

PARTICIPANT INFORMATION SHEET

Title of study: Dating after traumatic brain injury (TBI)

REC Reference No: ETH1920-1799

Name of investigator(s): Dr Nicholas Behn, Prof Jacinta Douglas and Dr Sarah Northcott

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to explore a person's experiences of dating after a brain injury. We want to learn about:

- Why you want to date?
- How do you find a date?
- How do you know if a date is going well

Why have I been invited to take part?

We are looking for 20 people with TBI to take part in this study.

People must be:

- English speaking
- Must have been single after your injury
- At least 6 months after your injury
- Have a computer with a good internet connection
- Able to hear and see easily

Do I have to take part?

Participation is voluntary, and it is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. You can withdraw at any stage of the project without being penalised or disadvantaged in any way.

What will happen if I take part?

The research will take place within your own home over the internet. We will interview you using Microsoft Teams about dating and the interview will be video-

recorded. The interview will last approximately one hour at a time convenient to you. The researchers will provide support on using Microsoft Teams if necessary.

What are the possible disadvantages and risks of taking part?

There are no known risks associated with this study. You may experience discomfort with being on a computer screen for a long period of time but you can request regular breaks and can stop participation in the study at any time.

What are the possible benefits of taking part?

You may not directly benefit from this research; however, we hope that you may enjoy taking part. Participation in this study may help researchers understand more about dating and how we can best support people to date after a brain injury.

Will my taking part in the study be kept confidential?

The following procedures will be used to protect the confidentiality of your data:

- The data files will not be labelled with any personal information.
- The researchers will keep all study records (including any codes to your data) locked in a secure location at City, University of London.
- Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords.
- At the conclusion of this study, the anonymised data will be kept indefinitely for future analyses and the researchers may publish their findings. Data may be shared with other researchers in the future.
- The records containing your personal information will be stored at City, University of London for 10 years and will be destroyed securely after this time.

Confidentiality may be broken where disclosures relate to safeguarding issues (i.e. risk of harm to yourself or others). Also, in the event of a disclosure, a researcher can seek the participant's consent to break confidentiality but, in the event, that this consent is not forthcoming, the researcher has a responsibility to break confidentially and inform the appropriate individual(s) or organisation(s).

What will happen to the results of the research study?

We will send you a summary leaflet and short video (that will be shared online) telling you what we found out. We will also use the results to write articles in scientific journals and talk about research at conferences and in training other students and professionals. Information may be shown to other researchers and

students who will help to analyse the data but your identity will be kept anonymous at all times.

What will happen if I do not want to carry on with the study?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

Who has reviewed the study?

This study has been approved by City, University of London School of Health Sciences Research Ethics Committee

Data privacy statement

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. The legal basis under which your data will be processed is a task in the public interest (often referred to as the public task legal basis) and any special category data processed, for example information about your health, is processed by virtue of the lawful basis for research (Article 9(2)(j) of the GDPR).

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible.

City, University of London will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only person at the University who will have access to your identifiable information will be Dr Nicholas Behn. The university will keep identifiable information about you from this study for 10 years after the study has finished.

You can find out more about how City, University of London handles data by visiting <https://www.city.ac.uk/about/governance/legal>. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) <https://ico.org.uk/>.

What if I have concerns about how my personal data will be used after I have participated in the research?

In the first instance you should raise any concerns with the research team, but if you are dissatisfied with the response, you may contact the Information Assurance Team at dataprotection@city.ac.uk or phone 0207 040 4000, who will liaise with the University's Data Protection Officer to answer your query.

If you are dissatisfied with the University's response you may also complain to the Information Commissioner's Office at www.ico.org.uk

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team.

If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: "Dating after brain injury".

You could also write to the Secretary at:
Anna Ramberg
Research Governance & Integrity Manager
Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

Insurance

City, University of London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Further information and contact details

If you want more information contact:
The Principal Investigator: Dr Nicholas Behn



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Thank you for taking the time to read this information sheet.