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Participant Information Sheet Next Generation Brain Health survey

You are invited to take part in a research study. To help you decide whether or not 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.

Study Background and Purpose

The Next Generation Brain Health survey is an online survey that aims to investigate knowledge of dementia and brain health among 18-39 year olds. We are looking for 5000 participants. To participate, you must be aged 18-39 years.

We are particularly interested to collect a diverse range of responses to ensure our findings are as widely representative as possible.

Who is doing this study?

The study is a collaboration between researchers at the University of Edinburgh (Scotland), Trinity College Dublin (Ireland), Leeds Beckett University (England) and Northwestern University (USA). The study is sponsored by the University of Edinburgh in the United Kingdom.

Do I have to take part?

No, participation is voluntary. If you decide to take part, you will be asked to complete an online consent form. You are free to withdraw at any time without giving a reason and this will not affect you or your legal rights.

Study Procedures

Participation will involve completing a one-time survey that asks about your knowledge of dementia and brain health, and your exposures to lifestyle-related factors that can influence brain health. We will also ask you to provide demographic information about yourself, this includes details such as your age, sex, sexual orientation and your ethnicity. Providing this information alongside your knowledge of brain health helps us to understand how these factors might relate to brain health. This will also help us understand what different people may know about brain health and dementia risk which is important for improving public awareness of brain health successfully.

The survey will be completed online using a survey platform called Qualtrics. We anticipate the survey will take about 20 minutes to complete. Before beginning, you will be asked to provide your consent. Consent will be collected anonymously and we will not be asking for your name or contact details. A copy of the information sheet and consent form can be downloaded for your records. Submission of the survey will be interpreted as your informed consent to participate and that you affirm you are between 18-39 years of age. Once you complete the survey, your involvement in the study is complete.



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Academic and Clinical Central Office for Research and Development

Compensation for Participation in the Study

There is no financial compensation for participating.

Study Risks/Discomforts

A small number of questions in the survey ask about sensitive topics like intimate partner violence, which may cause some discomfort or be upsetting to read. There will be a warning before these questions appear and you can choose not to answer them. We will also provide links to support resources at the end of the survey. We do not anticipate any other risks.

Study Benefits

There are no direct benefits to participating, but results from this study will improve scientific knowledge about brain health and exposure to lifestyle-related risk factors in young adults. Our findings could also help to inform risk reduction and prevention of dementia in the future.

What will happen if I don't want to carry on with the study?

You are free to withdraw at any point without providing a reason. You can withdraw from the study by closing the survey webpage. Because this is an anonymous online survey, it will not be possible to delete any information collected up to the point you choose to withdraw. The data already collected will be retained and included in the analysis.

What happens when the study is finished?

Data will be collected through the Qualtrics platform, which is hosted at Trinity College Dublin. Once data collection is complete, all data will be securely transferred to the research team working on the project for analysis. Data will be stored securely at the Universities of Edinburgh and Trinity College Dublin for up to 7 years, after which it will be deleted. All (or part) of the data may also be stored on the Open Science Framework to allow future use by other researchers.

Confidentiality

All information will be kept confidential and there are strict laws which safeguard your privacy at every stage.

How will we use information about you?

We will collect the following personal information for this study: your age, gender, sexual orientation, education level, country of residence, and racial and ethnic background.

We will not collect any information that contains personal identifiers including your computer's IP address, so you cannot be identified. The data will initially be stored in a secured Qualtrics database, which can only be accessed with a secure password by researchers working on the project.

Once collected, the data will be downloaded and stored in secure servers at Trinity College Dublin (Trinity College Institute of Neuroscience, Lloyd Building, Dublin, Ireland) for 7 years following the end of the study. After this period, the data will be deleted.



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Data will be transferred from Trinity College Dublin (Ireland) to the University of Edinburgh, Leeds Beckett University (United Kingdom) and Northwestern University (United States of America) via a secure, password-protected online platform and then stored on a secure, password-protected DataStore facility for 7 years following the end of the study. After this period, the data will be deleted.

If you have any concerns about how we will use your information, please contact:

- The University of Edinburgh Data Protection Officer: dpo@ed.ac.uk
- Contact the Principal Investigator Sarah Gregory: sarah.gregory@ed.ac.uk

Study Results

We plan to share study results on the website of our partner programme the PREVENT dementia programme: www.preventdementia.co.uk. We also aim to publish the findings in academic journals and at research conferences. You will not be identifiable from any published results.

Study Ethics Approvals

Ethical approval has been obtained from the University of Edinburgh EMREC committee.

Who to contact if I have a problem or I have questions about the study?

If you have any questions about the study or have a problem and wish to make a complaint, please contact Katie Wells email on: katie.wells@ed.ac.uk.

Thank you for taking the time to read this information sheet and considering if you will take part in this study.