

# **Participant Information Letter**

**Project title:** Supporting PTSD: Experiences of People in a Primary Support Role **Approval Number:** 2020-01263-LILLICO **Chief Investigator:** Craig Lillico **Supervisor:** Dr Bronwyn Harman

## An invitation to participate in research

You are invited to participate in a project titled Supporting PTSD: Experiences of People in a Primary Support Role, which seeks to understand the experiences of people supporting a friend diagnosed with posttraumatic stress disorder (PTSD). You are being asked to take part in this project because you provide support to a friend diagnosed with PTSD. This research project is being undertaken as part of the requirements of the chief investigator's Psychology Honours course at Edith Cowan University. A \$20 Coles Myer gift card will be posted to you on completion of the research (October 2020) in appreciation for your time and input.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or friend. It is recommended that you discuss your participation in this study with your close friend diagnosed with PTSD to ascertain any of their concerns.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read,
- Consent to take part in the research project,
- Consent to be involved in the research described, and
- Consent to the use of your personal information as described.

## What is this project about?

This project aims to understand the experiences of people supporting a friend diagnosed with PTSD. Previous research suggests there is a multi-directional influence on both the person diagnosed with PTSD and the person/s supporting them. This research will provide further insight into this understudied area of PTSD. The outcome may potentially provide benefits both to people diagnosed with PTSD and those supporting them.

## What does my participation involve?

Your participation in this research project will involve participating an interview via telephone or online (e.g., Zoom, Skype) with the chief investigator. The interview will be a semistructured interview whereby questions will be asked to address the overall purpose of the research. The purpose of the interview is to gain a deep appreciation of your experiences in the role of a primary support person for a close friend diagnosed with PTSD. The interview will be audiotaped and should take approximately 60-90 minutes. During the interview, you are asked not to disclose names or any confidential information. It is also requested you allow for a post-research debrief approximately one week following the interview, by phone with the chief investigator. Once all participants have been interviewed and analyses conducted, you will be given a summary to read with the opportunity to comment on whether your experiences are reflected in the analysis.

## Do I have to take part in this research project?

Your participation in this research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any time without reason, until September 25<sup>th</sup> 2020. This date is set to allow time for the preparation of a thesis as part of the chief investigators Psychology Honours course.

If you do decide to take part, you will be given this Participant Information Letter and Consent form to sign and you will be given a copy of the information letter to keep. Your decision to take part, or to take part and later withdraw, will not affect your relationship with the research team.

## Your privacy

By signing the consent form, you consent to the research team collecting and using personal information about you or information about your health for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Any information linking you to the research will only be known by me as chief investigator and will be secured in a password protected computer. Short quotations from participants' interviews will be used as part of reports or articles. However, a pseudonym will be allocated to your data and any information identifying you will not be included in any research reports or articles produced from this research. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. Non-identifiable data will be made available for future use in similar research.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except where requested for specific reasons, and then you will be asked to provide written consent.

In accordance with relevant Australian and/or Western Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this letter if you would like to access your information. All data collected will be kept in a deidentified format and securely stored for a minimum period of 7 years on a password protected computer at Edith Cowan University.

# **Possible Benefits**

We cannot guarantee or promise that you will receive any benefits from this research. However, benefits from this study may include greater understanding and knowledge surrounding support networks for people with PTSD. This may lead to future benefits both to people diagnosed with PTSD and people such as yourself supporting them.

# Possible Risks and Risk Management Plan

Your decision to participate, or not, in this research will not affect the mental health services of your friend diagnosed with PTSD in any way. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. For information relating to the University's research participant insurance coverage, please go to: <a href="https://intranet.ecu.edu.au/staff/centres/strategic-and-governance-services/our-services/risk-and-assurance/insurance/practicum-work-experience-or-volunteer-activities">https://intranet.ecu.edu.au/staff/centres/strategic-and-governance-services/our-services/risk-and-assurance/insurance/practicum-work-experience-or-volunteer-activities</a>

Psychological Risk: There is a low psychological risk from participating in this study. However, the questions are limited to your experience in your supportive role. You are also free to answer some questions and not others and discuss only what you feel comfortable discussing.

Social Risk: There is a low social risk from participating in this study. You are encouraged to discuss your participation in this study, and any concerns about participating, with the friend you support, and to consider your friendship with him or her throughout the study should you decide to participate. The interview questions are limited to your experience in your support role and are not specifically related to the type or quality of your friendship. You may answer some questions and not others. Additionally, you are encouraged only to discuss experiences that you feel will not jeopardise your friendship.

These risks will be discussed prior to the start of the interview and again at a post-research debrief by phone with the chief investigator to assist in managing any concerns or issues resulting from participating in this study.

## What happens when this research study stops?

We will advise you of the outcomes via email to give you the opportunity to respond to whether your experiences are reflected in the research. We also intend to publish our results in research journals and/or present them at research conferences locally, nationally and internationally. Your name or any other identifying information will not be included in any of the publications or presentations.

## Has this research been approved?

This research project has received the approval of Edith Cowan University's Human Research Ethics Committee, in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)*. The approval number is **2020-01263-LILLICO**.

## Contacts

If you would like to discuss any aspect of this project, please contact the following people.

## **Chief Investigator**

Craig Lillico Edith Cowan University P: 0420 841 549 E: clillico@our.ecu.edu.au

#### **Student Supervisor**

Dr Bronwyn Harman Edith Cowan University P: 6304 5021 E: b.harman@ecu.edu.au

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

#### Independent Person Research Ethics Support Officer

Edith Cowan University P: 6304 2170 E: research.ethics@ecu.edu.au

If you wish to participate in this research, please contact the chief investigator via email (<u>clillico@our.ecu.edu.au</u>)

Sincerely,

Craig Lillico Chief Investigator