Alzheimer’s Disease Measure Testing & Development

Introduction

The National Quality Forum (NQF) Measure Incubator®, an innovative effort that facilitates efficient measure development and testing through collaboration and partnership, is soliciting information from measure developers to transform one measure concept into a fully specified and tested measure. This Measure Incubator project is supported by Genentech.

This request for proposal (RFP) describes the measure concept to be further developed and tested, and requests information on a development and testing plan for the concept from potential measure developers. NQF encourages innovative approaches to measure development and testing that promote efficiencies in the processes and associated budget, which do not necessarily have to follow traditional blueprints for measure development and testing.

In 2019, NQF, with support from Genentech, convened a strategy session with a multistakeholder expert panel to facilitate the development of a suite of measure concepts focused on Alzheimer’s disease (AD) screening and assessment, and purposeful engagement with caregivers that could be translated into performance measures through development and testing. AD is an irreversible, progressive disorder and the most common cause of dementia among older Americans.\(^1\)\(^2\) AD has a significant public health and personal impact due to premature mortality and disability and substantial financial burden.\(^1\) As AD progresses, patients experience poorer quality of life and require more supervision and care, and caregiver burden increases.\(^1\) 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.\(^3\) 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.

The Expert Panel identified a suite of six measure concepts, including one 2-part measure, that could become performance measures for AD. These concepts focus on integrating routine screening for and assessment of cognitive impairment and caregiver engagement within clinical practice. Expert Panelists included individuals with AD, caregivers, clinicians, payers, researchers, data experts, and measure developers. The following 2-part measure concept was selected for testing and development:

1. **Caregiver Identification (2-part measure):**
   a. Part 1 – Percentage of patients asked if there is a person (or persons) who:
      i. Helps with functional tasks/daily activities
      ii. Is designated to act as a surrogate decision maker
   b. Part 2 – Percentage of patients whose medical record includes the name(s) of the person(s) who:

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i. Helps with functional tasks/daily activities
ii. Is designated to act as a surrogate decision maker

Project Overview

The NQF Measure Incubator seeks to identify an organization with proven experience in developing and testing healthcare performance measures—particularly measures that focus on or incorporate AD and/or caregivers—to serve as the primary measure developer for the Caregiver Identification (2-part measure) measure concept. Tables 1-2 provide early draft specifications for the measure concept recommended by the Expert Panel along with questions for the measure developer to address in development and testing. The concept requires formal development (i.e., concept refinement and detailed specification) and testing (i.e., feasibility, reliability, and validity testing with risk adjustment/stratification, as appropriate) to produce a finalized measure that is evidence-based and determined to be feasible, reliable, and valid.

Table 1. Caregiver Identification for Alzheimer’s Disease Measure Concept; Part 1 of 2

<table>
<thead>
<tr>
<th>Measure Concept</th>
<th>Caregiver Identification for Alzheimer’s Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Percentage of patients asked if there is a person (or persons) who:</td>
</tr>
<tr>
<td></td>
<td>• Helps with functional tasks/daily activities</td>
</tr>
<tr>
<td></td>
<td>• Is designated to act as a surrogate decision maker</td>
</tr>
<tr>
<td>Numerator</td>
<td>Number of patients whose medical record indicates that the patient was asked if there is a person(s) who:</td>
</tr>
<tr>
<td></td>
<td>• Helps with functional tasks/daily activities</td>
</tr>
<tr>
<td></td>
<td>• Is designated to act as a surrogate decision maker</td>
</tr>
<tr>
<td>Denominator</td>
<td>All patients with diagnosed dementia</td>
</tr>
<tr>
<td>Care Setting</td>
<td>Ambulatory</td>
</tr>
<tr>
<td>Stratification</td>
<td>Age, severity of dementia</td>
</tr>
<tr>
<td>Level of Measurement</td>
<td>Clinician/practice, potentially health plan</td>
</tr>
<tr>
<td>Data Source(s)</td>
<td>Electronic Health Records (EHR), registry (new reporting system/database)</td>
</tr>
<tr>
<td>Time Point</td>
<td>Within 12 months of diagnosis and at least annually thereafter</td>
</tr>
<tr>
<td>Expert Panel Suggested Questions to Explore for Measure Development</td>
<td><strong>Definition</strong>: Should the measure be patient-reported?</td>
</tr>
<tr>
<td></td>
<td><strong>Timeframe</strong>: Should the measurement timepoint be triggered by disease events?</td>
</tr>
<tr>
<td></td>
<td><strong>Data Source</strong>: How can this information be gathered? Can it be collected via proxy?</td>
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<tr>
<td></td>
<td><strong>Attribution</strong>: How should attribution be assigned? Who should receive/act on these data?</td>
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<tr>
<td></td>
<td><strong>Implementation considerations</strong>: Should this measure be used for internal Quality Improvement (QI), accountability, or both? What minimum sample size is needed for assessment?</td>
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Table 2. Caregiver Identification for Alzheimer’s Disease Measure Concept; Part 2 of 2

<table>
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<td>Description</td>
<td>Percentage of patients whose medical record includes the name(s) of the person(s) who:</td>
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**Expert Panel Suggested Questions to Explore for Measure Development**

**Definition:** Should the measure be patient-reported?

**Timeframe:** Should the measurement timepoint be triggered by disease events?

**Data Source:** How can this information be gathered? Can it be collected via proxy?

**Attribution:** How should attribution be assigned? Who should receive/act on these data?

**Implementation considerations:** Should this measure be used for internal QI, accountability, or both? What minimum sample size is needed for assessment?

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**Roles and Responsibilities**

**NQF Measure Incubator® (Facilitator)**

The NQF Measure Incubator brings together the necessary resources—such as measure developers, clinicians, patients, and funding—to spur development of needed measures. In its role as project facilitator, the Measure Incubator will facilitate measure development and testing by others. The Measure Incubator will conduct activities such as coordinating monthly calls with the measure developer(s) to facilitate the work and provide suggestions and opportunities for efficiencies based on other Measure Incubator projects. However, the Measure Incubator will not enter into contractual agreements with any other partners the measure developer might work with, particularly data vendors and test sites. NQF does not develop measures and will not be involved in day-to-day measure development and testing activities.

**Genentech (Funder)**

This Measure Incubator project is supported by Genentech. In its role as project funder, Genentech will not directly engage with the measure developer, data partner(s), and/or potential test sites. Genentech will not specify or influence the outcome or processes of measure development and testing, in accordance with NQF Measure Incubator® COI principles.

**Measure Developer**

The measure developer will lead development and testing of the measure concept (including stratification and risk adjustment, where appropriate) using a process that is cost-effective and efficient; novel development and testing approaches are encouraged. The developer is not required to submit the incubated measure to NQF for endorsement review. If the developer elects to pursue endorsement, the incubated measure is conferred no advantage in the endorsement process in terms of endorsement or fast track review.

**Scope of Work**

The measure developer will be responsible for the following tasks:

- **Task 1:** Solicit expert input to refine measure specification and development.
  
  *Note: NQF is able to facilitate introductions between the measure developer and the Expert Panelists from the NQF-convened strategy session, as requested, and NQF will facilitate identification of additional experts, as needed. The developer is encouraged to propose novel...*
ways to integrate expert input into the process outside of the typical Technical Expert Panel process.

• **Task 2**: Collate and synthesize scientific evidence to support measure intent and specifications, along with performance gaps.
  *Note*: The measure developer can build upon the environmental scan and strategy session summary produced by NQF.

• **Task 3**: Identify and secure an appropriate data partner(s) and/or test site(s).
  *Note*: The measure developer will be responsible for identifying and securing the appropriate data source(s) and test beds. The measure developer should identify how the data partner(s) can be utilized throughout the development and specification process. The measure developer will enter into agreements with the data vendor and test site organizations.

• **Task 4**: Create measure specifications, along with stratification and/or risk adjustment approach(es), as appropriate, and determine feasibility of initial set of data elements.
  *Note*: Measure specifications should contain sufficient details to support testing and implementation.

• **Task 5**: Refine measure specifications and stratification approach(es), based on expert input, initial data analyses, and broad multistakeholder input (e.g., public commenting, and engaging patients and caregivers).

• **Task 6**: Develop and execute a detailed measure testing plan, with timeline and quality assurance protocols, to demonstrate the feasibility, reliability, and validity for the measure (including stratification and/or risk adjustment).

• **Task 7**: Provide monthly project status updates, including work completed, in progress, and upcoming, potential risks or delays, problems experienced, mitigation strategies, and proposed solution(s).

• **Task 8**: Summarize measure development and testing results, including final measure specifications and risk stratification/risk adjustment methodology, in a final report for the measure.

**Deliverables**

The measure developer will be responsible for producing the following deliverables throughout the project’s lifecycle:

• **Task 2**: Summary of scientific evidence to support measure intent and specifications, along with performance gaps

• **Task 3**: Identify and secure appropriate data partner(s) and/or test site(s)

• **Task 4**: Initial measure specifications and feasibility assessments for collection of broad multistakeholder input

• **Task 5**: Refined measure specifications, if multistakeholder input and initial data analyses generates refinements to the initial measure specifications

• **Task 6**: Detailed measure testing plan with timeline and quality assurance protocols

• **Task 7**: Written monthly project status updates

• **Task 8**: One fully specified and tested two-part measure on caregiver identification for AD

• **Task 8**: Complete final report for the measure with measure specifications, stratification methodology, detailed feasibility, reliability, and validity testing results, and recommendations for implementation and further refinement
Estimated Measure Development Timeline

The measure developer should create a timeline outlining the estimated time by task for measure development and testing.

Estimated Measure Development Budget

The measure developer should provide an estimated budget outlining the costs by task with justification.

Minimum Qualifications of Key Personnel

Staff identified to be a part of the project team should include one or more methodologists, project managers, statisticians, data analysts, quality improvement experts, and subject matter experts in AD and/or caregiver engagement. Measure developers may contract with outside individuals or organizations to ensure that the project team has the necessary expertise to support this project. The key personnel should be able to demonstrate the following qualifications:

- Established track record for successful evidence-based measure development, including AD-specific measures, caregiver measures, eCQMs, composites, and/or paired measures
- Substantial experience with all aspects of design and execution for measure development and testing, such as scientific evidence review, measure specification and testing (for feasibility, reliability, and validity), data analysis, risk adjustment (including clinical and social risk factors), and report writing
- Depth and breadth of relevant expertise, such as clinical practice, measurement methodology, health services research and/or epidemiology, clinical informatics, professional and technical claims coding, statistics, quality improvement, electronic health record (EHR) data systems and workflows, other healthcare data sources (including claims and registries), quantitative and qualitative data analysis, programming, and technical writing
- Strong project management skills, including the ability to manage accelerated and overlapping timelines
- Familiarity with testing rigorous methods, such as those outlined in NQF guidance for measure developers

*Note: In accordance with NQF Measure Incubator® COI principles, incubated measures are conferred no advantage in the NQF endorsement process, nor is pursuit of NQF endorsement a requirement for incubated measures.*

RFP Requirements

The measure developer should include the following information in the response to this RFP:

- **High-level work plan outlining measure development and testing activities** including feasibility, reliability, and validity testing and risk stratification (or risk adjustment) methodology, as appropriate

  *Note: The work plan should address the methods, processes, procedures, and protocols necessary for effective and efficient completion of all measure development and testing activities and associated deliverables. There should be sufficient description so that Measure Incubator staff can evaluate the appropriateness and adequacy of the proposed testing methods.*

- **Project timeline with key milestones and dates**

  *Note: At a minimum, the proposed project timeline should include each task, with key milestones and dates.*

- **Summary-level budget**

Applications due by September 3, 2020, 5:00 pm ET
Note: At a minimum, the proposed budget should include estimated hours and fees for each task.

- **Staffing and management roles and responsibilities** (including contracted resources) for each task. Please provide resumes or curriculum vitae for key personnel, which demonstrate specific experience with measure development and validation (including AD and caregiver-specific measures, eCQMs, composites, paired measures and/or outcome measures)
- **Measure development and project management capabilities**, including examples of previous measure development and references, specifying which capabilities are in-house and which capabilities would be outsourced

Responses to the RFP should be no more than 10 pages in length, excluding resumes and references.

**Evaluation of the Responses**

Responses will be evaluated based on the following criteria:

- **Overall Suitability**: Proposed measure development and testing approach must meet the scope and needs outlined above and be presented in a clear and organized manner.
- **Value and Cost**: Respondents will be evaluated on the timeline and cost of their approach based on the work to be performed in accordance with the scope of this project.
- **Past Experience/Qualifications**: Respondents will be evaluated based on their experience as it pertains to the scope of this project. Respondents must provide descriptions and documentation of assigned key personnel’s technical expertise and experience.
- **Novelty and Efficiency**: Proposed development and testing approach will be evaluated for their novelty and ability to provide efficient and cost-effective measure development and testing.

**Submission Instructions**

*Responses should be submitted via email to incubator@qualityforum.org by 5:00pm Eastern Time on September 3, 2020.*

Please direct any questions regarding the RFP to incubator@qualityforum.org.