
PARTICIPANT INFORMATION SHEET AND CONSENT FORM *(for Consumers, families/carers).*

Title: Lived experiences of borderline personality disorder and help-seeking within Australian healthcare services: consumer and family carer perspectives

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Description of the study

This research involves a survey with people with lived experience of borderline personality disorder (BPD) as either a consumer or family carer. It builds on earlier surveys conducted in 2011 and again in 2017 by Lived Experience Australia. Few studies have explored the lived experiences of BPD across mental health systems and services, and no longitudinal studies exist. Given it has been 10 years since the last survey, and significant reforms have taken place across Australia's mental health service sector, it is timely to explore whether and to what extent the experiences of people with a BPD diagnosis (and their family carers) has improved. The survey for this project has been developed and distributed under the auspices of Lived Experience Australia. Flinders University has been engaged by Lived Experience Australia to analyse the survey data. The de-identified survey data will be sent to Sharon Lawn at Flinders University for analysis.

Purpose of the study

This research will provide a detailed understanding of the current state of mental health care and support needs and experiences for people with a BPD diagnosis and their families and carers. It will provide a longitudinal picture of if and what has changed over time, where improvements have been achieved, where gaps persist, and where further research, reform and advocacy efforts are needed.

Benefits of the study

Sharing your experiences will help you feel heard. It will build understanding of consumers and family carer experiences of BPD. Whilst you may not receive any direct benefit from your involvement in this study, the feedback you provide will help us to understand the current experiences of services and support for people with a BPD diagnosis and their families and carers. This will help inform lived experience advocacy, research, mental health system reform and service improvement.

Participant Involvement

If you agree to participate in this study, you will be asked to complete an anonymous online survey which will take between 30-60 minutes. If you wish or need to, you may seek assistance from a trusted family member, friend or peer to help you access or complete the survey. You may also save your progress and return to complete the survey later if you need to. By consenting to and completing this survey, you agree to your responses being available for future projects. We would seek further ethics approval before doing so.

The survey includes questions about your contact with mental health service providing, including those located in general practice, emergency departments, hospitals, community mental health services and other supports, and any experiences associated with suicide and self-harm. The survey also asks general questions about you, such as your age, gender, the state or territory where you live, your diagnoses, and any medications, therapies or other supports you use.

In recognition of your participation, you can choose to enter a random draw for one of five \$50 gift vouchers. If your name is drawn, we would contact you to confirm your preferred means of receiving it. You can include your preferred contact details at the end of the survey via a link to a separate confidential online area so that your survey responses and contact details are stored separately. We will not be able to link it back to your survey answers.

Potential Risks of Participating in the study

We anticipate low to medium risks from your involvement in this study. **Some people may become upset by recounting past negative or traumatic experiences of BPD** or of contact with mental health services. If you are concerned that you may experience any distress by completing the survey, you may wish to discuss this information sheet, the project, of the survey questions with a support person you trust prior to making a decision.

If you experience feelings of distress as a result of participating in this study, please seek support. This may be a trusted family member, friend, GP, consumer or carer support group, or your mental health support service. Alternatively, you may wish to contact the following organisations for support:

- LifeLine **13 11 14** or <https://www.lifeline.org.au/>
- Beyond Blue Support Service on **1300 22 4636** or <https://www.beyondblue.org.au/>
- Suicide Call Back Service **1300 659 467** www.suicidecallbackservice.org.au/
- For Indigenous Australian **13YARN** <https://www.13yarn.org.au/contact-us-13yarn>
- Roses in the Ocean Peer Connection Warmline **1800 77 PEER or 1800 77 7337**. This is not a crisis line. It is a safe space for peer connection and understanding for people who experience suicidal thoughts and people supporting for someone through a suicidal crisis or bereaved by suicide
- The Carer Gateway Counselling Service **1800 422 737** or www.carergateway.gov.au

More information and resources on BPD can be found here: <https://bpdfoundation.org.au/resources.php>

Withdrawal Rights

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. You may elect to not answer any survey question or just close the internet browser and leave the online survey at any time freely and without prejudice or obligation. Participation or withdrawal in this survey will not impact your relationship with or connection to Lived Experience Australia or the Australian BPD Foundation. Participants leaving the survey will have their responses up to that point included in the study. Once you have provided your survey responses, it will not be possible to withdraw your survey contributions due to the inability to identify them from the overall responses.

Confidentiality and Privacy

Only the researchers listed on this form have access to the information you provide, and only de-identified information will be included in the analysis of survey data. All members of the project team have current certificates for working with vulnerable groups and will take all possible steps to ensure privacy and confidentiality are adhered to at all times.

In recognition of your participation, you can choose to enter a random draw for one of five vouchers. We would contact you to confirm your preferred means of receiving it, if your name is selected from the drawn. You can include your preferred contact details at the end of the survey via a link to a separate confidential online area so that your survey responses and contact details are stored separately. We will not be able to link it back to your survey answers. We anticipate study results will be published and presented in a variety of forums. In any publication or presentation information will be provided in such a way that you cannot be identified. Non-identifiable and de-identified datasets may be shared or used in future research projects.

Data Storage

The information collected will be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All analysed data will be securely transferred to and stored at Flinders University for five years after publication of the results. Following the required data storage period, all data will be

securely destroyed according to university protocols. The raw survey data will be stored securely with Lived Experience Australia's password-protected SurveyMonkey site which houses the survey. It will be retained for five years, then deleted.

How will I receive feedback?

On project completion, a report and short summary of the outcomes will be provided through Lived Experience Australia's monthly e-news, and from the Lived Experience Australia website:

<https://www.livedexperienceaustralia.com.au/research>

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (HREC No: 10079).

Queries and Concerns

If you want any further information concerning this project you can telephone the principal researcher, Professor Sharon Lawn on 0459 098 772 or sharon.lawn@flinders.edu.au. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics and Compliance Office team either via telephone (08) 8201 2543 or by emailing the Office via human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet. By completing/submitting this survey, you are consenting to participate in this study and to the conditions outlined in the Participant Information Form.