

Frequently Asked Questions: Virtual Advisory Panel on BPD

Thank you for your interest in participating in a survey about your experiences with **Borderline Personality Disorder (BPD)**. NAMI is working with a clinical research partner that is in the early stages of researching a possible new medication to target symptoms of BPD. Your survey responses will help inform patient-centered research on the lived experience of people living with BPD.

If you have further questions, please contact us at researchstudy@nami.org or call toll-free at 888-780-4167.

1. What is this study?

This study is an anonymous online survey for adults with diagnosed BPD and their adult family members/ caregivers. The survey includes questions about symptoms associated with BPD and the current resources and treatments available for people with BPD. Participants who complete the survey will receive a \$50 Visa gift card in appreciation for their time.

2. Why is NAMI involved?

NAMI actively advocates for research that advances discovery of newer and more effective treatment options for mental health conditions. When a clinical research partner asked us to help them better understand what patients and their families are looking for in treatment for symptoms of BPD, we determined this was a valuable opportunity. By asking people what they need to help their symptoms that they aren't getting with existing treatments, we are putting patient and family voices first as researchers develop processes for future clinical studies.

3. Who is eligible to participate?

Anyone 18 years of age or older who has a current diagnosis of BPD or is a family member/ caregiver of a person with a current diagnosis of BPD is eligible to participate in the survey. To participate you will need access to the internet through a computer, tablet or smartphone at the time of the survey.

4. How do I know if I'm selected?

If you are interested in participating in the survey, you must first answer a brief eligibility survey either online (https://www.research.net/r/P63M9QK) or by phone (888-780-4167). NAMI will review your responses to the eligibility survey and will let you know if you have been selected to participate in the research study no later than Friday, November 9, 2018.

5. Are my responses confidential?

Yes. NAMI will not share your name or any identifying information with anyone. You will be assigned a "Participant Identification Number" that will keep your responses separate from others for comparison.

6. What will be done with my responses?

Your responses will be shared with NAMI's clinical research partner after being stripped of all identifying information (name, email, etc.). Responses will only be associated with a "Participant Identification Number" assigned by NAMI. Your responses will be stored on NAMI's data base which follows industry confidentiality and ethical guidelines.

7. Does this mean I'll be selected for a clinical trial?

This research study is looking to learn from your experiences with BPD and your thoughts about the treatment you or your family member has received in the past. This study is not connected to any clinical trials of new products or treatment approaches.

8. When will I receive the gift card?

Once you have completed the survey, you can expect your \$50 Visa gift card mailed to you within 3-4 weeks.