



Privacy Notice – Smart4Hearing

Purpose

This privacy notice describes how personal information will be processed within the Smart4Hearing (S4H) service, for the purposes of providing the Newborn Hearing Screening Programme in Northern Ireland.

The Newborn Hearing Screening Programme (NHSP) offers all newborn babies in Northern Ireland hearing screening tests soon after birth. The aim of the programme is to identify babies born with a permanent childhood hearing impairment (PCHI) early, to allow timely intervention and improved outcomes.

What are the participation requirements for the programme?

Those with parental responsibility must provide consent in order for their baby to take part in the NHSP.

Newborn hearing screening is recommended for your baby; however you may contact the Newborn Hearing Screening Coordinator in your HSC Trust at any time to withdraw your consent, using contact details in this link

<https://www.publichealth.hscni.net/publications/newborn-hearing-screening-english-and-translations>

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 or hospital number, address and your name and contact details. We will also collect health related data including your baby's hearing screening results, wave forms, 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 Northern Ireland Maternity System (NIMATS). Currently, a feed from this system automatically imports demographic information into the Child Health System (CHS), which also contains the details of any children who move into Northern Ireland from elsewhere. A 'registration feed' will routinely upload this information from CHS to S4H (by an electronic interface).

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 may need to share your information with other healthcare bodies such as the Health and Social Care Board (to inform service development), GPs, Health Visitors and other relevant professionals.

Why are you processing my/my baby's personal information?

Data will be collected to offer and complete newborn hearing screening, in line with legislation and governance requirements.

In order to support the monitoring of programme performance, quality assurance of the programme and oversight of adherence to nationally agreed standards, S4H will retain data on all eligible babies (i.e. all babies who are born in, resident, or who move into N.I. aged up to 182 days) and those with parental responsibility.

This is important to allow: proper monitoring of the performance of the programme; quality assurance of the programme and oversight of adherence to nationally agreed standards e.g. determining uptake. S4H will, therefore, hold 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 lawful basis for doing so. The lawfulness of processing is determined by EU GDPR regulations

- Article 6(1)(e) Public Task which states that *'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

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

Yes. Relevant data will be shared with the Health Service Executive (HSE) in RoI or the appropriate professional in another UK country in the instances whereby baby is born in Northern Ireland but is resident in another UK country or the Republic of Ireland (RoI) or if a Northern Ireland resident baby moves to RoI, or another UK country, before screening is complete (or when a follow-up is required). The sharing of data to another UK country or RoI will **only occur where necessary**, in order to facilitate the completion of newborn hearing screening.

How long do you keep my personal data?

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 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

Should 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/publications/newborn-hearing-screening-english-and-translations>

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/your baby's personal information is being processed, please contact the Data Protection Officer within your Trust <https://www.publichealth.hscni.net/directorate-public-health/service-development-and-screening/newborn-screening>

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/global/contact-us/>
<https://ico.org.uk/concerns/handling/>

Changes to our Privacy Notice

This Privacy Notice will be kept under regular review and any updates will be placed on our website.

01 March 2021