

School of Psychology
Information Sheet



Can autistic traits predict changes in cognition and mobility in older adults?

Ethics Approval Number: F1528

Researchers: Sarah Ottahal, Harriet Allen, Danielle Ropar

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This is an invitation to take part in a research study on cognition and mobility changes in older adults. The current study is especially interested in assessing whether there are differences in cognition and mobility depending on levels of autistic personality traits. Before you decide if you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

If at any point before, during or after the study, you have any questions, please feel free to contact the researchers; Sarah Ottahal: sarah.ottahal@nottingham.ac.uk or Harriet Allen: h.a.allen@nottingham.ac.uk.

If you participate, you will be asked a series of questions about yourself, such as your age and biological sex. You will then be asked to answer 4 sets of questionnaires, whereby one will ask you about your behaviour and feelings, one will ask about changes in your cognition (such as memory), one will ask you about changes in your ability to move, and, lastly, your quality of life. The whole procedure will last about 30 minutes. Please note that you cannot take part if you have a formal diagnosis of autism spectrum disorder, as this study investigates non-clinical autistic traits.

As indicated above, this research is investigating cognition and mobility in older adults based on levels of autistic traits. Therefore, it is possible that thinking about some of these topics may cause distress. This research was designed with autistic people on the team and in the best interest of furthering our knowledge about ageing with autism spectrum disorder or autistic traits. Please note, that this research is not used to diagnose participants if no prior diagnosis has been given and no feedback can be given. If you experience any distress as a result of taking part, it is advised that you terminate your participation in the study immediately and seek appropriate support. I have listed the contact details for relevant support agencies below, which you may find useful to contact.

Participation in this study is totally voluntary and you are under no obligation to take part. You are free to withdraw at any point before or during the study. All data collected will be

kept confidential and used for research purposes only. It will be stored in compliance with the Data Protection Act.

As an online participant in this research, we are obliged to make you aware that there is always a potential risk of intrusion by outside agents, for example through hacking, and therefore the possibility of being identified.

If you have any questions or concerns please don't hesitate to ask now. We can also be contacted after your participation at the above address.

If you have any complaints about the study, please contact:
Stephen Jackson (Chair of Ethics Committee)
stephen.jackson@nottingham.ac.uk

If you feel like you need any support after completing this study, please contact

Mind Infoline 0300 123 3393

SANeline: 0300 304 7000

Shout: 85258 a free, confidential, 24/7 text messaging support service for anyone who is struggling to cope

Living Autism: 0800 756 2420

Participant Privacy Notice

Why we collect your personal data

We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning. Specific purposes for data collection on this occasion are clinical or medical (which means research into treating, diagnosing or alleviating the symptoms of disease) or physiology (which means understanding how the body works, whether in a healthy state or while unwell).

Legal basis for processing your personal data under UK GDPR

The legal basis for processing your personal data on this occasion under Article 6(1e) of the UK General Data Protection Regulations "processing is necessary for the performance of a task carried out in the public interest".

Source of Data

Where data is not collected directly from research participants, the University may obtain data from trusted partners such as NHS Digital (who provide the University with HES/Mortality data, for example).

Special category personal data

In addition to the legal basis for processing your personal data, the University must meet a further basis when processing any special category data, including: personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data

concerning a natural person's sex life or sexual orientation.

The basis for processing your sensitive personal data on this occasion is Article 9(2j) "processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes".

How long we keep your data

The University may store your data for up to a period of no less than 7 years after the research project finishes and is published. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research. You will not be identifiable in data used in this way. Measures to safeguard your identity in stored data include encryption, pseudonymisation and full anonymisation, whichever is applicable to the particular research study

Who we share your data with

Extracts of your data about you may be disclosed in published works that are posted online for use by the scientific community. Your data may also be stored indefinitely on external data repositories (for example, the UK Data Archive) and be further processed for archiving purposes in the public interest, or for historical, scientific or statistical purposes. It may also move with the researcher who collected your data to another institution in the future.

Transfers of your data outside Europe

If data is transferred out of the European Union we will endeavour to only transfer to countries who are on the [EU list of adequate countries](#) or to apply [adequate safeguards as stated above to protect your privacy](#).

The University of Nottingham also works with suppliers and partners who may make use of Cloud and/or hosted technologies. We undertake data security due diligence on our partners, ensure that suitable contracts are in place and that these partners conform to appropriate accreditations.

Wherever these transfers take place, the University will have an appropriate contract in place and there are strict rules regarding the confidentiality and security of your information in place to safeguard it.

We will keep this privacy notice under regular review and we will place any updates on this web page. This privacy notice was last updated on 4 June 2018.

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The University of
Nottingham

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Informed Consent

	Yes	No
Have you read and understood the Information Sheet?	<input type="radio"/>	<input type="radio"/>
Are you aware that you can ask questions about this study using the email addresses provided?	<input type="radio"/>	<input type="radio"/>
If you did have any questions about this study, have they been answered satisfactorily (also, if you did not have questions, please click yes)?	<input type="radio"/>	<input type="radio"/>
Do you understand that you are free to withdraw from the study? (at any time and without giving a reason)	<input type="radio"/>	<input type="radio"/>
I give permission for my data from this study to be shared with other researchers provided that my anonymity is completely protected.	<input type="radio"/>	<input type="radio"/>
Do you understand that this study cannot be used as a diagnosis?	<input type="radio"/>	<input type="radio"/>
Do you agree to take part in the study?	<input type="radio"/>	<input type="radio"/>