If you have any questions or would like to learn more about our research study, please contact:

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If you would like to take part in SEQaBOO Manchester, please go to http://research.bmh.manchester.ac.uk/ManCAD/SEQaBOOManchester/ And click on the SEQaBOO Manchester Consent link, or type https://redcap.link/SEQaBOO_Manchester_Consent into your web browser

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Manchester University
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DNA technologies help us to uncover the causes of many conditions, potentially leading to treatments and improving the quality of life for patients and those who care for them.

By participating in SEQaBOO Manchester you are helping us make steps towards these new DNA technologies being implemented in newborn screening and advancing the diagnosis and management of hearing loss in the future.

Want to learn more?

Your Baby Has a Hearing Loss
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/402685/Your_Baby_has_a_HL.pdf

Additional resources:

Newborn screening:
https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby/hearing-loss

Childhood hearing tests:
https://www.nhs.uk/conditions/hearing-tests-children/

General support for children with hearing loss:
https://www.ndcs.org.uk/

Visit our sister website and watch our video:
http://SEQaBOO.bwh.harvard.edu

Pamphlet V2.1 4 August 2020

SEQaBOO Manchester
SEQuencing a Baby for an Optimal Outcome

Charting a Path for Newborn Screening

Funded by NIHR

Hearing loss is the most common sensory disorder in humans. One in 1000 newborns have hearing loss and that number increases to 1 in 500 children by school age.

As part of standard care, every newborn has a hearing screen. Newborns who do not pass this initial hearing screen are scheduled at approximately 1 month of age for a follow-up diagnostic hearing test.

Clinical diagnosis often does not distinguish among different types of hearing loss. Through genomic sequencing, we hope to provide optimal management at the earliest possible time and eliminate unnecessary medical tests.

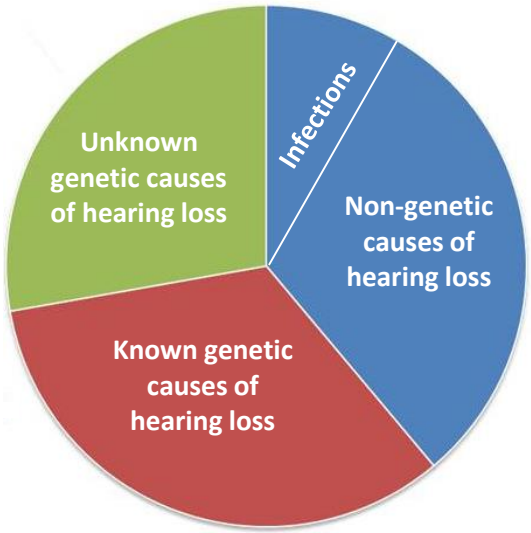
SEQaBOO Manchester

SEQuencing a Baby for an Optimal Outcome

Our research study will investigate how genomic information may benefit and assist in providing care and management of newborns with hearing loss. By participating in our study, you will be helping us to:

- ✓ Understand the initial and evolving opinions of parents toward genomic sequencing.
- ✓ Learn how genomic information can be used, along with the standard care treatment, in making decisions and diagnoses for newborns with hearing loss.

Causes of Hearing Loss



The NIHR Manchester Biomedical Research Centre is participating in a research study:

Surveys

All parents of babies who attend for audiology testing at any of the Manchester University NHS Foundation Trust (MFT) sites will be offered the chance to participate in annual SEQaBOO surveys.

These surveys will ask questions about:

- Your family's health
- Your knowledge and attitudes towards newborn screening
- Your knowledge and attitudes towards genomic sequencing

Genome Sequencing + Surveys

Those parents whose babies who do not pass follow-up audiology testing will also be offered the chance to enroll themselves and their baby in the Genomic Medicine Service through which they can receive Genome Sequencing (GS).

This occurs at a separate appointment. Results from this genetic testing may help doctors manage your child's hearing loss in the future.