# Evidencing the need for routine sensory-motor assessment and support for autistic adults

| Submission date   | Recruitment status  No longer recruiting        | <ul><li>[X] Prospectively registered</li><li>[X] Protocol</li></ul> |  |  |
|-------------------|---|---|--|--|
| 06/08/2024        |   |   |  |  |
| Registration date | Overall study status Ongoing Condition category | Statistical analysis plan   |  |  |
| 15/08/2024        |   | Results   |  |  |
| Last Edited       |   | Individual participant data   |  |  |
| 24/11/2025        | Mental and Behavioural Disorders                | [X] Record updated in last year                                     |  |  |

# Plain English summary of protocol

Background and study aims

Autism is a naturally occurring, largely genetic condition that affects how that person understands their environment and interacts with other people, with around 1-1.5% of people diagnosed in the UK. Sensory and motor difficulties (SMD), such as hypersensitivity to sound and light, and difficulties with carrying out physical movements, occur in ~80% of autistic people. SMD can cause significant problems with day-to-day tasks, such as getting dressed, eating and maintaining employment – often leading to anxiety, depression, fatigue, a restricted lifestyle and reduced quality of life. Despite the serious impact of SMD, autistic adults do not receive routine assessment and support for their SMD unless they also have a diagnosed Learning Disability (LD), which is usually picked up in early childhood and supported accordingly. This study aims to show the need for routine SMD assessments and treatment for autistic people without LD and what kinds of support would help, leading towards an innovative new SMD pathway. The study will start by showing what proportion of autistic adults that do not have a LD need SMD support and how many are likely to take this up.

Who can participate?
Autistic adults aged 18 years old and over

#### What does the study involve?

Participants will be recruited via autism diagnostic clinics to receive an SMD assessment (involving tasks such as positioning one's own body) and a follow-up appointment with a specialist clinician. These will show how many patients offered the assessment wanted to be assessed, the range of their SMD and what types of support were useful. Second, information will be collected on what the volunteers thought about the assessment and how they benefitted, this will help plan how to test the new pathway. Third, workshops with the research team and a survey of clinicians will identify which of the assessments and support options should be included in the pathway.

# Patient and Public Involvement and sharing our findings

Previous work with autistic people confirmed the importance of but lack of SMD assessment and support and guided our decisions around recruitment and assessment to maximise benefit for volunteers. This project will be co-produced with two autistic team members who will attend

team meetings and workshops. Advice will also be sought from ~15 members of the Autism@Manchester Expert by Experience advisory group and implemented where practicable. Participants will benefit immediately by acquiring greater personal awareness and understanding, together with recommendations to help manage their SMD. The longer-term goal of introducing an SMD pathway is to improve the quality of life for autistic people. Blogs and presentations about the findings will be shared with autistic people and clinicians through Autism@Manchester, support groups, charities, NHS trusts and related social media. The study team will reach professionals via conferences and publications.

What are the possible benefits and risks of participating? Where is the study run from? Autism clinics at Greater Manchester Mental Health (GMMH) and Merseycare NHS trusts

When is the study starting and how long is it expected to run for? April 2024 to March 2026

Who is funding the study?

The National Institute for Health and Care Research (NIHR) Research for Patient Benefit (RfPB) programme

Who is the main contact?

Dr Emma Gowen, emma.gowen@manchester.ac.uk

# Contact information

## Type(s)

Public, Scientific, Principal investigator

#### Contact name

Dr Emma Gowen

#### Contact details

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# Additional identifiers

Clinical Trials Information System (CTIS)

Nil known

Integrated Research Application System (IRAS)

330960

ClinicalTrials.gov (NCT)

Nil known

#### Protocol serial number

X730, IRAS 330960, NIHR206138, CPMS 57232

# Study information

#### Scientific Title

Evidencing the need for routine sensory-motor assessment and support for autistic adults and identifying appropriate intervention pathways

## Study objectives

To provide evidence for the need and acceptability of routine sensory motor assessments and treatment for autistic adults and to identify and map existing intervention pathways

#### Ethics approval required

Ethics approval required

## Ethics approval(s)

approved 06/08/2024, North West - Greater Manchester Central Research Ethics Committee (2 Redman Place, Stratford, London, E20 1JQ, United Kingdom; -; gmcentral.rec@hra.nhs.uk), ref: 24 /NW/0157

#### Study design

Non-randomized cross-sectional study

#### Primary study design

Interventional

# Study type(s)

Diagnostic, Treatment

## Health condition(s) or problem(s) studied

Sensory motor conditions in autistic people

#### Interventions

For phase 1, consented autistic participants will be offered the Evaluation in Ayres Sensory Integration (EASI) assessment. Study OTs will collect demographics, perform the EASI, the Occupational Circumstances Interview and complete assessment reports detailing any need for sensory motor support (Objective 1) and specific support recommendations. Participants will receive a report detailing any sensory-motor difficulties and any support recommendations.

Within 2 weeks of this first visit, participants will be sent an online survey asking about their experience of the assessment, using an acceptability survey and bespoke questions. This has the benefit of (a) participants being more likely to remember the assessment and (b) maintaining engagement in the study.

Participants will have a 1-hour follow-up appointment ~6 weeks after receiving the report for the clinician to provide further advice and collect proof of concept and feasibility data (Objective 2). This will consist of data to determine participant views around the acceptability of the report and perceived impacts of open-ended qualitative survey items. Feasibility data will be collected to test whether it is possible to collect reliable outcome measures for future economic

evaluation (validated QoL questionnaires recommended for use in economic evaluation: European Quality of Life 5 Dimensions 5 Level Version (EQ-5D-5L) and to identify additional outcome measures from the participants' comments for evaluation in future studies.

#### Phase 2: Workshops and survey

During phase 2, the assessment and support recommendations extracted from the EASI reports in phase 1, will be presented at a stakeholder workshop involving the multidisciplinary research team to generate a list of additional assessments and existing support options. These lists will be circulated via a survey to a wider group of clinicians (~100 OTs and physiotherapists, recruited via our networks) to identify their preferred options and any additional assessments and interventions. A second workshop with the research team will involve a discussion of the survey findings and agreement on recommendations for assessment and support pathways, based on clinical and scientific evidence. Workshops will employ a Nominal Group Technique to refine the content of the toolkit and assess the level of consensus around assessment and support. This technique follows set stages of silent idea generation, 'round robin', clarifications and scoring enabling workshop participants time to think in silence and all to contribute. This is important as we wish to obtain information as well as develop guidance and the group is comprised of a mix of autistic people, clinicians and researchers so will allow everyone to raise issues. The scoring stage will only be conducted after workshop 2 using an online private Likert scale form for each individual.

#### Intervention Type

Behavioural

## Primary outcome(s)

Evidence on the level of need for sensory and motor difficulties (SMD) assessment in autistic adults without LD will be measured using the % of autistic adults without LD who are willing to take up an SMD assessment and the % of these that are identified as needing support following assessment recorded in study data at one time point

# Key secondary outcome(s))

- 1. Proof of concept and feasibility measured using open-ended qualitative survey items and Quality of life (European Quality of Life 5 Dimensions 5 Level Version) to facilitate future development and evaluation of the toolkit and pathway at one time point
- 2. A prototype SMD toolkit providing an itemised list of resources, detailing when they could be used (based on patient presentation), what they measure or support, available evidence base and what training might be required enabled and measured using study data at one time point

# Completion date

31/03/2026

# **Eligibility**

# Key inclusion criteria

Phase 1:

- 1. Diagnosis of an Autism Spectrum condition without a Learning Disability (LD)
- 2. >18 years without LD
- 3. Presenting at participating adult autism diagnostic clinics (GMMH and Merseycare)

#### Phase 2:

1. Clinicians who assess and support autistic adults with sensory motor needs

- 2. Able to understand written English and access the internet
- 3. >18 years of age

## Participant type(s)

Health professional, Patient

# Healthy volunteers allowed

No

## Age group

Mixed

# Lower age limit

18 years

# Upper age limit

100 years

#### Sex

All

#### Total final enrolment

18

#### Key exclusion criteria

Phase 1:

- 1. Outside of stated age range.
- 2. Diagnosis of a Learning Disability
- 3. Unable to understand verbal and written English as they will need to respond to both verbal and written questions
- 4. Outside-stated diagnostic clinics.

#### Phase 2:

Clinicians who do not assess and support autistic adults for sensory motor needs

# Date of first enrolment

01/10/2024

#### Date of final enrolment

22/11/2024

# Locations

#### Countries of recruitment

**United Kingdom** 

England

#### Study participating centre

#### Greater Manchester Mental Health NHS Foundation Trust

Prestwich Hospital Bury New Road Prestwich Manchester England M25 3BL

# Study participating centre Merseycare NHS Trust

V7 Building Kings Business Park Prescot England L34 1PJ

# Sponsor information

#### Organisation

Greater Manchester Mental Health NHS Foundation Trust

#### **ROR**

https://ror.org/05sb89p83

# Funder(s)

# Funder type

Government

#### **Funder Name**

Research for Patient Benefit Programme

#### Alternative Name(s)

NIHR Research for Patient Benefit Programme, Research for Patient Benefit (RfPB), The NIHR Research for Patient Benefit (RfPB), RfPB

## **Funding Body Type**

Government organisation

# **Funding Body Subtype**

National government

#### Location

**United Kingdom** 

# **Results and Publications**

# Individual participant data (IPD) sharing plan

The study report, anonymised participant-level data set and any statistical code will be made openly available using Open Science Framework (https://osf.io/) once the results have been published.

# IPD sharing plan summary

Stored in publicly available repository

# **Study outputs**

| Output type   | Details   | Date created | Date added | Peer reviewed? | Patient-facing? |
|---------------|-----------|--------------|------------|----------------|-----------------|
| Protocol file | version 1 | 04/04/2024   | 08/08/2024 | No             | No              |
| Protocol file | version 3 |              | 14/11/2025 | No             | No              |