



**KarXT for Schizophrenia
Response to Public Comments on Draft Evidence Report from Individuals Living
with Schizophrenia**

January 25, 2024

ICER would like to thank all individuals living with schizophrenia who took the time to share their experiences, real-world perspectives, and to express the need for new and better treatments. There were key themes around the impact of the disease on daily life, the challenges experienced with current medications available, and hopes for new therapies, which we have summarized below.

Additional details from these perspectives have been included in Section 2, Patient and Caregiver Perspectives, of the Evidence Report. These comments have also been incorporated into the public comment folio posted to [ICER's website](#) on January 25, 2024, along with this summary. Both the folio and this summary will also be shared with the voting council members participating in the upcoming public meeting on February 9th, 2024 to help inform their deliberation on the evidence.

Impact of Disease on Daily Life

Individuals living with schizophrenia shared that they strive to be productive members of society, but the disease makes it challenging as it has drastically changed their day-to-day lives. For many individuals, both schizophrenia itself and the side effects of some of the medications have made it difficult to hold a job or pursue higher education. Many individuals shared that they had to give up on their career goals or dream jobs because of symptoms of their disease or side effects of medication. Even after finding a medication that worked for them, some individuals shared that day-to-day tasks, like going to the grocery store, can still be challenging. Maintaining personal relationships was also mentioned as a challenge, leading to feelings of isolation and loneliness. Many of the symptoms highlighted as most challenging include, but are not limited to, delusions, auditory hallucinations, anxiety, paranoia, and intrusive thoughts.

Challenges with Current Medications

Even with medication, individuals highlighted that their challenging symptoms are not all well managed. Many individuals mentioned that the need to try many different drugs (more than 20 for one individual) over many years (a decade for another individual) before finding one that worked well enough. Individuals highlighted many burdensome side effects of even the drugs that worked best for them, including restlessness, sedation, weight gain, lethargy, and suppressed emotions. These side effects often interfered with the quality of their day-to-day life and limited their ability to participate in activities they enjoy.

Hope for New Therapies

All individuals mentioned how a therapy with fewer side effects would be very valuable to improving their quality of life, particularly if a therapy has fewer metabolic complications and/or did not cause emotional suppression. There was also hope that future medications would address the “killers” associated with schizophrenia, such as weight gain/diabetes, isolation/loneliness, and suicide. In terms of symptom relief, individuals expressed a need for a medication that would work for all symptoms associated with schizophrenia in order to minimize the number of medications needed, especially for symptoms such as negative thoughts. Overall, individuals shared that they are looking for a reliable medication that works day-to-day that could also be taken over longer intervals (monthly or bi-monthly). The goal should be complete recovery, but individuals emphasized that even a medication that better reduces symptoms with minimal side effects would be valuable.