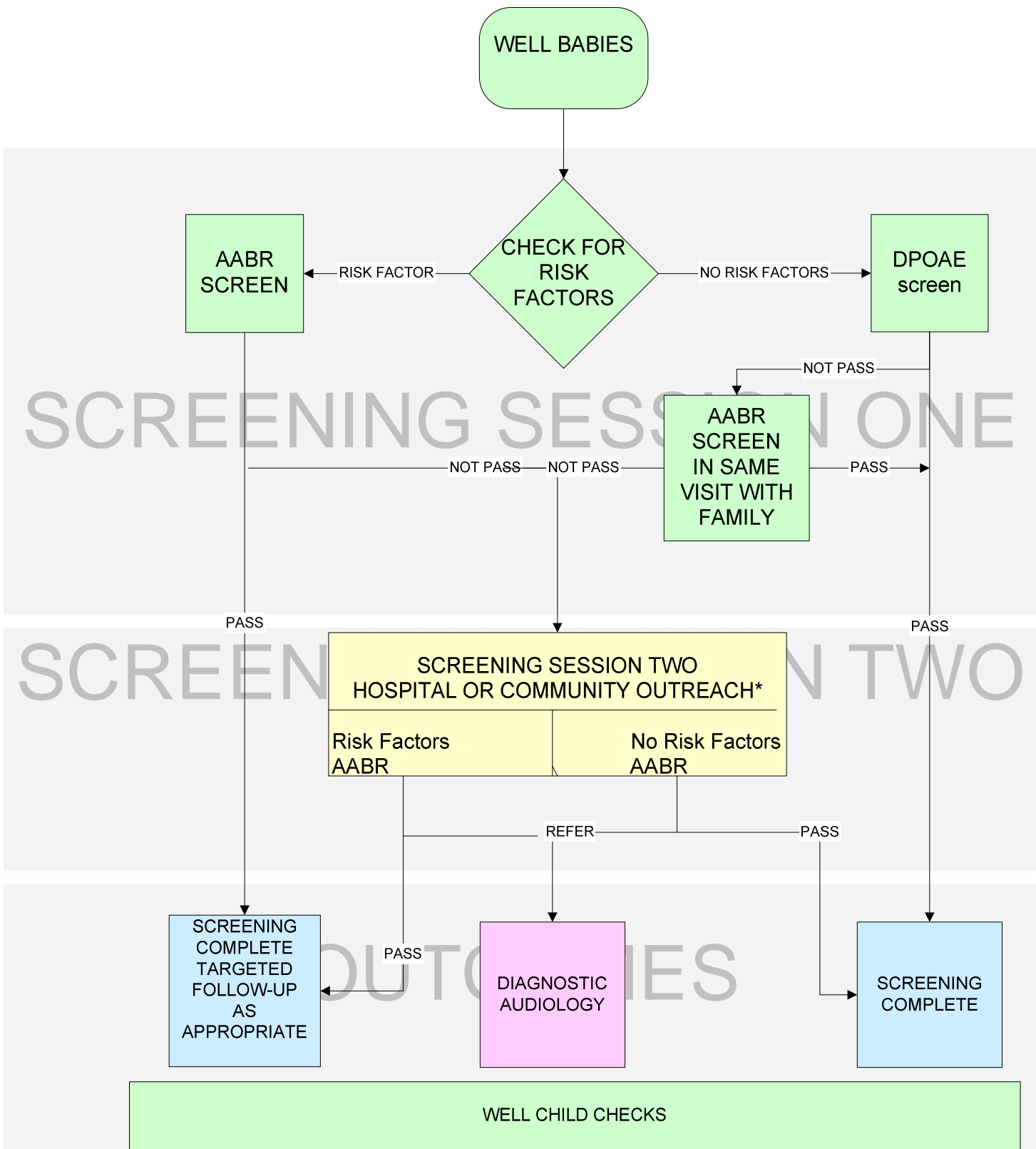
Screening session two

- Ideally, screening session two will take place while the baby is still in the maternity facility. If this is not possible, then screening session two will take place in a community setting.
- The *minimum time* between screening sessions one and two is five hours.
- Babies should be screened again using AABR only.
- If both ears pass AABR, screening is complete for the baby.
- If one ear or both ears do not pass AABR, the baby will be referred for a diagnostic audiology appointment.[‡]

Readmittance

Once a screen has been carried out, completed and an outcome determined (Pass or Refer) the baby should not be rescreened as part of the national programme. If it is deemed clinically appropriate, the paediatrician responsible for the care of the baby will arrange referral directly to audiology.

[‡] If a baby has not passed two screening sessions, and was under 72 hours of age when screening was completed, the family and whānau can be given the option of a third screening session, rather than referral to audiology. Decisions regarding this option should be made on an individual basis.



Appendix D

NEWBORN HEARING SCREENING PROTOCOL FOR NEONATAL CARE BABIES (NICU/SCBU)

Scope of the Screening Protocol for Neonatal Care Babies

This protocol describes screening for hearing loss in babies who have been admitted to level three or level two neonatal care (NICU or SCBU) for more than 48 hours continuously (referred to in this model as neonatal care babies).

Overview of the Screening Protocol for Neonatal Care Babies

Neonatal care babies will be screened using automated auditory brainstem response (AABR) technology only. Ideally, screening should be completed as close to discharge as possible, when the baby is deemed to be well. For babies who are not screened before discharge, AABR screening should be carried out in a community setting.

Neonatal care babies should be screened only once, and those who do not pass screening should be referred for a diagnostic audiology appointment (as per the protocol flow chart).

Approximately 10% of babies born in New Zealand require special neonatal care. Level two units generally care for babies born at 32–40 weeks, and babies who have been transferred from level three units after being clinically stabilised. Level three units provide intensive care and high dependency care.

General Principles

Screening

- Screening should take place as close to discharge as possible.
- The screening process should be sensitive to any other clinical needs.
- The baby should be calm and the room should be quiet. If this is not the case, screening should not be initiated.
- A maximum of three attempts can be made to initiate screening, and each unsuccessful attempt must be recorded as an 'incomplete' result.
- The Universal Newborn Hearing Screening Programme Patient Data Form must be used to record the screening, and screening data transferred to an appropriate electronic database/information system.

Equipment

- Equipment checks are to be done daily.
- AABR must be done using ear cups.
- AABR ear cups and sensors are for single use only.

Infection control

- Screeners who are unwell must not enter the NICU or SCBU.

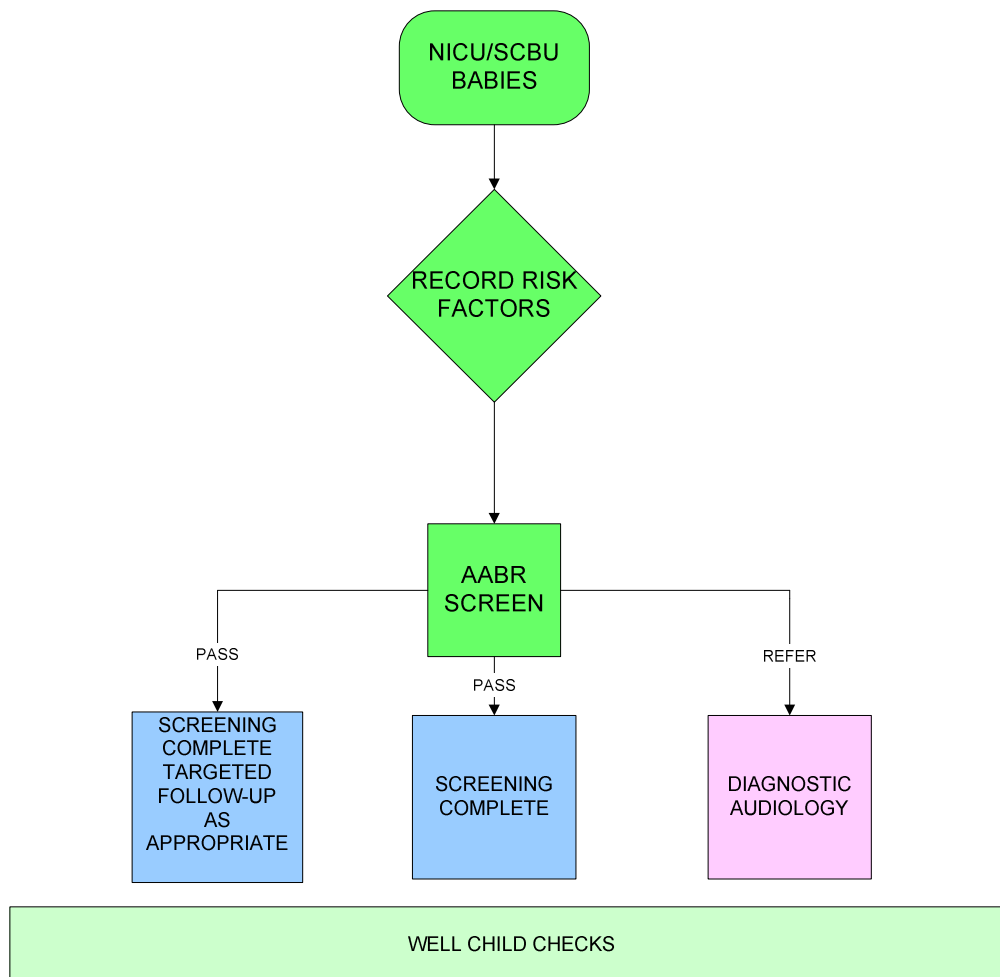
- Hands must be washed with anti-microbial soap (disinfectant) upon entry to the unit.
- Gloves may be required.
- Each DHB will have infection control protocols and procedures which must be adhered to.

AABR screening

- If a 'pass' result is obtained on both ears using AABR, screening is complete for the baby.
- If one or both ears do not pass the AABR, then the baby should be referred for a diagnostic audiology appointment.

Readmittance

Once a screen has been carried out, completed and an outcome determined (Pass or Refer) the baby should not be rescreened as part of the national programme. If it is deemed clinically appropriate, the paediatrician responsible for the care of the baby will arrange referral directly to audiology.



NICU Risk Factors for targeted follow up

Baby's Name _____

Baby's NHI No. _____ **DOB** _____

1. Does the baby have cranio-facial anomalies, including those involving the pinna, ear canal, ear tags, ear pits, cleft lip and palate?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
2. Has the baby received a head trauma, including skull fracture, prematurely fused fontanelle, brain haemorrhage?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
3. Does the baby have a confirmed or suspected post natal infection such as bacterial meningitis?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
4. Does the baby have a confirmed or suspected syndrome related to hearing loss?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
5. Does the baby have a proven or possible congenital infection due to toxoplasmosis, rubella, CMV, herpes or syphilis?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
6. Was the baby jaundiced at transfusion level?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
7. Has the baby been ventilated using ECMO (extracorporeal membrane oxygenation) or IPPV (intermittent positive-pressure ventilation) for any length of time; CPAP (continuous positive airway pressure) for more than 48 hours?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
8. Has the baby been admitted to NICU for more than 5 days?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
9. Is there any other reason the baby should be referred for a targeted follow-up for hearing loss?	YES <input type="checkbox"/>	NO <input type="checkbox"/>

Completed by _____ full name

Position _____

Date _____

Appendix E

Universal Newborn Hearing Screening Programme

Use of Information (Privacy) Notification

This statement applies to information collected by the DHB for its own purposes and for the Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)

Personal Information Collected.

Your consent to your newborn's participation in the Universal Newborn Hearing Screening and Early Intervention Programme (the Programme) includes authorisation for the information you have provided on admission to hospital (or your LMC registration for a home birth) along with your newborn's screening results to be used by the DHB for the purposes of the Programme. The purposes of the Programme are to screen for hearing loss and to provide your newborn with any necessary follow up services.

In order to see how well the Programme is working if your child is found to have a hearing loss at any time during their childhood, information may be collected from Well Child and Special Education services and may also be collected from clinical services such as Ear, Nose and Throat or Genetic services. Access by external evaluators to your newborn's/child's personal health records may be required for the purpose of monitoring the Programme. It is only by monitoring the care and outcomes for all newborns screened that the ongoing quality of the Programme can be properly assessed.

Uses and Sharing.

The information that is collected will be held securely by the DHB or their agent and authorised personnel within the DHB will have access to it for the purposes of the Programme. Information will also be forwarded to the Ministry of Health (or its agents e.g. another entity designated by the National Screening Unit.) In order to assess the effectiveness of the UNHSEIP and monitor the quality of the UNHSEIP information may be collected from screening, and if your newborn is referred, also from audiology services.

- If your newborn is found to have a hearing loss at any time during their childhood, information related to that may be collected from Well Child Services, and Special Education services and other specialist services involved such as Genetic services or ORL services. This is to monitor the Programme's effectiveness.

- Your contact details and your newborn's personal health information are not shared with any agencies other than those mentioned above.

Your Rights

You have the right to see and if necessary correct the information collected about you and your newborn. If you wish to do so ask your screener or the UNHSEIP Programme Manager at the DHB or the DHB Privacy Officer. You may also contact the UNHS Programme Manager at the NSU Write to: UNHSEIP Programme Manager, Private Bag 92522, Wellesley St, Auckland, NZ

If you decline a screening test for your newborn you will be asked if you agree to your newborns name, NHI, date of birth and ethnicity being kept and entered into the UNHSEIP information system. This will help us monitor how effective the Programme is.