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Participant Information Letter – Person with Lived Experience

Project title: Family involvement in inpatient mental health care: perspectives of the person with lived experience, the family and the nurses

Approval Number: 2022-03280

Principal Investigator: Karen Foster supervised by Dr Linda Coventry

An invitation to participate in research:

You are invited to participate in a project titled “Family Involvement in Inpatient Mental Health Care: Perspectives of the Person with Lived Experience, the Family and the Nurses” which seeks to explore the experiences of and collaboration between people with lived experience of mental illness, their families and nurses to detect changes in mental state during an admission. You are being asked to take part in this project because you have had a recent admission to an acute mental health setting in support of your mental health.

This research project is being undertaken as part of the requirements of a Doctor of Philosophy degree at Edith Cowan University.

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.

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;
- Consent to the use of your personal information as described. You will provide this voluntarily and it may include demographic information such as your age, who or what supports you to maintain your health.

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Appendix E: Participant Information Letter – Lived Experience

This will be reviewed each time that you have contact with the researcher.

To thank you for your willingness and commitment to participate in this study, you will be provided with a \$50 voucher.

What is this project about?

This project aims to examine how people with lived experience, their family members, and mental health nurses work together during an inpatient admission to detect changes in mental state (either deterioration or improvements) to provide more individualised care.

What does my participation involve?

Participation will involve a brief initial phone discussion with the researcher, to determine if you are eligible to participate, and your attendance at two meetings. The first meeting with the researcher will last for approximately 30 minutes, then a second meeting with the researcher of approximately one hour duration. The researcher will contact you by phone between the two meetings (approximately 1-2 weeks after the first meeting) to check on your welfare and progress. At the first meeting, you will be provided with art materials and be asked to use these materials, or others you have at home, to help describe your experiences of working together with your family members and nursing staff to support you during your mental health admission during the times when your mental health deteriorated and/or improved. Please also describe in words or pictures, the discharge planning process and how you felt on returning to live in the community when your mental health improved. You will be invited to bring any drawings, photographs or music that you have used to represent your experiences with you to the second meeting to discuss these with the researcher. If the meetings are online or by phone you can arrange to either collect the art materials from the researcher or they can be posted to you. You can either email a copy of any art you produce to the researcher or post it via a postage paid envelope which will be provided.

All meetings will be audiotaped to enable analysis and reporting of the results. Any art that you create will be photographed to assist with the reporting of this research.

All meetings with the researcher will be one to one and conducted in a private location. These meetings can be in person in a mutually convenient location, by telephone or online if you prefer.

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 up until data analysis commences.

If you do decide to take part, you will be given (either by hand or email) this Participant Information Letter and consent form to sign and you will be given a copy of the information letter to keep. If all meetings are online or by phone, consent will be recorded verbally. Your decision to take part, or to take part and later withdraw, will not affect your relationship with the research team and your hospital or treating 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 experiences and health for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Only the research team will have access to your personal information, which will be stored securely and nobody else will have access. Before publication of results, all identifying information will be removed and you will be asked to choose a pseudonym which will be used for publication of results. 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.

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 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 accordance with ECU's Data Management Policy. Electronic data will be stored on a secure Microsoft SharePoint site provisioned by ECU's IT Services. All records will be stored as required in ECU's Records Management Policy. The data will be retained for 7 years and destroyed, if appropriate at the end of the retention period. Data will be de-identified when stored and at the end of the retention period, the data will be destroyed, if appropriate under the State Records Act.

Possible Benefits

This research may not provide benefit to you personally but may provide benefits for people with mental illness and their families in the future. The results will assist nursing staff to provide more individualised and timely nursing care.

Possible Risks and Risk Management Plan

It is possible that some distress may result from participating in this research. It is possible that people known to you (family and nurses) will also participate, to talk about their own experiences. The research has a protocol where you would be provided with immediate support and an offer of ongoing support where needed.

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 worried as a result of your participation in the research project please seek the advice of your GP or relevant health professional. You may also wish to contact an organisation listed on the support contact list provided during the study.

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What happens when this research study stops?

If you wish you will be provided with a summary of the results. This can be emailed to you if you provide your email address, or posted to an address that you provide. We also intend to publish our results in research journals and 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 approval number 2022-03280, in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*.

Contacts

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

Chief Investigator

Name: Karen Foster
Role: HDR Student
Edith Cowan University
P: 0458 230 924
E: kpfo1@our.ecu.edu.au

Supervisor

Name: Dr Linda Coventry
Role: Supervisor
Edith Cowan University
P: (08) 6304 3459
E: l.coventry@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 sign the Consent Form and return to kpfo1@our.ecu.edu.au or hand them to Karen Foster

Sincerely,

Name
Karen Foster
Chief Investigator