

## **Participant Information Sheet**

UCL Research Ethics Committee Approval ID Number: 12585/009

**Title of Study:** Development of parent experience-based information resources for families of children age 0-4 years with mild/unilateral deafness.

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**Department:** UCL Ear Institute

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### **Name and Contact Details of the Principal Researchers:**

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### **Name and Contact Details of the Researchers:**

Jamila Dorner, [Jamila.dorner@ucl.ac.uk](mailto:Jamila.dorner@ucl.ac.uk)

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We would like to invite you to take part in a research project. Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **1. What is the project's purpose?**

We want to find out about what it's like for parents to make decisions for their baby and young child with mild or unilateral deafness.

The aim of the newborn hearing screening programme is to find babies with moderate or greater deafness in both ears so that they can access support from a very early age. However, because of the way the screening programme works, children with other types of deafness, such as mild deafness, or deafness in only one ear (unilateral deafness), are also identified. There is limited evidence and no guidelines about how to manage these types of deafness in babies and young children and so services are different for families across the country.

Making decisions when there is limited information can be difficult for parents and professionals. We want to know about parents' experiences of finding out about their child's mild or unilateral deafness, how they made decisions and their views about information needs for other parents in this situation.

**2. Why have I been chosen?**

You have been asked to participate as your child has mild or unilateral deafness and is under 4 years old. We would like to hear more about your experiences and thoughts about your child's deafness and the support and help you received. We are hoping to talk to 20 families for this research.

**3. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to agree to this on the next page.

**4. What will happen to me if I take part?**

You will be asked to fill in a consent form and to tell us about yourself and your baby. The information we would like to know is your baby's age and some information about their deafness. We would also like to know briefly about your age and education level.

You will be invited for a one-hour interview with our researcher at a time that is convenient for you. The interview will be online. During the interview we will ask you to talk about your experiences of finding out about your child's deafness and how you decided what to do about it. With your permission we will record our conversation so it can be written up later.

**5. What are the possible disadvantages and risks of taking part?**

The main disadvantage is the time it will take for the interview – about 1 hour. While we hope that the interviews will be a positive experience, it can sometimes be difficult to discuss personal things about your child. If at any time during the interview anything we discuss is too difficult for you, we can take a break or stop the interview.

**6. What are the possible benefits of taking part?**

We will give you a £20 gift voucher to say thank you for taking part. You may also have the chance to take part in creating information for other parents.

**7. What if I change my mind?**

You can withdraw up to two weeks after your interview without giving a reason. After that, your data will have been anonymised and it won't be possible to remove it from the study. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up to that point.

**8. What if something goes wrong?**

If you have any problems or concerns you should contact the principal researcher, Dr Hannah Cooper (details on front page).

If you feel that any complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee:

Research Ethics Co-ordinator  
Office of the Vice-Provost (Research) University College London  
2 Taviton St, London WC1E 6BT

Tel: 020 7679 8717

Extension: 28717, Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

**9. Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. All data will be collected and stored in accordance with the Data Protection Act 1998. Information will only be made available to our small research team. When we write a report about the study we may use quotes from your interview but we will make sure that you and your child are not identifiable from this.

**10. Limits to confidentiality**

Confidentiality will be strictly adhered to subject to legal constraints and professional guidelines.

**11. What will happen to the results of the research project?**

We will use the results to make some online resources for parents of young children who have recently been diagnosed with mild or unilateral deafness. We will write a report about the project for the National Deaf Children's Society. They will use this to develop their guidance and policies. We will also write a summary of the project for parents and families, and for professionals working with deaf children.

The data collected will be stored for two years following completion of the project. At this point the data will be reviewed and if it is no longer needed, it will be disposed of in a secure manner. You will not be able to be identified in any reports or publications which stem from this project.

**12. Local Data Protection Privacy Notice**

**Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The personal data being collected is as follows:

Baby and parents' names  
Baby's sex  
Family ethnicity  
Month/year of birth of baby  
Parental age bracket  
Parents' education levels  
Information about baby's deafness and health

The lawful basis that would be used to process your personal data will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will do this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [dataprotection@ucl.ac.uk](mailto:dataprotection@ucl.ac.uk).

**13. Who is organising and funding the research?**

UCL is organising the research. The National Deaf Children's Society is funding the research.

**14. Contact for further information**

Hannah Cooper  
The UCL Ear Institute  
332 Gray's Inn Road  
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Email: [Hannah.cooper@ucl.ac.uk](mailto:Hannah.cooper@ucl.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research study.**