**MIDDLESEX UNIVERSITY**

**PARTICIPANT SHEET (PIS)**

Participant ID Code:……………………………………………

1. **Study title**

The Experiences of Fathers in Families where two or more Children have a diagnosis of Autism- An interpretative Phenomenological Analysis

**2.** **Invitation paragraph**

You are being invited to take part in a research study. Before you decide 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 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.

**3.** **What is the purpose of the study?**

This study aims to explore the experience of being a father to children with autism. To help me conduct this study, I will like to ask you some questions about your experiences.

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

It is important that we assess as many participants as possible, and you have indicated that you are interested in taking part in this study. This study will need 8 father participants and with fluent English. The father will have to have children who have a full diagnosis.

**5. 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 given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do decide to withdraw from the study then please inform the researcher as soon as possible, and they will facilitate your withdrawal. If, for any reason, you wish to withdraw your data please contact the researcher within two weeks of your participation. After this data it may not be possible to withdraw your individual data as the results may have already been published. However, as all data are anonymised, your individual data will not be identifiable in any way.

*A decision to withdraw at any time, or a decision not to take part, will not affect your employability, care, or the care that you receive in any way.*

**6. What will I have to do?**

If you agree to take part I would like to meet with you to ask you some questions. I will only need to meet with you once. The interview can take place via skype if recruited from Facebook or at Earlsfield or Tooting library if recruited from support group which will last for between 45minutes to 1 hour in a private space. The interview will be recorded using an audio recording device, which then I will use it to transcribe it later. All recordings will be kept in a secure place on word documents with a password protection, in which I will only have access to. All folders with recordings and transcriptions will be encrypted.

During transcribing I will ensure that any information such as your children’s names, your own name or any services you attend which identify you in any way will be removed. Approximately, around November 2019 the recordings will be destroyed once the research project has been written up.

In addition, before we begin with the interview, I will also ask you to complete a short questionnaire, providing me with some background information about your occupation, children’s age and their diagnosis.

I will ensure to send you a summary of the results.

Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the committee.  This means that the designated member can request to see signed consent forms.  However, if this is the case your signed consent form will only be accessed by the designated auditor or member of the audit team.

**7. Will I have to provide any bodily samples (i.e. blood/saliva/urine)?**

No

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

Some people may find talking about their experiences distressing or embarrassing. I do intend to conduct the interviews with respect and care. I will ensure the interview is conducted with sensitivity and I appreciate that you have taken up your precious time to speak to me.

Appropriate risk assessments for all procedures have been conducted, and will be followed throughout the duration of the study.

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

We hope that participating in the study will help you. However, this cannot be guaranteed. The information we get from this study may help us to understand the impact of Autism and other special needs in parenting. Some people will use this as an opportunity to talk about their life experiences. In addition, the reason for this study is to allow professionals and support services understand the impact of having more than one child with autism and other needs in the family. This will also be a useful piece of research for professionals looking to work with families of children with ASD and additional needs.

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

The research team has put a number of procedures in place to protect the confidentiality of participants. You will be allocated a participant code that will always be used to identify any data you provide. Your name or other personal details will not be associated with your data, for example, the consent form that you sign will be kept separate from your data. All paper records will be stored in a locked filing cabinet, accessible only to the research team, and all electronic data will be stored on a password protected computer. All information you provide will be treated in accordance with the UK Data Protection Act.

**10.** **What will happen to the results of the research study?**

The results of the research study will be used as part of a Postgraduate dissertation. The results may also be presented at conferences or in journal articles. However, the data will only be used by members of the research team and at no point will your personal information or data be revealed.

**11.** **Who has reviewed the study?**

The study has received full ethical clearance from the Research ethics committee who reviewed the study.

**12.** **Contact for further information**

If you require further information, have any questions or would like to withdraw your data then please contact:

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Thank you for taking part in this study. You should keep this participant information sheet as it contains your participant code, important information and the research teams contact details

**Middlesex University Guide to Research Privacy Notices**

Privacy notices need to be presented whenever data is collected and should be understandable and accessible. Privacy notices must explain the type and source of data that will be processed. They will also set out the processing purpose, data retention schedules and data sharing. Privacy notices must include details of the subject’s rights and who the subject can complain to.

The following example may be used and completed for your research purposes.

**Middlesex University Privacy Notice for Research Participants**

The General Data Protection Regulation (GDPR) protects the rights of individuals by setting out certain rules as to what organisation can and cannot do with information about people. A key element to this is the principle to process individuals’ data lawfully and fairly. This means we need to provide information on how we process personal data.

The University takes its obligation under the GDPR very seriously and will always ensure personal data is collected, handled, stored and shared in a secure manner. [The University’s Data Protection Policy can be accessed here](https://www.mdx.ac.uk/about-us/policies/?a=449245): <https://www.mdx.ac.uk/__data/assets/pdf_file/0023/471326/Data-Protection-Policy-GPS4-v2.4.pdf>.

The following statements will outline what personal data we collect, how we use it and who we share it with. It will also provide guidance on your individual rights and how to make a complaint to the Information Commissioner’s Officer (ICO), the regulator for data protection in the UK.

**Why are we collecting your personal data?**

As a university we undertake research as part of our function and in our capacity as a teaching and research institution to advance education and learning. The specific purpose for data collection on this occasion is to … This study aims to explore the experience of being a father to children with autism and other additional needs.

The legal basis for processing your personal data under GDPR on this occasion is Article 6(1a) consent of the data subject.

**Transferring data outside Europe**

In the majority of instances your data will be processed by Middlesex University researchers only or in collaboration with researchers at other UK or European institutions so will stay inside the EU and be protected by the requirements of the GDPR.

In any instances in which your data might be used as part of a collaboration with researchers based outside the EU all the necessary safeguards that are required under the GDPR for transferring data outside of the EU will be put in place. You will be informed if this is relevant for the specific study you are a participant of.

**Your rights under data protection**

Under the GDPR and the DPA you have the following rights:

* to obtain access to, and copies of, the personal data that we hold about you;
* to require that we cease processing your personal data if the processing is causing you damage or distress;
* to require us to correct the personal data we hold about you if it is incorrect;
* to require us to erase your personal data;
* to require us to restrict our data processing activities;
* to receive from us the personal data we hold about you which you have provided to us, in a reasonable format specified by you, including for the purpose of you transmitting that personal data to another data controller;
* to object, on grounds relating to your particular situation, to any of our particular processing activities where you feel this has a disproportionate impact on your rights.

Where Personal Information is processed as part of a research project, the extent to which these rights apply varies under the GDPR and the DPA. In particular, your rights to access, change, or move your information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we may not be able to remove the information that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. The Participant Information Sheet will detail up to what point in the study data can be withdrawn.

If you submit a data protection rights request to the University, you will be informed of the decision within one month. If it is considered necessary to refuse to comply with any of your data protection rights, you also have the right to complain about our decision to the UK supervisory authority for data protection, the Information Commissioner’s Office.

None of the above precludes your right to withdraw consent from participating in the research study at any time.

**Collecting and using personal data**

**Data sharing**

Your information will usually be shared within the research team conducting the project you are participating in, mainly so that they can identify you as a participant and contact you about the research project.

Responsible members of the University may also be given access to personal data used in a research project for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your records. All of these people have a duty to keep your information, as a research participant, strictly confidential.

If we are working with other organisations and information is shared about you, we will inform you in the Participant Information Sheet. Information shared will be on a ‘need to know’ basis relative to achieving the research project’s objectives, and with all appropriate safeguards in place to ensure the security of your information.

**Storage and security**

The University takes a robust approach to protecting the information it holds with dedicated storage areas for research data with controlled access.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of University information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Training is provided to new staff joining the University and existing staff have training and expert advice available if needed.

**Retention**

Under the GDPR and DPA personal data collected for research purposes can be kept indefinitely, providing there is no impact to you outside the parameters of the study you have consented to take part in.

Having stated the above, the length of time for which we keep your data will depend on a number of factors including the importance of the data, the funding requirements, the nature of the study, and the requirements of the publisher. Details will be given in the information sheet for each project.

**Contact us**

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Call: 07508475488

The Principal Investigator leading this

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The University’s official contact details are:

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