

Sickle Cell Disease

Care for People of All Ages

Measurement Guide

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**Ontario
Health**

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1. How to Use the Measurement Guide

This document is meant to serve as a measurement guide to support implementation of the sickle cell disease quality standard. Care for people with sickle cell disease is a critical issue, and there are significant gaps and variations in the quality of care that people with sickle cell disease receive in Ontario. Recognizing this, Ontario Health 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 implement the sickle cell disease quality standard, 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 monitor the progress being made to improve care on a provincial level using existing provincial data sources

1.1 Important Resources for Quality Standard Implementation

Ontario Health has created resources to assist with implementation of quality standards:

- Our [placemat](#), which summarizes the quality standard and includes links to helpful resources and tools
- Our [Getting Started Guide](#), which includes links to templates and tools to help you put quality standards into practice. This guide shows you how to plan for, implement, and sustain changes in your practice
- [Quorum](#), an online community dedicated to improving the quality of care across Ontario. This is a place where health care providers can share information and support each other, and it includes tools and resources to help you implement the quality statements within each standard
- The [Health Equity Impact Assessment tool](#), which can help your organization consider how programs and policies impact population groups differently. This tool can help maximize positive impacts and reduce negative impacts, with an aim of reducing health inequities between population groups

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 element 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

The process, structure, and outcome indicator framework was developed by [Donabedian](#) in 1966. 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 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 can be measured given existing local data sources.

2.2 Process Indicators

Process indicators assess the activities involved in providing care. They measure the percentage of individuals, episodes, or encounters for which an activity (process) is performed. In most cases, the numerator should specify a time frame 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 time frame) can also appear in the background and definitions sections. 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. Please refer to the published [quality standards](#) for more examples.

2.3 Structural Indicators

Structural indicators assess the structures 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 to measure 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 local availability of cognitive behavioural therapy (CBT) programs, the existence of discharge planning protocols, and 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 intended 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 time frame.

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. Although they are not the focus of the standard and generally not included in the standard, the intention of these types of measures is to monitor the unintended consequences.

3. Local Measurement

As part of the sickle cell disease quality standard, *specific* indicators 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 indicators in the standard and come up with a draft measurement plan.

Here are some concrete next steps:

- Review the list of identified indicators for each quality statement (see Appendix 2 in the quality standard), and determine which ones you will use as part of your implementation planning, given your knowledge of current gaps in care
- Determine the availability of data related to the indicators you have chosen
- Identify a way to collect local data related to your chosen indicators. This may be through clinical chart extraction or administration of local surveys for example
- 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 or survey databases (such as databases held by the Institute for Clinical Evaluative Sciences [ICES] or the Canadian Institute for Health Information). Examples of local data 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 of data quality.

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 and over time 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. For all three types of data, it is important to consider clinical relevance when analyzing results (i.e., not every change is a clinically relevant change).

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).

$$\text{Rate of 30-day hospital readmission} = \frac{\text{Number of hospital readmissions within 30 days of discharge [numerator]}}{\text{Number of discharges from hospital [denominator]}}$$

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 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, Ontario Health 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, their current performance 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. Time frame 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. For example, someone might not receive care in a wait time benchmark due to patient unavailability. This is why it is important to track these indicators over time, to compare results against those of colleagues, to track progress, and to aim for the successful implementation of the standard.

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, Ontario Health 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 users to create custom analyses to help you calculate results for identified measures of success. Examples of these platforms include IntelliHealth and eReports. Please refer to the links below to determine if you have access to the platforms listed.

4.1.1 IntelliHealth—Ministry of Health

[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.

4.1.3 eReport—Ontario Health

The eReport portal provides authorized individuals in the health care system with easy and secure web access to reports containing patient health information, personal information, or performance information.

4.1.4 Applied Health Research Questions (AHRQ) — Institute for Clinical Evaluative Sciences

ICES receives funds from the Ministry of Health to provide research evidence to organizations from across the Ontario health care system (Knowledge Users). This knowledge is used to inform planning, policy and program development. Knowledge Users can submit an [Applied Health Research Question](#) (AHRQ) to ICES. As a health services research institute that holds Ontario's administrative data, ICES is well positioned to respond to AHRQs that directly involve the use of ICES data holdings.

5. Measurement to Support Improvement

This measurement guide accompanies Ontario Health's sickle cell disease quality standard. Early in the development of each quality standard, several performance indicators are chosen to monitor the progress being made to improve care for people with sickle cell disease. 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:

- Percentage of people with an unscheduled emergency department visit for sickle cell disease
- Percentage of repeat unscheduled emergency department visits for sickle cell disease within 30 days
- Percentage of people with sickle cell disease who visited the emergency department for a mental health concern
- Percentage of people who were hospitalized for sickle cell disease
- Percentage of people with sickle cell disease who report an improvement in their quality of life
- Percentage of people with sickle cell disease who report being satisfied with their interaction with their health care provider

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 (there are well defined or validated data sources available)
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 (Appendix 2).

5.1 Quality Standard Scope

This quality standard addresses **care for children, young people, and adults with sickle cell disease**. Where appropriate, it also addresses the needs of families and caregivers or other substitute decision-makers (for definitions of these roles, see Appendix 3, Glossary). It addresses screening for and the prevention of complications, the assessment and management of acute and chronic complications, and the use of disease-modifying therapies. It applies to all pediatric and adult health care settings relevant to sickle cell disease (including hospitals, emergency departments, urgent care clinics, and primary care, specialist care, and home and community care settings).

Although many of the statements may apply to pregnant people, this quality standard does not directly address the management of sickle cell disease in pregnancy.

The [Clinical Handbook for Sickle Cell Disease Vaso-occlusive Crisis](#) by the Provincial Council for Maternal and Child Health and the Ontario Ministry of Health addresses care for sickle cell crisis (referred to as a “vaso-occlusive acute pain episode” in this quality standard) and applies to quality statement 3 (Provincial Council for Maternal and Child Health, Ministry of Health and Long-Term Care, 2017).

This quality standard includes 8 quality statements. They address areas identified by Ontario Health’s Sickle Cell Disease Quality Standard Advisory Committee as having high potential for improving the quality of care in Ontario for people with sickle cell disease.

5.2 Cohort Identification

Individuals with sickle cell disease can be identified through the Discharge Abstract Database, National Ambulatory Care Reporting System, using the following diagnosis codes: ICD9 code 2826 and ICD10 codes D570, D571, D572, and D578. To capture newborns with sickle cell disease, the Newborn Screening Ontario database can be searched for diagnoses of Hb SS, Hb Sβ, SC, SE, and S/HPFH ([Kim et al, 2018](#)).

5.2.1 Equity Considerations

Consider collecting data and measuring indicators by various equity stratifications that are relevant and appropriate for your population, such as patient socioeconomic and demographic characteristics. These may include age, education, gender, income, language, race/ethnicity, and sex. Please refer to Appendix 4, Values and Guiding Principles, in the quality standard for additional equity considerations.

5.3 Indicators That Can Be Measured Using Provincial Data

The Sickle Cell Disease Quality Standard Advisory Committee identified a number of overarching goals **for this quality standard**. These have been mapped to indicators that may be used to assess quality of care provincially. The following indicators are currently potentially measurable in Ontario’s health care system:

- Percentage of people with an unscheduled emergency department visit for sickle cell disease
- Percentage of repeat unscheduled emergency department visits for sickle cell disease within 30 days
- Percentage of people with sickle cell disease who visited the emergency department for a mental health concern
- Percentage of people who were hospitalized for sickle cell disease

Methodologic details are described in the tables below.

Table 1: Percentage of people with an unscheduled emergency department visit for sickle cell disease

General Description	
Indicator description	Name: Rate of unscheduled emergency department visits for sickle cell disease per 100 individuals with sickle cell disease Directionality: A lower rate is better
Measurability	Measurable at the provincial level
Dimension of quality	Safe
Quality statement alignment	All quality standard statements align
Definition and Source Information	
Calculation: General	<p>Denominator Total number of individuals in the province with sickle cell disease</p> <p>Numerator Number of unscheduled ED visits for sickle cell disease</p> <p><i>Inclusions</i> Unscheduled ED visits for sickle cell disease (all diagnosis fields)</p> <p>ICD-10-CA codes: D570, D571, D572, and D578.</p> <p>Method $\text{Numerator} \div \text{Denominator} \times 100$</p> <p>Data source National Ambulatory Care Reporting System</p>
Additional Information	
Limitations	<ul style="list-style-type: none"> • Data from ED visits capture only those who visit the ED and may not reflect the total burden in the population • Data for Ontario residents who visit an ED or die outside of the province are not included • Dependent on coding accuracy (e.g., ICD-10-CA codes)
Comments	None

Table 2: Percentage of repeat unscheduled emergency department visits for sickle cell disease within 30 days

General Description	
Indicator description	Name: Rate of unscheduled emergency department revisits within 30 days per 100 visits for sickle cell disease Directionality: A lower rate is better
Measurability	Measurable at the provincial level
Dimension of quality	Safe
Quality statement alignment	All quality standard statements align
Definition and Source Information	
Calculation: General	Denominator Number of ED visits for sickle cell disease Numerator Number of ED revisits within 30 days for sickle cell disease <i>Inclusions</i> Unscheduled ED visits for sickle cell disease (all diagnosis fields) ICD-10-CA codes: D570, D571, D572, and D578. Method $\text{Numerator} \div \text{Denominator} \times 100$ Data source National Ambulatory Care Reporting System
Additional Information	
Limitations	<ul style="list-style-type: none"> • Data from ED visits capture only those who visit the ED and may not reflect the total burden in the population • Data for Ontario residents who visit an ED or die outside of the province are not included • Dependent on coding accuracy (e.g., ICD-10-CA codes)
Comments	None

Table 3: Percentage of people with sickle cell disease who visited the emergency department for a mental health concern

General Description	
Indicator description	Name: Rate of emergency department visits for mental health reasons per 100 individuals with sickle cell disease Directionality: A lower rate is better
Measurability	Measurable at the provincial level
Dimension of quality	Safe
Quality statement alignment	All quality standard statements align
Definition and Source Information	
Calculation: General	<p>Denominator Total number of individuals in the province with sickle cell disease</p> <p>Numerator Number of ED visits for mental health reasons</p> <p><i>Inclusions</i> ED visits for mental health reasons (all diagnosis types)</p> <p>ICD-10 codes include:</p> <ul style="list-style-type: none"> • Schizophrenia and other psychotic disorders: ICD-10-CA: F20, F21, F22, F23, F24, F25, F28, F29 • Mood disorders: ICD-10-CA: F30, F31, F32, F33, F34, F38, F39, F53.0, F53.1 • Anxiety disorders: ICD-10-CA: F40, F41, F93.0, F93.1, F93.2, F94.0 • Selected disorders of personality and behaviour: ICD-10-CA: F60, F61, F62, F68 (excluding F68.1), F69 • Other disorders: ICD-10-CA: F42, F43, F44, F45, F48.0, F48.1, F48.8, F48.9, F50, F51, F52, F53.8, F53.9, F54, F59, F63 (excluding F63.0), F64, F65, F66, F68.1, F70–F73, F78, F79, F80–F84, F88, F89, F90, F91, F92, F93.3, F93.8, F93.9, F94.1, F94.2, F94.8, F94.9, F95, F98.0, F98.1, F98.2, F98.3, F98.4, F98.5, F98.8, F98.9, F99, O99.3 <p>Method $\text{Numerator} \div \text{Denominator} \times 100$</p> <p>Data source National Ambulatory Care Reporting System</p>

Additional Information

Limitations

- Data from ED visits capture only those who visit the ED and may not reflect the total burden in the population
- Data for Ontario residents who visit an ED or die outside of the province are not included
- Dependent on coding accuracy (e.g., ICD-10-CA codes)

Comments

None

Table 4: Percentage of people who were hospitalized for sickle cell disease

General Description	
Indicator description	Name: Rate of hospitalizations for sickle cell disease per 100 individuals with sickle cell disease Directionality: A lower rate is better
Measurability	Measurable at the provincial level
Dimension of quality	Safe
Quality statement alignment	All quality standard statements align
Definition and Source Information	
Calculation: General	<p>Denominator Total number of individuals in the province with sickle cell disease</p> <p>Numerator Number of hospitalizations for sickle cell disease</p> <p><i>Inclusions</i> Hospitalizations for sickle cell disease (all diagnosis fields) ICD-10-CA codes: D570, D571, D572, and D578.</p> <p>Method $\text{Numerator} \div \text{Denominator} \times 100$</p> <p>Data source Discharge Abstract Database</p>
Additional Information	
Limitations	
Comments	None

5.4 Indicators That Can Be Measured Using Only Local Data

You might want to assess the quality of care you provide to your patients with sickle cell disease. 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 with sickle cell disease who report an improvement in their quality of life
- Percentage of people with sickle cell disease who report being satisfied with their interaction with their health care provider

Methodologic details are described in the tables below.

Table 5: Percentage of people with sickle cell disease who reported an improvement in their quality of life

General Description	
Indicator description	Name: Percentage of people with sickle cell disease who reported an improvement in their quality of life Directionality: Higher is better
Indicator status	Developmental
Dimension of quality	Effective
Quality statement alignment	All quality statements align
Definition and Source Information	
Calculation: General	<p>Denominator Number of people with sickle cell disease</p> <p>Numerator Number of people who reported an improvement in their quality of life</p> <p>Method $\text{Numerator} \div \text{Denominator} \times 100$</p> <p>Data source Local data collection</p>
Additional Information	
Limitations	Data sources are not currently available
Comments	The following tools can be used to assess Quality of Life in individuals with sickle cell disease: The Pediatric Quality of Life Inventory (PedsQL), which measures health-related quality of life in healthy children and adolescents and those with acute and chronic conditions, providing a physical and psychosocial health summary score. ¹ The Patient-Reported Outcome Measurement Information System (PROMIS), a set of person-centred measures designed to assess how people with a chronic disease feel and function. ² Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me) may be used to assess the quality of life for adults with sickle cell disease. ³
Potential proxy indicator	N/A

1. Panepinto JA, Torres S, Bendo CB, McCavit TL, Dinu B, Sherman-Bien S, et al. PedsQL™ sickle cell disease module: feasibility, reliability, and validity. *Pediatr Blood Cancer*. 2013;60(8):1338-44.
2. Keller S, Yang M, Treadwell MJ, Hassell KL. Sensitivity of alternative measures of functioning and wellbeing for adults with sickle cell disease: comparison of PROMIS® to ASCQ-Me™. *Health Qual Life Outcomes*. 2017;15(1):117.
3. Treadwell MJ, Hassell K, Levine R, Keller S. Adult sickle cell quality-of-life measurement information system (ASCQ-me): conceptual model based on review of the literature and formative research. *Clin J Pain*. 2014;30:902.

Table 6: Percentage of people with sickle cell disease who report being satisfied with their interaction with their health care provider

General Description	
Indicator description	Name: Percentage of people with sickle cell disease who report being satisfied with their interaction with their health care provider Directionality: Higher is better
Indicator status	Developmental
Dimension of quality	Effective
Quality statement alignment	All quality statements align
Definition and Source Information	
Calculation: General	Denominator Number of people with sickle cell disease Numerator Number of people who reported being satisfied with their interaction with their health care provider Method $\text{Numerator} \div \text{Denominator} \times 100$ Data source Local data collection
Additional Information	
Limitations	Data sources are not currently available
Comments	Tools that could be used to measure this could include: <ul style="list-style-type: none"> • Satisfaction with Treatment for Pain Questionnaire (STPQ)¹, a tool developed specifically for assessing patient satisfaction among patients with sickle cell disease. • Patient Satisfaction Questionnaire Short Form (PSQ-18)², a general tool that is designed to understand patient satisfaction in a variety of patients and settings.
Potential proxy indicator	N/A

1. Elander, J., Bij, D., Kapadi, R., Schofield, M.B., Osias, A., Khalid, N., Kaya, B. and Telfer, P. (2019), Development and validation of the Satisfaction with Treatment for Pain Questionnaire (STPQ) among patients with sickle cell disease. *Br J Haematol*, 187: 105-116. <https://doi.org/10.1111/bjh.16015>
2. Thayaparan AJ, Mahdi E. The Patient Satisfaction Questionnaire Short Form (PSQ-18) as an adaptable, reliable, and validated tool for use in various settings. *Med Educ Online*. 2013 Jul 23;18:21747. <https://doi.org/10.3402/meo.v18i0.21747>

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 [case for improvement deck](#) provides data on why a particular quality standard has been created and the data behind it

6.2 Questions?

Please contact QualityStandards@OntarioHealth.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.

Ontario Health 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 that can be 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 Ontario Health used to produce the indicators are noted below.

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. 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 card 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. Data are collected, maintained, and validated by the institute.

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

Ontario Health Insurance Plan—Ministry of Health

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.

Patient Experience Surveys—National Research Corporation Canada, Ontario Hospital Association

The National Research Corporation Canada Patient Experience Surveys have been implemented in many Ontario hospitals since 2002. Surveys are provided for the following sectors:

- Inpatient, including acute adult, maternity and obstetrics, and pediatrics, and neonatal intensive care
- Emergency department
- Urgent care centre
- Rehabilitation
- Ambulatory clinics
- Ambulatory oncology
- Day surgery
- Long-stay resident experience (formerly complex continuing care and long-term care)
- Mental health (long stay, short stay, outpatient)

The Ontario Hospital Association works closely with the National Research Corporation Canada to report and improve patient and family experiences with their hospital care.

QUALITY STANDARDS

Looking for more information?

Visit [HQOntario.ca](https://www.hqontario.ca) or contact us at QualityStandards@OntarioHealth.ca if you have any questions or feedback about this guide.

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