PARTICIPANT INFORMATION SHEET

PROTECT sub-study:
Exploring traits of neurodivergence

Thank you for taking part in the PROTECT Study. We would now like to invite you to take part in the above sub-study led by King's College London and sponsored by the University of Exeter. Before you decide whether to participate 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 and discuss it with friends and relatives if you wish. Please ask a member of the research team if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part. If you decide to take part, you may keep this information sheet.

This study has been granted full ethical approval from King's College London (MRA-24/25-45747).

What is the purpose of the study?

There is an increasing awareness that different types of neurodivergence are underdiagnosed in adulthood, and particularly in older age. Neurodivergence is a broad term used to describe differences in how people think and behave.

This study will ask you a set of questions related to traits and characteristics related to different types of neurodivergence. These questions will explore the identification of emotions, your concentration and attentiveness, your reading and writing skills, and your physical coordination. We will use this information alongside the questions already included in the main PROTECT study to explore how traits of neurodivergence interact with mental health and cognitive ability as people age.

Why have I been invited to take part?

You have been invited to take part because you have previously consented to take part in the PROTECT Study. We are giving you the opportunity to take part in this sub-study because it may help us to understand more about neurodivergence and ageing.

All participants are invited from the PROTECT Study to take part in this sub-study.

Do I have to take part?

It is up to you to decide whether or not to take part in this sub-study. If you decide to take part, you are still free to withdraw at any time, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your participation in the PROTECT Study.

What will happen if I take part?

If you choose to take part in the sub-study you will be asked to fill in a short questionnaire, which will take approximately 5–10 minutes.

The first part of the questionnaire will explore how you identify emotions (e.g.: “It is difficult for me to find the right words for my feelings”). The second part will explore your concentration and attentiveness (e.g.: “How often do you have difficulty concentrating on what people are saying to you even when they are speaking to you directly?”). The final part will explore your reading and writing skills (e.g.: “I have inconsistent or poor spelling”) and your physical coordination (e.g.: “I am often clumsy and bump into things”).

Your responses to these questions will then be added to your already collected responses as part of the main PROTECT study, which will help us to analyse how traits of neurodivergence interact with mental health and cognitive ability as people age.

What are the possible benefits and risks of taking part?

There is an extremely small risk that some people may find certain questions difficult to answer. You should only answer those questions that you are comfortable with. You do not need to answer any questions that you are not sure about or do not wish to.

The main advantage of this research is that participants will be taking part in an important study that could provide valuable new knowledge about how traits of neurodivergence influence health and cognition as people age.

What will happen to the data I provide?

The University of Exeter is the sponsor for this study. In working with the PROTECT Study team we will be using information from you in order to undertake this study and will act as data controller. This means that we are responsible for looking after your information and using it properly. The PROTECT Study team will keep identifiable information about you and we researchers will have only the anonymised data. Anonymised information collected as part of this study will be kept indefinitely in accordance with the PROTECT Study privacy policy. For more information about how the PROTECT Study uses your personal data, please see the PROTECT Study privacy policy (https://www.protectstudy.org.uk/Home/PrivacyPolicy).

To safeguard your rights, we will use the minimum personally identifiable information possible. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep all anonymised information about you that we have already obtained.

Individuals from the University of Exeter may look at your research records to check the accuracy of the research study. The only people in the University of Exeter who will have access to information that identifies you will be people who need to contact you to discuss issues directly relating to the study or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Will participation be kept confidential?

Your data will be processed in accordance with the General Data Protection Regulation (GDPR). All of the data collected as part of this project will be regarded as strictly confidential and will be held securely until the research is finished. No study data will be available in any identifiable format to anyone outside of the immediate research team. We may share anonymised data from this study with other researchers, within the remit of PROTECT Study policy and following necessary approvals.

All data for analysis will be anonymised. In reporting on the research findings, we will not reveal the names of any participants. All research staff are provided with training regarding GDPR and University of Exeter standards for handling data. Any data provided electronically will be stored on a database on a restricted server only accessible by specified members of the research team who have been given authorisation to access the database.

Questions, comments and requests about your personal data can be sent to:

The Administrator
PROTECT Study
College House 1.23
St Luke's Campus
The University of Exeter
Exeter, EX1 2LU
United Kingdom

Alternatively, you may also contact the University of Exeter's Data Protection Officer who is responsible for monitoring compliance with relevant legislation in relation to personal data, by emailing dataprotection@exeter.ac.uk. You have the right to lodge a complaint with the Information Commissioner's Office at https://ico.org.uk/concerns.

What if I change my mind about taking part?

Your decision to participate in this study is voluntary. You can withdraw from the study at any time without giving a reason by logging into your PROTECT Study account and clicking on the Withdraw from Study option in the Manage Account section of the website. Alternatively, you can contact the PROTECT Study helpdesk by emailing support.protect@exeter.ac.uk or by telephoning 01392 725010. By withdrawing you are making the decision not to provide any further information or responses to the study questionnaire and you will not receive any further communications about it. However, if you withdraw from the study, we will retain all anonymised data that we have collected up to the time you withdraw. This includes all anonymised data from questionnaires.

Who is organising this study?

This sub-study is being led by King's College London, nested within the main PROTECT Study, which is led by the University of Exeter, King's College London and South London and Maudsley NHS Trust.

Contact for further information

If you have any questions or require more information about this study, please contact the PROTECT helpdesk by emailing support.protect@exeter.ac.uk.

What if there is a problem?

If you wish to complain or have concerns about any aspect of the way you have been approached or treated during the course of this study, you can contact the University of Exeter Medical School Ethics Committee (uemsethics@exeter.ac.uk).

Additional information and Frequently Asked Questions are available on the PROTECT Study website. If this does not answer your query you can contact the PROTECT Study team by calling 01392 725010.

Thank you for reading this information sheet and for considering taking part in this research.

Consent to Take Part

- I confirm that I have read and understand the Participant Information Sheet version 1.0 dated 09/04/2025 for the above sub-study, led by King's College London and sponsored by the University of Exeter. I have had the opportunity to consider the information and ask questions, which have been answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- I consent to the processing of my personal information for the purposes explained to me via the Participant Information Sheet. I understand that such information will be handled and stored in accordance with the General Data Protection Regulation (GDPR) and other Data Protection Laws.
- I give my consent for the researchers to access relevant information already being collected about me from the PROTECT Study.
- I understand that my information may be subject to review by responsible individuals from the University of Exeter on for monitoring and audit purposes.
- If I chose to withdraw, I understand that all anonymised data will be retained in the study up to the point of my withdrawal, and no further data will be collected.
- I agree to take part in the PROTECT sub-study: "Exploring traits of neurodivergence"