PARTICIPANT INFORMATION and consent form

**The University of Melbourne/Orygen, the National Centre of Excellence in Youth Mental Health**

Participant Information and Consent Form for family members: South Perth

**Study component 2**

Version: 2

Dated: September 2018

Site: headspace (Rockingham, Fremantle, Armadale, Mandurah), YouthReach South, Cockburn Youth Centre, Ruah Centre, Youth Focus Inc, Helping Minds, Bentley Adolescent Unit, Youth Advisory Council of WA, Office of the Commissioner for Children and Young People, 4families - Relationships Australia; Other

**Full Project Title:** Adaption of “*Coping with self-harm: A Guide for Parents and Families*” for the Australian context

**Principal Researcher:** Dr Jo Robinson

**Associate Researcher(s):** Sarah Hetrick, Alison McRoberts, Simon Rice, Pinar Thorn, Yasmine Hooper, Han Duong, Anne Ferrey, Michelle Lamblin, Yael Perry, Ashleigh Lin, Nina Stefanac, Sadhbh Byrne

This Participant Information and Consent Form is 6 pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information sheet contains detailed information about this research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it. Please read this information carefully and feel free to ask questions about any information in the document.

Once you understand what the project is about, and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

Unfortunately mental health problems are common in young Australians. One in four young people have experienced a mental health issue in the past 12 months – a higher prevalence than all other age groups. Although difficult to track, the rates of mental health problems and self-harm in young people are increasing in both community and clinical settings. Despite self-harming behaviours appearing to decline as adolescent year’s progress, there are a number of worrying negative effects of the behaviour for the young person themselves, as well as their family members/support person.

In 2016, Researchers at the University of Oxford in the UK developed a resource for parents and family members of young people who self-harm. Our study will aim to review and adapt this existing resource so that it is suitable for use in an Australian, youth mental health setting. The existing resource takes the form of a 12-page brochure aimed at parents and family members who have discovered a young person’s self-harm. The booklet provides information for parents and families about self-harm and its causes and effects. It is based on current research on self-harm and on interviews with parents whose children self-harmed. It contains quotes from them with advice for other parents as well as evidence-based information and links to sources of help.

You are invited to take part in this project because you have identified that you are a family member or support person who has supported a young person engaging in self-harm and you or the person that you support has had involvement with one of the services listed above. We are interested in talking to you about your experiences, and to know what you think about the existing resource, and how it could be improved. Your feedback will help guide the development of an adapted resource for the Australian mental health setting.

3. Procedures

If you agree to take part you will be asked to participate in either one small focus group with at least one member of the research team, or, if you prefer, an individual interview. The focus group will consist of approximately six to 12 people, and will occur between in 2018. The interview will involve a one-on-one discussion with one researcher. It is anticipated that both the focus group and interview will take approximately 45-60 minutes, which will allow time for introductions, discussions, feedback, and refreshments. You will be asked a short number of semi-structured questions such as “What skills are necessary in terms of providing support, for family members/support people of young people who engage in self-harm?” You will not be asked about your personal experiences. Focus groups and interviews will be audio-recorded.

4. Possible Benefits

A key advantage of taking part in this research component will be your ability to provide valuable feedback that will influence the development of an adapted resource aimed at supporting family members/support people of young people who engage in self-harm. However, we cannot guarantee any benefits from taking part. What we do hope is that the information we collect will allow us to implement a helpful and useful resource across Australian youth mental health settings, which in turn is expected to improve the mental health of more young people in the future.

5. Possible Risks

There are no physical risks associated with being in this study; however there may be unforeseen or unknown risks. You will be given the option to complete a Wellness Plan which includes an emergency contact, topics you might find distressing, signs of distress, and things that help you when distressed. If you feel upset while participating in focus groups, please let one of the research team members present know and if necessary they can arrange additional support for you from your doctor or a local support service. The researchers have run similar focus groups in the past, and no negative effects have been reported, however you can withdraw from being in the study at any time. You can also ask for your project records to be destroyed or erased.

6. Alternatives to Participation

You do not have to participate and it is important for you to know that if you decide not to participate this will **not** affect in any way your family’s involvement with services. If you decide to take part you can change your mind and withdraw from the project at any time.

7. Privacy, Confidentiality and Disclosure of Information

Any identifying information we collect about you will remain confidential. It will only be disclosed with your permission, or as required by law and for safety concerns. If this does occur you will be consulted. All information you provide, including audio recordings of interviews, will be stored securely on password-protected computers and only the research team will have access to it.

We plan to present the findings from this project in a report, as well as written articles in scientific journals or presentations at scientific conferences. There will be no way of identifying any individual in the project. The information provided by you will be kept securely for fifteen years and then will be destroyed.

*How you can access the information:*

The only information we will have about you is what you tell us. Should you want to see this information you can ask the research staff and it will be made available to you.

8. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

9. Results of Project

Results from the study will be available in a final study report, and also via the journals in which they are published, copies of which will be made available to you on request.

If you have any questions at any time during the study please feel free to contact the principal researcher on the phone numbers or e-mail below. You can ask the researcher doing the assessment any questions which you may have. If you would like more information about the study, or if you have some concerns about it, either now, or in the future, do not hesitate to contact one of the researchers involved.

10. Further Information or Any Problems

If you require further information or if you have any problems concerning this project you can contact the principal researcher or any of the research team. The researcher responsible for this project is **Dr Jo Robinson – 03 9342 2866 or jo.robinson@orygen.org.au.**

11. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Position: Executive Officer, Human Research Ethics, The University of Melbourne

Telephone: (03) 8344 2073

You will need to tell the officer the name ofone of the researchers given in section 10 above.

12. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. You may also wish to discuss this project with a friend or family member. If so, you should feel free to do this. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

13. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the University of Melbourne Human Research Ethics Committee. The project is being funded by the North West Melbourne PHN.

CONSENT FORM
(Attach to Participant Information)

The University of Melbourne/Orygen

Consent Form Version: 2

Dated: September 2018
Site: Orygen

**Full Project Title:** Adaption of “*Coping with self-harm: A Guide for Parents and Families*” for the Australian context

**Principal Researcher:** Dr Jo Robinson

**Associate Researcher(s):** Sarah Hetrick, Alison McRoberts, Simon Rice, Pinar Thorn, Yasmine Hooper, Han Duong, Anne Ferrey, Michelle Lamblin, Yael Perry, Ashleigh Lin, Nina Stefanac, Sadhbh Byrne

I have read and I understand the Participant Information version 2 dated September 2018.

I freely agree to participate in this project according to the conditions in the Participant Information statement.

I understand that my involvement in the project is for research purposes, is voluntary and that I am free to withdraw at any time, and free to withdraw any unprocessed identifiable data previously supplied.

I understand that any identifying information collected about me will remain confidential and will only be disclosed with my permission, or as required by law and for safety concerns.

I will be given a copy of the Participant Information and Consent Form to keep.

Participant’s Name (printed) ………………………………………….

Signature Date

If you would like to be emailed the findings from this project, please supply your email address below.

Email: ……………………………………………………

Researcher’s Name (printed) ……………………………………………………

Signature Date

*Note:* All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM

*(To be used for participants who wish to withdraw from the project.)*

(Attach to Participant Information)

The University of Melbourne/Orygen

Revocation of Consent Form

**Full Project Title:** Adaption of “*Coping with self-harm: A Guide for Parents and Families*” for the Australian context

**Principal Researcher:** Dr Jo Robinson

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I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with ORYGEN.

Participant’s Name (printed) …………………………………………………….

Signature Date