

# Quality Standards

## Dementia: Care for People Living in the Community

### Measurement Guide

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**Health Quality  
Ontario**

*Let's make our health system healthier*



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# 1 How to Use the Measurement Guide

This document is meant to serve as a measurement guide to support the adoption of the quality standard *Dementia: Care for People Living in the Community*. Dementia care is a critical issue, and there are significant gaps and variations in the quality of care that people with dementia who live in the community receive in Ontario. Recognizing this, Health Quality Ontario released this quality standard to identify opportunities that have a high potential for quality improvement.

This guide is intended for use by those looking to adopt the quality standard *Dementia: Care for People Living in the Community*, including health care professionals working in regional or local roles.

This guide has dedicated sections for each of the two types of measurement within the quality standard:

- **Local measurement:** what you can do to assess the quality of care that you provide locally
- **Provincial measurement:** how we can measure the success of the quality standard on a provincial level

## Important Resources for Quality Standard Adoption

Health Quality Ontario has created resources to assist with the adoption of quality standards:

- A [Getting Started Guide](#) that outlines a process for using quality standards as a resource to deliver high-quality care. It includes links to templates, tools, and stories and advice from health care professionals, patients, and caregivers. You can use this guide to learn about evidence-based approaches to implementing changes to practice
- A [Quality Improvement Guide](#) to give health care teams and organizations in Ontario easy access to well-established quality improvement tools. The guide provides examples of how to adapt and apply these tools to our Ontario health care environments
- An online community called [Quorum](#) that is dedicated to working together to improve the quality of health care across Ontario. Quorum can support your quality improvement efforts

## 2 Quality Indicators in Quality Standards

Quality standards inform providers and patients about what high-quality health care looks like for aspects of care that have been deemed a priority for quality improvement in the province. They are intended to guide quality improvement, monitoring, and evaluation.

Measurability is a key principle in developing and describing the quality statements; each statement is accompanied by one or more indicators. This section describes the measurement principles behind the quality indicators, the process for developing these indicators, and the technical definitions of the indicators.

An effective quality statement must be measurable. Measurement is necessary to demonstrate if a quality statement has been properly implemented, and if it is improving care for patients. This is a key part of the [Plan-Do-Study-Act](#) improvement cycle. If measurement shows there has been no improvement, you need to consider a change or try something different.

### 2.1 Measurement Principles

Health Quality Ontario uses the process, structure, and outcome indicator framework developed by [Donabedian](#) in 1966 to develop indicators for quality standards. The three indicator types play essential and interrelated roles in measuring the quality of health care and the impact of introducing and using quality standards.

The indicators provided are merely suggestions. It is not expected that every provider, team, or organization will be able to measure all of them (or even want to measure all of them), but they can identify which indicators best capture areas of improvement for their care and what is easiest to measure given existing local data sources.

### 2.2 Process Indicators

Process indicators assess the activities involved in providing care. They measure the percentage of specified individuals, episodes, or encounters for which an activity (process) is performed. In most cases, the numerator should specify a timeframe in which the action is to be performed, established through evidence or expert consensus. When a quality statement applies to a subset of individuals rather than the total population, the denominator should reflect the population of the appropriate subgroup, rather than the entire Ontario population. If exclusions are required or stratifications are suggested, they are reflected in the indicator specifications.

Process indicators are central to assessing whether or not the quality statement has been achieved; nearly all quality statements are associated with one or more process indicators. In most cases, the numerator and denominator for process indicators can be derived from the language of the quality statement itself; additional parameters (such as a timeframe) can also appear in the definitions section. In some cases, a proxy indicator is provided that indirectly measures the process. Proxy indicators are used only when the actual indicator cannot be measured with currently available data.

While most quality statements focus on a single concept and are linked with a single process indicator, some statements include two or more closely related concepts. In these cases, multiple process indicators can be considered to capture all aspects of the quality statement.

For example, a quality statement might suggest the need for a comprehensive assessment with several components, and each of those components might have a process indicator.

Examples of process indicators include the percentage of patients with hip fracture who receive surgery within 48 hours, or the percentage of patients with schizophrenia who are offered clozapine after first- and second-line antipsychotics have been ineffective. Please refer to the published [quality standards](#) for more examples.

### 2.3 Structural Indicators

Structural indicators assess the characteristics and resources that influence and enable delivery of care. These can include equipment; systems of care; availability of resources; and teams, programs, policies, protocols, licences, or certifications. Structural indicators assess whether factors that are in place are known to help in achieving the quality statement.

Some quality statements have structural indicators associated with them. Structural indicators are binary or categorical and do not require the definition of a numerator and denominator. However, in some cases it could be useful to specify a denominator defining an organizational unit, such as a hospital, a primary care practice, or a local region. In many cases data for structural indicators are not readily available using existing administrative data, so local data collection might be required. This local data collection might require regional or provincial level data collection systems to be developed.

Structural indicators should be defined for a quality statement or for the quality standard as a whole when there is strong evidence that a particular resource, capacity, or characteristic is important for enabling the effective delivery of a process of care. It should be theoretically feasible for these structural elements to be implemented across Ontario, even if adoption is aspirational in some cases. In rare instances, a quality statement might have two or more associated structural indicators, if the quality standard advisory committee decides that multiple factors are crucial to the delivery of the quality statement.

Examples of structural indicators include the availability of a stroke unit, the existence of discharge planning protocols, or access to a specialized behavioural support team. Please refer to the published [quality standards](#) for more examples.

### 2.4 Outcome Indicators

Outcome indicators assess the end results of the care provided. They are crucial and are arguably the most meaningful measures to collect, but many health outcomes—such as mortality or unplanned hospital readmissions—are often the product of a variety of related factors and cannot be reliably attributed to a single process of care. For this reason, although relatively few quality statements are directly linked to an outcome indicator, a set of overall measures—including key outcome indicators—is defined for the quality standard as a whole, reflecting the combined effect of all of the quality statements in the standard. Similar to process indicators, outcome indicators should be specified using a defined denominator and a numerator that, in most cases, should include a clear timeframe.

Examples of outcome indicators include mortality rates, improvement (or decline) in function, and patients' experience of care. Please refer to the published [quality standards](#) for more examples.

## 2.5 Balancing Measures

Balancing measures indicate if there are important unintended adverse consequences in other parts of the system. Examples include staff satisfaction and workload. Balance measures are embedded throughout the standard. Although they are not the focus of the standard, the intention is to monitor the unintended consequences.

## 3 Local Measurement

As part of the *Dementia: Care for People Living in the Community* quality standard, *specific* measures were identified for each of the statements to support measurement for quality improvement.

As an early step in your project, we suggest that your team complete an *initial assessment* of the relevant measures in the standard and come up with a draft measurement plan.

Here are some concrete next steps:

1. Review the list of identified measures (in the quality standard), and determine which measures you will use as part of your adoption planning, given your knowledge of current gaps in care
2. Determine the availability of data related to the measures you have chosen
3. Identify a way to collect local data related to your chosen measures
4. Develop a draft measurement plan

The earlier you complete the above steps, the more successful your quality improvement project is likely to be.

### 3.1 Local Data Collection

Local data collection refers to data collection at the health provider or team level for indicators that cannot be assessed using provincial administrative databases (such as databases held by the Institute for Clinical Evaluative Sciences or the Canadian Institute for Health Information). Examples include data from electronic medical records, clinical patient records, regional data collection systems, and locally administered patient surveys. Indicators that require local data collection can signal an opportunity for local measurement, data advocacy, or improvement.

Local data collection has many strengths: it is timely, can be tailored to quality improvement initiatives, and is modifiable on the basis of currently available data. However, caution is required when comparing indicators using local data collection between providers to ensure consistency in definitions, consistency in calculation, and validity across patient groups.

### 3.2 Measurement Principles for Local Data Collection

Three types of data can be used to construct measures in quality improvement: continuous, classification, and count data.

#### 3.2.1 Continuous Data

Continuous data can take any numerical value in a range of possible values. These values can refer to a dimension, a physical attribute, or a calculated number. Examples include patient weight, number of calendar days, and temperature.

#### 3.2.2 Classification Data

Classification (or categorical) data are recorded in two or more categories or classes. Examples include sex, race or ethnicity, and number of patients with depression versus number of patients without depression. In some cases, you might choose to convert continuous data into

categories. For example, you could classify patient weight as underweight, normal weight, overweight, or obese.

Classification data are often presented as percentages. To calculate a percentage from classification data, you need a numerator and a denominator (a percentage is calculated by dividing the numerator by the denominator and multiplying by 100). The numerator includes the number of observations meeting the criteria (e.g., number of patients with depression), and the denominator includes the total number of observations measured (e.g., total number of patients in clinic). Note that the observations in the numerator must also be included in the denominator (source population).

Examples of measures that use classification data include percentage of patients with a family physician and percentage of patients who receive therapy.

### 3.2.3 Count Data

Count data often focus on attributes that are unusual or undesirable. Examples include number of falls in a long-term care home and number of medication errors.

Count data are often presented as a rate, such as the number of events per 100 patient-days or per 1,000 doses. The numerator of a rate counts the number of events/nonconformities, and the denominator counts the number of opportunities for an event. It is possible for the event to occur more than once per opportunity (e.g., a long-term care resident could fall more than once).

*Rate of 30-day hospital readmission =*

$$\frac{\text{No. of hospital readmissions within 30 days of discharge [numerator]}}{\text{No. of discharges from hospital [denominator]}}$$

### 3.2.4 Benefits of Continuous Data

It is common practice in health care to measure toward a target instead of reporting continuous measures in their original form. An example would be measuring the number of patients who saw their primary care physician within 7 days of hospital discharge instead of measuring the number of days between hospital discharge and an appointment with a primary care physician. Targets should be evidence-based or based on a high degree of consensus across clinicians.

When a choice exists, continuous data sometimes are more useful than count or classification data for learning about the impact of changes tested. Measures based on continuous data are more responsive and can capture smaller changes than measures based on count or classification data; therefore, it is easier and faster to see improvement with measures based on continuous data. This is especially true when the average value for the continuous measure is far from the target. Continuous data are also more sensitive to change. For example, while you might not increase the number of people who are seen within 7 days, you might reduce how long people wait.

## 3.3 Benchmarks and Targets

Benchmarks are markers of excellence to which organizations can aspire. Benchmarks should be evidence-based or based on a high degree of consensus across clinicians. At this time, Health Quality Ontario does not develop benchmarks for the indicators. Users of these

standards have variable practices, resources, and patient populations, so one benchmark might not be practical for the entire province.

Targets are goals for care that are often developed in the context of the local care environment. Providers, teams, and organizations are encouraged to develop their own targets appropriate to their patient populations and their quality improvement work. Organizations that include a quality standard indicator in their quality improvement plans are asked to use a target that reflects improvement. Timeframe targets, like the number of people seen within 7 days, are typically provided with process indicators intended to guide quality improvement.

In many cases, achieving 100% on an indicator is not possible. This is why it is important to track these indicators over time, to compare results against those of colleagues, to assess progress, and to aim for improvement rather than a perfect record.

For guidance on setting benchmarks and targets at a local level, refer to:

- [Approaches to Setting Targets for Quality Improvement Plans](#)
- [Long-Term Care Benchmarking Resource Guide](#)

## 4 Provincial Measurement

In its quality standards, Health Quality Ontario strives to incorporate measurement that is standardized, reliable, and comparable across providers to assess the impact of the standards provincially. Where possible, indicators should be measurable using province-wide data sources. However, in many instances data are unavailable for indicator measurement. In these cases, the source is described as local data collection.

For more information on the data sources referenced in this standard, please see the **appendix**.

### 4.1 Accessing Provincially Measurable Data

Provincial platforms are available to create custom analyses to help you calculate results for identified measures of success. Examples of these platforms include IntelliHealth, eReports, and Query.

#### 4.1.1 *IntelliHealth—Ministry of Health and Long Term Care*

“IntelliHealth is a knowledge repository that contains clinical and administrative data collected from various sectors of the Ontario healthcare system. IntelliHealth enables users to create queries and run reports through easy web-based access to high quality, well organized, integrated data.”

#### 4.1.2 *eReports—Canadian Institute for Health Information*

Quick Reports offer at-a-glance comparisons for the organizations you choose. The tool also provides some ways to manipulate the pre-formatted look and feel of the reports. Flexible or Organization Reports offer you many choices to compare your organization’s data with those of other organizations. With these customizable reports, you can view data by different attributes and for multiple organizations.

Both report types allow trending over time and provide a comparison of organizations with regions, provinces or territories, or the entire database.

#### 4.1.3 *Query—Public Health Ontario*

“Query is a dynamic tool that allows public health professionals to instantly explore, manipulate and analyze health data using pre-defined reports and variables.” Query tools are available for reportable infectious disease data (ID Query) and health care-associated infection data (HAI Query).

## 5 How Success Can Be Measured for This Quality Standard

This measurement guide accompanies Health Quality Ontario's quality standard *Dementia: Care for People Living in the Community*. Early in the development of each quality standard, a few performance indicators are chosen to measure the success of the entire standard. These indicators guide the development of the quality standard so that every statement within the standard aids in achieving the standard's overall goals.

This measurement guide includes information on the definitions and technical details of the indicators listed below:

- Rate of emergency department visits for people living with dementia in the community
- Rate of hospitalizations for people living with dementia in the community
- Average length of stay in hospital for people living with dementia in the community
- Alternate-level-of-care days for people living with dementia in the community
- Average length of stay in the community for people living with dementia
- Percentage of people living with dementia in the community and their caregivers who each have optimized quality of life
- Percentage of people living with dementia in the community who are confident with self-care
- Percentage of caregivers of people living with dementia in the community who are confident with their ability to work collaboratively with people living with dementia to provide care based on their needs and preferences
- Percentage of people living with dementia in the community and their caregivers who reported being satisfied or very satisfied with care and services received in the community

This guide includes data sources for indicators that can be consistently measured across providers, across the sectors of health care, and across the province.

Indicators are categorized as:

- Provincially measurable (the indicator is well defined and validated) *or*
- Locally measurable (the indicator is not well defined, and data sources do not currently exist to measure it consistently across providers and at the system level)

For more information on statement-specific indicators, please refer to the quality standard.

### 5.1 Quality Standard Scope

This quality standard addresses care for community-dwelling people living with dementia, including the assessment of people suspected to have dementia or mild cognitive impairment. The quality standard focuses on primary care, specialist care, hospital outpatient services, home care, and community support services. It also provides guidance on support for caregivers of people living with dementia.

This quality standard does not apply to care provided in an emergency department or hospital in-patient setting or to people living in long-term care homes. Nor does it address specific aspects of palliative care for people living with dementia.

For a quality standard that addresses care for people living with dementia and the specific behaviours of agitation or aggression who are in an emergency department, admitted to a hospital, or in a long-term care home, refer to Health Quality Ontario's quality standard *Behavioural Symptoms of Dementia: Care for Patients in Hospitals and Residents in Long-Term Care Homes*.

For a quality standard that addresses palliative care, refer to Health Quality Ontario's quality standard *Palliative Care: Care for Adults with a Progressive, Life-Limiting Illness*.

## 5.2 Cohort Identification

The cohort used is the total number of community-dwelling people living with dementia. Table 1 outlines the algorithm used to identify the cohort.

## 5.3 How Success Can Be Measured Provincially

The Dementia Care in the Community Quality Standard Advisory Committee identified a few overarching goals for this quality standard. These goals have been mapped to indicators that can be used to assess quality of care provincially and locally. The following five indicators are currently measurable in Ontario's health care system:

- Rate of emergency department visits for people living with dementia in the community
- Rate of hospitalizations for people living with dementia in the community
- Average length of stay in hospital for people living with dementia in the community
- Alternate-level-of-care days for people living with dementia in the community
- Average length of stay in the community for people living with dementia

Methodologic details are described in the tables below.

Table 1: Rate of Emergency Department Visits for People Living With Dementia in the Community

GENERAL DESCRIPTION	Indicator description	Name: Rate of emergency department visits for people living with dementia in the community
	<b>Measurability</b>	<b>Measurable</b>
	Dimensions of quality	Effectiveness
DEFINITION & SOURCE INFORMATION	Calculation: General	<p><b>Denominator</b> Total number of people living with dementia in the community Algorithm used to identify people living with dementia in the community consists of the following<sup>a</sup>:</p> <ul style="list-style-type: none"> <li>• One hospitalization record from CIHI's DAD with a dementia-related diagnosis or</li> <li>• At least 3 physician claim records at least 30 days apart in a 2-year period from OHIP database with a dementia-related diagnosis or</li> <li>• One prescription drug reimbursement record for dementia medications funded by the ODB (e.g., donepezil, galantamine, or rivastigmine)</li> </ul> <p><b>Numerator</b> Total number of admissions to the emergency department among people in the denominator</p> <p><b>Exclusions</b></p> <ul style="list-style-type: none"> <li>• Invalid OHIP number</li> <li>• Patients who are not Ontario residents</li> <li>• Sex not recorded as male or female</li> <li>• Records with an invalid date of birth</li> <li>• Age &gt; 120 y</li> </ul> <p><b>Method</b> Numerator ÷ Denominator</p> <p><b>Data sources:</b> NACRS, DAD, OHIP, and ODB</p>
GEOGRAPHY & TIMING	Levels of comparability	Province, LHIN

ADDITIONAL INFORMATION	Limitations	<p>This indicator cannot demonstrate if emergency department visits for people living with dementia in the community were appropriate. It does not capture emergency department visits in which care could be best managed elsewhere, nor underlying reasons (e.g., lack of community support/care, housing, other non–dementia-related conditions, health factors) for the emergency department visit</p> <p>People living with dementia in the community can be identified via the algorithm developed by Jaakkimainen and colleagues in 2016.<sup>a</sup> The algorithm has a sensitivity of 79.3%, a specificity of 99.1%, a positive predictive value of 80.4%, and a negative predictive value of 99.0%.<sup>a</sup></p> <p>Some challenges of using administrative data to study dementia include the following:</p> <ul style="list-style-type: none"> <li>• Not all community-dwelling people living with dementia can be identified from health administrative data</li> <li>• People living with dementia who do not have a physician diagnosis or dementia-specific drug recorded in Ontario's administrative data will not be counted</li> <li>• People who have MCI or who lack a formal physician diagnosis will not be counted</li> <li>• Timeliness of administrative data available</li> </ul>
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Abbreviations: CIHI, Canadian Institute for Health Information; DAD, Discharge Abstract Database; LHIN, local health integration network; MCI, mild cognitive impairment; NACRS, National Ambulatory Care Reporting System; ODB, Ontario Drug Benefit; OHIP, Ontario Health Insurance Plan.

<sup>a</sup>Source: Jaakkimainen RL, Bronskill SE, Tierney MC, Herrmann N, Green D, Young J, et al. Identification of physician-diagnosed Alzheimer's disease and related dementias in population-based administrative data: a validation study using family physicians' electronic medical records. *J Alzheimers Dis* 2016 Aug 10 [cited 2017 Dec 11];54(1):337-49. Abstract available at: <https://www.ncbi.nlm.nih.gov/pubmed/27567819>

Table 2: Rate of Hospitalizations for People Living With Dementia in the Community

GENERAL DESCRIPTION	Indicator description	Name: Rate of hospitalizations for people living with dementia in the community
	<b>Measurability</b>	<b>Measurable</b>
	Dimensions of quality	Effectiveness
DEFINITION & SOURCE INFORMATION	Calculation: General	<p><b>Denominator</b> Total number of people living with dementia in the community</p> <p>Algorithm used to identify people living with dementia in the community consists of the following<sup>a</sup>:</p> <ul style="list-style-type: none"> <li>• One hospitalization record from CIHI’s DAD with a dementia-related diagnosis or</li> <li>• At least 3 physician claim records at least 30 days apart in a 2-year period from OHIP database with a dementia-related diagnosis or</li> <li>• One prescription drug reimbursement record for dementia medications funded by the ODB (e.g., donepezil, galantamine or rivastigmine)</li> </ul> <p><b>Numerator</b> Total number of acute care discharges among people in the denominator</p> <p><b>Exclusions</b></p> <ul style="list-style-type: none"> <li>• Invalid OHIP number</li> <li>• Patients who are not Ontario residents</li> <li>• Sex not recorded as male or female</li> <li>• Age &gt; 120 y</li> <li>• Records with an invalid date of birth</li> <li>• Records with an invalid admission date or time</li> <li>• Records with an invalid discharge date or time</li> <li>• Records with an admission category of stillbirth or cadaveric donor</li> </ul> <p><b>Method</b> Numerator ÷ Denominator</p> <p><b>Data sources:</b> DAD, OHIP, and ODB</p>

GEOGRAPHY & TIMING	Levels of comparability	Province, LHIN
ADDITIONAL INFORMATION	Limitations	<p>This indicator cannot demonstrate whether hospitalizations for people living with dementia in the community were appropriate. It does not capture underlying reasons for hospitalizations (e.g., comorbidities)</p> <p>People living with dementia in the community can be identified via the algorithm developed by Jaakkimainen and colleagues in 2016.<sup>a</sup> The algorithm has a sensitivity of 79.3%, a specificity of 99.1%, a positive predictive value of 80.4%, and a negative predictive value of 99.0%.<sup>a</sup></p> <p>Some challenges of using administrative data to study dementia include the following:</p> <ul style="list-style-type: none"> <li>• Not all community-dwelling people living with dementia can be identified from health administrative data</li> <li>• People living with dementia who do not have a physician diagnosis or dementia-specific drug recorded in Ontario's administrative data will not be counted</li> <li>• People who have MCI or who lack a formal physician diagnosis will not be counted</li> <li>• Timeliness of the administrative data available</li> </ul>

Abbreviations: CIHI, Canadian Institute for Health Information; DAD, Discharge Abstract Database; LHIN, local health integration network; MCI, mild cognitive impairment; ODB, Ontario Drug Benefit; OHIP, Ontario Health Insurance Plan.

<sup>a</sup>Source: Jaakkimainen RL, Bronskill SE, Tierney MC, Herrmann N, Green D, Young J, et al. Identification of physician-diagnosed Alzheimer's disease and related dementias in population-based administrative data: a validation study using family physicians' electronic medical records. *J Alzheimers Dis* 2016 Aug 10 [cited 2017 Dec 11];54(1):337-49. Abstract available at: <https://www.ncbi.nlm.nih.gov/pubmed/27567819>

Table 3: Average Length of Stay in Hospital for People Living With Dementia in the Community

GENERAL DESCRIPTION	Indicator description	Name: Average length of stay in hospital for people living with dementia in the community
	<b>Measurability</b>	<b>Measurable</b>
	Dimensions of quality	Effectiveness
DEFINITION & SOURCE INFORMATION	Calculation: General	<p><b>Step 1:</b> Identify people living with dementia in the community</p> <p>Algorithm used to identify people living with dementia in the community consists of the following<sup>a</sup>:</p> <ul style="list-style-type: none"> <li>• One hospitalization record from CIHI’s DAD with a dementia-related diagnosis or</li> <li>• At least 3 physician claim records at least 30 days apart in a 2-year period from OHIP database with a dementia-related diagnosis or</li> <li>• One prescription drug reimbursement record for dementia medications funded by the ODB (e.g., donepezil, galantamine, or rivastigmine)</li> </ul> <p><b>Step 2:</b> Calculate length of stay for each person living with dementia in the community who stayed in hospital (e.g., length of time spent from date of admission to date of discharge)</p> <p><b>Step 3:</b> Apply exclusion criteria</p> <p><b>Exclusions</b></p> <ul style="list-style-type: none"> <li>• Invalid OHIP number</li> <li>• Patients who are not Ontario residents</li> <li>• Sex not recorded as male or female</li> <li>• Age &gt; 120 y</li> <li>• Records with an invalid health card number</li> <li>• Records with an invalid date of birth</li> <li>• Records with an invalid admission date or time</li> <li>• Records with an invalid discharge date or time</li> <li>• Records with an admission category of stillbirth or cadaveric donor</li> </ul> <p><b>Step 4:</b> Average the data (i.e., calculate the mean)</p> <p><b>Data sources:</b> DAD, OHIP, and ODB</p>

GEOGRAPHY & TIMING	Levels of comparability	Province, LHIN
ADDITIONAL INFORMATION	Limitations	<p>This indicator cannot determine the appropriate length of stay in hospital for people living with dementia in the community. Appropriate length of stay depends on several factors, including severity and conditions for the hospital stay, extent of care needed, and availability of resources elsewhere in the health system outside of hospital that provide the type of care patients need, such as a long-term care home, home care, or community support services</p> <p>People living with dementia in the community can be identified via the algorithm developed by Jaakkimainen and colleagues in 2016.<sup>a</sup> The algorithm has a sensitivity of 79.3%, a specificity of 99.1%, a positive predictive value of 80.4%, and a negative predictive value of 99.0%.<sup>a</sup></p> <p>Some challenges of using administrative data to study dementia include the following:</p> <ul style="list-style-type: none"> <li>• Not all community-dwelling people living with dementia can be identified from health administrative data</li> <li>• People living with dementia who do not have a physician diagnosis or dementia-specific drug recorded in Ontario’s administrative data will not be counted</li> <li>• People who have MCI or who lack a formal physician diagnosis will not be counted</li> <li>• Timeliness of administrative data available</li> </ul>

Abbreviations: CIHI, Canadian Institute for Health Information; DAD, Discharge Abstract Database; LHIN, local health integration network; MCI, mild cognitive impairment; ODB, Ontario Drug Benefit; OHIP, Ontario Health Insurance Plan.

<sup>a</sup>Source: Jaakkimainen RL, Bronskill SE, Tierney MC, Herrmann N, Green D, Young J, et al. Identification of physician-diagnosed Alzheimer’s disease and related dementias in population-based administrative data: a validation study using family physicians’ electronic medical records. *J Alzheimers Dis* 2016 Aug 10 [cited 2017 Dec 11];54(1):337-49. Abstract available at: <https://www.ncbi.nlm.nih.gov/pubmed/27567819>

Table 4: Alternate-Level-of-Care Days for People Living With Dementia in the Community

GENERAL DESCRIPTION	Indicator description	Name: Alternate-level-of-care days for people living with dementia in the community
	<b>Measurability</b>	<b>Measurable</b>
	Dimensions of quality	Effectiveness
DEFINITION & SOURCE INFORMATION	Calculation: General	<p><b>Denominator</b></p> <p>Total number of inpatient days in a given period for people living with dementia in the community</p> <p>Algorithm used to identify people living with dementia in the community consists of the following<sup>a</sup>:</p> <ul style="list-style-type: none"> <li>• One hospitalization record from CIHI's DAD with a dementia-related diagnosis or</li> <li>• At least 3 physician claim records at least 30 days apart in a 2-year period from OHIP database with a dementia-related diagnosis or</li> <li>• One prescription drug reimbursement record for dementia medications funded by the ODB (e.g., donepezil, galantamine, or rivastigmine)</li> </ul> <p><b>Exclusions</b></p> <ul style="list-style-type: none"> <li>• Patient days contributed by patients in the emergency department</li> <li>• Invalid OHIP number</li> <li>• Patients who are not Ontario residents</li> <li>• Sex not recorded as male or female</li> <li>• Age &gt; 120 y</li> </ul> <p><b>Numerator</b></p> <p>Total number of inpatient days designated as ALC in a given period (e.g., monthly, quarterly, or yearly) for the number of people living with dementia in the community in the denominator. Inpatient service type is identified in the WTIS</p> <p><b>Exclusions</b></p> <ul style="list-style-type: none"> <li>• ALC cases discontinued owing to data entry error</li> <li>• ALC cases where Inpatient Service = Discharge Destination for Post-Acute Care (exception: Bloorview Rehab, complex continuing care to complex continuing care)</li> <li>• ALC cases identified by facility for exclusion</li> </ul> <p><b>Method</b></p> <p>Numerator ÷ Denominator × 100</p>

		<b>Data sources:</b> WTIS-ALC, DAD, OHIP, and ODB
<b>GEOGRAPHY &amp; TIMING</b>	Levels of comparability	Province, LHIN
<b>ADDITIONAL INFORMATION</b>	Limitations	<p>ALC indicator excludes facilities that are currently not reporting ALC data to WTIS. WTIS-ALC data are available only beginning in July 2011. BCS has a 3-month reporting lag. Validation is required to ensure that specific bed types (in BCS) correspond to those in WTIS. Information for both numerator (WTIS) and denominator (BCS) is based on data available at a specific time. Therefore, rates calculated using these data are subject to change depending on when calculations are made</p> <p>People living with dementia in the community can be identified via the algorithm developed by Jaakkimainen and colleagues in 2016.<sup>a</sup> The algorithm has a sensitivity of 79.3%, a specificity of 99.1%, a positive predictive value of 80.4%, and a negative predictive value of 99.0%.<sup>a</sup></p> <p>Some challenges of using administrative data to study dementia include the following:</p> <ul style="list-style-type: none"> <li>• Not all community-dwelling people living with dementia can be identified from health administrative data</li> <li>• People living with dementia who do not have a physician diagnosis or dementia-specific drug recorded in Ontario administrative data will not be counted</li> <li>• People who have MCI or who lack a formal physician diagnosis will not be counted</li> <li>• Timeliness of administrative data available</li> </ul>
	Comments	<ul style="list-style-type: none"> <li>• Day of ALC designation is counted as an ALC day, but date of discharge or discontinuation is not counted as an ALC day</li> <li>• For cases with an ALC designation date on last day of a reporting period and no discharge or discontinuation date, ALC days = 1</li> <li>• ALC rate indicator method makes the assumption that the Inpatient Service data element (as defined in the WTIS) is comparable to the Bed Type data element (as defined in the BCS)</li> </ul>

Abbreviations: ALC, alternate levels of care; BCS, Bed Census Summary; CIHI, Canadian Institute for Health Information; DAD, Discharge Abstract Database; LHIN, local health integration network; MCI, mild cognitive impairment; ODB, Ontario Drug Benefit; OHIP, Ontario Health Insurance Plan; WTIS, Wait Time Information System.

<sup>a</sup>Source: Jaakkimainen RL, Bronskill SE, Tierney MC, Herrmann N, Green D, Young J, et al. Identification of physician-diagnosed Alzheimer's disease and related dementias in population-based administrative data: a validation study using family physicians' electronic medical records. *J Alzheimers Dis* 2016 Aug 10 [cited 2017 Dec 11];54(1):337-49. Abstract available at: <https://www.ncbi.nlm.nih.gov/pubmed/27567819>

Table 5: Average Length of Stay in the Community for People Living With Dementia

GENERAL DESCRIPTION	Indicator description	Name: Average length of stay in the community for people living with dementia
	Indicator status	Measurable
	Dimensions of quality	Patient-centred
DEFINITION & SOURCE INFORMATION	Calculation	<p><b>Step 1:</b> Identify people living with dementia in the community</p> <p>Algorithm used to identify people living with dementia in the community consists of the following<sup>a</sup>:</p> <ul style="list-style-type: none"> <li>• One hospitalization record from CIHI's DAD with a dementia-related diagnosis or</li> <li>• At least 3 physician claim records at least 30 days apart in a 2-year period from OHIP database with a dementia-related diagnosis or</li> <li>• One prescription drug reimbursement record for dementia medications funded by the ODB (e.g., donepezil, galantamine, or rivastigmine)</li> </ul> <p><b>Step 2:</b> Calculate length of stay in the community for each person living with dementia (i.e., time from dementia diagnosis to long-term care home placement or death)</p> <p><b>Step 3:</b> Apply inclusion and exclusion criteria</p> <p><b>Inclusions</b></p> <ul style="list-style-type: none"> <li>• People living with dementia in the community who are admitted to a long-term care home</li> <li>• People living with dementia in the community who die before admission to a long-term care home</li> </ul> <p><b>Exclusions</b></p> <ul style="list-style-type: none"> <li>• People living with dementia in the community who are not Ontario residents</li> <li>• Records with an invalid long-term care home admission date or time</li> <li>• Records with an invalid dementia diagnosis date or time</li> <li>• Death records that cannot be matched to RPDB</li> </ul> <p><b>Step 4:</b> Average the data (i.e., calculate the mean)</p> <p><b>Data sources:</b> OHIP, DAD, ODB, CCRS, RPDB, NACRS, and NRS</p>

ADDITIONAL INFORMATION	Limitations	<p>People living with dementia in the community can be identified via the algorithm developed by Jaakkimainen and colleagues in 2016.<sup>a</sup> The algorithm has a sensitivity of 79.3%, a specificity of 99.1%, a positive predictive value of 80.4%, and a negative predictive value of 99.0%.<sup>a</sup></p> <p>Some challenges of using administrative data to study dementia include the following:</p> <ul style="list-style-type: none"> <li>• Not all community-dwelling people living with dementia can be identified from health administrative data</li> <li>• People living with dementia who do not have a physician diagnosis or dementia-specific drug recorded in Ontario administrative data will not be counted</li> <li>• People who have MCI or who lack a formal physician diagnosis will not be counted</li> <li>• Timeliness of administrative data available</li> </ul> <p>The stage of dementia progression at diagnosis also varies</p> <p>Exact date of discharge from home care to long-term care may require further validation</p>
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Abbreviations: CIHI, Canadian Institute for Health Information; CCRS, Continuing Care Reporting System; DAD, Discharge Abstract Database; MCI, mild cognitive impairment; NACRS, National Ambulatory Care Reporting System; NRS, National Rehabilitation System; ODB, Ontario Drug Benefit; OHIP, Ontario Health Insurance Plan; RPDB, Registered Persons Database.

<sup>a</sup>Source: Jaakkimainen RL, Bronskill SE, Tierney MC, Herrmann N, Green D, Young J, et al. Identification of physician-diagnosed Alzheimer's disease and related dementias in population-based administrative data: a validation study using family physicians' electronic medical records. *J Alzheimers Dis* 2016 Aug 10 [cited 2017 Dec 11];54(1):337-49. Abstract available at: <https://www.ncbi.nlm.nih.gov/pubmed/27567819>

## 5.4 How Success Can Be Measured Locally

You might want to assess the quality of care you provide to your patients with dementia who live in the community. You might also want to monitor your own quality improvement efforts. It can be possible to do this using your own clinical records, or you might need to collect additional data. We recommend the following list of potential indicators, some of which cannot be measured provincially using currently available data:

- Percentage of people living with dementia in the community and their caregivers who each have optimized quality of life
- Percentage of people living with dementia in the community who are confident with self-care
- Percentage of caregivers of people living with dementia in the community who are confident about their ability to work collaboratively with people living with dementia to provide care based on their needs and preferences
- Percentage of people living with dementia in the community and their caregivers who reported being satisfied or very satisfied with care and services received in the community

Methodologic details are described in the tables below.

Table 6: Percentage of People Living With Dementia in the Community and Their Caregivers Who Each Have Optimized Quality of Life

GENERAL DESCRIPTION	Indicator description	Name: Percentage of people living with dementia in the community and their caregivers who each have optimized quality of life Directionality: A higher percentage is better
	Indicator status	<b>Developmental</b>
	Dimensions of quality	Patient-centred
DEFINITION & SOURCE INFORMATION	Calculation	<p><b>Denominator</b></p> <ul style="list-style-type: none"> <li>• Number of people living with dementia in the community or</li> <li>• Number of caregivers for people living with dementia in the community</li> </ul> <p><b>Numerator</b> Number of people in the denominator who have optimized quality of life (The word “optimized” was used because quality of life would vary from person to person and depending on stage of disease. Please refer to comments for more details on the rationale)</p> <p><b>Method</b> Numerator ÷ Denominator × 100</p>
	Data source	Local data collection
ADDITIONAL INFORMATION	Limitations	There is no standardized tool to measure quality of life for people living with dementia in the community and their caregivers. Several quality-of-life tools are examined in the literature, such as the Affect and Activity Ratings, ADRQL, CBS, DQoL, PWB-CIP, QOL-AD, QOLAS, and QUALID Scale <sup>a</sup>
	Comments	<p>The word “optimized” was used because it emphasizes improving and enhancing quality of life. It also recognizes that each person’s definition of quality of life is different and unique; therefore, it is important to treat each person (i.e., people living with dementia and their caregivers) as an individual and to continue to maintain or improve their quality of life based on their strengths, needs, and preferences</p> <p>Caregivers can be defined as family members and friends who provide some type of support to people living with dementia in the community</p>
	Potential proxy indicator	

Abbreviations: ADRQL, Alzheimer Disease–Related Quality of Life; CBS, Cornell-Brown Scale for Quality of Life; DQoL, Dementia Quality of Life; PWB-CIP, Psychological Well-Being in Cognitively Impaired Persons; QOL-AD, Quality of Life–Alzheimer’s Disease; QOLAS, Quality of Life Assessment Schedule; QUALID, Quality of Life in Late-Stage Dementia.

<sup>a</sup>Source: Ready RE, Ott BR. Quality of Life measures for dementia. *Health Qual Life Outcomes* 2003 Apr 23 [cited 2017 Dec 11];1:11. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/27567819>

Table 7: Percentage of People Living With Dementia in the Community Who Are Confident With Self-Care

GENERAL DESCRIPTION	Indicator description	Name: Percentage of people living with dementia in the community who are confident with self-care Directionality: A higher percentage is better
	<b>Indicator status</b>	<b>Developmental</b>
	Dimensions of quality	Patient-centred
DEFINITION & SOURCE INFORMATION	Calculation	<b>Denominator</b> Number of people living with dementia in the community  <b>Numerator</b> Number of people in the denominator who are confident about the care they provide for themselves  <b>Method</b> $\text{Numerator} \div \text{Denominator} \times 100$
	Data source	Local data collection
ADDITIONAL INFORMATION	Limitations	
	Comments	Definition of confidence can vary depending on the organization, service provided, and individual factors. For example, education and training can increase confidence of people living with dementia because they can better understand dementia, its progression, and treatment options. They can continue to live well and contribute to society. Information about available supports allows people to make informed decisions about their care and plan for the future  The definition of self-care can vary and can include physical care, social care, emotional care, and other forms of care  Learning from the development and delivery of educational materials can be expected to further influence development of this indicator
	Potential proxy indicator	

Table 8: Percentage of Caregivers of People Living With Dementia in the Community Who Are Confident About Their Ability to Work Collaboratively With People Living With Dementia to Provide Care Based on Their Needs and Preferences

GENERAL DESCRIPTION	Indicator description	Name: Percentage of caregivers of people living with dementia in the community who are confident about their ability to work collaboratively with people living with dementia to provide care based on their needs and preferences Directionality: A higher percentage is better
	<b>Indicator status</b>	<b>Developmental</b>
	Dimensions of quality	Patient-centred
DEFINITION & SOURCE INFORMATION	Calculation	<b>Denominator</b> Number of caregivers for people living with dementia in the community  <b>Numerator</b> Number of people in the denominator who are confident about their ability to work collaboratively with people living with dementia to provide care on the basis of their needs and preferences  <b>Method</b> $\text{Numerator} \div \text{Denominator} \times 100$
	Data source	Local data collection
ADDITIONAL INFORMATION	Limitations	
	Comments	Definition of confidence can vary depending on the organization, service provided, and individual factors. For example, education and training can increase caregivers' confidence because they can better understand dementia, its progression, and treatment options. Information about available supports allows caregivers to make informed decisions about services available to recipients of their care  Caregivers can be defined as family members and friends who provide some type of support to people living with dementia in the community  Learning from the development and delivery of educational materials can be expected to further influence development of this indicator
	Potential proxy indicator	

Table 9: Percentage of People Living With Dementia in the Community and Their Caregivers Who Reported Being Satisfied or Very Satisfied With Care and Services Received in the Community

GENERAL DESCRIPTION	Indicator description	Name: Percentage of people living with dementia in the community and their caregivers who reported being satisfied or very satisfied with care and services received in the community  Directionality: A higher percentage is better
	<b>Indicator status</b>	<b>Developmental</b>
	Dimensions of quality	Patient-centred
DEFINITION & SOURCE INFORMATION	Calculation	<p><b>Denominator</b></p> <ul style="list-style-type: none"> <li>• Number of people living with dementia in the community or</li> <li>• Number of caregivers for people living with dementia in the community</li> </ul> <p><b>Numerator</b> Number of people in the denominator who reported being satisfied or very satisfied with care and services received in the community</p> <p><b>Suggested survey question and response options:</b> Overall how would you rate the dementia care and services that you received from people who provided care to you?</p> <ul style="list-style-type: none"> <li>• Very satisfied</li> <li>• Satisfied</li> <li>• OK</li> <li>• Dissatisfied</li> <li>• Very dissatisfied</li> </ul> <p>Please note that the wording of the question and the response options can be tailored to the service being surveyed</p> <p><b>Inclusions</b> Caregivers should be surveyed in place of patients if the person with dementia had opportunities to answer the question but was unable to respond</p> <p><b>Exclusions</b> Patients and caregivers who were unable to complete the survey (i.e., language barrier)</p> <p><b>Method</b> Numerator ÷ Denominator × 100</p>
	Data source	Local data collection

ADDITIONAL INFORMATION	Limitations	<p>Patients or caregivers might believe they cannot respond honestly because of risk to their services. This belief can be mitigated if the survey is not conducted by their direct provider</p> <p>Patients' responses can be influenced by other services received (i.e., other health care being delivered)</p>
	Comments	Caregivers can be defined as family members and friends who provide some type of support to people living with dementia in the community
	Potential proxy indicator	

## 6 Resources and Questions

### 6.1 Resources

Several resources are available for more information:

- The **quality standard** provides information on the background, definitions of terminology, numerators and denominators for all statement-specific indicators
- The **Getting Started Guide** includes quality improvement tools and resources for health care professionals, including an action plan template
- The **infobrief** provides data on why a particular quality standard has been created and the data behind it
- The **data tables** provide data that can be used to examine variations in indicator results across the province

### 6.2 Questions?

Please contact [qualitystandards@hgontario.ca](mailto:qualitystandards@hgontario.ca). We would be happy to provide advice on measuring quality standard indicators, or put you in touch with other providers who have implemented the standards and might have faced similar questions.

Health Quality Ontario offers an online community dedicated to improving the quality of health care across Ontario together called [Quorum](#). Quorum can support your quality improvement work by allowing you to:

- Find and connect with others working to improve health care quality
- Identify opportunities to collaborate
- Stay informed with the latest quality improvement news
- Give and receive support from the community
- Share what works and what doesn't
- See details of completed quality improvement projects
- Learn about training opportunities
- Join a community of practice

## 7 Appendix: Data Sources Referenced in This Quality Standard

Within this quality standard, there are several data sources used for provincial measurement. The data source(s) for each indicator are listed within the individual indicator specifications. More details on the specific data sources that Health Quality Ontario used to produce the indicators are noted below.

### **Continuing Care Reporting System—Canadian Institute for Health Information**

The Canadian Institute for Health Information developed the Continuing Care Reporting System to enhance the collection of standardized information on facility-based long-term care and complex continuing care, for national comparative reporting. This reporting system contains demographic, administrative, clinical, and resource use information on individuals receiving continuing care services in hospitals or in long-term care homes in Canada. Participating organizations also provide information on facility characteristics to support comparative reporting.

The clinical data are collected using an internationally accepted standard, the Resident Assessment Instrument Minimum Data Set Version 2.0 (RAI-MDS 2.0). Each resident in a long-term care home is assessed at admission and then every 3 months, or whenever they experience a significant change in health status. The assessment includes patient-level measures of function, mental and physical health, social supports, and service use. It was modified by the institute, with permission, for Canadian use. All long-term care homes in Ontario have submitted data to the institute on a quarterly basis since 2009.

### **Discharge Abstract Database—Canadian Institute for Health Information**

The Discharge Abstract Database by the Canadian Institute for Health Information contains information abstracted from hospital records that capture administrative, clinical, and patient demographic data on all hospital in-patient separations, including discharges, deaths, sign-outs, and transfers. The institute receives Ontario data directly from participating facilities, from their respective regional health authorities, or from the Ministry of Health and Long-Term Care. The database includes patient-level data for acute care facilities in Ontario. Data are collected, maintained, and validated by the institute.

The main data elements of this database are patient identifiers (e.g., name, health care number), patient demographics (e.g., age, sex, geographic location), clinical information (e.g., diagnoses, procedures), and administrative information.

### **National Ambulatory Care Reporting System—Canadian Institute for Health Information**

The National Ambulatory Care Reporting System by the Canadian Institute for Health Information contains data for all hospital- and community-based emergency and ambulatory care, including day surgeries, outpatient clinics, and emergency departments. Data are collected, maintained, and validated by the institute. The institute receives Ontario data directly from participating facilities, from their respective regional health authorities, or from the Ministry of Health and Long-Term Care. Data are collected, maintained, and validated by the institute.

Data elements of this reporting system include patient identifiers (e.g., name, health care number), patient demographics (e.g., age, sex, geographic location), clinical information (e.g., diagnoses, procedures), and administrative information.

### **National Rehabilitation Reporting System—Canadian Institute for Health Information**

The National Rehabilitation Reporting System was developed by the Canadian Institute for Health Information in 2001 to support data collection by hospitals for in-patient rehabilitation clients, most of whom are age 18 or older. The rehabilitation services are usually provided in specialized rehabilitation hospitals and in rehabilitation units, programs, or groups of rehabilitation beds within general hospitals. This reporting system captures information on clients with a range of health conditions, including strokes, orthopedic conditions, and amputations.

### **Ontario Drug Benefit Claims Database**

The Ontario Drug Benefit claims database contains records of all prescriptions dispensed to patients covered by the program, which include people living in long-term care facilities in Ontario. Records include the Drug Identification Number, date the drug was dispensed, and the number of days each dispensed prescription is to be taken. The record also identifies which of the claims are made in long-term care. Data are collected through the Health Network System by the ministry.

### **Ontario Health Insurance Plan—Ministry of Health and Long-Term Care**

The Ontario Health Insurance Plan (OHIP) claims database covers all reimbursement claims to the ministry made by fee-for-service physicians, community-based laboratories, and radiology facilities. The OHIP database at the Institute for Clinical Evaluative Sciences contains encrypted patient and physician identifiers, codes for services provided, dates of service, associated diagnoses, and fees paid. Services missing from OHIP data include some laboratory services, services received in provincial psychiatric hospitals, services provided by health service organizations and other alternative providers, diagnostic procedures performed on an in-patient basis, and laboratory services performed at hospitals (both in-patient and same day). Also excluded is remuneration to physicians through alternative funding plans; this could distort analyses because of their concentration in certain specialties or geographic areas.

### **Registered Persons Database**

The Registered Persons Database provides basic demographic information about everyone who has an Ontario health card. This database is maintained by the Ministry of Health and Long-Term Care. It is used and enriched by the Institute for Clinical Evaluative Sciences, with information from other data sets.

### **Wait Time Information System**

Ontario's Wait Time Information System is maintained by Cancer Care Ontario on behalf of the Ministry of Health and Long-Term Care. The web-based system collects data on wait times, including surgical and diagnostic imaging and emergency room wait times, and alternate-level-of-care days. Alternate-level-of-care days include both acute care and post-acute care.

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