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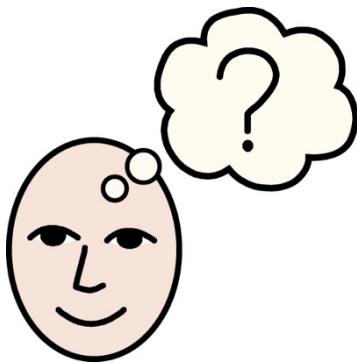
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Study Information Sheet: Acquired brain injury support and education through the use of social media and technology



Hello. Our names are

- Leanne Togher (speech pathologist)
- Emma Power (speech pathologist)
- Melissa Brunner (speech pathologist)
- Rachael Rietdijk (speech pathologist)
- Sarah Tran (speech pathologist)
- Melissa Miao (speech pathologist)
- Petra Avramovic (speech pathologist)
- Nick Rushworth (Brain Injury Australia)
- Renee Lim (Changineers)
- James Baker (Person with a brain injury)
- Stephen Cooper (Person with a brain injury)

We are doing a research study to find out more about whether participating in Facebook groups is helpful for people after a brain injury. We are also interested in finding out whether it works well for people with brain injury to moderate brain injury Facebook groups.

We are asking you to be in our study because you are a person with a brain injury.

You can decide if you want to take part in the study or not. You don't have to - it's up to you.

This sheet tells you what we will ask you to do if you decide to take part in the study. Please read it carefully so that you can make up your mind about whether you want to take part.

If you decide you want to be in the study and then you change your mind later, that's ok. All you need to do is tell us that you don't want to be in the study anymore. We can delete the information we have collected about you. It might not be possible for us to delete all of the posts and comments you make in the Facebook group.

If you have any questions, you can ask us or another person you trust. If you want to, you can call us any time on (02) 9351 9639.

What will happen if I say that I want to be in the study?

If you decide that you want to be in our study, we will ask you to do these things:

- For the first meeting, you will be asked to use your computer or tablet to **talk to a researcher using Zoom**. We can explain how to use Zoom if you have not used it before. You will be asked to answer some questions and do some assessments. The questions and assessments will be about your brain injury, your communication and how you use Facebook.
- Then you will be asked to do a **short online course**. This course is about using social media safely and is called 'social-ABI-lity'. You could do the course over several shorter lessons. You can do this course on your own, or together with a family member or carer.
- Then you can join a **private Facebook group** with 5-10 other people with a brain injury. There will also be 4 people called "moderators". Two moderators are people with brain injury, and two moderators are researchers. The moderators help the group run well. The moderators will post topics to discuss and questions to answer. The moderators will also delete any posts or comments which do not follow the group rules.
- You will be asked to **use the group actively for 8 weeks**. This means adding a post or comment to the group at least twice each week.
- If you don't add a post or a comment to the group for a week, a moderator will contact you. The moderator will **check if you need help** using the group and can provide you with support to join conversations in the group.
- We will also send you a short **email survey** about your social media use each week. We are sending a weekly survey as we know it can be hard to remember your feedback if we just ask you at the end. This survey is **optional**.
- At the end of the 8 weeks, you will again be asked to use your computer or tablet to **talk to a researcher using Zoom**. You will be asked to answer some questions. The questions will be about what you thought about the Facebook group.
- After another 6 weeks, you will again be asked to use your computer or tablet to **talk to a researcher using Zoom**. You will be asked to answer some questions. The questions will be about your communication and how you use Facebook. This will help us know whether doing the private Facebook group helps people over the long term.

When we ask you questions, you can choose which ones you want to answer. If you don't want to talk about something, that's ok. You can stop talking to us at any time if you don't want to talk to us anymore. If you say it's ok, we will record what you say with a voice

recorder. If we record you and you want it to be deleted later, we can do this as well. We will also make notes about how people use the Facebook group.

What information will you collect?

When we have the Zoom meetings, we will write down your answers to questions. For the follow-up Zoom meetings after the group, we will ask you about what you thought about the group and will audio-record your answers. We will save these recordings. We won't put your name on your answers or on your recordings.

We will also collect and save notes about how you use the Facebook group. These notes will be about your posts, your comments and how often you use the group. We won't save copies of photos you share with the group. We won't save your name or Facebook photo in our notes.

Will anyone else know what I say in the study?



We won't tell anyone else what you say to us, except if required by law. All the information about you from the study will be stored securely. We won't put your name on your information. A transcription service will help us to write down what you say in the voice recordings. This service will sign a confidentiality agreement. We will write a report about the study but this won't show your name.

You will need to use your Facebook account to access the group. This means that other people in the group will see the name and photo you use for your Facebook account. Facebook will also be able to access data about what you post in the Facebook group.

How long will the study take?



- Step 1:** Interview and assessments – Up to 2 hours
- Step 2:** Online course – Up to 2 hours
- Step 3:** Facebook group and weekly email surveys – Up to 6 hours total (0.5 hour/week for 12 weeks)
- Step 4:** Interview – Up to 1 hour
- Step 5:** Interview – Up to 1 hour
- TOTAL:** 12 hours

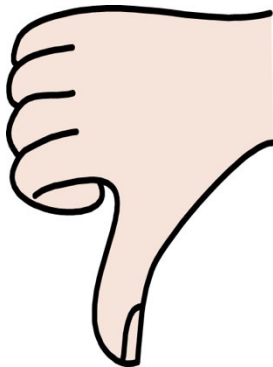
Are there any good things about being in the study?



We are doing this study to find out about how best to help people with brain injury. It may not directly help you.

We will give you Coles or Woolworths vouchers to say thank you for your time. You can choose which type you prefer. We will send you a \$100 voucher after you finish the first interview.

Are there any bad things about being in the study?



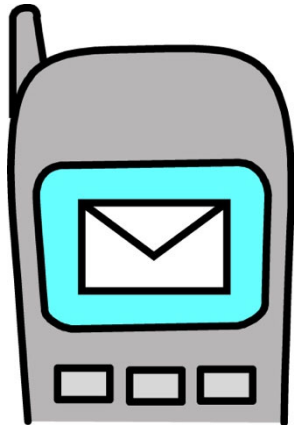
Sometimes problems can happen when you are using Facebook. Problems can include bullying or scams. If you have a problem online, you can contact the eSafety commissioner at www.esafety.gov.au. If you need advice on a possible scam, you can get help from Scamwatch at www.scamwatch.gov.au.

You might get upset, frustrated or tired when doing the interviews or course, or when using the Facebook group. We are happy to talk to you about any problems with the study. You can also contact Lifeline on 13 11 14. You can tell us contact details of your usual support person on the study consent form. We can let this person know if you need some help.

Will you tell me what you learnt in the study at the end?

Yes, we will email you with a report about what we learnt at the end of the study.

What if I am not happy with the study or the people doing the study?



If you are not happy with how we are doing the study or how we treat you, then you or someone who supports you can:

- **Call** the university on +61 2 8627 8176 or
- Write an **email** to human.ethics@sydney.edu.au

This sheet is for you to keep.

The pictures we used in this sheet are from Microsoft Clip Art and from the people at Inspired Services Publishing (www.inspiredservices.org.uk). They said it's ok for us to use them.