

A photograph of a family of three is the background for the top half of the page. On the left is an older man with grey hair and a beard, wearing a blue and white striped shirt. In the center is a young boy with dark hair, wearing a blue shirt. On the right is a younger man with dark hair, wearing a green and white long-sleeved shirt. They are all smiling and looking down at something out of frame.

# AMPLIFYING THE VOICES OF ALZHEIMER'S

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## ICER TOOLKIT

# OVERVIEW

Alzheimer's disease and other forms of dementia have long burdened families and communities across the country. More than 5 million Americans live with Alzheimer's disease, a figure that's projected to double by 2050. The nation now approaches a potential milestone as the Food and Drug Administration considers the drug aducanumab, which could be the first disease-modifying treatment approved to treat Alzheimer's.

As the FDA carries out its approval process, however, a concurrent conversation explores the cost and value of Alzheimer's treatment. Steering that conversation is the Institute for Clinical and Economic Review, better known as ICER. The private, Boston-based health economics organization analyzes available clinical trials data in an attempt to gauge medications' cost-effectiveness.

In the short term, ICER's review could influence whether patients can access aducanumab. In the long term, the review could set the stage for future cost-value discussions about other treatments for dementia and related conditions.

**That's why it's critical for Alzheimer's advocates, patients, and health care providers to provide input.**



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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

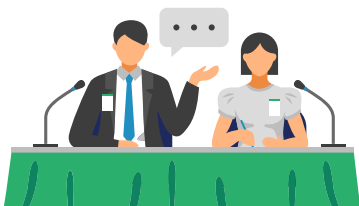


### DRAFT EVIDENCE REPORT

May 5 - June 2, 2021

#### 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

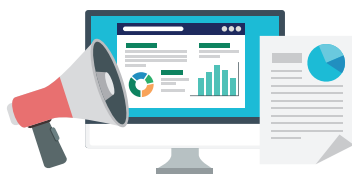


### PUBLIC MEETING

July 15, 2021

#### WHAT YOU CAN DO:

- Testify at virtual ICER meeting
- Continue engaging in social media
- Spread the word via newsletters, blogs or email



### FOLLOW UP

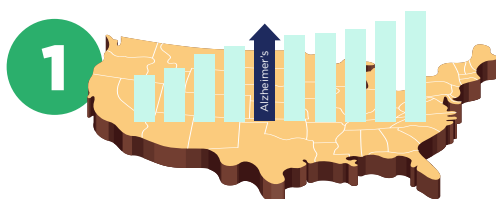
Final Evidence Report  
& Meeting Summary

August 5, 2021

#### WHAT YOU CAN DO:

- Reiterate key messages using social media, email, and newsletters

# CORE MESSAGES



## A National Health Crisis Demands Treatment.

- a. The more than 5 million Americans living with Alzheimer's disease have no available treatment options to prevent, cure or slow the onset of disease.
- b. The annual number of Americans living with Alzheimer's is expected to double by 2050.
- c. Each year, around 500,000 American lives are lost to Alzheimer's, making it the sixth-leading cause of death.



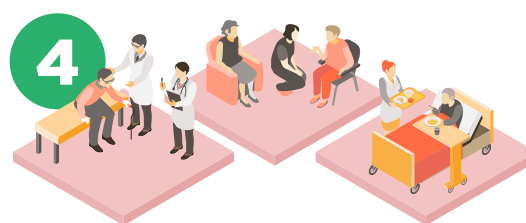
## Reducing Disparities Begins with Accessible Treatment.

- a. About two-thirds of Americans with Alzheimer's are women.
- b. Communities of color are disproportionately impacted by Alzheimer's, yet they fail to be accurately captured by the clinical trials ICER conducts.
- c. Access to treatment will give patients of all races, genders and socio-economic backgrounds a better chance at fighting Alzheimer's.



## Number Crunching Alone Can't Capture Alzheimer's Disease.

- a. Beyond loss of memory and daily function, people with Alzheimer's experience a loss of self, robbing their loved ones of meaningful relationships.
- b. Moderate to severe Alzheimer's symptoms such as confusion and decline in physical abilities require a full-time caregiver.
- c. Accessible treatment could reduce the financial, emotional and physical strain on patients and families.



## Caregivers and Patients Deserve Options.

- a. Eighty percent of patients receive in-home care, oftentimes from a family member or friend.
- b. Caregivers provide over 18 billion hours of unpaid assistance yearly, valued at an estimated \$233 billion.
- c. Accessible treatment options will give caregivers and patients alike a better quality of life.

# SOCIAL MEDIA GUIDE

## Hashtags

#Alzheimers

#ICER

#Advocacy

#patient

#TrustPatients

#aducanumab

#caregiver

## Tweets / Facebook Messages

Over 5 million Americans live with [#Alzheimers](#). Expanding treatment options is critical to preventing this growing health crisis. [#ICER](#)



DYK? Almost two-thirds of Americans living with [#Alzheimers](#) are women. Advocate for greater treatment options to lower the health disparity. [#ICER](#)



Up to 80% of all [#Alzheimers](#) patients receive in-home care. Tell [@ICER\\_review](#) how expanding treatment options will help your quality of life as a [#caregiver](#).



Communities of color in the U.S. are disproportionately impacted by [#Alzheimers](#). These patients need you to [#advocate](#) for accessible treatment options. [#ICER](#)



What would the first FDA-approved [#Alzheimers](#) treatment option be worth to you? Let [@ICER\\_review](#) know. [#TrustPatients](#)



Understanding [#Alzheimers](#) starts by sharing your story. Let [@ICER\\_review](#) know what it's like to live a day in your shoes and what accessible treatment would mean to you. [#TrustPatients](#)



# WHAT'S NEXT?



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



Questions? Contact John Bates at [jbates@allianceforpatientaccess.org](mailto:jbates@allianceforpatientaccess.org).

A conversation about Alzheimer's treatment and value is too important to happen in a vacuum. Together, the Alzheimer's advocacy community can raise awareness, inform dialogue and educate ICER on why breakthrough treatment options are critical for patients, their families and the health care system.



**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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