

## Plain Language Statement

PROJECT TITLE: **Our Turn to Speak: Living with mental health issues in Australia**

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### Introduction

With your help, the **Our Turn to Speak** survey will help us understand the life experiences of people living with severe and complex mental health issues.

The study will investigate your perception of if and how your mental health issues impact the way you are treated in life.

It is hoped the results of the survey will assist advocacy efforts for people affected by complex mental health issues in Australia.

### Who are we asking to participate in this study?

Any adult (18+) residing in Australia who has been living with the following severe and complex mental health issues in the last 12 months:

- Schizophrenia spectrum disorders (such as schizophrenia, schizoaffective disorder or schizopreniform disorder)
- Bipolar and related disorders
- Personality disorders (such as, but not limited to, borderline personality disorder)
- Obsessive-compulsive and related disorders (such as OCD, body-dysmorphic disorder, excoriation disorder, trichotillomania or hoarding disorder)
- Post-traumatic stress disorder
- Dissociative disorders
- Eating disorders (such as anorexia nervosa, bulimia nervosa, avoidant/restrictive food intake disorder, and binge-eating disorder)
- Severe and treatment-resistant depression and anxiety requiring multi-agency support.

We are inviting both people who have received a formal diagnosis, as well as those who have not been diagnosed formally but believe they may be experiencing one of these mental health issues, to participate.

We do not seek to recruit participants who experience **mild–moderate anxiety** or **mild–moderate depression** unless they have also been affected by one or more of the mental health issues listed above.

We also do not seek to recruit participants who experience Attention-Deficit Hyperactivity Disorder or Autism Spectrum Disorders exclusively; or participants who have experienced any mental health issue other than those described above. If this applies to you and you are interested in learning more about research in these areas, you may like to consider the [Beyond Blue Get Involved page](#).

### Who is conducting the study?

The **Our Turn to Speak** survey is the flagship project of SANE Australia's Anne Deveson Research Centre (ADRC), conducted in partnership with the Melbourne School of Psychological Sciences (MSPS) at the University of Melbourne, with the financial support of the Paul Ramsay Foundation. This project has been approved by the University of Melbourne's Research Ethics Committee (HREC Project no. 1955446.2).

The study is overseen by Dr Christopher Groot (the Chief Investigator), in collaboration with Dr Michelle Blanchard (Co-researcher), Dr Imogen Rehm (Co-researcher), Dr Cal Andrews (Co-researcher), Beth Hobern (Co-researcher), Rebecca Hyland (Co-researcher), Lisa Sweeney (Co-researcher) and Rikki Morgan (Co-researcher).

### What will I be asked to do?

Participation in this study has two stages. Should you be interested in participating in this project, you will first be asked to complete an eligibility screening questionnaire. This screening questionnaire will ask about your experiences of mental health issues. Completion of the screening questionnaire will take no more than 5 minutes of your time. If it is deemed that you are eligible to participate, you will then be asked to answer some further questions about your mental health and to complete a survey that asks about experiences like being treated positively or negatively in your life because of your mental health issues. Completion of this second part of the survey takes approximately 30 minutes.

Before you can begin the survey, you will be asked to indicate your consent to participating in the project via a Consent Form (this form will follow on the next page). You will also be asked to indicate if you are willing to receive information about similar research participation opportunities in the future, and whether the data you submit during this survey can be used in that related future research. If you accept the invitation to receive

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information about future related research, your identifying information and contact details will be retained by named members of the research team in a secure databank for a period of 10 years. Your current survey data will also be retained in this secure databank for future analysis should you provide additional consent.

### What are the risks?

This project is investigating experiences related to mental health issues, which is a sensitive topic that some people may find confronting. Parts of the survey will ask about negative life experiences, like that of stigma and discrimination related to mental health issues. Some people may find these questions confronting or concerning. If you have concerns about these questions, then you might like to speak with a trusted friend, family member or health professional about participating in this study before deciding to do so. Alternatively, if you started or completed the survey and this experience has raised concerns for you, you can contact the project research team on **1800 998 983** or [ourturntospeak@sane.org](mailto:ourturntospeak@sane.org), or speak with a counsellor from Lifeline Australia on **13 11 14**.

Scores on the mental health issue screening questionnaire may indicate that you would benefit from further assessment, support and treatment, even if you have not previously received a diagnosis of a mental health condition. Mental healthcare service referral information will be provided in the debriefing statement following completion of the survey. Moreover, information about mental health services nationally can be obtained from the [SANE Australia website](http://SANE Australia website) or from the SANE Helpline on **1800 187 263** between 10am and 10pm Monday to Friday.

Given the nature of the study, you should not undertake the survey if you are in crisis. If you are currently in crisis, then you could consider calling Lifeline on **13 11 14** or **000** if there is an emergency.

### What are the benefits?

Should you complete the survey in this research project, you may be reimbursed for your time with a \$25 electronic gift card that can be redeemed at a broad range of retail outlets. You will be provided with debriefing information following participation. Should you choose to receive it, you will also be provided with a summary of the study findings so that you can learn more about the study and its outcomes. The findings from this study will be disseminated and made publicly available through a range of forums, including, but not limited to, scientific publications, student theses, media publications, workshops and presentations at conferences. We hope that the findings from this study will support SANE Australia and its partners to advocate for Australians living with severe and complex mental health issues.

### How will my confidentiality be protected?

All your responses will be kept confidential, subject to legal limitations (subpoena, freedom of information or mandated reporting). If you are willing to proceed, you will be asked to read and indicate your consent on an electronic form to follow. Any identifying information you may provide will be stored securely at SANE Australia and be accessible only by the named members of the SANE Australia and University of Melbourne research team. If you indicate that you are willing to receive information about related research opportunities in the future, then your survey data will be assigned a de-identification code and stored at SANE Australia in a secure databank to afford future data comparison. Only named members of the SANE Australia and University of Melbourne research team will have access to the databank. All data will be encrypted and password protected. This databank has approval from the University of Melbourne's Research Ethics Committee (HREC Project no. 1955446.2).

### What if I want to withdraw from the research?

Participation in this research is completely voluntary. In other words, you are free to choose to participate or not. If you choose to participate, then you will also be free to withdraw from the study at any time and to withdraw any unprocessed data previously supplied, provided it can be reliably identified. This would have no effect on your relationship with, or services provided by, any member of SANE Australia or the Melbourne School of Psychological Sciences at the University of Melbourne.

### Where can I get further information?

Should you like more information or be concerned about any of the questions or tasks in the study, please do not hesitate to contact the **Our Turn to Speak** Telephone Research Centre on **1800 998 983** or via [ourturntospeak@sane.org](mailto:ourturntospeak@sane.org). You can also read more about the project at the study website: [ourturntospeak.com.au](http://ourturntospeak.com.au).

If you have not understood any of this information, please contact the **Our Turn to Speak** Telephone Research Centre on **1800 998 983**. If you have any concerns or complaints about the conduct of this research project, then you can contact the **Our Turn to Speak** Telephone Research Centre on **1800 998 983** or via [ourturntospeak@sane.org](mailto:ourturntospeak@sane.org).

### How do I agree to participate?

If you wish to participate, please read the consent form that you will now be provided with and indicate your consent to participate as instructed.