

# NOF MEASURE INCUBATOR® Alzheimer's Disease Measures

## WHAT IS THE PROJECT?

Alzheimer's disease (AD) is an irreversible, progressive disorder and the most common cause of dementia among older Americans. AD has a significant public health and personal impact due to premature mortality and disability and substantial financial burden. As AD progresses, patients experience poorer quality of life and require more supervision and care, and caregiver burden increases. A timely and accurate diagnosis enables patients to plan and pursue interventions that can reduce or delay worsening symptoms. Yet, an estimated half of all patients never receive a diagnosis, and no existing measures evaluate timely diagnosis or caregiver needs in AD. Establishing measures focused on screening and caregivers will address high-priority gaps in AD measurement and help ensure that caregivers and patients receive the support they need.

This NQF Measure Incubator<sup>®</sup> project is the first step toward facilitating the development of needed performance measures to support early detection and patient- and caregiver-centered care in Alzheimer's disease.

#### STRATEGY SESSION

NQF convened a Measure Incubator strategy session with a multistakeholder Expert Panel in July 2019. At this meeting, panelists discussed a range of measures that evaluate screening and assessment and purposeful engagement with caregivers. The Panel emphasized the importance of routine screening as patients often struggle to get a diagnosis due to the initial subtlety of AD symptoms.

The Expert Panel highlighted the importance of engaging family caregivers—and ensuring their wellbeing—as valued members of the core care team. The Expert Panel identified and prioritized six measure concepts, including one 2-part measure, that could become measures for AD. These concepts focus on integrating routine screening for and assessment of cognitive impairment and caregiver engagement within clinical practice. Panelists recommended further exploration of innovative approaches and educational resources needed to support earlier detection of cognitive impairment and well-coordinated, high-quality, interdisciplinary care to address patient and caregiver needs.

NQF engaged a broad-based stakeholder group in this Measure Incubator project, including individuals with AD, caregivers, clinicians, payers, researchers, data experts, and measure developers.

### WHAT IS THE ENVISIONED OUTCOME?

Building on the recommendations from the NQF-convened strategy session, NQF seeks to facilitate the development of one or more measure concepts into fully specified and tested performance measures. NQF will explore funding to support measure development and testing beginning in fall 2019.

This work creates a solid foundation for measures that will improve the care and health outcomes of patients with Alzheimer's disease—and their caregivers by ensuring more timely and accurate diagnosis of AD and improved access to needed treatment and support services.

NQF is delivering this project through the Measure Incubator with financial support from **Genentech**, **Inc.** In accordance with the **NQF Measure Incubator Conflict of Interest Principles**, Genentech, Inc. has not influenced the outcomes and activities associated with this project.

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