

Participant Information Sheet- Questionnaire

Study title

“An examination of the opinions of parents of patients with Autism Spectrum Disorder (ASD) on patient experiences of diagnostic radiography examinations”

You are being invited to take part in this research project being carried out by a student of Ulster University as part of their MSc in Advancing Practice (Computed Tomography). Please read all of the information below before you decide if you would like to participate in this research, in order to ensure you fully understand why this research is being completed and what your role will be. Please ask any questions you have about any parts of the information which are unclear, and take time to decide whether or not you would like to participate. Thank you for your time and consideration.

What is the purpose of the study?

This research will seek to examine the experiences of patients with ASD who have attended a radiology department for imaging exams. The aim of the study is to identify positive and negative areas of practice. The findings of this research will help improve the services provided by radiology departments for patients with ASD; identifying useful tools and techniques to improve patient pathways and practice.

Why have I been chosen?

You have been contacted about this study through your connection with an organisation which provides support for individuals with ASD and their parents/guardians/carers. This study information has been circulated by these organisations on behalf of the research team.

Do I have to take part?

No- it is completely your choice to decide whether or not to participate. If you decide to take part in this research, you will indicate your consent by commencing the

questionnaire. You may withdraw from the study at any time, without giving a reason by contacting any member of the research team. As this study is being conducted independently of your healthcare provider, your decision to participate or not participate in this study will not impact your child's healthcare.

What will happen to me if I take part?

You will be asked to complete a short questionnaire (which will take approximately 20 minutes to complete). Instructions on how to complete the questionnaire will be provided by the research team. If any of the questions or statements are unclear, you can ask for support and guidance by contacting a member of the research team. A follow-up interview will be completed with up to ten of the participants who have completed the questionnaire study. You will be asked as part of the questionnaire whether you would like to participate in these interviews. Completing the first part of the study does not guarantee selection for the second part of the study- the participants will be selected from those who indicate their interest in participation. The results of this research will be communicated with you in due course, should you wish.

Are there any risks to taking part?

This study is minimal risk and involves no interventions or changes to your child's care. If you find any aspects of the research process distressing, supports are available by making contact with the research team.

Are there any possible benefits in taking part?

It is hoped that the data collected during this study will be used to inform our knowledge of past and current practice in radiology departments during imaging exams of patients with ASD. This data will help us improve our practice and patient pathways, ultimately improving the overall experiences of patients with ASD attending for radiology exams. It will also help in future service planning and development.

What happens when the study ends?

Your role in this study will end either with the completion of the initial questionnaire, or for those selected for interview, after this interview is conducted. If you require additional information or supports after this point, you can contact the research team. The data collected from both the questionnaires and interviews will be processed and analysed. It will be kept anonymised throughout the write-up process.

What if something goes wrong?

It is extremely unlikely that anything will go wrong throughout the research process. However, should you experience upset or distress, or if you are worried or uncomfortable about any aspect of the research project, please make contact with the research team. Any concerns or complaints will be taken seriously, in line with University guidance and procedures. Any complaints should be communicated to the Chief Investigator, Dr John Cathcart (j.cathcart@ulster.ac.uk).

Will my taking part in this study be kept confidential?

All data collected during this study will be kept securely and confidentially. Data will be anonymised during collection, with all identifiers removed. All data collected will automatically become property of Ulster University. It will be stored securely for a minimum of ten years and then discarded. Minimal personally identifiable information will be collected, as the focus of our study is on patient experience.

For more information on Ulster University's data protection policies, visit <https://www.ulster.ac.uk/about/governance/compliance/gdpr>

What will happen to the results of the study?

The information gathered in this study may be published at a later date; you will be informed if this is to happen. The results of this study may lead to further research on patient experiences during more specific examinations e.g. CT or Ultrasound exams, or in different departments of the hospital. The data gathered will help improve radiographers' daily practice in their interactions with patients with ASD, and may be used to inform future service developments and improvements.

Who is organising and funding the research?

This research is being facilitated by Ulster University as a student's MSc project. No applications for external funding have been made.

Who has reviewed this study?

This study design has been peer-reviewed in line with Ulster University's procedures for ethics in research. If further information is required about the review process, participants can contact the University Research Governance department. Further contact information is available at <https://www.ulster.ac.uk/departments/research/research-governance> .

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