

Project Information Sheet



Research project:

The Experience of Peer Support Groups for Adults with a Brain Injury

Researchers:

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Lead researcher

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Part A Why are we doing this research and what will happen?

1 Introduction

This **Project Information Sheet** tells you about this research project so you can decide if you want to take part.

You might want to talk to a relative, friend, or support worker, about whether you would like to participate in this project.



For more information or to ask any questions, please get in touch with Lauren, Marlena, or Rachel.

2 What is this research about?

This project is to help people understand the role of peer support groups in the lives of adults with acquired brain injury. We also want to learn about what makes a peer support group a success. We hope to share these findings with organisations who might run peer support groups, people who might be wondering whether they'd like to attend a peer support group, health care professionals and other people who might be involved in peer support groups.

3 What will I be asked to do if I participate?

Participating will involve doing an **interview** with either Rachel, Lauren or Marlena, to share your thoughts about peer support groups held by Brain Injury Matters.

First, you let us know if you are interested in participating in this research. You can do that by emailing or calling Lauren, or through the online form at https://melbourneuni.au1.qualtrics.com/jfe/form/SV_dohMUjXzw68Xvqm



Then, we will call or email you to arrange a time for the interview. When we do that, we will also ask if you mind answering a few questions about yourself. For example, we will ask about your age, gender, and some questions about your brain injury. We ask these so we can describe the group of people who participate, but we will not describe individual people. You do not have to answer any questions you don't want to. This conversation will take about 10 minutes. If you would prefer, you can fill this out using an online form instead.

What will happen in the interview?



In the interview, we will ask questions about your experiences in relation to BIM's peer support groups.

- The questions will be about how you use peer support group(s), any changes you experience since joining a peer support group(s), what you think about the way the support group runs, and if there are any challenges in attending support groups.

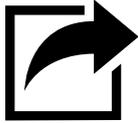
Please feel free to tell us if there are ways of communicating that might be useful for us to know for this conversation.



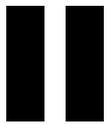
Your **support worker** or a **family member** can be with you if you would like.



We will ask your permission to record the interview.



You can **skip** any questions you don't want to answer.



We can **pause** to take **breaks** at any point.

We can even continue the interview on another day if you want.



You can **stop** the interview at any time you want.

How long will the interview take?



We think the conversation will take around **1 hour**.

It will depend on how much you would like to share and whether you would like to take breaks.

If you haven't attended a peer group, we expect the interview will be shorter.

When & where will it be?



We will do our best to find a day and time that works for you.

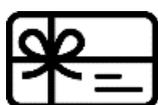


We will do the interviews **online** via **video conference**, or –



If you prefer, we may be able to find a place to do the interview in person. This could be at the Neighbourhood House where your group meets.

Other information



You will be given a \$50 gift card to thank you for your time.

If your support worker attends, the gift card will include \$30/hr to help with offsetting the cost of their services.

4 Do I have to agree to do an interview?

No. You do not have to be involved in this project.



If you decide to take part and then change your mind, you can withdraw from the project.

Nobody will think badly about you if you do not want to be involved. It will not affect your relationship with Brain Injury Matters if you do not want to participate or choose to stop an interview. Brain Injury Matters will not know who has or has not participated.

If you do an interview and then decide you do not want your information to be used, you can contact Lauren by email or phone up to **2 weeks** after your interview. You do not need to tell Lauren why, and she will not ask.

5 Will I get to know what you find out from this research?

We will be interviewing around 15-18 people. We hope to interview three people from each of the peer support groups. Once we have completed all the interviews, and thought carefully about what everyone has told us, we will summarise the findings into themes. This may take us several months to do.

At the end of the interview, we will ask if you would like to see a draft summary of the findings to tell us what you think about the themes that we develop. Once the draft is ready, we will send it to you by email. You will have **2 weeks** to let us know any thoughts or ideas you had when reading the findings.

We will also ask if you would like to be sent a brief summary of the findings at the very end of the project.

Part B How the research is being done

This section explains some other aspects of how this research will be carried out, including how the researchers will use what you share with them during the project.

6 What will we do with the information we collect?

The interviews will be audio recorded and then typed out by a professional service. Everything we collect will be kept on computers that only the researchers at University of Melbourne can access. We will have a privacy agreement in place with the service we use to type out each interview.



All the information you give us, and what you say in the interview will be kept confidential, meaning the details will be kept private.



You can ask us if you would like to see our record of the information you give us.



The findings of the research will be written into a report and may be published in a journal or talked about in a presentation.



Brain Injury Matters asked us to do this research. However, the researchers are independent of BIM. Only the researchers at the University of Melbourne (Lauren, Marlana and Rachel) will know who participated. BIM do not have access to any identifiable information collected in this study.



Five years after the last research publication all information recordings and written records will be disposed of in a confidential manner.

7 Are there benefits if I take part?

You may not directly benefit from this research. Some people like sharing their thoughts and experiences.

The findings might help Brain Injury Matters think about how they run the peer support program. They may also help other organisations who provide peer support.

8 Are there risks if I take part?

We think there are few risks and we have tried to keep the chance of these happening low. If you think of any others, please tell either Lauren, Marlana, or Rachel. Here is what we have thought of:



You may get tired during the interview. We can take breaks, or finish the interview on a different day, or stop the interview.

We'll check-in with you during the interview, please let us know if you feel tired.



There is a small chance you may become sad or uncomfortable talking about your experiences. If you let us know, we will support you if this happens. You don't have to talk about anything you do not want to.

Before participating you might want to think about if there is anyone you may like to talk to if you feel upset after the interview, like family or a friend. If you feel upset, you could also contact your GP to be put in touch with someone who can help, or Beyond Blue (available 24 hours a day) on 1300 224 636 or at <https://www.beyondblue.org.au/>



When we talk and write about the project so others can know what we find, it helps if we quote parts from what participants said. We will be careful not to include information that seems unique to you without asking you. That way it is less likely someone else will know if you were the person who said what we have quoted unless you are okay with that. However, it is still possible that someone who knows you well might be able to tell. If you are concerned about this, please let Lauren know.

9 Who is organising and funding this research?

This research project is being led by Dr Lauren Kosta, from the Department of Social Work at the University of Melbourne.

The research is being funded by the Melbourne Disability Institute.

Brain Injury Matters asked us (The University of Melbourne) to do this research and has helped us design the project. If you would like to confirm this, or ask about BIM's involvement, you can contact Peter Persson (BIM project manager) by phone 0478 505 913 or by email at peter.persson@braininjurymatters.org

Contact details



You can talk to us (the researchers) if you have any questions.



Dr Lauren Kosta



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Dr Marlana Klaic



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Rachel Blance-Palmer



rachel.blancepalmer@unimelb.edu.au

If you want to make a **complaint** about this research, you can talk to the Ethics Committee at the University of Melbourne.



You can ring the Ethics Committee on **03 8344 2073**



Or you can email the Ethics Committee at

HumanEthics-complaints@unimelb.edu.au

The Project ID number is: 26052