

# Privacy notice

# Newborn Hearing Screening Programme - Smart4Hearing (S4H)

**Purpose**

This privacy notice describes how personal information is processed by the Smart4Hearing service. Smart4Hearing is the IT system used to provide, manage and quality assure the Newborn Hearing Screening Programme in Northern Ireland.

Newborn hearing screening is offered to all babies who are over 34 weeks gestational age and are born in, reside in, or move into Northern Ireland from birth up to 6 months old (182 days).

The aim of the programme is to identify babies born with a permanent childhood hearing impairment. One to two babies in every 1,000 are born with a hearing loss in one or both ears. This increases to approximately 1 in 100 for babies who spend more than 48 hours in a neonatal unit or special care baby unit. Early detection and effective interventions result in improved outcomes for children, in particular improved speech and language development.

## Consent to participate

Those with parental responsibility must give consent for their baby to take part in the Newborn Hearing Screening Programme.

Newborn hearing screening is recommended for your baby. However, you may contact the Newborn Hearing Screening Coordinator in your Health and Social Care (HSC) Trust at any time to withdraw your consent, using the following link:

<https://www.publichealth.hscni.net/sites/default/files/2023-01/Contact%20details%20for%20Screening%20Offices_Apr22.pdf>

## What information is collected?

We only collect the information we need, in order to provide, manage and quality assure the programme. This will include, for example, your baby’s name; date of birth; gender; health and care number; address; as well as your name and contact details. We will also collect healthcare related data, including your baby’s hearing screening results, any conditions or factors associated with a higher risk of hearing loss (risk factors), referral and diagnostic information.

## Where do you get my/my baby’s personal data from?

Shortly after birth, data on all babies born in Northern Ireland are entered onto the Encompass IT system. This information is then linked to their mother’s data. Encompass is the electronic health care record used by all HSC Trusts in Northern Ireland. Currently, an electronic feed from this system automatically imports demographic information into the Child Health System, which also contains the details of any children who move to Northern Ireland from elsewhere. A ‘registration feed’ routinely uploads the necessary information from the Child Health System to Smart4Hearing (electronically). The Child Health System is a separate community-based IT system that supports services such as childhood vaccination and school health.

## Do you share my/my baby’s personal data with anyone else?

Yes. To help us provide the best care and service for you and your baby, we share information with other healthcare professionals such as your GP and health visitor. We also share information with other relevant healthcare professionals (such as audiologists) if a baby requires referral for further tests.

As well as being recorded in Smart4Hearing, the results of your baby’s hearing screen are recorded in your baby’s Personal Child Health Record (Red Book). Some information about hearing screening is also recorded on Encompass.

## Why are you processing my/my baby’s personal information?

Data are collected to offer and complete newborn hearing screening, make referrals to diagnostic services, if required, and provide information to relevant health care staff, in line with legislation and information governance requirements.

In order to support the monitoring of programme performance, quality assurance of the programme and oversight of adherence to nationally agreed standards, Smart4hearing retains data on all eligible babies (all babies who are born in, resident, or who move to Northern Ireland aged up to 182 days) and those with parental responsibility.

Smart4Hearing, therefore, holds data on all those who are offered newborn hearing screening, as well as those who participate, decline, withdraw, defer or ‘do not attend’ for newborn hearing screening.

## Processing requirements

To be able to process your personal information we are required to have a lawful basis for doing so. The lawfulness of processing is determined by UK GDPR regulations (2018):

Article 6(1)(e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;

Article 9(2)(h) processing is necessary for the purposes of preventive medicine, the provision of health or social care or treatment or the management of health or social care systems and services.

## Do you transfer my/my baby’s personal data to other countries?

Yes. Data may be shared with relevant healthcare professionals in the Republic of Ireland or other UK countries if a baby moves to that country.

Data are not shared with countries outside of the UK or Republic of Ireland.

## How long do you keep the personal data?

Personal data are retained for 25 years, in line with our Retention and Disposal Schedule and specific guidance issued by the Department of Health in Northern Ireland.

## What rights do I have?

* You have the right to obtain confirmation that your data are being processed, and have access to your personal data
* You are entitled to have personal data rectified if it is inaccurate or incomplete
* You have the right to ‘block’ or suppress processing of personal data, in specific circumstances
* You have the right to object to the processing, in specific circumstances

If you wish to exercise any of these rights, please contact your Newborn Hearing Screening Coordinator in your HSC Trust using the following link:

<https://www.publichealth.hscni.net/sites/default/files/2023-01/Contact%20details%20for%20Screening%20Offices_Apr22.pdf>

## How do I complain if I am not happy with any aspect of this Privacy notice?

If you are unhappy with any aspect of this privacy notice, or with how your, or your baby’s, personal information is being processed, please contact the Data Protection Officer within your HSC Trust using the following link:

<https://www.publichealth.hscni.net/sites/default/files/2024-03/Trust%20Data%20Protection%20Officers_Nov%2022.pdf>

If you are still not happy, you have the right to lodge a complaint with the Information Commissioner’s Office (ICO):

Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
Email: casework@ico.org.uk

<https://ico.org.uk/make-a-complaint/data-protection-complaints/>

**Changes to our Privacy notice**

This Privacy notice will be kept under review and any updates will be published on our website.