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## Participant Information Sheet

### Study title

What Do Parents Think About Their Children Taking Part in Research? A Survey of Families in Tower Hamlets and Newham.

### Version number and date

Version 1.0 dated 22 April 2025

### Researcher's name

Hafiza Khatun

### Queen Mary Ethics of Research Committee reference number:

QME25.1104

### Invitation paragraph

You are being invited to participate in a research study. Before you decide whether you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us questions if there is anything that is not clear or if you would like more information.

### What is the purpose of the study and what would taking part involve?

The aim of this study is to explore parental perceptions and willingness to participate in clinical research. This will be done through a one-time online survey, focusing on families residing in the Tower Hamlets and Newham areas. The study seeks to identify the barriers and facilitators that influence participation in clinical research, as well as assess parents' understanding of clinical research. The survey should take approximately 10 minutes to complete.

### Why am I being invited?

You are being invited to participate in this research study because you are a parent or legal guardian and a resident of Tower Hamlets or Newham. Your insights and experiences are

valuable to understanding parental perceptions and willingness to participate in clinical research.

You **should not take** part in this study if you are not a parent or guardian who are not the primary caregiver for your child / children.

### **Do I have to take part?**

This participant information sheet has been provided to help you decide whether you would like to take part in the study. Participation is entirely voluntary, and it is up to you to choose if you wish to take part. If you do decide to participate, you are free to withdraw at any time before submitting your responses, without providing a reason, and without any penalties or negative consequences.

### **What are the possible benefits of taking part?**

You may not receive any direct personal benefit from taking part in this study. However, answering the questions may help you learn more about clinical research. The information you provide could also help researchers better understand how to make clinical research more accessible and acceptable to families like yours.

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

Taking part in this survey is not expected to cause any harm. However, you may find some questions difficult or sensitive to answer. If at any point you feel uncomfortable or find the questions distressing, you are encouraged to stop completing the survey. You do not need to give a reason for stopping.

### **Expenses and payments**

You will not receive any payment for taking part in this survey. There are no costs involved in participating, and completing the survey should not result in any expenses for you.

### **What information about me will you be collecting?**

If you choose to take part in this study, you will be asked to complete an online survey. The survey has two parts:

- **Part 1** will collect basic demographic information such as your age, gender, ethnicity, and postcode (to confirm residency in Tower Hamlets or Newham).
- **Part 2** will ask about your understanding of clinical research and your views on allowing your child to take part in such research.

All information will be collected anonymously and treated confidentially.

### **How will my data be stored and who will have access to it?**

Your data will be stored in a fully anonymised format in a secure database. Only authorized personnel, including the research team, will have access to your data. Access will be strictly controlled to ensure the confidentiality of your responses.

## When and how will my data be destroyed?

Queen Mary University of London is the sponsor for this study and is responsible for managing your data in accordance with data protection laws. The University will act as the data controller, meaning it is responsible for looking after your information and using it appropriately.

All identifiable information will be securely stored and retained for 5 years after the study has finished, in line with regulatory requirements. After this period, your data will be securely destroyed.

Your rights to access, change, or move your information may be limited to ensure the research remains reliable and accurate. More information about how your data is used and protected can be found in Queen Mary's Privacy Notice for Research Participants:

<http://www.arcs.qmul.ac.uk/media/arcs/policyzone/Privacy-Notice-for-Research-Participants.pdf>

## How will my data be used and shared?

Participants' anonymised data will be used and published (i.e. peer reviewed journals/conferences).

We may have to share your anonymised survey data with other parties with whom we are in collaboration. For example, we often work closely with Barts Health NHS Trust and other universities in the U.K. and around the world. We will explain this to all research participants where it applies.

## Under what legal basis are you collecting this information?

Queen Mary University of London processes personal data for research purposes in accordance with the lawful basis of 'public task'.

Please read [Queen Mary's privacy notice for research participants](#) containing important information about your personal data and your rights in this respect.

If you have any questions relating to data protection, please contact Queen Mary's Data Protection Officer, Queens' Building, Mile End Road, London, E1 4NS or [data-protection@qmul.ac.uk](mailto:data-protection@qmul.ac.uk) or 020 7882 7596.

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### **What will happen if I want to withdraw from this study?**

Taking part in this study is entirely voluntary. You can agree to participate now and change your mind before submitting your responses without giving a reason. If you decide to stop taking part, there will be no consequences, and it will not affect you in any way.

If you choose to withdraw, you can exit the survey at any time before submitting the survey. After submitting, your data will be fully anonymized, and it will no longer be possible to identify or withdraw it.

### **What should I do if I have concerns about this study?**

If you have any concerns about the manner in which the study was conducted, in the first instance, please contact the researcher(s) responsible for the study: Hafiza Khatun.

If you have a complaint which you feel you cannot discuss with the researchers then you should contact the Research Ethics Facilitators by e-mail: [research-ethics@qmul.ac.uk](mailto:research-ethics@qmul.ac.uk).

When contacting the Research Ethics Facilitators, please provide details of the study title, description the study and QMERC reference number (where possible), the researcher(s) involved, and details of the complaint you wish to make.

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### **Who can I contact if I have any questions about this study?**

Hafiza Khatun

**Email:** h.khatun@qmul.ac.uk

**Telephone:** 02035941551