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Institute for Clinical and Economic Review (ICER)
Two Liberty Square
Ninth Floor
Boston, MA 02109

To Whom It May Concern,

On behalf of [Voices of Alzheimer's](#) (VoA), an advocacy organization led by people with lived experience with Alzheimer's, we appreciate the opportunity to provide comment on the Institute for Clinical and Economic Review (ICER) draft evidence report on Lecanemab and Donanemab for the treatment of Alzheimer's Disease (AD).

The Patient Perspective is Paramount

We would like to express our appreciation for the organization's efforts to interview people living with Alzheimer's in order to gain valuable insights and perspectives on the impact of the disease. This is an important step towards understanding the lived experiences of people living with the Alzheimer's and ensuring that their voices are heard in the development of programs and services.

However, we are disappointed to learn that the information gathered from people living with Alzheimer's did not seem to have been fully understood or incorporated by all evaluators. This is a missed opportunity to gain a deeper understanding of the needs and priorities of people living with the Alzheimer's and to make more informed decisions about the value of treatments.

We recommend that the organization take steps to ensure that the input from people living with the Alzheimer's and care partners is required reading for all evaluators. This could include providing training on how to understand and interpret the perspectives of people living with Alzheimer's, as well as incorporating their input into evaluations and decision-making processes. In addition, it's important to remember that people living with the disease and care partners have a unique and valuable perspective that cannot be replicated by any other group. By taking these steps, the ICER can ensure that the voices of people living with the Alzheimer's are truly heard and that their needs are fully taken into account as part of this and future value assessments.

ICER Should Consider What Matters Most to Patients

For those living with the Alzheimer's, care partners, and families, activities of daily living (ADLs) and quality of life (QoL) are of paramount importance. Measures of ADLs and QoL can provide important insights into the real-world impact of the disease. They can also help to identify areas where treatments along with other support may be particularly valuable to improve the quality of life for people living with Alzheimer's and their families.

Therefore, it is important that the organization's methodology gives great weight to the value of these measures. This could include using validated tools and instruments to assess ADLs and QoL, as well as incorporating the perspectives of people living with Alzheimer's and care partners into the evaluation process. Additionally, the organization should consider using multiple sources of data to gather information about ADLs and QoL, such as interviews, surveys, and observation.

Moreover, it's important to incorporate the patient-centered outcome measures that are most meaningful to the people living with Alzheimer's. The organization should consider including measures of patient-reported outcomes (PROs) such as the Patient-Reported Outcomes Measurement Information System (PROMIS) and the European Quality of Life-5 Dimensions (EQ-5D) which are widely used in the research community and can provide a more comprehensive understanding of the patient's experience.

For those living with the disease, care partners and families, activities of daily living and quality of life are of paramount importance when it comes to understanding and valuing the impact of new treatments. It is important that the organization's methodology for this and future evaluations gives sufficient consideration to the value of these measures and incorporates patient-centered outcome measures that are most meaningful to the people living with Alzheimer's.

We Must Act Urgently

The proposed value assessment will impact access to new treatments for patients, and so it is critical the ICER understands and acts with urgency. The patient community calls on ICER to act in reconsidering its framework for assessing these and future Alzheimer's treatments. As these treatments are only effective for those in the earlier stages of AD, time is of the essence. It is critical we have a patient-centered approach to treatment value so patients who need these therapies the most are able to benefit.

Thank you for considering our comment.

Sincerely,

Jim Taylor
President and CEO
Voices of Alzheimer's