

Terms of Reference

Universal Newborn Hearing Screening and Early Intervention Programme Advisory and Working Groups

National Screening Unit Background

The National Screening Unit (NSU) in the Ministry of Health has a leadership role for the National Cervical Screening Programme, BreastScreen Aotearoa, Universal Newborn Hearing Screening and Early Intervention Programme, Newborn Metabolic Screening Programme (NMSP), the quality improvements to antenatal screening for Down syndrome and other conditions and the Universal Offer Antenatal HIV Screening Programme.

The National Screening Unit is responsible for:

- Providing leadership and strategic direction for the cancer, antenatal and newborn screening programmes
- Ensuring nationally consistent policy and quality standards for screening programmes
- Providing national monitoring, audit, evaluation and quality improvement processes for screening programmes
- Providing educational resources for health care practitioners and consumers in relation to screening programmes
- Funding the provision of screening services.

The NSU seeks external advice from a range of sources to support its work.

Universal Newborn Hearing Screening and Early Intervention Programme Background

New Zealand's Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) commenced a three year phased implementation in 2007 and is now offered by all 20 DHBs. The UNHSEIP aims to provide 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.

To achieve this aim the UNHSEIP is overseen by both Ministry of Health and Ministry of Education. The Ministry of Health is accountable for the screening of all babies, and audiology and medical early intervention services for babies diagnosed with hearing loss. Ministry of Education is accountable for the remaining early intervention services for babies diagnosed with hearing loss e.g. Advisers on Deaf Children (AODCs).

The core goals of the UNHSEIP are described as '1-3-6' goals which are based on international programmes:

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

Current estimates indicate that if all of the approximately 61,000 babies born annually are screened, up to 1,200 babies will be referred for an audiological assessment, and

of those babies who undergo an audiological assessment 80 to 120 babies will be found to have moderate or more severe hearing loss requiring early health intervention and special education services.

Functions of the Groups

The UNHSEIP Advisory Group supports the NSU to provide high quality and accessible screening. The Group will meet quarterly dependent on the NSU's workplan requirements.

The roles of the UNHSEIP Advisory Group include:

- To review, critique and interpret UNHS monitoring and evaluation reports and make recommendations to the NSU
- To provide recommendations to the NSU Clinical Governance Group on UNHSEIP issues
- To provide advice on the strategic direction of the UNHSEIP
- To share responsibility with the NSU, for providing liaison back to their respective formal bodies and constituencies where appropriate¹.

There will also be a subgroup for discussing clinical and technical programme matters and developments (Working Group). This group will also meet quarterly dependent on the NSU's workplan requirements.

The roles of the UNHS Working Group include:

- To provide advice to the NSU and the Advisory Group regarding technical and clinical aspects of the UNHS
- To provide advice to the NSU and the Advisory Group from time to time on other areas of the UNHS as agreed by the Group and the NSU
- To share responsibility with the NSU, for providing liaison back to their respective formal bodies and constituencies where appropriate².

Each group will be chaired either by an elected Group member or by an independent chair selected by the NSU. The chairs' role includes:

- Chairing the meetings
- Assisting the NSU with preparing the agenda and advising on papers required for each meeting
- Assisting the NSU, as required, with media matters relating to the UNHSEIP.

Principles of the Groups

There is an expectation that members of the Groups will make every effort to attend all meetings and devote sufficient time to prepare for the meeting.

The Groups will:

- involve key stakeholder groups, including consumers;
- use the best available evidence to inform their work;
- have a strong focus on quality improvement and equity;
- have a population perspective with an understanding of the principles of screening programmes.

¹ For those members who are endorsed by their college/body.

² For those members who are endorsed by their college/body.

Person Specification

Members of the Group need to have an understanding of the UNHSEIP. They must have an understanding of and special interest in population based screening. Other attributes required are:

- skills in data interpretation and review/analysis of monitoring reports
- strong communication skills, ideally with a track record of working constructively in multidisciplinary groups
- an ability to think about issues from a professional, regional, and national programme perspective.

Nomination Process

Membership to the Group is achieved through a combination of the NSU requesting nominated representatives from relevant organisations and societies and invitation to specific individuals that hold specialist knowledge that meet the required attributes of the Group.

Composition of the Groups

The groups will be comprised of members who collectively have wide knowledge and experience of the UNHSEIP.

The following representation will be included in the Advisory Group:

- Audiology
- Ear, Nose and Throat
- UNHSEIP Programme Coordinator
- Scientist (from a hearing related field)
- Epidemiologist
- Public Health Physician
- Parents
- Maori advisor
- Pacific advisor
- Chief Advisor, Child and Youth Health – Ministry of Health.
- Ministry of Education, with Advisor on Deaf Children knowledge.

A quorum of the Advisory Group for any meeting is 8 members.

The following representation will be included in the Working Group:

- Audiology
- Ear, Nose and Throat
- Paediatrician
- UNHSEIP Programme Coordinator
- Scientist (from a hearing related field).

A quorum of the Working Group for any meeting is 3 members.

The Working reports to the Advisory Group.

The NSU may co-opt other members as required to either group.

Meetings will also be attended by members of the NSU including the Manager Antenatal and Newborn Screening, UNHSEIP Programme Leader and relevant Senior Service Development Analysts. Other members of the NSU may also attend as appropriate.

Terms and Conditions of Appointment

The term of office for members will be one year. Membership may be renewed for a further term/s.

If a vacancy arises, the Manager Antenatal and Newborn Screening will appoint a replacement after taking into account the advice of the group on desirable skills and experience.

The groups will meet quarterly as required by the UNHSEIP workplan. The meetings will be held in Auckland from 0930 - 1530 unless otherwise advised.

Papers for the meetings will be distributed at least one week prior to the meeting. The NSU will endeavor to disseminate these documents as far in advance of the meeting as possible.

Teleconferences may be arranged if required to discuss particular issues.

The groups are not decision making bodies but rather a forum at which advice can be given to the NSU and the NSU clinical governance group. Final decisions rest with the NSU.

The NSU will provide funding and administrative support for the groups.

The Manager Antenatal and Newborn Screening has the discretion to form additional sub-groups for specific issues if required.

Conflicts of interest protocol

The members of each group should perform their functions in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Proper observation of these principles will protect them and will enable public confidence to be maintained.

When members believe they have a conflict of interest on a subject which will prevent them from reaching an impartial decision or undertaking an activity consistent with the UNHSEIP Advisory or Working Group's functions, then they must declare a conflict of interest or absent themselves from the discussion and/or activity.

Confidentiality

Meetings, including agenda material and minutes, of the UNHSEIP Advisory or Working Group are confidential. Members of the Group must ensure that the confidentiality of UNHSEIP Advisory or Working Group business is maintained.

Members are free to express their own views within the context of UNHSEIP Advisory or Working Group meetings, or the general business of the UNHSEIP Advisory or Working Group.

UNHSEIP Advisory or Working Group members must publicly support a course of action decided by the UNHSEIP Advisory Group or Working Group, or if unable to do that, must not publicly comment on decisions.

At no time shall UNHSEIP Advisory or Working Group members individually divulge details of the groups' matters or discussions within the Groups to persons who are not Groups members. Disclosure of UNHSEIP Advisory or Working Group business to anyone outside the Groups must be the decision of the Groups, or between meetings, at the discretion of the Chair of the UNHSEIP Advisory Group or Working Group.

UNHSEIP Advisory or Working Group members must ensure that the groups' documents are kept securely to ensure the confidentiality of the groups' work is maintained. Release of correspondence or papers can only be made with the approval of the Groups and the Ministry. At the end of a member's term all UNHSEIP Advisory or Working Group information must be returned to the office.

Work Plan development

The groups will meet quarterly as required by the UNHSEIP workplan.

Reporting Requirements

The UNHSEIP Advisory and Working Group report to the Manager, Antenatal and Newborn Screening.

Fees and Allowances

Members of the UNHSEIP Advisory or Working Group are paid fees for attendance at meetings. The level of attendance fees are set in accordance with the State Services Commission's framework for fees for statutory bodies. A fee of \$325.00 (exclusive of GST) will be paid for attendance at face-to-face meetings and is based upon a full day meeting including travel time. A fee of \$162.50 (exclusive of GST) will be paid for preparation prior to meetings and is based on up to 4 hours preparatory work. Any fee for teleconferencing will depend upon the time required and the Ministry of Health will advise you in advance whether a fee applies. This is reviewed annually. The National Screening Unit meets the cost of travel, accommodation and meals within specified administrative arrangements.

Media Policy

Group members are not agents of the Ministry of Health and therefore are not permitted to speak on behalf of the groups, the NSU or the Ministry of Health. However, this does not restrict members to media statements relating to their personal expertise.

If a member receives a media request or enquiry relating to the UNHSEIP, they must inform the Manager Antenatal and Newborn Screening or the Ministry of Health Communications Manager (Appendix 1).

Any media enquiry relating to the strategic intent, funding or any activity in which the Ministry of Health is responsible for, shall be directed to the NSU Group Manager or the Ministry of Health Communications Manager.

Appendix 1: Contact details for the Ministry of Health

Programme Leader, Vickie Rydz
UNHSEIP, NSU

Ministry of Health
650 Great South Road
Penrose
Auckland

Private Bag 92522
Wellesley St
Auckland

Phone: 09 580 9086

Fax: 09 580 9001

Manager, Antenatal Jane McEntee
and Newborn
Screening, NSU

Ministry of Health
650 Great South Road
Penrose
Auckland

Private Bag 92522
Wellesley St
Auckland

Phone: 09 580 9067

Fax: 09 580 9001

Communications Peter Abernethy
Manager

Ministry of Health
Molesworth Street
Wellington

P O Box 5013
Wellington

Phone: 04 496 2008

Fax: 04 496 2010
