**Consent form for storing aetiological investigation data on the national IT system**

**Section 1: information for parents**

You are being asked to give your consent for the storage of aetiological investigation data for your child on the NHS newborn hearing screening national IT system. Your doctor will discuss this with you further and answer any questions you may have. This leaflet provides you with more information to help you decide.

**What are aetiological investigations?**

There are a range of medical tests that can be carried out to try and find the cause of your child’s deafness. The process to find out why a child is deaf is sometimes called aetiological investigation.

**Why carry out aetiological investigations?**

Every child with a permanent deafness will be offered investigations. Knowing the cause of the deafness is important for planning your child’s care. You may find it helpful to know what caused your child’s deafness or if a specific cause cannot be identified you may find it helpful to know some things that did not cause your child’s deafness. It is important to know about any associated medical conditions so you can consider appropriate treatment or ways of managing the deafness or condition. In some cases identifying the cause can help prevent further deterioration of the hearing.

For further information see “Understanding your child’s hearing tests: A guide to the hearing and medical tests that are used to find out the type, level and cause of deafness” published by the National Deaf Children’s Society at <http://www.ndcs.org.uk/>.

**What is the national IT system?**

A national database was established in 2006, maintained by Public Health England and used within the NHS newborn hearing screening programmes. It records details of all babies born in England so that the screening programme can ensure that all babies are offered a newborn hearing screen. It records the results of the screen and any subsequent audiological assessments (hearing tests) so that the performance of the programme can be monitored and checked.

**Who has access to aetiological investigation data?**

If you consent for data to be stored on the National IT system it will be visible to:

* the doctors who are carrying out the aetiological investigation
* the audiologists who are looking after your child
* the clinician who is responsible locally for the newborn hearing screening programme

It will also be available to a very limited group within the national programme team but in an anonymised form. This means they will not be able to see any personal details such as yours and your baby’s, name, address, date of birth, NHS number or any other identifying information.

All requirements of the Data Protection Act 1998 will be met during the storage and use of the data. All staff that work in or with the NHS are required as a matter of law to keep information about you and your baby confidential.

**Why store aetiological data?**

This will help your own ‘aetiology doctor’ to check that any tests and investigations you agree to have been carried out and that all the results of the tests and investigations have come back to the doctor. It will help your doctor to check that all the tests you should be offered have been offered.

The anonymised information will be used by the national team for planning services for deaf children and their families and research into causes and prevention of hearing loss.

**What happens if I do not give consent to storage of aetiological data in the national IT system?**

If you do not give consent we will record that you have had an appointment with the doctor to discuss aetiological investigations but no further information about the investigations or diagnoses will be recorded on the system. **This will not affect the clinical care or tests and investigations offered to you and your baby** but does mean that your data will not contribute to future planning and research into the causes and prevention of hearing loss.

**What can I do if I have more questions?**

You can ask your aetiology doctor who will give you more information and answer your questions.

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**Section 2: consent form**

I …………………………………………………………………… (Name of consent giver)

Relationship to child…………………………………………………………………………..

Name of child……………..…………………………………………………………………..

Date of birth (of child)...………………………………………………………………………

Hospital number / NHS number (of child)…………………………………..………………

I agree to the storage of aetiological investigation data for of my child whose name is shown above, on the national IT system.

I confirm that I have read and understood the information sheet and my questions have been answered satisfactorily.

Signature: ……………………………………………………………..……………………

Date: …………………………………………………………………………….………….

Aetiology Doctor’s name: ………….…………………………………………………….

Doctor’s signature: ………………………………..……………………………………….

Date: …………………………………………………………………………………………

*Please file this copy in the hospital notes*.