



Frequently Asked Questions: Schizophrenia Clinical Research Survey & Focus Group

Thank you for your interest in participating in this survey. NAMI is working with a clinical research partner to better understand the lived experience of schizophrenia and to hear from individuals and their families how they feel about participating in clinical research. We are looking for adults to participate in an anonymous survey to help inform our partner's future work. Following the survey, NAMI will also conduct focus groups for individuals with schizophrenia and their family members/caregivers.

If you have further questions, please contact us at researchstudy@nami.org.

1. What is the survey study about?

This study is an anonymous online survey for adults diagnosed with schizophrenia and their adult family members/care partners. The survey includes questions about your experiences with diagnosis, desires relating to treatment, and perspectives on clinical research. The survey should take approximately 20 minutes to complete.

2. Who is eligible to participate in the survey?

People who are 18 years of age or older, are residents of the United States, and have a current diagnosis of schizophrenia or are a family member/ care partner of a person with a current diagnosis of schizophrenia are eligible to participate in the survey. To participate you will need access to the internet through a computer, tablet or smartphone.

3. 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.

4. What will be done with my responses?

Your responses will be summarized and 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 database which follows industry confidentiality and ethical guidelines.

5. Is there compensation for completing the survey?

Participants who complete the survey will have the option to enter a drawing to receive a digital gift card with a maximum value of \$35. To be eligible for the drawing, you will be required to provide an email address at the close of the survey. NAMI will distribute the gift cards by email no later than May 31st, 2022.

6. Does taking this survey mean I'll be selected for a clinical research study?

No. This survey is designed for NAMI and our partner to learn from your experiences with schizophrenia. This study is not connected to any clinical trials of new products or treatment approaches.

7. Does taking this survey mean I'll also have to be in a focus group?

No. At the close of the survey, you will have the option to indicate if you would like to participate in a focus group. NAMI will select up to 24 survey participants to invite to the focus groups. Invitations will be sent no later than Monday, May 9.

8. What is required to participate in the focus group?

Focus groups will be conducted by NAMI virtually over Zoom. The virtual sessions will be 60 minutes in length. In advance of the session, participants will be required to sign a privacy/consent form and to spend up to 30 minutes reading a brief document to prepare for the discussion.

9. Is there additional compensation for the focus group?

Focus group participants will receive additional compensation, based on fair market value for participation in clinical research efforts. Individuals with a diagnosis will receive a digital gift card with a value of \$150, and family member/caregivers will receive a digital gift card with a value of \$75. NAMI will distribute the gift cards by email no later than May 31, 2022.