



Frequently Asked Questions: Clinical Research on Schizophrenia and Related Psychosis Conditions Survey

Thank you for your interest in participating in a survey about your perceptions of clinical research on schizophrenia and related psychosis conditions. NAMI is working with a partner that is preparing to launch a clinical research study on the biology of these conditions to learn more about how to identify and treat them. Your survey responses will help NAMI and our partner understand the experiences and concerns of people with schizophrenia and related psychosis conditions and their family members, so we can better support the participants of the upcoming clinical research study.

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

1. What is this survey?

This survey is an anonymous online questionnaire for adults with a diagnosis of schizophrenia or a related psychosis condition (including schizoaffective disorder, schizophreniform disorder, and brief psychotic disorder) and their adult family members/ caregivers. The survey includes questions about what you know about clinical research and what concerns you might have if you or your family member were participating in a clinical research study.

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 partner asked us to help them understand what individuals with a diagnosis and their family members need to feel comfortable and supported when participating in a clinical research study, we determined this was a valuable opportunity. By asking people what they know and what they think about clinical research, we can directly benefit from their lived experience to better support future research study participants.

3. Who is eligible to participate?

Anyone who is 18 years of age or older, is a resident of the United States, and has a current diagnosis of schizophrenia or a related psychosis condition (including schizoaffective disorder, schizophreniform disorder, and brief psychotic

disorder) or is the family member of a person with a current diagnosis 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 you decide to take the survey.

4. 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.

5. 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 data base which follows industry confidentiality and ethical guidelines.

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 what you know and what you think about clinical research, so we can better support the participants of an upcoming clinical research study. If you are interested in participating in that upcoming research study, you will have the option at the end of the survey to provide your email address to receive more information from NAMI.