

Participant Information Leaflet and Informed Consent

Title of the Project: Autism: Competencies, Care and Experience of Service Settings within Healthcare (ACCESS Health Intervention)

Researcher Contact Information:

Fiona Rigney
PhD Student
South East Technological University, Waterford.
Fiona.rigney@postgrad.wit.ie

Introduction

We invite you to participate in a research study aimed at understanding the experiences of autistic adults and carers/parents of autistic adults within the Emergency Department (E.D.). This study seeks to explore the perspective of these individuals who have had firsthand experience of the E.D. environment. Your insights are invaluable in helping us understand the level of knowledge of autism among healthcare professionals in the E.D. and how current practices impact the quality of care you received.

By sharing your experiences, you will play a crucial role in shaping future healthcare education and training strategies designed to help autistic individuals who are required to present to the E.D.

This leaflet provides important information about the study, including what participation involves and how your confidentiality will be protected. Before deciding to participate in this study please do read this information leaflet carefully. Take time to ask questions – do not feel rushed and don't feel under pressure to make a quick decision. You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'informed consent'. You do not have to take part in this study. You may wish to discuss the study with a family member or carer prior to making your decision.

Why is this study being done?

The purpose of this study is to gain insights into your experiences and to identify enablers, barriers and unmet needs when accessing the Emergency Department.

Who is invited to participate?

You are invited if you are an autistic adult who has had experience using the Emergency Department in a hospital, **OR** if you are a carer/parent of an autistic adult who has had experience of using the Emergency Department in a hospital.

What is going to happen?

You will participate in an audio-recorded interview, where you will share your experiences and insights of accessing the Emergency Department. You will be invited to take part in the study through an email invitation. The research team will send out the invitation, participant information leaflet, participant consent form and the interview topic guide in advance of the interview. The completed consent form should be e-mailed directly to Fiona.rigney@postgrad.wit.ie

Time Commitment

The interview will last approximately 30-60 minutes. If you prefer a shorter interview time, we can accommodate this request..

Location

The interview can be conducted at a location that is comfortable for you, whether that be in person or online.

Confidentiality

All information collected during the study will be kept confidential. All data will be anonymised, your identity will be protected, and data will be stored securely at South East Technological University, Waterford. The interview data will only be accessed by the research team subject to provision of the law. Any published results will not include identifying information about you.

Do I have to take part in this study?

Participation in this study is entirely voluntary. You can choose to withdraw from the study at any time up until the data analysis begins, which would be 4 weeks after the interview has taken place, and there will be no negative consequences for doing so. You will be given an opportunity to review the transcribed interview within this timeframe. You may also stop the interview at any point during the interview, and you do not have to give a reason.

What are the benefits and risks of taking part in the study?

Benefits: There won't be any direct benefit to you by taking part in this study. However, by sharing your experiences, you will contribute to a better understanding of the current environment and the healthcare professionals in the Emergency Department. These insights may help improve care and the training and education that healthcare professionals receive in the future, benefitting others who will need to access the Emergency Department in the future.

Risks: Discussing your personal experiences may cause emotional stress or discomfort. You may take breaks during the interview or choose not to answer any questions you find uncomfortable.

Support Available

If you experience emotional discomfort while participating, the following organisations can offer support:

- **Your GP:** Please contact your own General Practitioner for support.

- **AS I AM** – Ireland's Autism Charity

Phone (Mon-Thurs 10-3): 0818 234 234

E-mail: support@asiam.ie

- **Irish Society for Autism** –

Phone: (01) 874 4684

E-mail: admin@autism.ie

Data Protection

It is important to provide you with the following information as required by data protection law:

- **Purpose of Data Processing:** We will be using your personal information to study the experience of autistic adults and carers/parents of autistic adults in the Emergency Department.
- **Legal Basis:** We will rely on Article 6.1(e) 'public interest' and Art 9.2(j) 'scientific research purposes' of the General Data Protection Regulations to process your personal data.
- **Recipients of Data:** Your data will be anonymised and shared with members of the research team and may be shared with relevant health authorities as needed for research purposes.
- **Data Storage Duration:** Your data will be stored for a maximum of 10 years in line with South East Technological University data protection periods, after which it will be securely destroyed.
- **Risks and Implications:** There may be a risk of loss of confidentiality; however, we will implement measures to mitigate these risks. The implications for you may include emotional discomfort when discussing personal experiences.
- **Right to Withdraw Consent:** You have the right to withdraw consent to your personal data being used in this research project. You can do this by contacting Fiona Rigney at the above contact details.
- **Right to Lodge a Complaint:** You have the right to lodge a complaint with the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.
- **Right to Access Data:** You have the right to request access to your data and a copy of it. However individual data cannot be accessed once it has been collected and emerged for analysis as it is completely anonymised with no identifying data collected.
- **Right to Restrict Processing:** You have the right to restrict or object to the processing of your data.
- **Right to Correct Data:** You have the right to have any inaccurate information corrected or deleted.

- **Right to Delete Data:** You have the right to have data about you deleted.
 - **Right to Data Portability:** You have the right to request to move your data from one controller to another in a readable format.
 - **Automated Decision Making:** This research study will not involve automated decision-making or profiling.
 - **Further Processing:** Your data will be stored for possible future uses related to healthcare research that aligns with ethical standards.
 - **Data Transfer:** Your data will not be transferred outside the EU without appropriate safeguards in place to protect it.
-

Where can I get more information?

If you have any questions or require additional information about the study, please contact me at fiona.rigney@posgrad.wit.ie. I am more than happy to answer any questions you may have.

CONSENT FORM

Please indicate (by ticking the box) whether or not you wish to participate in this project by selecting one of the statements below, signing your name. Please return the below consent to myself, Fiona Rigney. You should sign both copies and retain one for your own records.

I consent to participate in the interviews to gain insights into your experiences and to identify enablers, barriers and unmet needs when accessing the Emergency Department.

I **do not consent** to participate in the interviews to gain insights into your experiences and to identify enablers, barriers and unmet needs when accessing the Emergency Department.

Your Signature

Printed Name

Date: _____

CONSENT FORM

Please indicate (by ticking the box) whether or not you wish to participate in this project by selecting one of the statements below, signing your name. Please return the below consent to myself, Fiona Rigney. You should sign both copies and retain one for your own records.

I consent to participate in the interviews to gain insights into your experiences and to identify enablers, barriers and unmet needs when accessing the Emergency Department.

I **do not consent** to participate in the interviews to gain insights into your experiences and to identify enablers, barriers and unmet needs when accessing the Emergency Department.

Your Signature

Printed Name

Date: _____



Autistic Adults and Carers/Parents: Experiences with Healthcare Professionals in the Emergency Department

Study Aim

To explore the experiences of autistic adults & carers of autistic adults in the Emergency Department.

Study Details

Interviews: Online or In Person at your convenience

Duration: Flexible, we will work with your schedule

Breaks: Frequent breaks to ensure your comfort

Who are we looking for?

Autistic adults (aged 18+) who have experience of attending the Emergency Department.

Carers/Parents who have supported autistic adults in the Emergency Department

Why participate?

Contribute valuable experience and insights to help guide the future education of healthcare professionals.

To express interest & receive more information contact:
fiona.rigney@postgrad.wit.ie

TOPIC GUIDE

Phase Two: Interviews with autistic adults and carers/parents of autistic adults.

Introduction:

- Briefly explain the purpose of the study.
- Reiterate the confidentiality and voluntary nature of participation.

Topic Guide:

Experience:

- Can you describe any experience you have had of the Emergency Department (E.D.)
- What was the outcome of presenting to the E.D. ?
- Based on your experience, what improvements do you feel are necessary to ensure comfort in future E.D. visits?

Understanding challenges:

- What challenges did you face while attending the E.D.?
- What challenges did you face in terms of the environment of the E.D.
- Were accommodations made by healthcare professionals to ensure comfort during the E.D. visit?

Recommendations:

- What changes or recommendations would you make in relation to the language that healthcare professionals use when the encounter autistic patients?
- What advice would you give healthcare professionals working in the E.D. who may encounter autistic patients?