



PARTICIPANT INFORMATION SHEET

Title of Study: Designing Computer-Mediated Communication Supports to Increase Social Participation After Traumatic Brain Injury

Principal Investigator:

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We are inviting you to participate in a research study conducted by Dr. Lyn Turkstra. We are inviting you to be in the study because you experienced a moderate or severe traumatic brain injury (TBI) at least 6 months ago, you are in the age range of 18-65 years, and you are a fluent English speaker and a social media user.

This form explains the study, so you can decide if you want to participate. To make that decision, you should understand what is involved and the potential risks and benefits. Please take your time, and feel free to ask questions if you do not understand anything in this form or anything about the study. If you wish to participate, we will ask you to sign this form.

WHAT IS THE PURPOSE OF THIS STUDY?

We want to learn how people with TBI use social media, including any challenges and barriers. We want to know this, so we can design computer software that will help people with TBI use social media successfully.

WHY IS THIS RESEARCH BEING DONE?

Studies have shown that using social media like Facebook can help people feel included in social life. People with TBI use social media less often than people without TBI. If we know what prevents people with TBI from using social media, then we can develop software to make it easier to use. We hope that using social media would be a way for people with TBI to be more included in social life.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

- You will come to the Turkstra lab at McMaster University for ONE 1-hour session.
- In that session, you will log in to your social media account.
- You will use the website as you typically would for a one-hour period.
- You will describe your thoughts and actions as you use the website.
- A video camera will be set up over your shoulder to record:

- Your actions on the social media site (e.g. your mouse movements, the content that you type and the content that you view)
- Your upper body and head, to determine where you are looking on the screen
- Audio of the experimenter's instructions and prompts
- Audio of statements you make during the session
- We will be collecting data on:
 - Challenges and barriers to using social media

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

The risks involved in participating in this study are minimal, and are risks you would encounter in everyday life:

- You could experience mental fatigue or distress
 - Using social media may cause you to become mentally fatigued or distressed. However, the risks of mental fatigue and distress in this study are low and are similar to the risks that you would experience during regular social media use.
 - You will be encouraged to take breaks as needed, and we will remind you that you can stop the session at any time for any reason.
- You will be recorded by an audio-video camera
 - An audio-video camera will record the comments you type, the content you view, any verbal comments you make during the session, the experimenter's instructions and prompts, and your upper body and head movements while viewing the computer screen.
 - Any personal information you share or view about yourself, your Facebook friends, or any other member of the Facebook community during the 1-hour session will be recorded by an audio-video camera and viewed by the research team. As a member of the Facebook community, it is your right to share any information you view or create on Facebook with whomever you choose online and offline. This is stated in Facebook's privacy policy. Therefore, you will not get in trouble for sharing other people's personal information by participating in this study. However, we will protect the information you share with us, it will not be shared with anyone outside of the research team and the audio-video data will be destroyed once it is reviewed by the research team during analysis.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

We are inviting 10 people with TBI to be in the study.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

The research will not benefit you directly. We hope that what is learned as a result of this study will help us to better understand how people with TBI are using social media, as well as the barriers and challenges they experience while using social media. What we learn in this study will help us design software to improve social media access for people with TBI, which we hope will improve social participation.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time during the one-hour period, even after signing the consent form or part-way through the study.

WHAT INFORMATION WILL BE KEPT PRIVATE?

We will make every effort to protect your privacy and confidentiality. To protect your privacy, you will complete

the one-hour session in a private room at the Turkstra lab at McMaster University. To protect your confidentiality, you will be assigned a coded identification, we will not use your name or any information that would allow you to be identified, and we will not quote you directly.

Audio-video data, which may contain identifying information, will be protected through file encryption on a password protected computer. This consent form, with your signature, will be kept in a locked cabinet where only members of our study team will have access to it. Coded responses kept on a computer will be protected by a password. Once the study is complete, we will only keep coded data without identifying information, all audio-video data will be destroyed. Consent forms will be kept indefinitely, as a record of the study.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you volunteer to be in this study, you may withdraw at any time prior to completing the one-hour session. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

After you complete the study, you will be compensated with \$25 to cover parking at McMaster or alternate transportation if you took a taxi or used public transportation, and you will receive \$25 as a thank you for your time.

WILL THERE BE ANY COSTS?

Your participation in this research project will not involve any additional costs to you.

WHAT HAPPENS IF I HAVE A RESEARCH-RELATED INJURY?

If you are injured as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost. Financial compensation for such things as lost wages, disability or discomfort due to this type of injury is not routinely available. However, if you sign this consent form it does not mean that you waive any legal rights you may have under the law, nor does it mean that you are releasing the investigator(s), institution(s) and/or sponsor(s) from their legal and professional responsibilities.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have questions or need more information about the study itself, please contact Dr. Turkstra by email at turkstrl@mcmaster.ca or by phone at 905-525-9140 Extension 28648.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name

Signature

Date

Person obtaining consent:

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study

Signature

Date