# Dementia Measures

## Disclosure of the Cause of Dementia

### Measure Description
Percentage of patients with a diagnosis* of a qualifying dementing disorder or disease whose diagnosis has been disclosed to them and, if available, their primary caregiver.

### Measure Components

<table>
<thead>
<tr>
<th><strong>Numerator Statement</strong></th>
<th>Patients and patient/caregiver dyads with a diagnosis* of a qualifying dementing disorder or disease who have been told (1) that they have dementia and (2) what disease is responsible.</th>
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</thead>
<tbody>
<tr>
<td><strong>Denominator Statement</strong></td>
<td>All patients with a diagnosis of a qualifying dementing disorder or disease (Diagnostic codes listed in Appendix A)</td>
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</table>
| **Denominator Exceptions** | - Diagnosis previously disclosed (i.e., patient or caregiver provides diagnosis to provider, previous disclosure documented in medical record, or patient or caregiver states they were previously informed.)  
- Disclosure offered, but patient declines information on their diagnosis  
- Patient does not have caregiver |
| **Exception Justification** | - An exception was created to address situations where patients and their caregiver were previously informed of their diagnosis and the provider has documentation of this disclosure.  
- A patient may also decline information on their diagnosis, and a provider should not force this information if it is detrimental to patient care.  
- An exception is needed, if a patient does not have a caregiver and lacks capacity to understand their diagnosis as disclosure could be a detriment to care. |
| **Supporting Guideline & Other References** | The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:  
- “Individuals concerned about cognitive and behavioral changes associated with aging generally come to the evaluation process seeking information as well as emotional support. This often is a severely distressing situation for the individual, who may or may not have been the key individual in making the decision to have an assessment conducted (ABA & APA, 2008; APA Presidential Task Force on the Assessment of Age-Consistent Memory Decline and Dementia, 1998). Provision of both information and support while maintaining a sense of respect and dignity for the individual, regardless of level of cognitive...” |
impact, reflect both professional ethics and sound clinical practice (APA, 2002).” (1)

- “Diagnosis of AD should be disclosed to patient (and caregivers as appropriate) (Level B). Disclosure of diagnosis should be individually tailored. It should be accompanied by information and counseling, as well as useful contacts such as Alzheimer's patient organizations. Patients and caregivers should be provided with education and support (Level A).” (2)

- The experience of the diagnosis of dementia is challenging both for people with dementia and family members and for healthcare professionals, so healthcare professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members (usually only with the consent of the person with dementia). Healthcare professional should be aware that people with dementia and family members may need ongoing support to cope with the difficulties presented by the diagnosis. (3)

- “Unless a patient suffering from dementia explicitly declines to know the diagnosis, the default mode should be to inform truthfully as it will enable the patient to:
  a. Plan for optimal life experiences in remaining years of intact capacities
  b. Designate and appoint a surrogate decision maker to take over the making of treatment decision upon eventual incompetence
  c. Settle personal financial and legal matters
  d. Participate in treatment decisions
  e. Consider possible enrolment in research programmes and
  f. Participate in informed consent process” (4)

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<tr>
<th>Relationship to Desired Outcome</th>
<th>Patient/caregiver dyads who understand their diagnosis are better able to seek a second opinion, are more likely to be involved in decision-making for their care, receive better medical care, and are better able to cope with their symptoms and access services for ongoing care, support, and safety. (5)</th>
</tr>
</thead>
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<tr>
<td>Opportunity for Improvement</td>
<td>Only 45% of people with Alzheimer’s disease or their caregivers report being told of their diagnosis. (6) Diagnosis is an unmet need for patients and patient/caregiver dyads. Many community-residing individuals with dementia and their caregivers have unmet dementia-related needs for care, services and support. In one recent study, almost one-third of individuals with dementia had not received a prior evaluation or diagnosis. (7) Providers should be aware that unmet needs may be higher among minority and low-income community residents, caregivers with lower education, and individuals with early-stage dementia.</td>
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| National Quality Strategy Domains | ☑ Patient and Family Engagement  
☑ Patient Safety  
☐ Communication and Care Coordination |

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<tr>
<th>Harmonization with Existing Measures</th>
<th>No known measures addressing disclosure of diagnosis.</th>
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| Measure Purpose (Check all that apply) | ☑ Quality improvement  
☑ Accountability |
| Type of Measure (Check all that apply) | ☑ Process  
☐ Outcome  
☐ Structure |
| Level of Measurement (Check all that apply) | ☑ Individual Provider  
☑ Practice  
☑ System |
| Care Setting (Check all that apply) | ☑ Outpatient  
☑ Inpatient  
☐ Emergency Departments and Urgent Care  
☑ Post-Acute Care (i.e., Long Term Care Hospitals, Skilled Nursing Facilities, Inpatient Rehabilitation Facilities, and Home Health Agencies) |
| Data Source (Check all that apply) | ☑ Electronic health record (EHR) data  
☐ Administrative Data/Claims  
☐ Chart Review  
☑ Registry |

**References**