

## Participant Information Sheet

**Project title: Older people with chronic mental illness and their carers: do the current models of care support their needs?**

### Researcher:

Sharon Leigh-Hazell, PhD student, National Institute for Mental Health Research (NIMHR)

## General Outline of the Project

### Project Description

The purpose of this PhD research study is to explore what services and supports meet both the mental and physical health needs of older people with chronic mental illness who are 60 years and over (older consumers). The study is also investigating what family, friends and other people who care or advocate for an older consumer (support person) need to feel supported in their caring role. Please refer to Attachment A for definitions of terms used in this study.

### Participants

I am conducting confidential interviews with about 30 older consumers and support people to find out their needs and which services and support they think work and what doesn't work.

## Participant involvement

### Voluntary participation and withdrawal

Participation is voluntary. Before I start the interview, you will be asked to sign a consent form. At any time you can choose to withdraw your consent for participating in the study. If you withdraw from the study after commencing an interview, any data collected from your interview will be destroyed and not be used in any publications unless you explicitly give permission for your data to be retained and used.

### What will participants have to do?

During the interview participants will be asked to answer some questions. The questions you will be asked will be mainly about your experience with the services and support that as an older consumer you use, have used or would like to use. Or as a support person your experiences with services in the past, present and future. Attachment B provides the types of questions that will be asked.

Older consumers may wish to have a support person with them during the interview. I am also conducting some discussions with older consumers and a support person nominated by them who together would like to share their journeys. Let me know if you are interested and I can discuss that with you.

### Location and duration of interviews

I will come to you at a place and time that is convenient for you. An interview may take around an hour but it can be as long or as short as you want. You can pass on a question, take a break or stop the interview at any time. If you would like to continue the interview another day, that can be arranged.

## Risks

Most people find participating in research studies like this a positive experience. However, talking about your mental illness or caring for someone with a mental illness can be upsetting. If this is the case we recommend that you stop the interview if you wish and contact one of the mental health services listed below (under useful support services) or your own health professional (eg your GP, psychologist, psychiatrist).

## Confidentiality

Confidentiality will be protected as far as possible. Individuals will be assigned a code or pseudonym unless you sign consent to be identified. The only persons with access to the audio records will be the project team and project staff employed by NIMHR to transcribe the recordings. Findings will not include names and all care will be taken but please be aware that some comments may be quoted in publications so there is a risk that a person can be identified by what you say.

## Data storage

Names will be stored separately from audio records of the interview and transcripts and kept under strict security. All identifying data will be destroyed after a period of five years after publication. Other genuine researchers may request access to this de-identified data in the future. Access will only be granted if they agree to preserve the confidentiality of the information as detailed in this information sheet. Their access will also require approval from the original research team.

## Use of data and feedback

I will be taking notes and also recording the interview so that I can be certain that I don't miss anything important that you say. The notes and recordings will be transcribed without names or other identifying information so that data can be analysed. The results will be published as part of a PhD thesis, in academic publications and academic and community conference presentations. You will be provided with a summary of the results which will be published in the ACACIA Insight newsletter (ACACIA is the ACT Consumer and Carer Mental Health Research Unit at NIMHR). Results will also be published through other organisations including ACT Mental Health Consumer Network, Carers ACT, Health Care Consumers Association and Mental Health Community Coalition ACT.

## Ethics committee clearance

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee. If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager

The ANU Human Research Ethics Committee

The Australian National University

Telephone: +61 2 6125 3427

Email: [Human.Ethics.Officer@anu.edu.au](mailto:Human.Ethics.Officer@anu.edu.au)

## Queries and concerns

More information?

If you have any questions about any aspect of this study, please contact Sharon Leigh-Hazell (02 6125 1624) or my supervisor Dr Michelle Banfield (02 6125 6547). Our contact details appear below. Information about the research study, including this information sheet is available from the project's website at

<http://nimhr.anu.edu.au/research/projects/older-people-and-chronic-mental-illness>

Useful support services

- Lifeline Australia: 13 11 14 (24 hours)
- Kids Helpline (for people aged 25 and under): 1800 55 1800 (24 Hours)
- Suicide Call-Back Service: 1300 659 467 (24 hours)
- ACT Health or 1800 629 354 (crisis team)
- Carers ACT and Carers NSW: 1800 24 26 36
- Beyondblue: 1300 22 4636 (24 hours)
- SANE: 1800 187 263 (9am to 5 pm)

Thank you for your interest in this project

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## Definitions

An “older consumer” is a person who is 60 years of age or older with a chronic mental illness.

A “support person” is defined as a family member, friend or salaried person who cares or advocates for an older person with a chronic mental illness. In the case of a salaried person, this is someone who receives a salary for their services and is nominated by the older consumer as their primary caregiver.

A “chronic mental illness” is a mental health condition (including affective disorders like depression, anxiety disorders and bipolar disorder and other mental illnesses like schizophrenia) that a person considers that they had for at least five years. Alzheimer’s Disease or other conditions causing cognitive impairment are not included in this definition. However an older person with a chronic mental illness who also has a diagnosis of Alzheimer’s Disease or similar are eligible to participate in this study.

A “model of care” can take many forms. For the purpose of this study it will describe the way policies, health services and other supports are delivered to the older consumer and support person. In doing so it will consider multiple “models of care”.

## Example interview questions

### Example questions for older consumers:

- Basic demographic questions like How old are you? What is your marital status? What is your highest level of education? How long have you lived at your current address? Who do you live with?
- What impact has your mental illness had on you and your family?
- What strategies do you have to calm you if you feel a mental health episode is starting?
- Do you think that having a mental illness has affected your physical health in any way – or perhaps your physical health has impacted on your mental health?
- Could you tell me about what supports or services you have to help you?
- Of the health services you have used which do you think supported you the most? Why?
- Do you feel there are any other services or support that you need but can't access or you don't think they exist?
- If you have a support person how do they help you?
- If you have had a hospital admission could you tell me the best care you have had in hospital? Could you tell me about the discharge process?
- Could you tell me about a time that you think your care in hospital could have been better? Could you tell me about the discharge process?
- What services and support do you think you need in the future?

### Example questions for support persons:

- Basic demographic questions like how old are you? What is your marital status? What is your highest level of education? I'll be also asking basic questions about the older consumer they are supporting like their age, how long they have had a mental illness and their physical health needs.
- Do you live with the person you are supporting? What is your relationship to the person? What is your role?
- How has being a support person impacted on your life?
- Do you think the services and support work well for the person you support?
- What services and support do you access to assist you in your caring role? Do you think they work well for you?
- Was there a time you supported the older person when they were in hospital? Could you tell me about it? What works well? What doesn't work well? How was the discharge process?
- Can you describe how being a support person has impacted on your own physical and mental health?
- What services and support do you think the person that you care for will need in the future? What do you think you will need in the future?