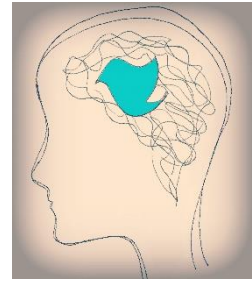


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Information Statement for the Research Project:

TwitterMind Study 2: Twitter use by people with communication disabilities after traumatic brain injury (TBI)

Document Version [3]; dated [09/09/16]

Investigators: Ms Melissa Brunner (PhD Student, The University of Newcastle)
A/Prof Bronwyn Hemsley (Primary Supervisor, The University of Newcastle)
Prof Leanne Togher (The University of Sydney)
A/Prof Stuart Palmer (Deakin University)
Dr Stephen Dann (Australian National University)

Aim of the Study:

The aim of this research is to use a survey to discover how Twitter is currently used by people with communication disabilities after a traumatic brain injury (TBI) and the nature and extent of any problems experienced in learning to use Twitter.



Who is invited to participate in this study?

We will invite 100 people (teenagers and adults aged 16 years and over), along with their family members/ partners/carers, who experience communication difficulties as a result of a traumatic brain injury (TBI) and who are able to give their own consent, to talk to us about their use of social media, particularly Twitter.

What does the Study involve?

Taking part in a survey

The survey is an interview (via meeting face-to-face or Internet videocall, e.g. Skype) that takes about 20-30 minutes. Participants can choose to answer or not answer any of the questions.



If you agree to participate in this study:

- We will ask you to sign a consent form with details of what you do or do not agree to.
- If you are under 18 years of age, we will ask that a parent/guardian sign the consent form in addition to your signature of consent. We will provide you with a copy of the signed consent form.

- We will ask you to provide information and confirm details about your age, brain injury, and communication difficulties (we will ask to see a report from your brain injury unit or your speech pathologist to confirm this information only – we will not keep a copy).
- We will send you a summary of your results for you to keep, and a summary of the results of the entire project when it is completed.
- The research will be completed by interview at your home or workplace.

You do not have to leave home to participate in this research - you can be interviewed at home, in person or by Skype. **Do I have to answer all of the questions if I agree to take part?**

You can refuse to answer any question that you do not want to answer. You can also stop the interview at any time.

What happens to the information that I give in answering the questions?

- We will keep the information provided by you private.
- Your name and any other information that could potentially identify you or other people will be changed or removed to ensure your privacy is protected.
- When we write reports, your identity will not be revealed. In anything we write about the study, we will change your name and make sure that we change or remove information that could identify you to other people who read reports about the study.
- All information you give us will be stored in a secure password protected computer and in a locked office at The University of Newcastle.
- Only the investigator team will have access to your personal details (name, address, telephone number, email address if collected).
- We will not pass on your personal details to any other party.
- Only the researchers on the study will have access to the full amount of the information kept about you.

Do I have to take part?

No. You do not have to take part in this research. Participation is voluntary and is your choice. Even if you do give your consent to take part, you can withdraw your consent before, during, or after taking part in the study. If you withdraw your consent to participate, we will remove all of your data from the study. There is no penalty to you for withdrawing your consent and there is no risk to you if you do not participate in the research.

Are there any risks involved in the research?

There are minimal risks to you if you take part in this research.

Risk to privacy. The researcher is responsible for keeping your information safe, private, and confidential. In our reports we do not include any information that might identify you to people who know you.

Risk to safety or wellbeing. There is a minimal (very small) risk, as with any public social media, that engaging with the general public will expose you to the negative aspects of public communication – such as might occur in ‘cyber-bullying’ situations (e.g. anonymous accounts or

'trolls' saying something negative about you). Depending on what topics you discuss and who you engage with in social media, you might experience this only very infrequently (by chance) or not at all. There is a small risk that by being surveyed about your use of social media you may experience emotional distress in recalling negative experiences. If this occurs, the interview will immediately cease.

What information are you collecting and keeping?

We are collecting your demographic information and details about your brain injury provided by you. We are collecting your interview responses to the survey about social media.

How will I know what information you are using in the research?

We will show you all of your survey responses. Anything that you do not wish to be included will be removed or changed to your satisfaction.

How will the information about me be stored by researchers? How long will it be kept?

The information that is kept about you will be stored in a secure password protected computer in the office of Ms Melissa Brunner or in the office of A/Prof Bronwyn Hemsley, in the Speech Pathology Department at The University of Newcastle. The data will be kept for 7 years following the last date of publication on the research and will then be destroyed securely and confidentially.

Will the study be of any benefit to participants?

We do not expect that people participating in this study will gain any benefit. While we expect that the outcomes of the study will be of benefit to people with disability after TBI in general this cannot be guaranteed.

If you have more questions, need more information, or want to take part:

Please ask for more information: **Ms Melissa Brunner** on melissa.brunner@uon.edu.au, or **A/Prof Bronwyn Hemsley** on (02) 4921 7352. You are of course, free to discuss your participation in this study with project staff.

Approvals:

This study has been reviewed and approved by the ethics committees at The University of Newcastle [Approval number H-2015-0057] and the [other participating organisation's ethics committee] [Approval pending] in accordance with the National Health and Medical Research Council's guidelines.

Complaints or concerns:

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, you can also speak to the Senior Human Research Ethics Officer by telephone (02) 4921 6333 or email human-ethics@newcastle.edu.au.



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