PARTICIPANT INFORMATION SHEET - FOCUS GROUPS

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1. Study Title: Understanding Experiences of Personality Disorders in Australia

2. Investigators: Dr Michelle Blanchard and Elise Carrotte, SANE Australia

3. Introduction:

You have been invited to participate in a research study which has been funded by the National Mental Health Commission. This is because you have experienced a personality disorder, or you identify as a carer for somebody living with a personality disorder.

This Participant Information Sheet tells you about the research project. It explains the purpose of the research, and the procedures and risks involved. It also describes information about you that will be collected, how that information will be used and with whom it will be shared. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully.

Please ask questions about anything that you don't 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, friend or discuss it with a health professional such as your regular psychologist or counsellor. Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to read the Participation Information Sheet. If you post in the discussion, it is assumed that you consent to participate. It is recommended that you download and keep a copy of this Participant Information Sheet.

4. Purpose of the Study:

This qualitative study aims to understand the complex experiences of Australians living with personality disorders, and their loved ones, with regards to prevention, treatment, recovery and relapse prevention.

5. Study Procedures:

In order to participate in this study, you must be:

- Aged 18 years or older
- Either:
 - a) have experienced a personality disorder, and have accessed treatment or support services in Australia for reasons relating to the personality disorder, or
 - b) identify as a carer for someone with a personality disorder, and this person you care for has accessed treatment or support services in Australia
- Able to write in and understand English

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If you wish to participate, you will be asked to participate in a two-hour focus group discussion on the SANE Australia forums. This discussion will cover a range of topics such as:

- Types of treatment support you (or your loved one) have accessed
- Your experiences with these services, focusing on what you found helpful
- What changes you would like to see regarding personality disorder treatment in Australia

6. Risks and Discomforts

It is possible that some topics discussed may be unpleasant or upsetting. You do not have to provide any information that you do not wish to and you may leave the discussion or take a break at anytime. You may wish to contact a trusted health professional, or other support services after the discussion, such as:

Telephone Counseling and Advice

Lifeline 13 11 14 SANE Australia 1800 18 7263

Information and Fact Sheets

Project Air Fact Sheets https://projectairstrategy.org/mpafactsheets

SANE Australia Family/Carer Information
SANE Australia Facts and Guides

https://www.sane.org/families-carers
https://www.sane.org/mental-health-and-

illness/facts-and-guides

Treatment

Spectrum - Personality Disorder Service for Victoria www.spectrumbpd.com.au https://headspace.org.au/

7. Possible Benefits

By participating in this study, you will be helping us understand what are the current benefits and challenges of personality disorder treatment in the Australian context. Your experiences and opinions are very valuable.

8. Voluntary Participation/Right to Refuse or Withdraw

There is no obligation for you to be involved in this study. Participation is voluntary and will not affect your relationship with forum moderators. You may withdraw from the study at any time. If you decide after the discussion that you do not want information you provided to be included in the study, please contact the Associate Investigator via email within a week of the discussion. Please provide your username and any comments you wish to be removed.

9. Confidentiality

During the discussion, please do not provide any information which would enable other participants to identify you, and respect the confidentiality of other participants. Any identifying information provided will be removed by moderators.

Your information relating to this study will be kept strictly confidential. Your username and identity will not be revealed and your confidentiality will be protected in any reviews and reports of this study, which may be published.

If you disclose anything during the focus group that indicates that you, or someone you know, has been harmed or is at risk of being harmed, the investigators may be required to contact relevant services (such as police) to prevent harm from occurring.

10. Results of Project

Results from this project will be included in a discussion paper and may be published in a peerreviewed journal. You can request a summary of the study results by emailing the Associate Investigator.

11. Consent

By participating in the focus group discussion, it is assumed that you consent to participate in the study and are willing for your anonymous responses to be included in the analysis. This may involve direct quotes or paraphrasing.

Your interviewer is required to provide you with all information regarding the nature and purpose of the research study and risks/benefits, and you should be given the opportunity to discuss these. It must be stated that you are free to withdraw anytime and that if you do not participate you will not suffer any prejudice.

12. Advice and Information

If you have any further questions regarding this study, please do not hesitate to contact Associate Investigator Elise Carrotte on 03 9190 0609 or via elise.carrotte@sane.org, or Principal Investigator Dr Michelle Blanchard on 0403 171 989 or via michelle.blanchard@sane.org.

The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2007) — incorporating all updates. This Statement has been developed to protect the interests of people who agree to participate in human research studies. Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Operations Manager, Bellberry Limited on 08 8361 3222.