QUALITY STANDARDS

# Transitions From Youth to Adult Health Care Services

## Care for Young People Aged 15 to 24 Years

Measurement Guide

March 2022

Ontario Health

# Contents

# 1 How to Use the Measurement Guide

This document is meant to serve as a measurement guide to support the adoption of the Transitions From Youth to Adult Health Care Services quality standard. Care for people transitioning from youth to adult health care services is a critical issue, and there are significant gaps and variations in the quality of care that people 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 adopt the Transitions From Youth to Adult Health Care Services 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 measure the success of the quality standard on a provincial level using existing provincial data sources

**Important Resources for Quality Standard Adoption**

Ontario Health 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
- *QI Essentials* including a *QI Science Guide*, *QI Development Guide*, and *Change Management Guide* to give health care teams and organizations in Ontario easy access to well-established quality improvement tools. These resources provide 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 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 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 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 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 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 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. 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 Transitions From Youth to Adult Health Care Services 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 adoption 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 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).

$$Rate\ of\ 30\text{-}day\ hospital\ readmission =$$

$$\frac{Number\ of\ hospital\ readmissions\ within\ 30\ days\ of\ discharge\ [\mathbf{numerator}]}{Number\ of\ discharges\ from\ hospital\ [\mathbf{denominator}]}$$

### *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. 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. 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 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 How Success Can Be Measured for This Quality Standard

This measurement guide accompanies Ontario Health's quality standard *Transitions From Youth to Adult Health Care Services*. Early in the development of each quality standard, several 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:

- Percentage of young people who have transitioned out of youth-oriented services who have their first visit with an adult service or another provider after transfer of care
- Percentage of young people who have transitioned out of youth-oriented services who have an unscheduled emergency department visit in the first year after transfer of care
- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services who had a designated most responsible provider for the transition
- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who completed a transition readiness assessment prior to transfer of care
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being satisfied with the transition
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services who report that they maintained their quality of life around the period of transfer of care

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 young people aged 15 to 24 years who are transitioning from youth to adult health care services. A *transition* is defined as the purposeful, planned movement of adolescents and young adults requiring a change from child- and youth-oriented services to adult-oriented services, with or without a transfer to a new provider. A *transfer* of care is a one-time event that occurs when a young person is transferred out of the child health system. It is important to note that preparation for the transition should be started as early as possible, as described in quality statement 1.

There are different models by which young people will transition from a pediatric health care service or provider, and some may transition to any combination of these models. At a minimum, all young people will need a primary care provider. For those young people who see a pediatric provider for primary care, they will need to transition to a primary care provider who offers an adult approach to care. In addition, some young people may also transition:

- To one or more adult (specialist) care services and/or
- Through services for young people (aged 15 to 24 years) that bridge pediatric and adult care, commonly called “adolescent and young adult clinics,” “transition to adulthood clinics,” or “transitional aged youth services”

We use *adult service or another provider* throughout the quality standard to mean any new service or health care provider who will take a role in the young person’s future care or who will transition them to an adult approach to care. Although we use *transition to adult services* throughout the quality standard, the term includes any transfer out of youth-oriented services at age 18 and into an adult approach to care.

The scope of this quality standard includes all clinical populations, including young people with disabilities or special health care needs such as those with chronic and/or complex physical, intellectual, or developmental conditions and/or with mental illness and substance use. Where appropriate, it also includes parents and caregivers or other substitute decision-makers (see Appendix 3, Glossary in the quality standard).

The scope of this quality standard includes all pediatric and adult health care settings and providers relevant to the transition to adult health care services.

### 5.2 Cohort Identification

For measurement at the provincial level, people who have transitioned from youth to adult-oriented health care services cannot be identified through current provincial data sources. As such, transfer at age 18 will be a proxy for young people who have transitioned out of youth-oriented services. However, given that not all young people may transition at age 18, the provincial cohort may capture some individuals who have not yet transitioned.

As well, to identify young people with specific health care needs, administrative data sources or validated algorithms can be used. In some cases, provincial data sources may not comprehensively capture the population of interest, and local data collection may be required. The following are *examples* of specific health care needs and the associated methods that can be used to identify individuals using provincial data sources:

- People with Type 1 Diabetes or Type 2 Diabetes can be identified using the Ontario Diabetes Database (ODD), which is held at ICES. This population-based cohort is constructed using a validated algorithm based on hospitalizations, physician visits, and drug benefit claims to identify individuals with diabetes in Ontario (Hux JE et al. Diabetes Care, 2002). The ODD uses the following administrative databases:
    - Discharge Abstract Database (DAD)
    - Ontario Health Insurance Plan (OHIP) Claims Database
    - Ontario Drug Benefit (ODB) Database
    - Registered Persons Database (RPDB)

  Individuals are considered to have diabetes if they had at least: one hospital admission for diabetes (ICD-10-CA [International Statistical Classification of Diseases and Related Health Problems, 10th Revision] codes: E10, E11, E13, or E14), two physician service claims for diabetes (OHIP diagnostic code 250), or one diabetes drug claim in the past year. The ODD cohort has a high sensitivity (90%) and specificity (97.7%) for identifying individuals with non-gestational diabetes.

- People with severe mental health conditions (schizophrenia and related psychotic disorders, eating disorders, and mood disorders) can be identified using DAD and Ontario Mental Health Reporting System (OMHRS), which are held at ICES. This cohort is constructed based on hospital discharge records and diagnostic codes to identify an index mental health hospitalization (Toulany et al. JAMA Network Open, 2019).

Additional inclusion and exclusion criteria may be applicable depending on the specific population.

For local measurement, people who are transitioning to adult-oriented health care services and their actual age of transfer may be determined using local data sources (such as electronic medical records or clinical patient records).

Note: health care need refers to any chronic, complex, long-standing, physical, intellectual, developmental, mental illness, substance use, or other need that the young person is receiving care for in youth-oriented services.

### *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, family income, region/geography, education, language, race, and sex. Please refer to Appendix 4, Guiding Principles, Social Determinants of Health, in the quality standard for additional equity considerations.

## 5.3 How Success Can Be Measured Provincially

The Transitions From Youth to Adult Health Care Services 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 young people who have transitioned out of youth-oriented services who have their first visit with an adult service or another provider after transfer of care
- Percentage of young people who have transitioned out of youth-oriented services who have an unscheduled emergency department visit in the first year after transfer of care

Methodologic details are described in the tables below.

## Table 1: Percentage of young people who have transitioned out of youth-oriented services who have their first visit with an adult service or another provider after transfer of care

| | | |
|---|---|---|
| GENERAL DESCRIPTION | Indicator description | Name: Percentage of young people who have transitioned out of youth-oriented services who have their first visit with an adult service or another provider after transfer of care<br>Directionality: A higher rate is better. The time period for a first visit may vary based on the health care need. |
| | **Measurability** | **Measurable at the provincial level**<br>(Although validated data sources are available, further indicator development and analysis is required.) |
| | Dimensions of quality | Effective, Patient-Centred, Timely, Safe, Efficient |
| | Quality statement alignment | **Quality Statement 4: Coordinated Transition**<br>Young people have a designated most responsible provider for the transition process. This provider works with the young person (and their parents and caregivers, where appropriate) to coordinate their care and provide support throughout the transition process and until the young person (and their parents and caregivers, where appropriate) confirms that the process is complete.<br>**Quality Statement 5: Introduction to Adult Services**<br>Young people (and their parents and caregivers, where appropriate) have a meeting with key adult services or other providers before the transfer, to facilitate and maintain continuity of care.<br>**Quality Statement 6: Transfer Completion**<br>Young people remain connected to the designated most responsible provider for their transition and are supported until health care service transitions are complete and confirmed by the young person (and their parents and caregivers, where appropriate). |
| DEFINITION & SOURCE INFORMATION | Calculation: General | **Denominator**<br>Total number of young people who have transitioned out of youth-oriented services<br>Notes:<br>• Refer to 5.2 Cohort Identification section for more information.<br>• Rates should be reported separately based on health care need. For local data collection, consider measuring this data for a specific health care need based on your population. |

|  |  |  |
|---|---|---|
|  |  | *Exclusions*<br>• Non-Ontario resident<br>• Additional exclusions such as age may be required<br>**Numerator**<br>Number of people in the denominator who have their first visit with an adult service or another provider after transfer of care<br>• Notes:<br>○ For measurement purposes, this could be a visit within 12 months after transfer (at age 18, as a proxy for age of transfer). However, the time period can be tailored based on health care needs.<br>○ If multiple providers are involved in care, collect and measure data separately for each adult service or other provider that the young person will transition to (e.g., if a young person is receiving care from a psychiatrist and an endocrinologist, the follow-up visits in adult health care services for each type of provider should be tracked separately)<br>○ This indicator is also included in quality statement 6.<br>*Inclusions*<br>• Visit to a primary care provider or specialist (depending on the health care need of interest, e.g., for cardiology, look at claims from cardiologist specialty using OHIP spec field)<br>• Use OHIP diagnostic code to capture reason for visit and to determine if the visit was for the health care need being tracked<br>The analysis may inform additional inclusion and exclusion criteria that can be used.<br>**Method**<br>Numerator divided by the denominator times 100<br>**Data sources:** Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS), Ontario Health Insurance Plan (OHIP) Claims Database, Registered Persons Database (RPDB). Additional administrative data sources may be required (e.g., if a validated algorithm is used to identify young people with a specific health care need). |
| ADDITIONAL INFORMATION | Limitations | Provincial data sources (such as OHIP) capture only physician visits. However, the individual may have had a visit to a provider not covered by OHIP. Local data collection maybe required, depending on the health care need and to track visits to nonphysician services. |

| | | |
|---|---|---|
| | | This indicator does not capture continuity of care in adult services beyond the first visit, or the quality and appropriateness of the visit. It is limited to capturing whether there was loss to follow-up in adult services.<br>If a young person transitions to a primary care provider, provincial data sources (such as OHIP) may not be sufficient in determining whether the individual had a first visit for the health care need being tracked.<br>It may not be possible to determine the reason for the physician visit in adult services if the visit is to a primary care provider, since only one diagnostic code can be captured per visit. |
| | Comments | This indicator is applicable to young people with health care needs that require a regular follow-up with a provider to prevent negative health outcomes (e.g., diabetes, sickle cell disease, etc.).<br>For measurement purposes, this indicator could be tracked based on whether a visit occurred within 12 months after transfer. However, this time period is not a target and can be tailored based on health care needs. For example, conditions such as diabetes may require follow-up sooner than 12 months after transfer.<br>For local measurement, you can consider using a proxy measure to track whether the young person had a first visit in adult services (e.g., among people with diabetes, determine if there was an HbA1c done using laboratory claims). |

Abbreviations: OHIP, Ontario Health Insurance Plan Claims Database.

## Table 2: Percentage of young people who have transitioned out of youth-oriented services who have an unscheduled emergency department visit in the first year after transfer of care

| | | |
|---|---|---|
| GENERAL DESCRIPTION | Indicator description | Name: Percentage of young people who have transitioned out of youth-oriented services who have an unscheduled emergency department visit in the first year after transfer of care<br>Directionality: A lower rate is generally better. While not all unscheduled emergency department visits are avoidable, appropriate transition in care can be effective in reducing the need for an emergency department visit. |
| | **Measurability** | **Measurable at the provincial level**<br>(Although validated data sources are available, further indicator development and analysis is required.) |
| | Dimension of quality | Safe, Effective, Patient-Centred, Timely, Equitable |
| | Quality statement alignment | **Quality Statement 4: Coordinated Transition**<br>Young people have a designated most responsible provider for the transition process. This provider works with the young person (and their parents and caregivers, where appropriate) to coordinate their care and provide support throughout the transition process and until the young person (and their parents and caregivers, where appropriate) confirms that the process is complete.<br>**Quality Statement 5: Introduction to Adult Services**<br>Young people (and their parents and caregivers, where appropriate) have a meeting with key adult services or other providers before the transfer, to facilitate and maintain continuity of care.<br>**Quality Statement 6: Transfer Completion**<br>Young people remain connected to the designated most responsible provider for their transition and are supported until health care service transitions are complete and confirmed by the young person (and their parents and caregivers, where appropriate). |
| DEFINITION & SOURCE INFORMATION | Calculation: General | **Denominator**<br>Total number of young people who have transitioned out of youth-oriented services<br>Notes:<br>• Refer to 5.2 Cohort Identification section for more information.<br>• Rates should be reported separately based on health care need. For local data collection, consider measuring this data for a specific health care need based on your population. |

|  |  |  |
|---|---|---|
|  |  | *Exclusions*<br>- Age: > 18 or < 19<br>- Non-Ontario resident<br>**Numerator**<br>Number of people in the denominator who have an unscheduled emergency department visit in the first year after transfer of care<br>*Inclusions*<br>- Emergency department visits for any reason (NACRS)<br>*Exclusions*<br>- Scheduled emergency department visits<br>The analysis may inform additional inclusion and exclusion criteria that can be used.<br>**Method**<br>Numerator divided by the denominator times 100<br>**Data sources:** National Ambulatory Care Reporting System (NACRS), Registered Persons Database (RPDB). Additional administrative data sources may be required (e.g., if a validated algorithm is used to identify young people with a specific health care need). |
| ADDITIONAL INFORMATION | Limitations | For provincial measurement, age 18 is defined as a proxy for age of transfer. However, actual age of transfer may depend on the health care needs of the young person and/or setting.<br>An emergency department visit may occur due to the lack of follow-up with an adult service or another provider, or a worsening condition. Risk adjustment can be considered. As well, some young people may use the emergency department to access primary care (e.g., in rural regions or if their usual provider is located in another city). |
|  | Comments | N/A |

Abbreviations: NACRS, National Ambulatory Care Reporting System; N/A: not applicable.

### 5.4 How Success Can Be Measured Locally

You might want to assess the quality of care you provide to young people who are transitioning to adult health care services. 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 young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services who had a designated most responsible provider for the transition
- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who completed a transition readiness assessment prior to transfer of care
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being satisfied with the transition
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services who report that they maintained their quality of life around the period of transfer of care

Methodologic details are described in the tables below.

## Table 3: Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan

| | | |
|---|---|---|
| GENERAL DESCRIPTION | Indicator description | Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan<br>• Data collected and measured separately for each subgroup:<br>○ Young people<br>○ Parents or caregivers<br>Directionality: A higher rate is better. |
| | **Indicator status** | **Not measurable** |
| | Dimensions of quality | Effective, Patient-Centred, Efficient |
| | Quality statement alignment | **Quality Statement 2: Transition Plan**<br>Young people have an individualized transition plan that is co-created, documented, and shared within their circle of care.<br>**Quality Statement 3: Transition Plan**<br>Young people have an individualized transition plan that is co-created, documented, and shared within their circle of care. |
| DEFINITION & SOURCE INFORMATION | Calculation: General | **Denominator**<br>Total number of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate)<br>• Data collected and measured separately for each subgroup:<br>○ Young people<br>○ Parents or caregivers<br>Note:<br>For local data collection, consider measuring this data for a young people with a specific health care need based on your population.<br>**Numerator**<br>Number of people in the denominator who report being involved as much as they want to be in co-creating the transition plan |

| | | |
|---|---|---|
| | | Notes:<br>- Refer to quality statement 3 for definitions of co-created and transition plan.<br>- This indicator is also included in quality statement 3.<br>- This question is adapted from the Health Care Experience Survey (Ministry of Health)[1], which has a validated survey question that can be used to inform your local data collection: “When you see your provider or someone else in their office, how often do they involve you as much as you want to be in decisions about your care and treatment?” (Response options: always, often, sometimes, rarely, never, don’t know, refused).<br>- Consider defining a time period at which this indicator will be tracked (e.g., 6 months after transfer of care)<br>**Method**<br>Numerator divided by the denominator times 100 |
| | Data source | Local data collection |
| ADDITIONAL INFORMATION | Limitations | N/A |
| | Comments | This indicator can be tracked separately for young people and their parents/caregivers, where appropriate and if involved. In some cases, it may only be tracked for one subgroup. |
| | Potential proxy indicator | N/A |

Abbreviation: N/A, not applicable.

*Source*: [1]Government of Ontario. Health care experience survey (HCES) [Internet]. Toronto (ON): Queen's Printer for Ontario; 2012-21 [cited 2022 Mar 1]. Available from: https://data.ontario.ca/dataset/health-care-experience-survey-hces.

## Table 4: Percentage of young people who have transitioned out of youth-oriented services who had a designated most responsible provider for the transition

| | | |
|---|---|---|
| GENERAL DESCRIPTION | Indicator description | Name: Percentage of young people who have transitioned out of youth-oriented services who had a designated most responsible provider for the transition<br>Directionality: A higher rate is better. |
| | **Indicator status** | **Not measurable** |
| | Dimension of quality | Safe, Effective, Patient-Centred, Timely, Efficient |
| | Quality statement alignment | **Quality Statement 4: Coordinated Transition**<br>Young people have a designated most responsible provider for the transition process. This provider works with the young person (and their parents and caregivers, where appropriate) to coordinate their care and provide support throughout the transition process and until the young person (and their parents and caregivers, where appropriate) confirms that the process is complete.<br>**Quality Statement 6: Transfer Completion**<br>Young people remain connected to the designated most responsible provider for their transition and are supported until health care service transitions are complete and confirmed by the young person (and their parents and caregivers, where appropriate). |
| DEFINITION & SOURCE INFORMATION | Calculation: General | **Denominator**<br>Total number of young people who have transitioned out of youth-oriented services<br>Note:<br>For local data collection, consider measuring this data for a young people with a specific health care need based on your population.<br>**Numerator**<br>Number of people in the denominator who had a designated most responsible provider for the transition<br>Notes:<br>• Refer to quality statement 4 for definition of designated most responsible provider.<br>• This indicator is also included in quality statement 4.<br>• Consider defining a time period at which this indicator will be tracked (e.g., 6 months after transfer of care)<br>**Method**<br>Numerator divided by the denominator times 100 |

| | | |
|---|---|---|
| | Data source | Local data collection |
| ADDITIONAL INFORMATION | Limitations | N/A |
| | Comments | N/A |
| | Potential proxy indicator | N/A |

Abbreviation: N/A, not applicable.

## Table 5: Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who completed a transition readiness assessment prior to transfer of care

| | | |
|---|---|---|
| GENERAL DESCRIPTION | Indicator description | Name: Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who completed a transition readiness assessment prior to transfer of care<br>• Data collected and measured separately for each subgroup:<br>○ Young people<br>○ Parents or caregivers<br>Directionality: A higher rate is better. |
| | **Indicator status** | **Not measurable** |
| | Dimension of quality | Effective, Patient-Centred |
| | Quality statement alignment | **Quality Statement 1: Early Identification and Transition Readiness**<br>Young people who will transition out of child- and youth-oriented services are identified as early as possible and have regular collaborative reviews of transition readiness to support their ongoing preparation needs for transition (and the needs of their parents and/or caregivers).<br>**Quality Statement 3: Transition Plan**<br>Young people have an individualized transition plan that is co-created, documented, and shared within their circle of care. |
| DEFINITION & SOURCE INFORMATION | Calculation: General | **Denominator**<br>Total number of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate)<br>• Data collected and measured separately for each subgroup:<br>○ Young people<br>○ Parents or caregivers<br>Note:<br>For local data collection, consider measuring this data for a young people with a specific health care need based on your population.<br>**Numerator**<br>Number of people in the denominator who completed a transition readiness assessment prior to transfer of care<br>Note: Consider defining a time period at which this indicator will be tracked (e.g., 6 months after transfer of care). |

| | | |
|---|---|---|
| | | **Method**<br>Numerator divided by the denominator times 100 |
| | Data source | Local data collection |
| ADDITIONAL INFORMATION | Limitations | Completion of a readiness assessment would not provide information about the readiness score and how the results are used. |
| | Comments | There are several validated tools that can be used to measure transition readiness for young people and parents/caregivers, such as:<br>Transition Readiness Assessment Questionnaire (TRAQ)[1]<br>Am I ON TRAC? for Adult Care Questionnaire for youth and for parents[2]<br>You may also want to consider using a validated tool that has been customized for a particular health care need.<br>For local level measurement, you may want track whether a transition readiness assessment was completed at multiple points in time prior to the transfer of care. |
| | Potential proxy indicator | N/A |

Abbreviation: N/A, not applicable.

*Sources*: [1] East Tennessee State University. Transition Readiness Assessment Questionnaire [Internet]. Johnson City (TN): East Tennessee State University; no date [cited 2022 Mar]. Available from: https://www.etsu.edu/com/pediatrics/traq/default.php.

[2] Moynihan M, Saewyc E, Whitehouse S, Paone M, McPherson G. Assessing readiness for transition from paediatric to adult health care: revision and psychometric evaluation of the Am I ON TRAC for Adult Care questionnaire. J Adv Nurs. 2015;71(6):1324-35.

## Table 6: Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being satisfied with the transition

| | | |
|---|---|---|
| GENERAL DESCRIPTION | Indicator description | Name: Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being satisfied with the transition<br>• Data collected and measured separately for each subgroup:<br>○ Young people<br>○ Parents or caregivers<br>Directionality: A higher rate is better. |
| | **Indicator status** | **Not measurable** |
| | Dimension of quality | Effective, Patient-Centred |
| | Quality statement alignment | All statements in the quality standard align. |
| DEFINITION & SOURCE INFORMATION | Calculation: General | **Denominator**<br>Total number of young people who have transitioned out of youth-oriented services<br>• Data collected and measured separately for each subgroup:<br>○ Young people<br>○ Parents or caregivers<br>Notes:<br>For local data collection, consider measuring this data for a young people with a specific health care need based on your population.<br>**Numerator**<br>Number of people in the denominator who report being satisfied with the transition<br>Notes: Consider the following:<br>• Which aspect of the transition of care you would like to track at the local level (e.g., satisfaction with a transition program, satisfaction with the provider, or satisfaction with the overall transition process)<br>• Using an existing patient or parent/caregiver survey or tool based on the area of satisfaction that you would like to track, or developing your own question to measure satisfaction<br>• Defining a time period at which this indicator will be tracked (e.g., patient and parent/caregiver survey administered 6 months after transfer of care). |

| | | |
|---|---|---|
| | | **Method**<br>Numerator divided by the denominator times 100 |
| | Data source | Local data collection |
| ADDITIONAL INFORMATION | Limitations | N/A |
| | Comments | To track this indicator, you may use an existing tool based on which aspect of satisfaction with transition you would like to measure. For example, the Mind the Gap[1] scale has been validated in various populations to track satisfaction and may be useful in certain settings or clinics. However, it has not been validated for all young people with chronic illness and may not be suitable for certain health care needs (e.g., those with mental health or developmental needs) or settings.<br>Alternative to using an existing tool, you may want to develop your own measure of satisfaction (e.g., a specific question) based on your local needs and processes of care.<br>As well, you may be interested in exploring other tools that have been developed to measure satisfaction for studies in Ontario (e.g., Navigator Evaluation Advancing Transitions [NEAT] study) as a resource for this indicator. |
| | Potential proxy indicator | N/A |

Abbreviation: N/A, not applicable.

*Source*: [1]Kiziler E, Yildiz D, Fidanci B. Validation of the "Mind the Gap" Scale to Assess Satisfaction with Health Care among Adolescents. Balkan Med J. 2019;36(2):113-120.

## Table 7: Percentage of young people who have transitioned out of youth-oriented services who report that they maintained their quality of life around the period of transfer of care

| | | |
|---|---|---|
| GENERAL DESCRIPTION | Indicator description | Name: Percentage of young people who have transitioned out of youth-oriented services who report that they maintained their quality of life around the period of transfer of care<br>Directionality: A higher rate is better. |
| | **Indicator status** | **Not measurable** |
| | Dimension of quality | Safe, Effective, Patient-Centred |
| | Quality statement alignment | **Quality Statement 4: Coordinated Transition**<br>Young people have a designated most responsible provider for the transition process. This provider works with the young person (and their parents and caregivers, where appropriate) to coordinate their care and provide support throughout the transition process and until the young person (and their parents and caregivers, where appropriate) confirms that the process is complete.<br>**Quality Statement 5: Introduction to Adult Services**<br>Young people (and their parents and caregivers, where appropriate) have a meeting with key adult services or other providers before the transfer, to facilitate and maintain continuity of care.<br>**Quality Statement 6: Transfer Completion**<br>Young people remain connected to the designated most responsible provider for their transition and are supported until health care service transitions are complete and confirmed by the young person (and their parents and caregivers, where appropriate). |
| DEFINITION & SOURCE INFORMATION | Calculation: General | **Denominator**<br>Total number of young people who have transitioned out of youth-oriented services<br>Notes:<br>For local data collection, consider measuring this data for a young people with a specific health care need based on your population.<br>**Numerator**<br>Number of people in the denominator who report that they maintained their quality life around the period of transfer of care |

| | | |
|---|---|---|
| | | Notes: Consider the following:<br>- Using a validated quality of life survey to track this indicator.<br>- Using the time period for measuring ‘maintained quality of life’ as the time from discharge from youth-oriented services to follow-up with an adult service or another provider.<br>- Defining a time period at which this indicator will be tracked (e.g., patient survey administered 6 months after transfer of care).<br>**Method**<br>Numerator divided by the denominator times 100 |
| | Data source | Local data collection |
| ADDITIONAL INFORMATION | Limitations | The young person’s quality of life could be impacted by factors unrelated to the transfer of care (e.g., a worsening disease). In an effort to focus on the transition process, the indicator measures whether quality of life was maintained around the period of transfer of care. |
| | Comments | There are a number of validated generic and condition-specific surveys that can be used to measure quality of life. One example is the 36-Item Short Form Survey (SF-36; RAND Health Care), and another version of this survey is the 12-Item Short Form Survey (SF-12; RAND Health Care). In some cases, it may be appropriate to use a functional survey, such as the Columbia Impairment Scale.<br>Although this indicator focuses on quality of life for young people, you may also be interested in tracking quality of life for parents or caregivers, where appropriate. Note that quality of life could be impacted by factors unrelated to the transfer of care (e.g., a worsening disease). |
| | Potential proxy indicator | N/A |

Abbreviation: N/A, not applicable.

# 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 are noted below.

**Discharge Abstract Database (DAD) —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 (NACRS)—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 (OHIP)—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.

**Registered Persons Data Base (RPDB)—Ministry of Health**
The RPDB provides basic demographic information about anyone who has ever received an Ontario health card number. The RPDB is a historical listing of the unique health numbers issued to each person eligible for Ontario health services. This listing includes corresponding demographic information such as

date of birth, sex, address, date of death (where applicable) and changes in eligibility status. At the Institute for Clinical Evaluative Sciences (ICES), data from the RPDB are enhanced with available information through other administrative data sources; however, even the enhanced dataset overestimates the number of people living in Ontario for several reasons, including the source of death information and record linkage issues. Although improvements have been made in recent years, the RPDB still contains a substantial number of individuals who are deceased or no longer living in Ontario. As such, the RPDB will underestimate mortality. To ensure that rates and estimates are correct, a methodology has been developed to adjust the RPDB so that regional population counts by age and sex match estimates from Statistics Canada.

# 8 Acknowledgements

## 8.1 Measurement Working Group

Ontario Health thanks the following individuals for their generous, voluntary contributions of time and expertise to help develop the definitions and technical specifications for the measures of success that can be used to assess quality of care provincially and locally for the Transitions From Youth to Adult Health Care Services Quality Standard:

*Lysa Boisse Lomax, Kristin Cleverley, Marilyn Crabtree, Scarlett Davidson, Beverly Guttman, Megan Henze, and Alene Toulany.*

# Looking for more information?

**Visit** hqontario.ca **or** contact us at qualitystandards@ontariohealth.ca if you have any questions or feedback about this guide.

**Ontario Health**
130 Bloor Street West, 10th Floor
Toronto, Ontario
M5S 1N5

**Tel:** 416-323-6868
**Toll Free:** 1-866-623-6868
**Fax:** 416-323-9261
**Email:** qualitystandards@ontariohealth.ca
**Website:** hqontario.ca

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