

Participant Information Sheet

How do parents make sense of the experience of diagnosis of deafness in their children?

Invitation to research

I would like to invite you to take part in a research project. My name is Sarah Mills, and I am a postgraduate student at Manchester Metropolitan University (MMU) studying MSc in Childhood Development and Well-being in Practice. My research project is looking at the experiences of parents around diagnosis of deafness.

Why have I been invited?

Parents play an important part in supporting deaf children with establishing hearing aid or cochlear implant wear so they can facilitate the development age-appropriate language and communication skills. To achieve this, it is important that parents receive suitable support from key services. This study wishes to get the experiences of parents around the diagnosis of deafness so any suggestions for changes in support can be shared with the relevant services. For example, audiology, sensory services and speech and language. There will be up to 8 people taking part in the study and they can be from different ethnic groups and families. For example, two parents or single parents. Due to the sensitive nature of the experience, your child needs to have been diagnosed with deafness at least a year ago if you wish to take part.

Do I have to take part?

It is up to you to decide and participation is voluntary. This information sheet will describe the study and you will be able to ask us any questions before taking part. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time until 2 weeks after the interview, without giving a reason. This research is separate from any support you may be receiving from outside services such as local sensory services, speech and language, audiology, and any information shared will be completely anonymised.

What will I be asked to do?

You will take part in an interview with myself where you will be asked questions around the diagnosis of your child's deafness. For example, questions about your experience before your

child was diagnosed as deaf, your experiences when you found out your child was deaf, and your experiences now sometime after diagnosis. The interviews will be up to an hour and will take place by video call using Microsoft Teams or face to face depending on parents' preferences. The interviews will be recorded either on Teams or through a Dictaphone and then transcribed.

Are there any risks if I participate?

Individuals who feel that due to the sensitivity of the topic, they may become acutely distressed in the interview, should self-exclude themselves from the study.

Are there any advantages if I participate?

There are no direct advantages or incentives for participation. However, it is hoped, through parents sharing their experiences around the diagnosis of deafness, it may help services to review and improve their practice to better support parents of deaf children going forward.

Informed consent

For Teams interviews, before the interview starts, each clause of the consent form will be read aloud by myself, and participants will be required to give verbal consent. The recording of this verbal consent will be stored separately from the recordings of the interviews on MMU's One Drive storage system.

For face-to-face interviews, you will be given a consent form to read and then sign, one copy will be for you to keep, and one will be for me that will be scanned and stored on MMU's One Drive.

All interview recordings will be stored securely on MMU's One Drive. You will have two weeks post interview to withdraw after which data will be transcribed and analysed. Data cannot be withdrawn after transcription. After transcription, the recordings will be deleted.

Your data will be anonymised and all information and data that is collected during this project will be kept strictly confidential and will only be used for the purpose of this study.

What information about me will you collect and why?

The information collected in the interviews will be about your experiences around of the diagnosis of your child's deafness. The information will be used in the final report and may inform any changes to policy and practice. Your experiences may also be shared in professional publications, conferences, or be used for training sessions within sensory services.

How will my information be stored and how will you look after it?

Your information will be stored anonymised and securely stored on the MMU's One Drive system. Only my supervisor and I will have access to the data. Besides us, authorised representatives from MMU may access the data to permit study-related monitoring, audits, and inspections.

How will you use my information?

The information will be included in the final report and may be used in professional publications, conferences, or training sessions.

Will my data be sent anywhere else, or shared with other people or organisations?

All data will be anonymised, and pseudonyms will be assigned. The interview recordings themselves will not be shared but anonymised quotations of interviews may be used in the dissemination of study findings.

When will you destroy my information?

Upon completion of the project in September 2023, your information will be transferred to my dissertation supervisor at MMU where it will be stored securely on the university's One Drive storage system.

Data Protection Law

Data protection legislation requires that we state the ‘legal basis’ for processing information about you. In the case of research, this is ‘a task in the public interest.’ If we use more sensitive information about you, such as information about your health, religion, or ethnicity (called ‘special category’ information), our basis lies in research in the public interest. Manchester Metropolitan University is the Controller for this information and is responsible for looking after your data and using it in line with the requirements of the data protection legislation applicable in the UK.

This project also includes the use of filming. Please refer to the additional consent form for further information about this aspect of the project, including our lawful basis for using your data in this way.

You have the right to make choices about your information under the data protection legislation, such as the right of access and the right to object, although in some circumstances these rights are not absolute. If you have any questions, or would like to exercise these rights, please contact the researcher or the University Data Protection Officer using the details below.

You can stop being a part of the study at any time, without giving a reason. You can ask us to delete your data at any time, but it might not always be possible. If you ask us to delete information within two weeks of your interview, we will make sure this is done. If you ask us to delete data after this point, we might not be able to. If your data is anonymised, we will not be able to withdraw it, because we will not know which data is yours.

What will happen to the results of the research study?

The results will be included in the final report. They may also be shared with professional publications such as BATOD magazine or relevant deaf organisations such as National Deaf Children’s Society, Manchester Deaf Centre, and Deafness Support Network. It will also be shared with sensory services to support staff training and development, and any updates to policies and practice.

Who has reviewed this research project?

This research study has been reviewed and approved by Manchester Metropolitan University’s Research and Ethics Committee.

Who do I contact if I have concerns about this study or I wish to complain?

If you have any concerns regarding this study, you can contact:

The project lead, Sarah Mills at SARAH.MILLS7@stu.mmu.ac.uk.

The project supervisor, Dr Joseph Keenan at J.Keenan@mmu.ac.uk, or in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

The Faculty of Health and Education Ethics Committee at Manchester Metropolitan University, at FOHE-Ethics@mmu.ac.uk, in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: <https://ico.org.uk/global/contact-us/>

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT