AMPLIFYING THE VOICES OF ALZHEIMER’S

ICER TOOLKIT
OVERVIEW

Alzheimer’s disease and other forms of dementia have long impacted families and communities across the country. Today, about 6 million Americans live with Alzheimer’s disease — a number that will more than double by 2050.

But groundbreaking research gives families a reason to hope. Three innovative medications — aducanumab, donanemab and lecanemab — offer Alzheimer’s patients potential treatment options. Access to these treatments, however, is not guaranteed.

An organization known as the Institute for Clinical and Economic Review, or ICER, is leading a critical conversation about the medications’ cost and value. ICER is a private, Boston-based health economics organization that analyzes available clinical trials data in an attempt to gauge medications’ cost-effectiveness.

The conversation could impact insurers’ decisions about whether, or how comprehensively, to cover the Alzheimer’s drugs.

It’s critical for Alzheimer’s advocates, patients and health care providers to make their voices heard in the conversation.

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

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ICER ASSESSMENT TIMELINE
WHAT YOU CAN DO

DRAFT EVIDENCE REPORT
December 22, 2022 – February 2, 2023

WHAT YOU CAN DO:
• Submit comment
• Engage in social media to raise awareness about key issues
• Share information via newsletters, blogs and email
• Encourage members and colleagues to participate

PUBLIC MEETING
March 17, 2023

WHAT YOU CAN DO:
• Testify at ICER’s meeting
• Continue engaging in social media
• Spread the word via newsletters, blogs or email

FOLLOW UP
Final Evidence Report & Meeting Summary
April 17, 2023

WHAT YOU CAN DO:
• Reiterate key messages using social media, email and newsletters
Americans can’t wait any longer for accessible treatment options.

- More than 6 million Americans live with Alzheimer’s disease. They need treatment options.
- Nearly 13 million Americans are projected to have Alzheimer’s by 2050.
- Alzheimer’s is the nation’s sixth leading cause of mortality.

Easier access to treatments can reduce disparities.

- About two-thirds of Americans living with Alzheimer’s are women.
- Communities of color are disproportionately impacted by Alzheimer’s but under-represented in the clinical trials analyzed by ICER.
- Access to treatment will give patients of all races, genders and socio-economic backgrounds a better chance at fighting Alzheimer’s.

Caregivers and patients need options.

- More than 11 million Americans today serve as unpaid caregivers for friends or family members with Alzheimer’s.
- Labor-intensive and time consuming, caregiving often requires people to sacrifice hobbies, social interactions and professional opportunities.
- Accessible treatment options will give caregivers and patients alike a better quality of life.

Patients and providers deserve a role in decisions that impact their lives.

- ICER has revised the scope of its Alzheimer’s treatment review three times, making a difficult process even harder for patients to navigate.
- The comment period has been scheduled at the onset of the holiday season, undermining patients’ ability to participate.
SOCIAL MEDIA GUIDE

Hashtags

#Alzheimers  #ICER  #Advocacy  #patient
#TrustPatients  #caregiver  #EndAlzheimers

Tweets / Facebook Messages

6 million Americans today live with #Alzheimers. By decade’s end, nearly 9 million will. Americans can’t wait any longer for treatment options. #ICER

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DYK? People of color are more likely to develop #Alzheimers. Often, these groups are under-represented in the trials reviewed by ICER for its assessments. #ICER

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Women in the U.S. are disproportionately affected by #Alzheimers. They need you to #advocate for accessible treatment options. #ICER

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Up to 80% of all #Alzheimers patients receive in-home care. Tell @ICER_review how expanding treatment options will improve your life as a #caregiver.

Understanding #Alzheimers starts by sharing your story. Let @ICER_review know what it’s like to live a day in your shoes and why the time for accessible treatment is NOW. #TrustPatients

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WHAT’S NEXT?

Look for more information from the Alliance for Patient Access, including specific instructions related to the ICER response effort.

Questions? Contact Elizabeth Simpson at esimpson@allianceforpatientaccess.org

Alzheimer’s treatments, and their value to patients, are too significant to be assessed by health economists without patients’ and clinicians’ input. Together, the Alzheimer’s advocacy community can raise awareness, shape the value conversation and educate ICER on why breakthrough treatment options are critical.

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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