

A woman with long dark hair, wearing a pink knit sweater and blue jeans, is sitting on a brown leather couch. She is holding her hands to her temples, looking down with a distressed expression, suggesting she is experiencing a headache or mental anguish. This image serves as the background for the entire page.

ELEVATING THE EXPERIENCES OF **SCHIZOPHRENIA** **PATIENTS AND** **PROVIDERS**

ICER TOOLKIT

OVERVIEW

Schizophrenia is a serious mental illness that affects roughly 2 million Americans.

Patients may experience and interpret reality in an abnormal manner, leading to hallucinations, delusions and disordered thinking. The disease burdens patients and those around them physically, mentally, emotionally, financially and socially.

Managing schizophrenia can be challenging, and finding stability often requires lifelong treatment. But innovative treatment options can ease the burdens that patients face. Getting access to these treatments, however, can be difficult.

One new schizophrenia treatment, called xanomeline-trospium, is currently undergoing clinical trials, and early data suggest it may be effective. Expanding the range of available treatments will help providers tailor care and find the best option for each patient.

Xanomeline-trospium was only recently submitted to the FDA for approval. Yet the Institute for Clinical and Economic Review, known as ICER, is already trying to assess the drug's value.

The private, Boston-based health economics organization analyzes clinical trials data in an attempt to gauge medications' cost-effectiveness. ICER's reports often influence health plans' decisions about how, or whether, to cover new drugs.

Without complete data, ICER may not adequately assess the value of xanomeline-trospium. That could lead to access barriers for patients.

That's why it's critical for schizophrenia patients, advocates and health care providers to share their experiences and opinions with ICER.

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This toolkit provides the information you need to bring your experience, expertise and insights to ICER's process.

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ICER ASSESSMENT TIMELINE

OPPORTUNITIES TO GET INVOLVED

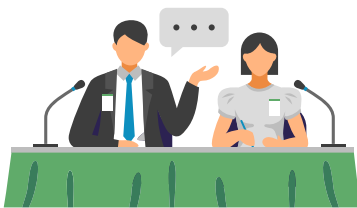


DRAFT EVIDENCE REPORT

November 28 –
December 22, 2023

WHAT YOU CAN DO:

- Submit comment
- Use social media to raise awareness about key issues
- Share information via newsletters, blogs and email
- Encourage members and colleagues to participate

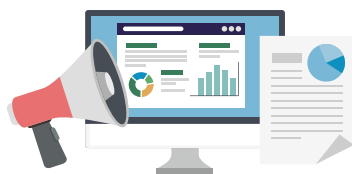


PUBLIC MEETING

February 9, 2024

WHAT YOU CAN DO:

- Testify at ICER's meeting
- Stay active on social media
- Spread the word via newsletters, blogs or emails



FINAL EVIDENCE REPORT & MEETING SUMMARY

March 11, 2024

WHAT YOU CAN DO:

- Reiterate key messages using social media, email and newsletters

KEY MESSAGES



Having innovative treatment options could help patients find and stay on a medication that works for them.

- Schizophrenia manifests in different ways for each patient.
- About half of patients with schizophrenia don't take their medication as prescribed. Different treatments have different side effects for each patient.
- Having untreated schizophrenia shortens the average patient's lifespan by 28.5 years.



The ability to manage schizophrenia benefits patients and society.

- Caregivers benefit from better-managed schizophrenia.
- Patients whose schizophrenia is well controlled are less likely to go untreated and require emergency care, reducing the financial burden on the health care system.
- Patients who effectively treat their condition can return to the workforce.



Access to treatment helps minority and at-risk communities.

- Communities of color are disproportionately affected by schizophrenia. Black Americans are three to four times more likely to have schizophrenia.
- About one in three homeless people have a serious mental illness like schizophrenia.
- One in seven people in prison have a serious mental illness.



Patients deserve accurate, comprehensive assessments of treatment value.

- Xanomeline-trospium is still undergoing clinical trials and has yet to receive FDA approval.
- ICER's process looks at aggregate clinical trials data and doesn't consider a treatment's true value for individual patients.
- ICER's determination will influence how health plans choose to cover schizophrenia drugs in the future.

SOCIAL MEDIA GUIDE

Hashtags

#Schizophrenia

#ICER

#Advocacy

#patient

#TrustPatients

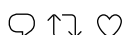
#mentalhealth

#brainhealth

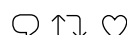
#schizophreniatreatment

Tweets / Facebook Messages

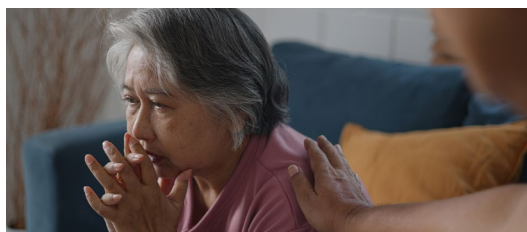
DYK? [#ICER](#) is evaluating treatments that have yet to complete clinical trials. Future treatment options could benefit [#schizophrenia](#) patients – but patients will need access.



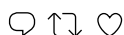
[#ICER](#) is doing a disservice to [#schizophrenia](#) [#patients](#) with its premature and incomplete assessment of new Rx. Clinical trials for this new treatment aren't finished, and ICER's decision may undermine coverage for people who need it.



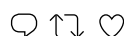
Understanding the value of [#schizophreniatreatments](#) starts with sharing your experience. Tell [@ICER_review](#) about what a day in the life of a [#schizophrenia](#) patient is like and why treatments should be fairly evaluated.



Roughly 2 million Americans live with [#schizophrenia](#), which impacts patients, caregivers, families and communities. Share your [#caregiver](#) story with [@ICER_Review](#)



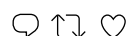
Black Americans are 3-4x more likely to develop [#schizophrenia](#). Now is the time to [#advocate](#) for fair assessments of treatment options.



1 in 3 people experiencing homelessness have a serious mental illness. Accessible treatment options can help. [#BrainHealthMatters](#)



[#ICER](#) scheduling its evaluation of a [#schizophrenia](#) drug in the [#holidays](#) shuts patients & providers out of the conversation. Advocates must make sure their experiences are heard during their assessment.



WHAT'S NEXT?



Look for more information from the Alliance for Patient Access at allianceforpatientaccess.org/ICER



Questions? Contact Casey McPherson at cmcpherson@allianceforpatientaccess.org

Innovative schizophrenia treatments can benefit patients, but they need access. ICER's premature evaluation of this treatment lacks comprehensive data and makes it harder for patients and advocates to speak into the conversation.

Patients and clinicians deserve to share their perspectives in fair assessments of schizophrenia treatments.



**Institute for
Patient Access**

ABOUT THE INSTITUTE FOR PATIENT ACCESS

The Institute for Patient Access is a physician-led nonprofit 501(c)(3) research organization promoting the benefits of the physician-patient relationship in the provision of quality health care.



@patientaccess



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InstituteforPatientAccess.org