Evaluating a Strengths and Needs Assessment for Autistic Adults

Participant Information Sheet

We would like to invite you to join the Strengths and Needs Assessment Study. This is being run by a research team at the University of Sheffield in collaboration with Sheffield Health and Social Care NHS Foundation Trust, Leeds and York Partnership NHS Foundation Trust, and Cambridge and Peterborough NHS Foundation Trust.

We want to recruit 72 people who have recently received a diagnosis of Autism from one of these diagnostic services to help us understand what people think of a new assessment for autistic adults.

Our goal is to find out if this new assessment is helpful and acceptable for newly diagnosed Autistic adults and diagnostic clinicians.

We will look at how easy it is to use the assessment and whether it helps people understand their strengths and needs.

The study's findings will help in the development of this new assessment and may help to improve support and services for Autistic adults in the future.

Before you decide whether to participate, it is important for you to understand why the study is being conducted and what is involved. Please take the time to read the following information carefully and discuss it with others if you wish. If anything is not clear, or if you would like more information, please contact the researcher: **marianne.r.day@sheffield.ac.uk**.

Thank you for your time and consideration.

Why is the study needed?

This study aims to address a significant gap in post-diagnostic support for Autistic adults in the UK. Currently, a diagnosis alone does not provide enough information to tailor specific support plans or for a person to understand what their diagnosis means for them.

To address this issue, researchers are evaluating a new assessment: the Strengths and Needs Assessment. This assessment helps people identify their strengths, challenges, and the environmental factors that help or hinder their daily lives. By completing this assessment, Autistic adults may gain a better understanding of themselves. The assessment generates personalised reports that can be shared with others, such as employers or healthcare providers. This report highlights areas of strength as well as areas where additional support could be helpful.

The Strengths and Needs Assessment has been developed by the Karolinska Institutet which is a medical university in Sweden. You can find information about the assessment here: ICF Core Sets for ADHD and autism | Karolinska Institutet

Ultimately, the goal is to develop a standardised tool that can be widely used to enhance post-diagnostic support for Autistic adults. This study will help to determine the feasibility and effectiveness of the Strengths and Needs Assessment. If it is helpful, it could be implemented in clinical practice in the future.

Why have I been invited and am I eligible?

You have been invited to participate in this study because you have recently received an Autism diagnosis from one of our collaborating diagnostic services.

To be eligible to participate in this study, you must:

- Have recently (within the last 4 weeks) received an Autism diagnosis from one of the participating NHS clinical services (Sheffield Adult Autism and Neurodevelopmental Service, Leeds Autism Diagnostic Service, or Cambridge Lifespan Autism Spectrum Service).
- Be at least 18 years old.
- Be able to understand and consent to participate in the study.
- Be able to understand and complete the study questionnaires in English.

Do I have to take part?

No, it is completely up to you. If you decide to take part, you will be asked to sign a consent form: INPUT LINK. You are free to withdraw from the study at any time, without giving a reason. **Your decision whether to take part in this study has no influence on the post-diagnostic care you will receive from your service.** Your clinicians will not be told whether or not you decide to take part in the study. You can withdraw from the study at any time by contacting the researcher.

What does taking part in the study involve?

Taking part in the study involves:

1. **Reading Study Information:** You will receive information about the study, including what it involves and why it's important. Please read this information and ask any questions you may have before deciding if you would like to take part in the study. We understand that you have recently received your Autism diagnosis and you will have a lot of information to process. Because of this, there is a period of four weeks for you to decide whether you would like to take part. This date has been written for you on the study leaflet you received at your diagnostic appointment.

2. **Providing Consent:** If you are interested in taking part, you will be asked to give your consent to participate. This means you agree to be part of the study and understand what it involves. You can find the consent form by following this link: INPUT LINK

3. **Demographic questionnaire:** After consenting to take part in the study, you will be asked to complete a short questionnaire. This will ask you which service you received your diagnosis from and when you received your diagnosis. You will also be asked for your age, gender and ethnicity. We will ask you to provide your GP name and practise. Please note that we will not contact your GP unless we have serious concerns about your wellbeing during the study. This would only be if you score in the severe range for depression on one of the measures included in the study or if you mention something in an interview which raises serious concerns about your personal wellbeing (e.g., suicidal ideation, self harm). If you would like to discuss this further, please contact the researcher.

4. **Randomisation:** After completing the initial questionnaire you will be randomly assigned to one of two groups:
    1. **Intervention Group:** You will complete the Strengths and Needs Assessment and other standard questionnaires. You will continue to receive the usual post-diagnostic care provided by your service.
    2. **Treatment as Usual (TAU) Group**:You will complete only the standard questionnaires. You will also continue to receive the usual post-diagnostic care provided by your service.

Randomisation means that you will have an equal chance of being allocated to a group which completes the Strengths and Needs assessment and a group which does not. You will not be able to choose which group you are put into. So, before you agree to join the study, it is important that you are willing to be in either group. It is very important that we have one group which does not complete the Strengths and Needs assessment so we can compare this group to the group which does complete it. This is a vital part of the development of the assessment. We will email you to let you know which group you are in.

5. **Completing Questionnaires:** You will be emailed links to questionnaires which will ask about your mental health, and well-being. These questionnaires can be completed online at your own pace. They will take between 10-20 minutes to complete. You will be asked to complete these questionnaires at 2 timepoints (when you start the study and 3 months later).

6. **Completing the Strengths and Needs Assessment (Intervention group only):** If you are assigned to the intervention group, you will be asked to complete the Strengths and Needs assessment which is done online. This assessment takes between 30-60 minutes to complete, depending on how much additional information you include in the form. There are 254 questions. You do not have to complete the whole assessment in one sitting as your

answers will be saved as you go along. Following the ICF assessment you will be asked to answer a short questionnaire asking about your experience of completing the assessment such as how easy and acceptable you found it.

After you complete the assessment, you will be emailed a summary report of your results. This summary report will include areas which you have rated highest for strengths and areas where you may require additional support. It will also include the environmental factors which you rated as most helpful or unhelpful.

7. **Follow-up Interview (Optional):** A small number of participants (12 in total) will be invited to participate in a follow-up interview to discuss their experiences with the study and their experiences of post-diagnostic support. The interviews will take around half an hour. You will be able to do them online or at your diagnostic service if this is possible.

   You do not need to consent to take part in an interview now and you can still take part in the study if you do not want to take part in an interview.

What if I do not have a computer at home to complete the assessments?

If you are unable to complete the assessments at home but would like to take part in the study please contact the researcher and we will try to make alternative arrangements (e.g., completing the assessments in your diagnostic service). You can use the address or phone number which is included at the end of this information sheet to contact the research team if you do not have access to email.

Can I take part if English is not my first language?

The study materials, including the Strengths and Needs Assessment and questionnaires, are currently only available in English. You will need to be able to complete these using written English. If you can do this you are welcome to take part in the study. If you are invited to take part in an interview and would prefer to speak in your native language if this is not English, we will provide a translator.

What should I do if I want to take part?

If you have any questions before deciding whether to take part you can contact the researcher by email: marianne.r.day@sheffield.ac.uk. If you would like to take part in the study, you can follow this link to give consent: INPUT LINK. You will then be contacted by the research team with links to the study questionnaires and to let you know which group you have been assigned to.

How long will I be involved in the study?

For most participants, the study will last for approximately 3 months. This includes:

- **Baseline assessments:** Completing initial questionnaires and the Strengths and Needs Assessment if you are in the intervention group.
- **Follow-up assessments:** Completing questionnaires again after 3 months.

The total time input for these questionnaires will be around 40 minutes for the TAU group and 100 minutes for the Intervention group.

A small number of participants may be invited to participate in a follow-up interview which will be held within 2 months of the follow-up assessments. This will take around 30 minutes.

Are there any benefits for me in joining the study?

Both groups may benefit from:

Contributing to Research: Your participation will help researchers develop the Strengths and Needs assessment which may lead to better support strategies for Autistic adults.

Financial Compensation: You will receive financial compensation for your time completing the study. These payments will be emailed to you as vouchers (Love2Shop or Amazon depending on your preference). You will receive a £20 voucher for your baseline questionnaires and a £10 voucher for completion of your follow-up questionnaires. The Intervention and TAU groups are paid the same amount. If you are invited to take part in an interview, and you choose to do so, you will receive an additional £20.

If you are assigned to the Intervention group and complete the Strengths and Needs Assessment there may be some additional benefits:

Personal Insight: By completing the Strengths and Needs Assessment, you may gain a deeper understanding of your own strengths and the areas where you might require additional support that are relevant to Autism.

Personalised Summary Report: You will receive a report which summarises your answers to the Strengths and Needs assessment. This information could be useful to you in planning your post-diagnostic support.

Are there any risks for me in joining the study?

While the risks associated with participating in this study are minimal, it's important to be aware of the following:

Time Commitment: Participating in the study will require time to complete questionnaires. If you are assigned to the intervention group your time input is likely to be higher as you will be asked to complete the Strengths and Needs Assessment which may take up to one hour.

Emotional Discomfort: Some of the questions in the questionnaires and the assessment may be personal or sensitive as they ask about your mental health and quality of life, as well as your experiences as an Autistic adult.

Potential Disappointment: If you are randomised to the treatment as usual group, you will not be asked to complete the Strengths and Needs assessment and may not directly benefit from the intervention. However, the contribution of the treatment as usual group is just as important to the study as the intervention group.

The research team will take steps to minimize these risks, such as by ensuring that questionnaires can be completed at a time which is convenient to you and over a period of time. You will have 2 weeks to complete the questionnaires after we send you the links. We will also provide debriefs following the questionnaires which will include signposting to resources and support organisations. However, it is important to note that the research team is not able to provide direct clinical treatment or support.

What will happen to my data?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

What data will we collect about you?

The study will collect the following data from you:

Personal Information:

- **Demographic Information:** Age, gender, ethnicity, and contact information (name, email address).
- **Clinical Information:** The diagnostic service which gave you your diagnosis and when you received your diagnosis. Your GP’s name and address.

Research Data:

- **Strengths and Needs Assessment (Intervention group only):** Your responses to questions about your abilities, activities, and environmental factors.

- **Quality of Life and Mental Health Measures:** Your responses to questionnaires assessing your overall quality of life, depression, anxiety, and other mental health symptoms.
- **Interview Data (optional):** The interview will be recorded using GoogleMeets. Once transcripts of your interview (written copies) have been produced the recordings will be deleted.

Why do you need to collect my personal data?

We need to collect your email address so we can contact you about the study. We will use this email address to send you links to the questionnaires, provide payment and inform you about the results of the study. Your email address and name will be stored separately from your study data and only the lead researcher (Prof. Megan Freeth) and research associate (Dr Marianne Day) will have access to your personal information. Your email address will not be used for any other purposes.

How will my study data be kept confidential?

Your data will be treated with the utmost confidentiality and will be used solely for research purposes.

We will keep your data confidential in the following ways:

- **Anonymisation:** Your personal information, such as your name and contact details, will be stored separately from the study data. Your research data will be identified by an anonymous and unique identifier (a random 4 digit number) only.

- **Data Security:** All data will be stored securely and accessed only by authorised researchers. Data will be stored in a password protected folder on the University of Sheffield’s Drive.

- **Data Retention:** Your personal data will be retained for a specific period, after which it will be securely destroyed. We will delete your personal information within 3 months of the end of the study. We will only use your personal data to provide links to study materials and share the results of the study.

- **Data Sharing and Storage:** Your study data will be shared with other members of the research team but only in an anonymised form. At the end of the study we will store some of the anonymised data on the University of Sheffield’s data repository where it can be accessed by other researchers. This is done to encourage transparent research processes. However, this will not include any demographic information, clinical information or personal information. We will not include responses to the Strengths and Needs

Assessment in this repository as this is not publicly available and we will not include the transcripts from interviews.

- **Reporting results**: Results from the project will be written up as reports and as publications in journals, blogs, and conference presentations. No identifiable data will be included in any reports or publications. The data will also contribute to the development of the Strengths and Needs assessment.

If you have any further questions about data privacy and security, please don't hesitate to contact the research team.

The NHS Health Research Authority has also produced a leaflet which explains how your information is used in research: Patient data and research leaflet - Health Research Authority

How do I withdraw if I want to do so?

The study will be most valuable if few people withdraw from it, so it is important to discuss any concerns you may have with a member of the study team before you agree to participate. However, you can withdraw from the study at any time and without giving a reason by emailing the researcher: marianne.r.day@sheffield.ac.uk.

We will be able to remove your data from the study up until the point that the personal data is deleted (within 3 months of the end of the study).

Who is organising and funding the study?

The study is being run by a research team at the University of Sheffield in collaboration with Sheffield Adults Autism and Neurodevelopmental Service, Leeds Autism Diagnostic Service, and Cambridge Lifespan Autism Spectrum Service.

Funding has been provided by the Research for Patient Benefit program of the National Institute for Health and Care Research.

Who has approved the study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee which is there to protect your safety, rights, wellbeing and dignity. This project has been reviewed and was given a favourable review by tbc….

Who do I contact if I have any concerns?

If you are dissatisfied with any aspect of the research and wish to make a complaint or report a concern/incident, please contact Professor Megan Freeth (m.freeth@sheffield.ac.uk) in the first instance. If you feel your complaint has not been handled in a satisfactory way you can contact the Head of the Department of Psychology (Dr Chris Martin; psy-hod@sheffield.ac.uk and/or the University's Research Ethics & Integrity Manager (Lindsay Unwin; l.v.unwin@sheffield.ac.uk). If the complaint relates to how your personal data has been handled, you can find information about how to raise a complaint in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Contact Details:

This research is being led by **Professor Megan Freeth** (Professor of Neurodevelopmental Psychology and Director of the Sheffield Autism Research Lab) who can be contacted at:
Email: m.freeth@sheffield.ac.uk.
Phone: 0114 2226533

The contact details for the research associate (**Dr Marianne Day**) are:
Email: marianne.r.day@sheffield.ac.uk.
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You can contact the researchers at the following address:

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