Plan Overview

A Data Management Plan created using DMPonline

Title: Mental Health and Wellbeing Among Autistic Students in Higher Education: Exploring Lived Experiences Through a Qualitative Study

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Project abstract:

This project forms part of a PhD project that aims to develop a specialised mental health and wellbeing assessment measure for autistic university students. To inform this development, the current study involves conducting semi-structured interviews with 15–20 autistic students who are currently enrolled in, or have recently graduated from, UK universities. The purpose of these interviews is to explore how autistic students define and experience mental health and wellbeing, the challenges they face, and how their autistic identity interacts with these experiences. Existing mental health assessments used in university settings often fail to capture the distinct stressors experienced by autistic students, such as sensory sensitivities or masking. By centring the voices of autistic students through in-depth qualitative interviews, this study seeks to ensure that the future measure is grounded in real-world, lived experiences. All collected data will be analysed using Reflexive Thematic Analysis (RTA). The findings will directly inform the development of the psychometric tool's items.

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Mental Health and Wellbeing Among Autistic Students in Higher Education: Exploring Lived Experiences Through a Qualitative Study

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Assessment of existing data

Provide an explanation of the existing data sources that will be used by the research project, with references

There are no existing data sources which will be used by the research project.

Provide an analysis of the gaps identified between the currently available and required data for the research

Existing research on autistic students in higher education largely focuses on academic integration, transitions, or service access. While some studies (e.g., Scott & Sedgewick, 2021) explore mental health, they focus on external influences rather than how autistic students themselves define and experience mental health and wellbeing. There is a lack of data capturing the language, concepts, and identity-based factors (e.g., masking, sensory overload) that shape these experiences. This study addresses that gap by collecting first-person qualitative data through interviews, which will inform the development of a tailored psychometric measure.

Information on new data

Provide information on the data that will be produced or accessed by the research project

This project will generate original qualitative data from semi-structured interviews with 15–20 autistic university students in the UK. The data will consist of:

- Audio recordings of each interview (with participant consent)
- Full anonymised transcripts of the interviews
- Demographic details collected via a short questionnaire to confirm participant eligibility (e.g., age, student status, diagnosis) and used in the write-up to contextualise findings
- Reflexive journal entries from the researcher documenting analytic decisions and researcher positioning
- Thematic coding frameworks and analysis files created during Reflexive Thematic Analysis (e.g., NVivo project files, Excel tracking sheets)

No external or pre-existing datasets will be accessed or analysed. All data will be securely stored and managed in line with GDPR and University of Sheffield protocols.

Quality assurance of data

Describe the procedures for quality assurance that will be carried out on the data collected at the time of data collection, data entry, digitisation and data checking.

Several procedures will be implemented to ensure data quality at each stage of the research process:

- The interview schedule will be reviewed through Patient and Public Involvement (PPI) sessions to ensure questions are accessible, relevant, and inclusive. Following this, a pilot interview will be conducted with an autistic student to test the format, pacing, and clarity of questions. Any necessary revisions will be made based on feedback.
- All interviews will be conducted by the Principal Investigator (PI), who is autistic themselves and has experienced working with autistic individuals. A semi-structured interview guide will be used to maintain consistency across participants while allowing for flexibility. Audio recordings will be reviewed immediately after each interview to confirm clarity and completeness.
- Interviews will be transcribed verbatim by the PI. Transcripts will be checked against the original audio recordings for accuracy. All identifying information will be removed during transcription to ensure anonymity.
- All data will be stored on secure, University-approved systems. Transcripts, demographic forms, and coding files will be organised using a unique participant ID system. Identifying information (e.g., email addresses) will be stored separately.
- A reflexive journal and code audit trail will be maintained throughout analysis. NVivo software and a structured Excel tracker will be used to monitor code development and ensure transparency. Supervisory review will support analytic consistency and rigour.

Backup and security of data

Describe the data security and backup procedures you will adopt to ensure the data and metadata are securely stored during the lifetime of the project.

Any personal data will be stored on the University's X: Drive. Study data will stored on the University's Google Drive. Only myself and my supervisors will have access to this data, All recording will immediately to the drive, the transcripts will be completed, then the recordings deleted from the drive after transcripts have been checked for accuracy. Copies of the meeting structure will be stored. A pseudonymisation key will be created so that participants can be reidentified after transcription if they request their data to be deleted. This key will be deleted 2 weeks after data collection.

Management and curation of data

Outline your plans for preparing, organising and documenting data.

To organise the data, I will create a README file, which will contain metadata and a detailed description to help others access, understand and reuse the data. The files will be organised consistently across the data collection period and will be stored systematically. File names will not contain any sensitive or personal information.

The international data format will be used in the name of each file (YYYY-MM-DD) to help with file order. Names of files will follow the following pattern:

FOLDER - Interviews

P1_YYYY_MM_DD_Recording

P1_YYYY_MM_DD_Transcription

P1 refers to this being data from the interview with participant 1. 'YYYY_MM_DD' refers to when the recording was made. 'Recording' denotes the file containing the audio recording, and 'Transcript' denotes the file containing the transcript of the recording. The same format will be used for the following meetings.

To store and organise demographic and personal data on the X drive, a structured and secure system will be implemented. The primary folder, labelled “Demographic and Personal Data,” will hold all sensitive information and will be segmented further into subfolders based on the type of data or phase of data collection. For instance, subfolders such as “Email Communications” and “Participant Demographics” will categorise the data accordingly.

Within these subfolders, files will be named using a clear and consistent convention that incorporates participant identifiers and the date information was collected. For example, emails might be stored as Email_p1_yyyy_mm_dd, indicating an email involving participant 1 on a specific date. Similarly, demographic data files could be named as Demographics_P1_YYYY_MM_DD.

Difficulties in data sharing and measures to overcome these

Identify any potential obstacles to sharing your data, explain which and the possible measures you can apply to overcome these.

It is intended that anonymised data will be shared more widely. Due to the potentially sensitive nature of the data, participant consent will need to be obtained. As such, details of potential data sharing will be included in the information sheets and consent forms provided to participants. These will need to be signed before the data can be collected. Participants' anonymity will be concealed, and any identifiable data will be redacted from the transcripts, including names, locations or personal/professional affiliations.

Consent, anonymisation and strategies to enable further re-use of data

Make explicit mention of the planned procedures to handle consent for data sharing for data obtained from human participants, and/or how to anonymise data, to make sure that data can be made available and accessible for future scientific research.

Participant information sheets and consent forms will be provided when they show interest in participating in the research. All consent forms must be completed to take part. Within these forms, it will be made clear what data will be shared, including their insights that may be used in the thesis write-up and any consequent publications. Participants can choose whether they would like to share their data or not. Participants will be allocated a pseudonym for the data write-up, including transcription of the analysis. All identifiable data will be redacted, including personal/professional affiliations, names and locations. Participants will be given a choice to retract from the data collection up until 2 weeks after data collection, as then all original data will be anonymised and transcribed, and the recording will be deleted. The decision is to avoid participants retracting their data after being anonymised, analysed and written up, which would prove difficult to redact.

Copyright and intellectual property ownership

State who will own the copyright and IPR of any new data that you will generate.

Following the data procedure, The University of Sheffield and ESRC White Rose DTP will own the copyright and intellectual property rights.

Responsibilities

Outline responsibilities for data management within research teams at all partner institutions

As the lead researcher, I will be responsible for adhering to the data management plan. The supervisory team, Prof Megan Freeth, Dr Emma Broglia, and Dr Lauren Powell, will also have access to the data and support in upholding this plan. The data management plan will be reviewed when necessary to ensure any changes to the project or data collection are reflected.

Preparation of data for sharing and archiving

Are the plans for preparing and documenting data for sharing and archiving with the UK Data Service appropriate?

Given the potential sensitivity of the data, data will be stored with the UK Data Service to ensure it is securely stored and available for reuse. Any identifiable or traceable data will be redacted prior to storing with the UK Data.

Is there evidence that data will be well documented during research to provide highquality contextual information and/or structured metadata for secondary users?

A README file will include metadata to detail the data collection method and what it contains. This will accompany the data stored with the UK Data Service.