



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

PARTICIPANT INFORMATION SHEET

Understanding different mechanisms underlying repetitive behaviours across mental health

Thank you for your interest in our research. You are being invited to participate in a research study led by Dr Eike Buabang (Research Lead), Professor Claire Gillan (Principal Investigator) and approved members of a research team at Trinity College Dublin. Before you decide to participate, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish.

Please Note: You will be asked to provide informed consent and indicate that you have read and understood this information sheet.

Part 1: The Study

Why is this study being done?

We are interested in how individual differences in demographic and clinical characteristics are related to how people learn and perform repeated behaviours, or “habits”. This study aims to further our understanding of habits and how different variations of habit may confer vulnerability to distinct clinical presentations.

Why have I been invited to take part?

We are looking to recruit participants who meet the following criteria:

- Aged 18 years or older
- Native English speaker or equivalent level of fluency
- Has access to a smartphone device
- Has access to stable internet connection
- Resident of either Ireland, UK, or USA
- Has normal colour vision (not colourblind)
- Has symptoms of any of the following:
 - Tourette’s Syndrome

- Tic Disorder
- Obsessive Compulsive Disorder
- Body-focused repetitive behaviours:
 - Hair pulling
 - Skin picking
 - Biting nails/cheeks/lips
- Has previously *not* been diagnosed with any of the following:
 - Psychosis
 - Schizophrenia
 - Bipolar disorder
 - A manic episode
 - A cognitive disability
 - A major neurological condition (e.g. dementia, Parkinson's disease, etc)

Do I have to take part? What happens if I change my mind?

It is entirely your choice whether you participate in the study. There will be no repercussions if you decide to withdraw from the study at any point. However, you must complete all study sessions in order to be reimbursed.

What will happen if I volunteer?

We will ask to meet via Zoom (with camera on) to discuss your symptoms in a semi-structured interview (maximum 90 minutes). You will then be asked to participate in a study that consists of 7 remote online sessions completed on your smartphone through the TCD Research app. Each session will consist of playing a gamified cognitive task. This will take no more than 20 minutes per day, but the first and last sessions will take longer to complete (maximum 30 minutes). Within the task, we will also ask you to complete some questionnaires related to your mental health. It is important that you are able to commit to the schedule of daily remote online sessions.

Are there any benefits from my participation?

There are no direct therapeutic benefits from your participation. However, your data will be used to identify the underlying disruptions contributing to repetitive behaviours, forwarding our scientific knowledge. The only direct benefit is the monetary compensation of €40 (or currency equivalent) for your time.

Are there any risks involved in participating?

The risks associated with participation are minimal; the study asks questions pertaining to your mental health which some individuals may find distressing.

What will happen to my data?

Your data will be securely archived by Trinity College Dublin for 10 years. When this study is finished, we will analyse the data and write a research paper with the intent to publish it in a scientific journal. We intend to publish in an Open Access journal (this means that anyone will be able to read the paper online, for free). Alongside Open Access publishing comes the idea of “open data”, which means that the dataset from the study is made publicly available so that other scientists across the world can download the dataset and conduct their own analyses, allowing them to decide for themselves whether our conclusions are valid.

To take part in this study, we ask your consent that after the study, anonymised study data will be made available as “open data”. This means the anonymised study data will be publicly available and may be used for purposes not related to this study. This data will be anonymised and it will not be possible to identify you from these data. If you consent, you agree to “open data” in addition to Trinity College Dublin keeping and processing the information that you have provided during the study. Your consent is conditional on the University complying with its duties and obligations under the Data Protection Act.

Will I be told the outcome of this study?

We will not contact you with the outcome of this study. However, if you wish to find out more about our findings you can contact the Research Lead, Dr. Eike Buabang (eike.buabang@tcd.ie). We also aim to publish the study in an Open Access scientific journal that will be available for everyone to read.

Part 2: Data & Data Protection

What information about me will be used as part of this study?

In this study will collect the following information:

- Your email address
- Basic demographics (e.g., age, gender, first language, education attainment, colourblind status, and country of residence)
- Medication intake
- Your experiences of a range of mental health symptoms
- Your responses on the cognitive tasks

Who will access and use my personal data? Will it be kept safe and confidential?

Only members of the research team will have access to your personal data. Prior to running this study, we conducted a Data Protection Impact Assessment. All data will be pseudonymised at the point of collection, under a unique participant ID number. This will be kept in an encrypted file on a password-protected computer. It will not be shared outside of the research team.

What is the lawful basis to use my personal data?

By law, we can use your personal information for scientific research (in the public interest). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

If I decide to join the study, what are my rights?

Participation in this study is completely voluntary and if you agree to participate you have the following rights:

Confidentiality: Information from this study will be kept strictly confidential and no identifiable information (i.e., data linked to your name, email address) will be made available to any person outside the research group. Your personal information will be stored in anonymised, encrypted form in a password-protected computer. We will aim to present and publish our results in conferences and scientific journals but any information we have will be completely anonymous. We aim to share the data collected in this study with other researchers so that they can test novel hypotheses in the future; we will do so in a fully anonymous way. That means that your personal information will never leave the lab – the data from your questionnaire responses, behavioural tasks, and other measures from this study will be shared in a fully anonymous way.

However, do note that statutory limits apply to confidentiality, which may be breached in circumstances in which:

- The Investigator has a strong belief, or evidence exists that there is a serious risk of harm or danger to either the participant or another individual. This may relate to issues surrounding physical, emotional, or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity
- Disclosure is required as part of a legal process or Garda investigation. In such instances information may be disclosed to significant others or appropriate third parties without permission being sought, where possible a full explanation will be given to the participant regarding the necessary procedures and intended actions that need to be taken

Right to withdraw: You can withdraw your data from the study at any time (until the point that your data has been analysed and a report based on the data has been submitted). To withdraw your data, you can contact the research team.

Access to information: Under the Freedom of Information Act 2014, you will have access to any information stored about you in relation to the current study for up to 10 years after you provided it.

Will my data be used in future studies?

The data from this study will be made openly available on a public data repository, meaning it may be used for purposes not related to the current study. This data will be anonymised and it will not be possible to identify you from these data.

Part 3: Ethical Approval

Has the study received ethical approval?

This study has been given ethical approval by the School of Psychology Research Ethics Committee of Trinity College Dublin (project code: 3705). No risks or adverse effects have been identified, and no personal identifying information will be available to researchers unless you choose to provide it. The procedures of this study have also been passed a Data Protection Inspection Assessment. You are free to withdraw from the study at any time without giving reason for doing so, however, you will only be reimbursed for your time if you complete all 7 sessions.

Part 4: Contact Information

Who can I contact if I have further questions?

If you are interested in participating or have any further queries about the research, please contact:

Dr Eike Buabang (Research Lead)

Lloyd Institute
Trinity College Dublin
Dublin 2

Email: eike.buabang@tcd.ie

Telephone: +353 1 896 8506

Prof Claire Gillan (Principal Investigator)

Lloyd Institute
Trinity College Dublin
Dublin 2

Email: gillancl@tcd.ie

Telephone: +353 1 896 8526

Data Protection Officer

Secretary's Office
Trinity College Dublin
Dublin 2

Email: dataprotection@tcd.ie

Website: www.tcd.ie/privacy

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

We will contact you by email during this study for administration purposes, such as sending you reminders to complete the sessions. We will not contact you again once the study data collection is complete unless consented to do so.