Implementation Toolkit

Sickle Cell Disease Quality Standard

Version 2.0, revised February 2025

Ontario Health

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IMPLEMENTATION TOOLKIT

Introduction and Overview

Introduction

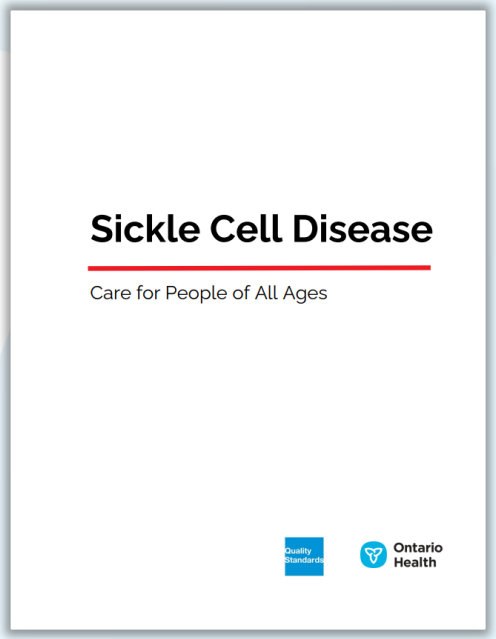
This toolkit is designed to support the implementation of the sickle cell disease (SCD) quality standard by organizations providing direct care for people with SCD.

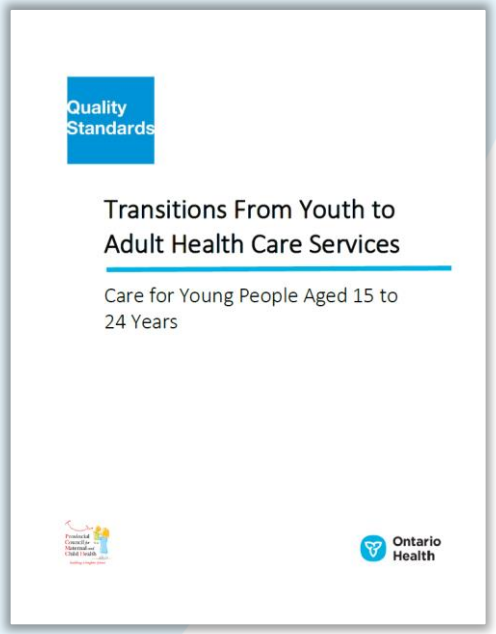
What's inside:

- An overview of quality standards
- A change package, including change ideas, resources, and measurement guidance

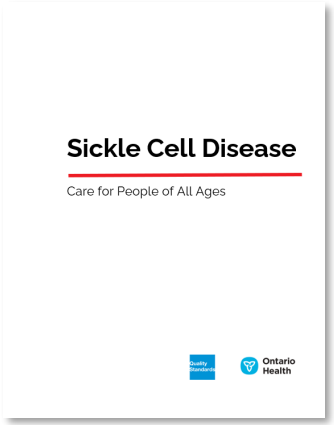
Quality standards

- Are part of Ontario Health's legislated mandate
- Inform clinicians and patients what high-quality care looks like
- Focus on conditions or processes where there are large variations in how care is delivered or where there are gaps between the care provided in Ontario and the care patients should receive
- Focus on areas for clinical improvement with measurement indicators
- Are grounded in the best available evidence
- Have a broad audience: clinicians, health system planners, patients, caregivers, and families

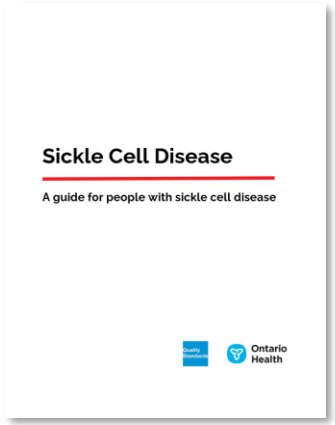




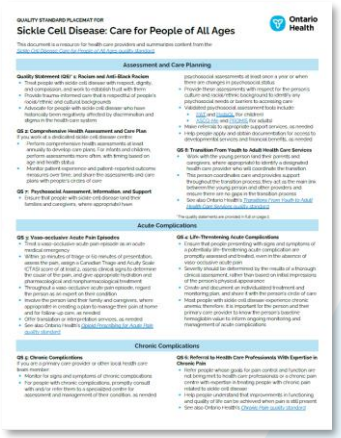
Quality standard resources



Quality Standard



Patient Guide



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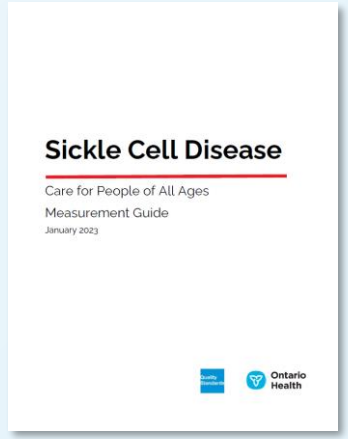
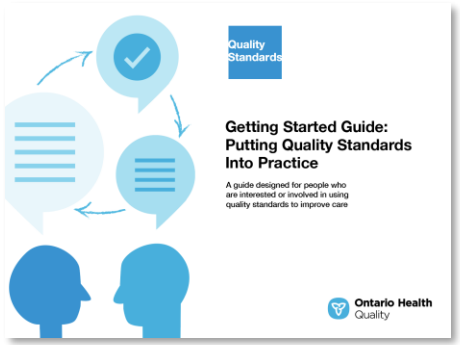
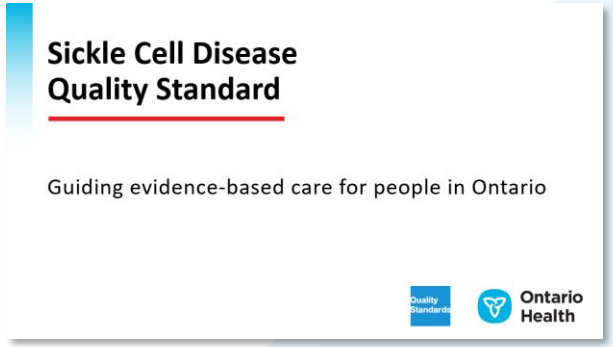


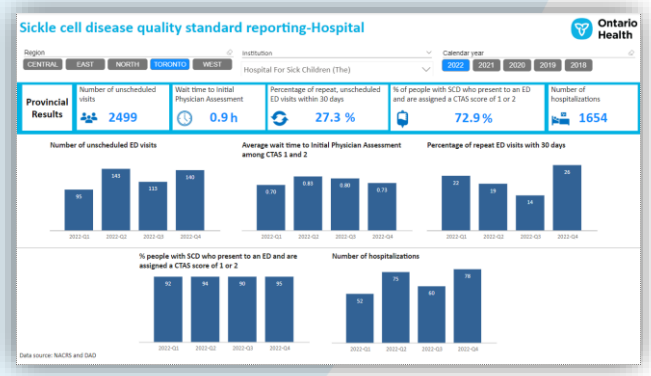
Measurement Guide



Getting Started Guide



Case for Improvement (slide deck)



eReport

Find these resources here:
https://www.hqontario.ca/Evidence-to-Improve-Care/Quality-Standards/View-all-Quality-Standards/Sickle-Cell-Disease

Sickle cell disease context

About **3,500** people in Ontario have SCD. These numbers are **expected to increase** with **immigration** and with **new births** from parents who carry the sickle cell trait.

SCD mostly affects racialized people, particularly those who **identify as Black**. Black people experience **anti-Black racism** in their **interactions with the health care system** that negatively impacts the quality of health care provided to them.

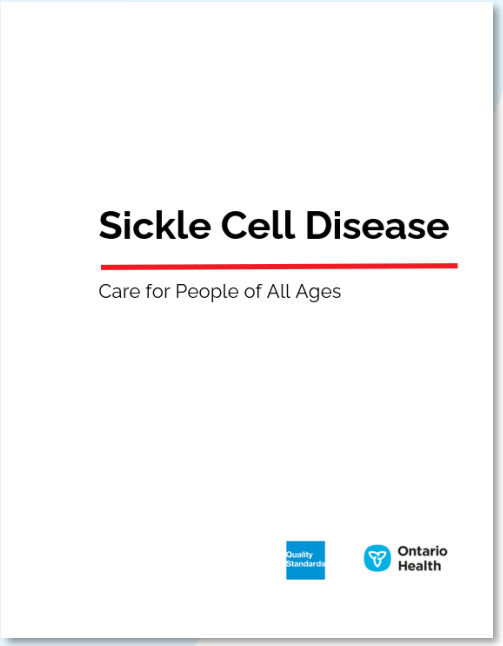
Living in **stressful social and economic conditions** can negatively affect the overall health and well-being of people with SCD.

Sickle cell disease quality standard

To provide guidance on the treatment and management of SCD, Ontario Health developed an SCD quality standard **consisting of 8 quality statements**. While the quality standard applies to all care settings, some statements apply to specific care settings.

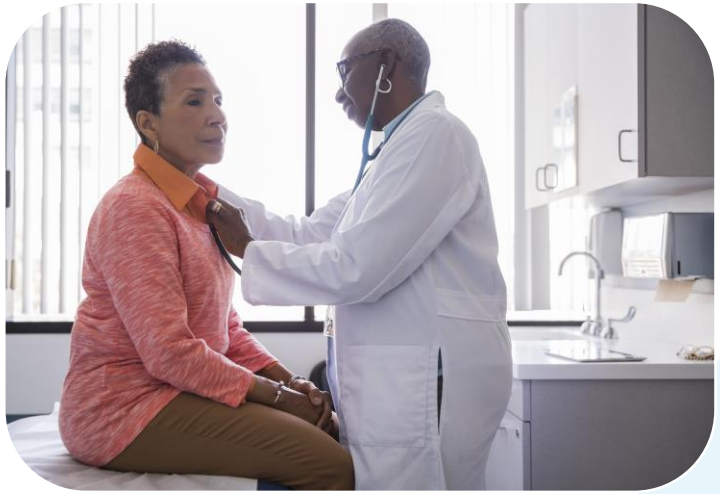
Quality statements

1. Racism and anti-Black racism
2. Comprehensive health assessment and care plan
3. Vaso-occlusive acute pain episodes
4. Life-threatening acute complications
5. Chronic complications
6. Referral to health care professionals with expertise in chronic pain
7. Psychosocial assessment, information, and support
8. Transition from youth to adult health care services



Scope of the sickle cell disease quality standard

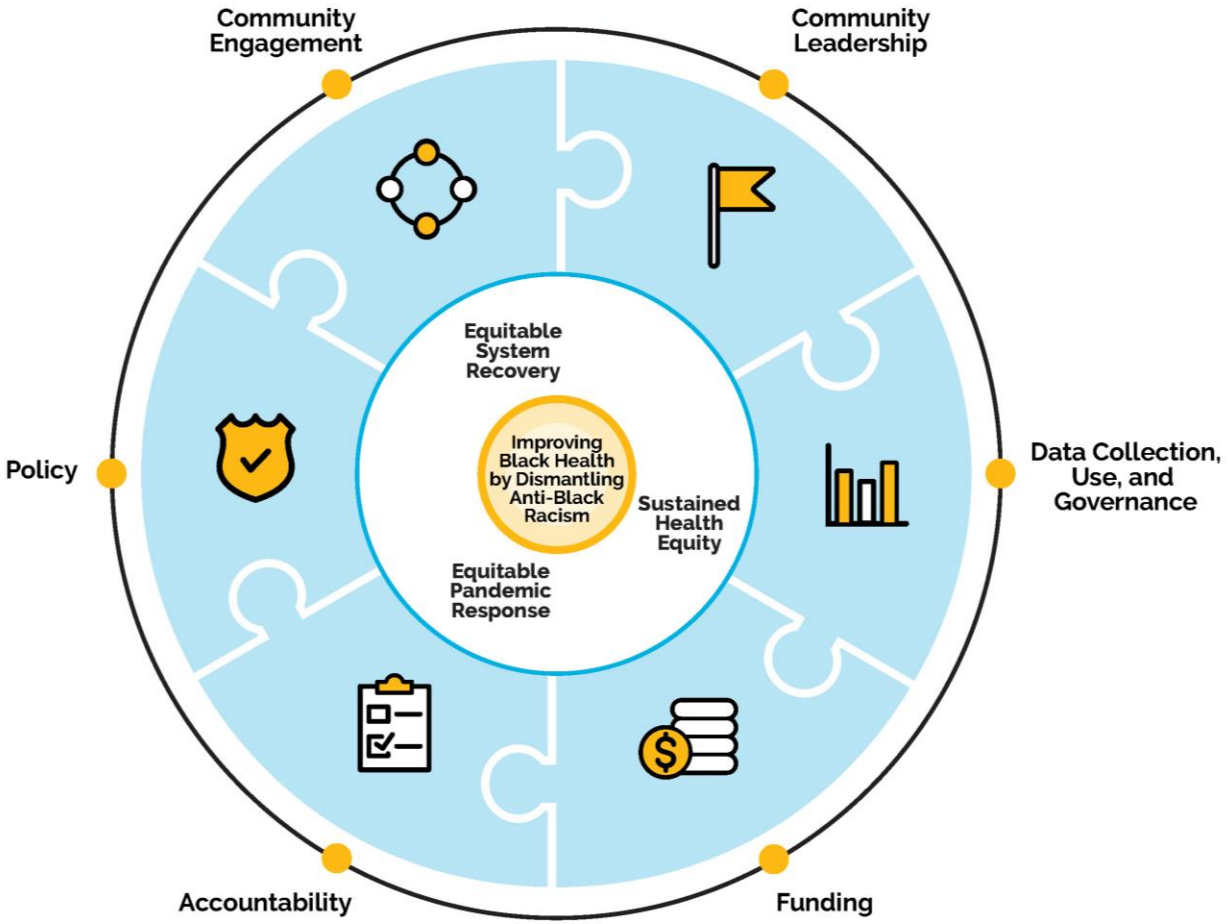
…**care for children, young people, and adults with SCD**. Where appropriate, it also addresses the needs of families and caregivers or other substitute decision-makers



…**screening** for and **preventing complications**, **assessing** and **managing acute and chronic complications**, and using disease-modifying therapies

…**pediatric and adult health care settings** (including hospitals, emergency departments, urgent care clinics, primary care, specialist care, and home and community care settings)

Sickle cell disease quality standard: Alignment with Ontario Health's Black Health Plan



Goal: To build a health system that delivers sustained health equity for Black populations and that aligns with and furthers several areas of action under Ontario Health's Equity, Inclusion, Diversity and Anti-Racism Framework

IMPLEMENTATION TOOLKIT

Implementation Support

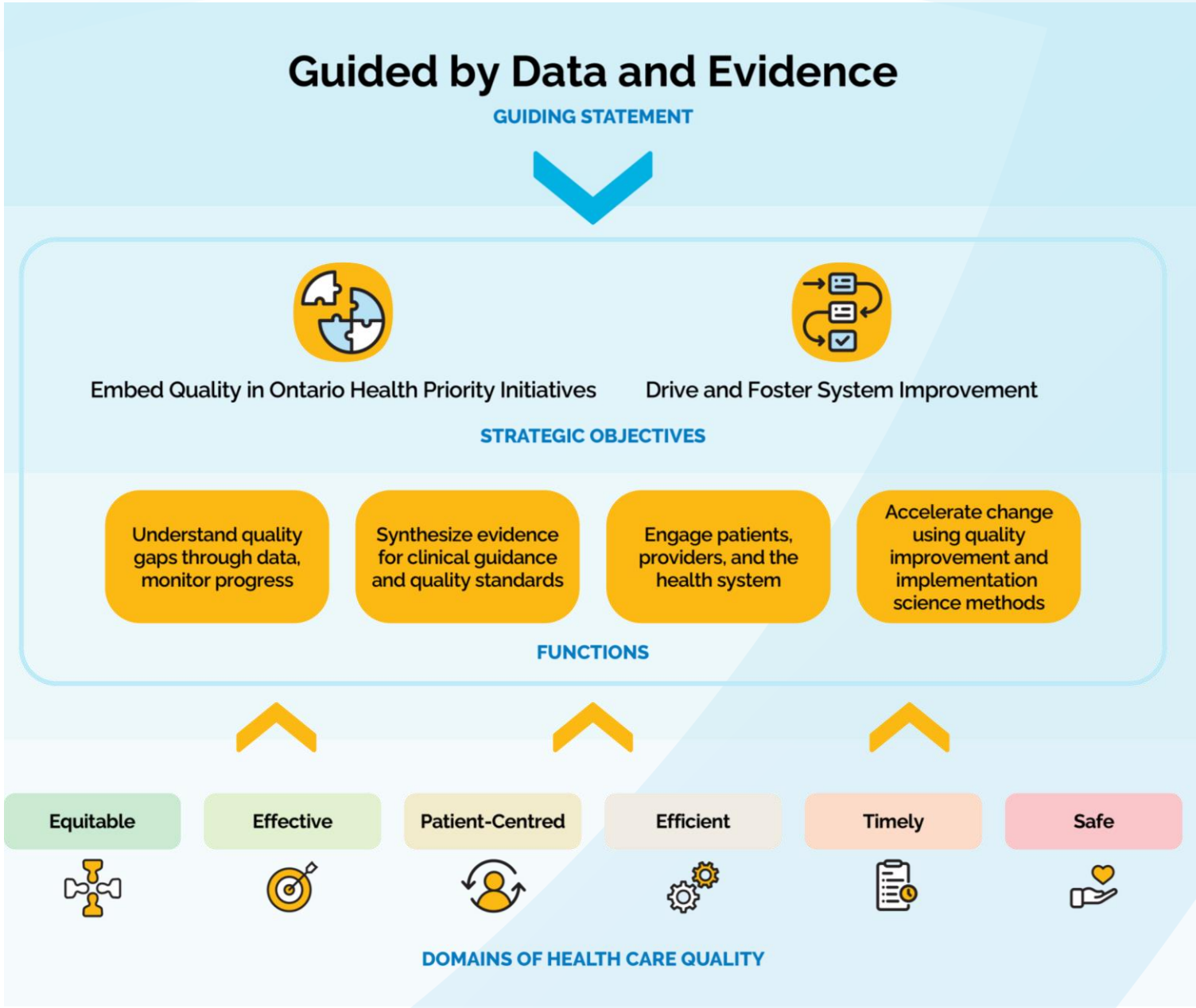
QUALITY STANDARD IMPLEMENTATION APPROACH: ALIGNED WITH THE ONTARIO HEALTH INTEGRATED QUALITY FRAMEWORK

UNDERSTAND QUALITY GAPS

- ✓ eReport data to drill down into and understand regional and organizational variation and where high and low performance exist
- ✓ Alignment with Ontario Health strategic priorities and annual business plan

SYNTHESIZE EVIDENCE

- ✓ Quality standard
- ✓ Patient guide and placemat
- ✓ Case for Improvement slide deck
- ✓ Indicator technical specifications



ENGAGE PATIENTS, PROVIDERS, AND THE HEALTH SYSTEM

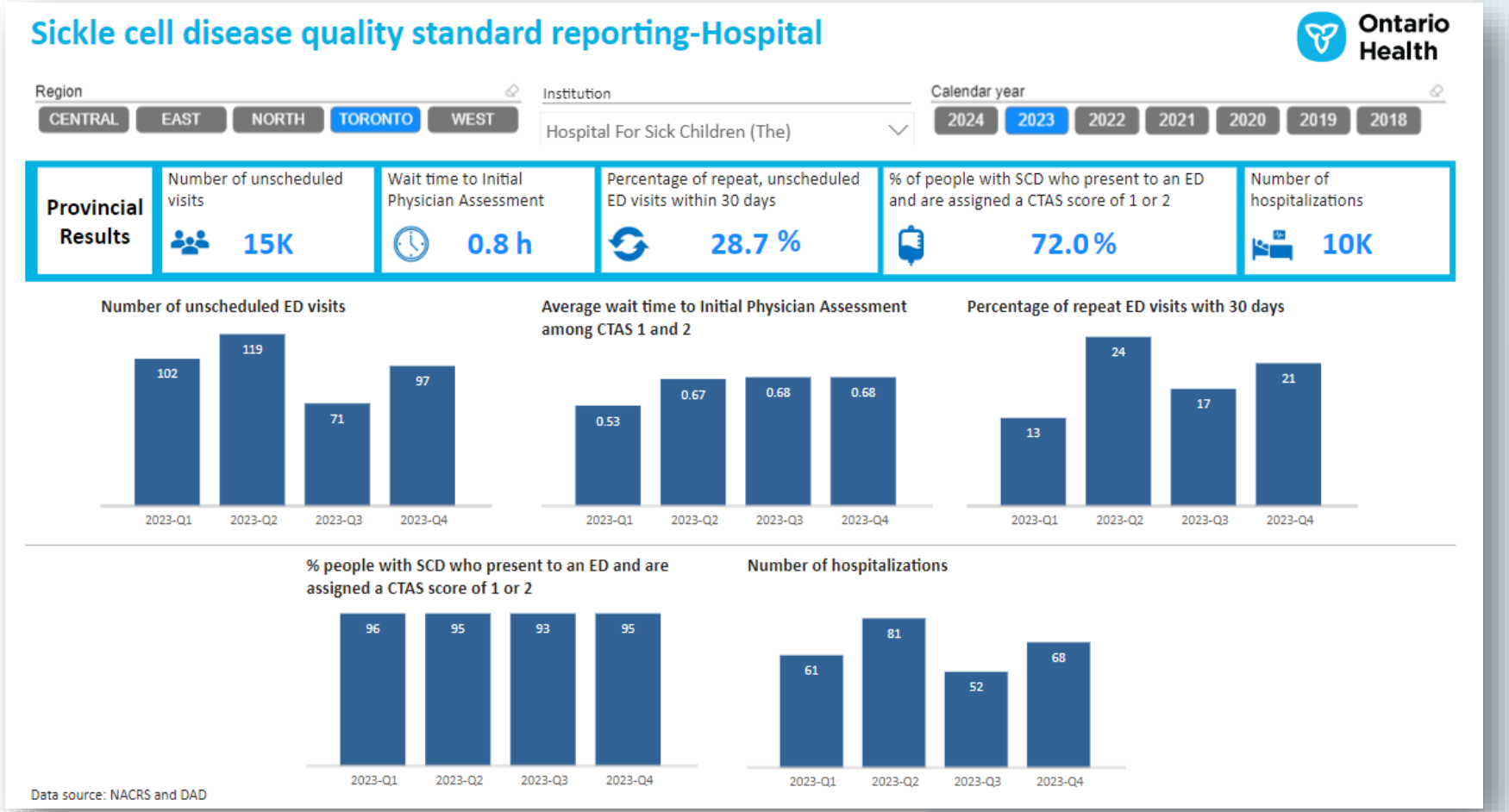
- ✓ Clinical leadership
- ✓ Communities of practice
- ✓ Engagement of regional leadership and provincial networks and tables
- ✓ Provincial training and educational modules
- ✓ Ongoing dissemination to build awareness

ACCELERATE CHANGE

- ✓ Funding agreements
- ✓ Implementation toolkits
- ✓ QIP program supports
- ✓ E2P program digital tools

Abbreviations: E2P, Evidence2Practice; QIP, Quality Improvement Plan.

Sickle cell disease quality standard eReport: Data-driven quality improvement



- Tracks implementation progress at the system level using quality indicators from the SCD quality standard
- Provides data at the hospital, regional, and provincial levels
- Can be used by regions and hospitals to support quality improvement initiatives
- Available for all clinicians and administrators
- Allows comparison of an individual hospital with region and province on key indicators and comparisons over time

Abbreviations: CTAS, Canadian Triage and Acuity Scale; ED, emergency department.

Sickle cell disease eReport indicators

- Number of unscheduled ED visits
- Average wait time to initial physician assessment
- Percentage of people with SCD who present to an ED and are assigned a CTAS score of 1 or 2
- Percentage of repeat ED visits within 30 days
- Number of hospitalizations for SCD

Abbreviations: CTAS, Canadian Triage and Acuity Scale; ED, emergency department.

Quality standard eReport access guide

Step 1

Do you have a ONE ID?

If you already have a ONE ID account, go to step 4.
If you do not have a ONE ID account, go to step 2.

ONE ID
Identity & Access Management

Step 2

Request ONE ID

Email Ontario Health Local Registration Authority (LRA) (QualityStandards@OntarioHealth.ca) or hospital LRA to request a ONE ID account to access the quality standard eReport platform (once connected, this process takes 10-15 minutes).

- **Physicians and surgeons can also follow these steps**

Step 3

ONE ID registration

The LRA requires 2 forms of personal identification to be shared with them via Teams or in person: provincial, federal, or professional identification (including licence registration number).

- For registration support, please contact QualityStandards@OntarioHealth.ca

Step 4

Provision ONE ID

Contact Ontario Health LRA or hospital LRA when ONE ID registration is complete. Ask to provision your ONE ID account with access to **QS_Reports/eReports**.

> Thanks for letting me know – I have provisioned your ONEID account with access to QS Reports under the sponsorship of Ontario Health.
>
> You can access this via the following link: https://ereport.ontariohealth.ca/
>
> I will now resolve the above ticket.
>
> Thanks!

Step 5

Log in to ONE ID

Enter your ONE ID email address and password.

Step 6

View eReports

Select appropriate eReport from the drop-down menu to view.

IMPLEMENTATION TOOLKIT

Sickle Cell Disease Change Ideas

Please consider these options as resources, tools, and programs for teams to leverage where needed

Getting started using data and change ideas

The following change ideas, associated tools, and resources are provided as suggestions to assist in the implementation of the SCD quality standard. In parallel with data and measurement for quality improvement, teams are encouraged to use selected change ideas to address known barriers to implementation.

- As a part of this work, consider using the Getting Started Guide as a quality improvement (QI) resource
- These Spotlight Reports for the Hip Fracture and Schizophrenia quality standards highlight real-world examples to help you understand what successful quality standard implementation looks like
- The SCD quality standard eReport provides regularly updated data to inform your QI efforts (ONE ID needed to access)
- Quality Improvement Plans (QIPs) for fiscal year 2024/25 include SCD indicators as a core element of quality care in alignment with Ontario Health's Black Health Plan and a commitment to equity (see QIP Indicator Technical Specifications)
- This toolkit will evolve over time based on feedback from teams and clinicians to reflect the best available evidence and shared learnings
- If you know of any tools or resources not identified in this change package, please let us know: QualityStandards@OntarioHealth.ca

Navigate by quality statement

Click on the link to go directly to the change ideas for each quality statement:

Quality statement 1: Racism and anti-Black racism

Quality statement: People with sickle cell disease (and their families and caregivers) experience care from health care providers within a health care system that is free from racism and anti-Black racism, discrimination, and stigma. Health care providers promote a culture that is compassionate, trauma informed, and respectful of people's racial/ethnic and cultural backgrounds. They build trust with people with sickle cell disease (and their families and caregivers), work to remove barriers to accessing care, and provide care equitably.

Who the audience is: All health care providers

Why this is important: Racism, particularly anti-Black racism, is the most significant source of stigma experienced by people with sickle cell disease. The traumatic impact of being subjected to racism and discrimination has a negative impact on a person's physical and mental well-being.

Gaps or barriers: Health care providers' preexisting biases, negative attitudes and behaviours, systemic racism (in systems, policies, and procedures)

Indicators and measurement (see Measurement Guide):

- Percentage of people with sickle cell disease who report receiving care from health care providers and a health care system that is free from racism, anti-Black racism, discrimination, and stigma

Change ideas: Racism and anti-Black racism

Change concept: Develop an organizational plan to provide care that is culturally responsive and free of racism

Change idea	Examples of tools and resources
Advance organizational equity by embedding anti-racism and anti-Black racism policies and procedures across your organization	• University Health Network's Anti-Racism and Anti-Black Racism Policy • Lakeridge Health's Inclusion, Diversity, Equity, Accessibility, and Anti-Racism Multi-Year Action Plan • The Black Health Collaborative's Anti-Black Racism and Pediatric Health Learning Series • The Institute for Healthcare Improvement's educational resources, tools, and initiatives to advance health equity
Support leaders to act as role models to create diverse, inclusive teams with an anti-racist team dynamic	
Encourage participation in or founding of educational initiatives and mentorship opportunities for clinicians and learners designed to address anti-Black racism	• The Black Physicians of Canada's Mentorship Program • The University of Toronto's Diversity Mentorship Program • The Black Student Application Program at the University of Toronto and the University of Ottawa

Provide teams with ongoing anti-racism and anti-oppression education and training	• Toronto Academic Health Science Network's Anti-Black Racism eLearning Module
	• Youth Research & Evaluation eXchange's Centering Black Youth Wellbeing: A Certificate on Combating Anti-Black Racism
	• The Black Health Equity Working Group's Engagement Government, Access and Protection Framework
	• The Sickle Cell Awareness Group of Ontario's educational modules:
	  ○ Module 1: Fundamentals of SCD
	  ○ Module 7: Moving Towards Anti-Oppressive, Anti-Racist Healthcare in SCD
	  ○ Module 8: Sustainable Advocacy in SCD
	• Black Health Collaborative:
	  ○ Webinar recording: Why Anti-Racist Healthcare Matters (with a focus on Black health and anti-Black racism in healthcare)
	  ○ Self-learning program: Black Health Primer: Empowering Learners with Tools and Resources to Address Anti-Black Racism and Revolutionize the Canadian Healthcare System

Use equity-based demographic information to identify and address race-based care gaps	
Provide opportunities for reflection on equity, diversity, and inclusion (EDI) in organizational quality improvement activities. For example, devote 1 huddle per week to teaching or learning about an EDI concept	

Quality statement 2: Comprehensive health assessment and care plan

Quality statement: People with sickle cell disease have a comprehensive health assessment at least annually from an interprofessional care team at a dedicated sickle cell disease centre to develop an individualized, person-centred care plan. The assessment and care plan are documented and shared with the person's circle of care

Who the audience is: Interprofessional care teams in all settings

Why this is important: Regular comprehensive health assessments provided at a dedicated sickle cell disease centre ensure that people with sickle cell disease receive appropriate preventive and specialized care from an interprofessional care team with expertise in sickle cell disease

Gaps or barriers: Lack of health care professionals with knowledge to provide appropriate care for people with sickle cell disease, limited resources to fund an adequate number of dedicated sickle cell disease centres across the province, geographic distance between homes of people with sickle cell disease and their nearest dedicated sickle cell disease centre

Indicators and measurement (see Measurement Guide):

- Percentage of people with sickle cell disease who have a comprehensive health assessment annually from an interprofessional care team at a dedicated sickle cell disease centre
- Percentage of people with sickle cell disease with a completed comprehensive health assessment who have an individualized, person-centred care plan
- Percentage of people with sickle cell disease who have their comprehensive health assessment and care plan shared with their circle of care

Change ideas: Comprehensive health assessment and care plan

Change concept: Establish a structured approach to comprehensive health assessments and care plans

Change idea	Examples of tools and resources

Educate and train dedicated SCD centre teams on the requirements of comprehensive care assessment and planning	• The Canadian Haemoglobinopathy Association's SCD Consensus Statement (Part I: Disease-Modifying Therapy and Part III: Comprehensive Care)
	• The Sickle Cell Awareness Group of Ontario's educational modules:
	  ○ Module 4: Transfusions, Hydroxyurea Use & Provincial Drug Coverage in SCD
	  ○ Module 9: Fertility, Contraception, and Pregnancy in SCD

Build capacity for interprofessional comprehensive health assessments to be delivered in person and virtually through telemedicine or other technologies	• OTN: virtual doctor's appointments | eVisits for patients
Build capacity at dedicated SCD centres and in local health care teams to document and share comprehensive health assessments and care plans	• Ontario Health community of practice webinar: Coordinating Care Between SCD Centres and Local Health Care
Develop a clinical notes template to ensure that comprehensive health assessments and care plans are performed routinely and in the same way for all patients	• Hamilton Health Sciences Epic ED order set note template (please join the Sickle Cell Disease community of practice on Quorum to access this template under Attachments > Implementation Resources > Sample Order Sets)
Embed standardized patient experience and patient-reported outcome measures in the comprehensive assessment and monitor over time	
Provide primary care and emergency department (ED) clinicians with contact information to refer people not already connected to a dedicated SCD centre	• Contact information for dedicated SCD centres in Ontario • The Evidence2Practice (E2P) program integrates the most up-to-date and relevant evidence and quality standards into digital frontline clinical systems
Build referral to dedicated SCD centres into ED and inpatient order sets	

Quality statement 3: Vaso-occlusive acute pain episodes

Quality statement: People with sickle cell disease who present to an emergency department or hospital with a vaso-occlusive acute pain episode receive a timely pain assessment and clinical assessment. Their treatment begins within 30 minutes of triage or 60 minutes of presentation. Before discharge, they are involved in the development of a plan for continuing to manage their acute pain episode at home. This plan includes symptom management strategies and information on how to access follow-up care and support from health care providers, as needed

Who the audience is: Interprofessional care teams in emergency department and acute care settings

Why this is important: Vaso-occlusive acute pain episodes are the most common cause of emergency department visits and hospitalizations for people with sickle cell disease. When inadequately treated, vaso-occlusive acute pain episodes can result in tissue hypoxia, which may result in life-threatening acute complications, chronic disease, and further pain management complications

Gaps or barriers: Emergency department delays may make it difficult for timely identification, triage, and treatment; lack of urgency for people with SCD from emergency department teams; limited clinician knowledge of treatment for people with sickle cell disease

Indicators and measurement (see Measurement Guide):

- Percentage of people with sickle cell disease who present to an emergency department or hospital with a vaso-occlusive acute pain episode and are assigned a Canadian Triage and Acuity Scale (CTAS) score of at least 2
- Percentage of people with sickle cell disease who present to an emergency department or hospital with a vaso-occlusive acute pain episode and have pain management started within 30 minutes of triage or 60 minutes of presentation
- Percentage of people with sickle cell disease discharged from hospital who receive information on how to continue managing their acute pain episode and on follow-up care and health care provider support

Change ideas: Vaso-occlusive acute pain episodes

Change concept: Optimize timely and appropriate management of vaso-occlusive acute pain episodes

Change idea	Examples of tools and resources

Educate and train emergency department teams to ensure timely and appropriate management of vaso-occlusive acute pain episodes	• The Sickle Cell Awareness Group of Ontario's educational modules:
	  ○ Module 3: Acute Pain in SCD
	  ○ Module 4: Transfusions, Hydroxyurea Use & Provincial Drug Coverage in SCD
	  ○ Module 5: Common Complications in SCD
	  ○ *Note:* Modules 4 and 5 are helpful for managing other complications that patients with SCD may be experiencing when they present with vaso-occlusive crisis
	• Duke University's Emergency Department SCD: Crisis Management and Beyond: educational resources to support clinicians caring for patients with SCD in the emergency department
	• Project ECHO's Pain in Blood Disorders program

Build standardized treatment protocols for patients with SCD, including mechanisms for clear, timely communication among patients, caregivers, and clinicians	• The Canadian Haemoglobinopathy Association's SCD Consensus Statement (Part II: Preventing and Managing Complications of SCD) • The Provincial Council for Maternal and Child Health and the Ministry of Health and Long-Term Care's Clinical Handbook for Sickle Cell Disease Vaso-occlusive Crisis (includes implementation recommendations for clinical organizations; see pp. 32–45) • American Society of Hematology SCD Guidelines: Management of Acute and Chronic Pain • Sample order sets from Trillium Health Partners are available on Quorum (adult and pediatric) • The Hospital for Sick Children's Clinical Practice Resources (see Sickle Cell section), including Acute Painful Episodes Vaso-occlusive Crisis: Guidelines for Management in Children with SCD • The Evidence2Practice (E2P) program integrates the most up-to-date and relevant evidence and quality standards into digital frontline clinical systems
Create or adapt existing order sets for SCD-related acute pain management so that clinicians can quickly initiate appropriate treatment. Add an order set entry to standardized treatment protocols to promote use	
Create medical directives to enable nursing staff to initiate rapid treatment (i.e., analgesics) and diagnostics	
Create a triage workflow plan to ensure that clinicians are notified as soon as possible when a patient with SCD arrives in the emergency department and that these patients are assigned an appropriate triage level (minimum acuity level: CTAS 2)	• Ontario Health SCD community of practice webinar: Vaso-occlusive Acute Pain Management Using Sublingual Fentanyl
Embed care plans into electronic health records to inform clinicians' treatment decisions	• Ontario Health SCD community of practice webinar: Using and Adapting Order Sets in Pediatric and Adult Care
Provide patients with SCD with a discharge information sheet in a language they understand	• OpenLab's Patient Oriented Discharge Summary (PODS): a simple tool and set of process changes to improve the hospital transition experience for patients, codesigned with patients, caregivers, and providers

Quality statement 4: Life-threatening acute complications

Quality statement: People who present to an emergency department or hospital with a potentially life-threatening acute complication of sickle cell disease have their condition and its severity identified through a prompt clinical assessment. Their condition is managed appropriately with an individualized treatment and monitoring plan

Who the audience is: Interprofessional care team in emergency departments and acute care settings

Why this is important: People with sickle cell disease typically have a shorter lifespan than those without the disease, in part because of outcomes related to acute complications such as vaso-occlusive acute pain episodes, infection, acute chest syndrome, and cerebrovascular conditions (e.g., stroke). Acute stroke is one of the most common and devastating of these complications

Gaps or barriers: Delays in recognizing life-threatening acute complications; referring people with sickle cell disease to the appropriate, individualized treatment for their acute complication in a timely manner

Indicators and measurement (see Measurement Guide):

- Percentage of people with sickle cell disease who present to an emergency department or hospital with a potentially life-threatening acute complication of sickle cell disease, are assigned a Canadian Triage and Acuity Scale (CTAS) score of 1 or 2, and have an initial physician assessment within 5 minutes of triage (for a CTAS score of 1) or within 15 minutes of triage (for a CTAS score of 2)
- Percentage of people diagnosed with a potentially life-threatening acute complication of sickle cell disease whose condition is managed with an individualized treatment and monitoring plan

Change ideas: Life-threatening acute complications

Change concept: Optimize accurate and timely assessment, diagnosis, and treatment of life-threatening acute complications

Change idea	Examples of tools and resources

Educate and train emergency department clinicians to ensure prompt clinical assessment of potentially life-threatening acute complications of SCD	• The Canadian Haemoglobinopathy Association's SCD Consensus Statement (Part II: Preventing and Managing Complications of SCD)
	• The Canadian Paediatric Society's position statement on the prevention and management of acute complications in children with SCD
	• The Sickle Cell Awareness Group of Ontario's educational modules:
	  ○ Module 4: Transfusions, Hydroxyurea Use & Provincial Drug Coverage in SCD
	  ○ Module 5: Common Complications in SCD

Build standardized treatment protocols for SCD, including systems for referral to specialized care when needed	• The American Society of Hematology's Pocket Guides, including Management of Acute Complications of Sickle Cell Disease • The Hospital for Sick Children's Clinical Practice Resources (see Sickle Cell section) • The Evidence to Practice (E2P) Program integrates the most up-to-date and relevant evidence and quality standards into frontline clinical systems
Create or adapt existing order sets for the prompt assessment and treatment of potentially life-threating acute complications of SCD	
Create medical directives to enable nursing staff to initiate rapid treatment (i.e., analgesics) and diagnostics	
Embed care plans into electronic health records to inform clinicians' treatment decisions	*None identified to date, but Ontario Health is eager to collaborate to create resources to support this change idea*

Quality statement 5: Chronic complications

Quality statement: People with sickle cell disease are monitored by their local health care team for signs and symptoms of chronic complications of sickle cell disease. People with chronic complications are promptly referred to a dedicated sickle cell disease or other specialized centre for consultation and/or assessment and management of their condition, as needed

Who the audience is: Primary care providers, home and community care providers, other individual physician specialists and health care providers, and smaller centres providing care for people with sickle cell disease

Why this is important: Despite their serious consequences, chronic complications of sickle cell disease are often dismissed or misdiagnosed in settings outside dedicated sickle cell disease or other specialized centres. Closely monitoring symptoms and managing chronic complications before they progress can improve health outcomes and lengthen life-spans for people with sickle cell disease

Gaps or barriers: Lack of clinicians with knowledge to appropriately identify signs and symptoms of chronic complications, limited health care resources to support management of chronic complications

Indicators and measurement (see Measurement Guide):

- Percentage of people with sickle cell disease who are monitored by their local health care team for signs and symptoms of chronic complications
- Percentage of people with chronic complications of sickle cell disease who are referred to a dedicated sickle cell disease or other specialized centre for consultation and/or assessment and management of their condition

Change ideas: Chronic complications

Change concept: Improve the capacity of health care teams to provide high-quality care for chronic complications of SCD

Change idea	Examples of tools and resources

Train clinicians to regularly monitor people with SCD for signs and symptoms of chronic complications	• The Sickle Cell Awareness Group of Ontario's educational modules:
	  ○ Module 10: Mental Health and Wellness in SCD
	  ○ Module 13: Partnering with Primary Care Providers to Optimize Outcomes for Individuals with SCD
	• The American Society of Hematology's pocket guides: Cardiopulmonary and Kidney Disease in SCD: Screening and Management and Management of Chronic Complications in Sickle Cell Anemia
	• The Red Blood Cell Disorders Hub (see Resources)
	• The Canadian Haemoglobinopathy Association's SCD Consensus Statement (Part II: Preventing and Managing Complications of SCD)
	• The American Society of Hematology SCD Guidelines: Management of Acute and Chronic Pain

Develop a clinical notes template to ensure routine monitoring of chronic complications of SCD at all visits	*None identified to date, but Ontario Health is eager to collaborate to create resources to support this change idea*
Identify people with chronic complications of SCD and promptly consult with or refer them to a dedicated SCD or other specialized centre	• Contact information for dedicated SCD centres in Ontario • eConsult for specialist advice[1]
Leverage digital tools for referral and access to specialized care	• eConsult for primary care providers[1] • eConsult for specialist advice[1]

[1] eConsult provides clinicians with timely access to specialists to ask specific questions; it is not meant for ongoing consultations. Please note that it may be challenging to access a specialist with expertise in SCD.

Quality statement 6: Referral to health care professionals with expertise in chronic pain

Quality statement: People whose quality of life is significantly impacted by chronic pain caused by sickle cell disease are referred to individual health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease and the ability to offer pharmacological and nonpharmacological interventions

Who the audience is: Interprofessional care teams in all settings

Why this is important: Managing chronic pain in people with sickle cell disease is complex and challenging. It requires an individualized approach that involves health care professionals with an understanding of the nature of chronic pain caused by sickle cell disease. Optimal management should include pharmacological and nonpharmacological interventions with the goal of providing pain relief, increasing function, and improving overall quality of life

Gaps or barriers: Limited number of chronic pain specialists with expertise in sickle cell disease, wait times for specialist appointments

Indicators and measurement (see Measurement Guide):

- Percentage of people whose quality of life is negatively impacted by chronic pain caused by sickle cell disease and who are referred to health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease
- Percentage of people with sickle cell disease who report an improvement in their quality of life and who have received treatment from health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease
- Local availability of health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease

Change ideas: Referral to health care professionals with expertise in chronic pain

Change concept: Improve the capacity of health care teams to refer people with SCD to chronic pain specialists

Change idea	Examples of tools and resources
Educate clinicians, including pain specialists, on the nature of chronic pain in people with SCD	• Ontario Health's Opioid Prescribing for Chronic Pain quality standard • Ontario Health's Chronic Pain quality standard • SickKids Project ECHO's training session on sickle cell pain (see Neuropathic Pain and Physical Treatments) • Project ECHO's Pain in Blood Disorders program
Build an inventory of health care professionals with expertise in managing chronic pain in people with SCD	
Leverage virtual care and access to telemedicine to reduce travel burden for people with chronic pain related to SCD	• OTN: virtual doctor's appointments | eVisits for patients • SickKids Project ECHO's educational module How to Optimize Clinician/Patient Communication During Virtual Visits

Quality statement 7: Psychosocial assessment, information, and support

Quality statement: People with sickle cell disease (and their families and caregivers, where appropriate) have regular psychosocial assessments to identify any psychosocial needs or barriers to accessing care. Those with unmet psychosocial needs are offered information and support to address these needs.

Who the audience is: Interprofessional care teams in all settings

Why this is important: Sickle cell disease is a chronic, often debilitating disease that presents physical, emotional, and social wellbeing challenges that begin at birth and continue throughout the lifespan. Parents of children or young people with sickle cell disease may experience symptoms of depression and anxiety owing to many stressors, including receiving news of the diagnosis and its implications, medical risks, health care costs, time required for care and appointments, barriers to accessing care, and the potential for their child to have a shortened life expectancy. Therefore, the management of sickle cell disease requires a coordinated, holistic approach that involves an interprofessional care team of providers representing multiple medical specialties, as well as relevant community and social services.

Gaps or barriers: Stigma associated with seeking psychosocial support, limited availability of counsellors familiar with sickle cell disease, psychosocial challenges associated with sickle cell disease, adverse social determinants of health

Indicators and measurement (see Measurement Guide):

- Percentage of people with sickle cell disease (and their families and caregivers) who report receiving psychosocial assessments annually
- Percentage of people with sickle cell disease (and their families and caregivers) who report receiving information and support to address any unmet psychosocial needs

Change ideas: Psychosocial assessment, information, and support

Change concept: Increase access to psychosocial assessment and supports for people with SCD

Change idea	Examples of tools and resources

Educate health care teams to provide routine psychosocial assessments	• The Sickle Cell Awareness Group of Ontario's educational modules:
	  ○ Module 6: Successful Transitions for Adolescents and Young Adults with SCD
	  ○ Module 10: Mental Health and Wellness in SCD
	• The Red Blood Cell Disorders (RBCD) Hub is an online space for people to connect about SCD and other red blood cell disorders in Ontario; it provides resources in many areas, including accommodations, advocacy, finances, employment, school, mental health, and relationships
	• The RBCD Clinic's Wholistic Health Series provides resources to increase knowledge and awareness of mental health concerns
	• Validated psychosocial assessment tools: PAT and PedsQL (for children); ASCQ-Me and PROMIS (for adults)

Facilitate access to the existing network of community-based organizations providing psychosocial supports for people with SCD	• The Sickle Cell Awareness Group of Ontario is a provincial community organization that provides information on programs, community services, supports, and educational resources, including counselling supports and respite, emergency, and transportation supports ○ Direct patients to the Sickle Cell Awareness Group of Ontario's Learning for Life webinar series and Patient Well-Being program • The Sickle Cell Association of Ontario is a charitable provincial community organization of volunteers that provides confidential one-to-one support and counseling to people with sickle cell anemia and their families and increases public awareness of sickle cell disorders through public education programs • Refer appropriate patients to culturally adaptive cognitive behavioural therapy for Black populations
Provide people with SCD with information about how to access developmental services and financial benefits	• Developmental Services Ontario provides an access point for adult developmental services in Ontario • Financial benefits include the Government of Canada's disability tax credit and Canadian Pension Plan disability benefits and the Ontario Disability Support Program

Quality statement 8: Transition from youth to adult health care services

Quality statement: Young people with sickle cell disease have a designated health care provider for the transition from youth to adult health care services. 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. The provider continues to provide support until the young person (and their parents and caregivers, where appropriate) confirms that the transition is complete

Who the audience is: Primary care providers, other health care providers, dedicated sickle cell disease centres, and smaller centres that provide care for people with sickle cell disease

Why this is important: The transition from youth to adult health care services is a critical and challenging time for young people with sickle cell disease and their parents and caregivers. The process is often complicated by health system barriers, including poor communication and coordination between youth and adult health care providers and a lack of person- and family-centred social supports and resources. Having a designated health care provider whom the young person (and their parents or caregivers, where appropriate) knows and trusts to oversee transition planning and coordination may lead to more positive experiences, better attendance in adult health care services, and better outcomes

Gaps or barriers: Lack of clear guidelines or protocols for transitions, gaps in communication between pediatric and adult care clinicians

Indicators and measurement (see Measurement Guide):

- Percentage of young people with sickle cell disease transitioning out of youth-oriented health care services who have a designated health care provider for the transition process
- Percentage of young people with sickle cell disease transitioning out of youth-oriented health care services (and their parents and caregivers, where appropriate) who feel their care is being adequately coordinated by their designated health care provider

Change ideas: Transition from youth to adult health care services

Change concept: Improve the capacity of health care teams to support the transition from youth to adult health care services

Change idea	Examples of tools and resources
Educate and train clinicians on coordinating the transition from youth to adult health care services, including arranging appointments for the young person, acting as their support person and advocate, and guiding them to other services and sources of support as needed	• Ontario Health's Transitions From Youth to Adult Health Care Services quality standard (quality statement 1: Early Identification and Transition Readiness) • The Canadian Haemoglobinopathy Association's SCD Consensus Statement (part III, section 7: Transitions of Care in Adolescents and Young Adults) • The Sickle Cell Awareness Group of Ontario's educational module: ○ Module 6: Successful Transitions for Adolescents and Young Adults with SCD • The American Society of Hematology's readiness assessment and clinical summary forms to support the Pediatric to Adult Hematologic Care Transition • The American College of Physicians' High-Value Care Pediatric-to-Adult Care Transition Toolkit: SCD Transition Readiness Assessments and Clinical Summary
Support clinicians and health care teams to perform regular collaborative transition readiness reviews that involve the young person, their parents and caregivers, and their clinicians; start these reviews as early as possible and update them regularly	
Ensure systems, processes, and resources are in place for health care providers[1] to coordinate care and provide support throughout the transition process until the transition is complete	• Ontario Health's Transitions From Youth to Adult Health Care Services quality standard and placemat
Educate and provide resources to support young people and their families and caregivers in the transition from youth to adult health care services	• The Sickle Cell Awareness Group of Ontario offers support for transitioning from pediatric to adult care programs, including programs to support transitions and resources for counselling and navigation support • Ontario Health's Transitions From Youth to Adult Health Care Services quality standard, guide for young people, and guide for caregivers • Ontario Health's list of resources for moving from youth to adult health care services

[1]The provider in charge of coordinating the transition is identified early (planning may start as early as young childhood, 10 or more years before age 18) and may change over time, given that the transition process is often prolonged.

Thank you

If you have questions, please contact:

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