

Sickle Cell Disease

Care for People of All Ages



Scope of This Quality Standard

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

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

The [Clinical Handbook for Sickle Cell Disease Vaso-occlusive Crisis](#) by the Provincial Council for Maternal and Child Health and the Ontario Ministry of Health addresses care for sickle cell crisis (referred to as a “vaso-occlusive acute pain episode” in this quality standard) and applies to quality statement 3.¹

What Is a Quality Standard?

Quality standards outline what high-quality care looks like for 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. They:

- Help patients, families, and caregivers know what to ask for in their care
- Help health care professionals know what care they should be offering, based on evidence and expert consensus
- Help health care organizations measure, assess, and improve their performance in caring for patients

Quality standards and their accompanying patient guides are developed by Ontario Health, in collaboration with health care professionals, patients, and caregivers across Ontario.

For more information, contact QualityStandards@OntarioHealth.ca.

Quality Statements to Improve Care: Summary

These quality statements describe what high-quality care looks like for people with sickle cell disease.

Quality Statement 1: Racism and Anti-Black Racism

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.

Quality Statement 2: Comprehensive Health Assessment and Care Plan

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.

Quality Statement 3: Vaso-occlusive Acute Pain Episodes

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.

Quality Statement 4: Life-Threatening Acute Complications

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.

Quality Statement 5: Chronic Complications

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.

Quality Statement 6: Referral to Health Care Professionals With Expertise in Chronic Pain

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.

Quality Statement 7: Psychosocial Assessment, Information, and Support

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.

Quality Statement 8: Transition From Youth to Adult Health Care Services

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.

Table of Contents

Scope of This Quality Standard.....	1
What Is a Quality Standard?	1
Quality Statements to Improve Care: Summary.....	2
Why This Quality Standard Is Needed.....	5
Measurement to Support Improvement.....	7
Quality Statements to Improve Care	9
Racism and Anti-Black Racism.....	10
Comprehensive Health Assessment and Care Plan	15
Vaso-occlusive Acute Pain Episodes	20
Life-Threatening Acute Complications	27
Chronic Complications.....	31
Referral to Health Care Professionals With Expertise in Chronic Pain.....	35
Psychosocial Assessment, Information, and Support.....	39
Transition From Youth to Adult Health Care Services	45
Appendices	49
Appendix 1. About This Quality Standard	50
Appendix 2. Measurement to Support Improvement.....	51
Appendix 3. Glossary	60
Appendix 4. Values and Guiding Principles.....	63
Acknowledgements.....	66
References.....	68
About Us.....	78

Why This Quality Standard Is Needed

Sickle cell disease is one of the most common inherited red blood cell disorders.¹⁻³ The disease can lead to serious health conditions including infection, stroke, organ damage, and acute and chronic pain.² It is most prevalent in regions of Africa, the Mediterranean, the Middle East, and India, although the sickle cell trait is found in all racial/ethnic groups.^{4,5} As a result of global migration, there has been an increase in the prevalence of sickle cell disease among people of African, Arab, and Indian racial/ethnic backgrounds in Canada.¹

About 3,500 people in Ontario and 6,500 people across Canada have sickle cell disease.^{6,7} These numbers are expected to increase with immigration from countries with high disease prevalence, with new births in Canada from parents who carry the sickle cell disease trait, and given improved care and treatment options, resulting in increased life expectancy.^{3,6,7} In Ontario and across Canada, sickle cell disease mostly affects racialized people, particularly those who identify as Black.⁷ These people often experience racism and anti-Black racism in their interactions with the health care system, which negatively impacts the quality of the health care provided to them.^{7,8} Owing to the systemic nature of anti-Black racism, Black people with sickle cell disease experience the intersections of ableism and racism in many areas, including education, housing, child welfare, employment,⁹⁻¹³ immigration, and justice systems,^{14,15} all of which negatively impact health and well-being.¹⁶⁻²¹ Further, sickle cell disease has historically been thought of as a “Black disease,” and the long societal and cultural association of sickle cell disease with people who identify as Black has led to structural marginalization, deprioritization, and neglect of care for impacted people in both high- and low-income societies around the world.^{16,22-28}

Living under stressful social and economic conditions can impact the overall health and well-being of people with sickle cell disease.^{29,30} Such stresses include social stigma, discrimination, and inadequate access to education, employment, income, and housing.^{6,31,32} Administrative data from Ontario show that while people with sickle cell disease live in all health regions, most live in areas around Toronto and Ottawa and that about 40% of patients live in the neighbourhoods with the lowest income. The communities in which most people with sickle cell disease live are also communities that are under-resourced with regard to access to social and health services and public transportation.^{33,34} More than half of caregivers surveyed reported that patient symptoms impacted various aspects of caregivers' lives, such as their ability to attend work or school (56%), earning potential (54%), mental health (52%), and overall well-being (53%).³⁵

People living in rural, remote, and Northern communities may face additional challenges to accessing comprehensive care compared with their urban peers.²⁹ These geographic barriers, which include the need to travel to large urban centres and hospitals and the time and financial resources required to do so, can further worsen continuity of care.²⁹

Acute pain episodes are the hallmark acute complication of sickle cell disease.^{1,2} Guidelines recommend rapid access to appropriate pain management, which for severe complications is often opioid analgesia.^{1,2} However, people with sickle cell disease often experience systemic racism and discrimination when they seek care in the emergency department for acute pain relief.^{31,36} Many report avoiding or delaying accessing care in the emergency department because of previous experiences of being stigmatized and falsely accused of "drug-seeking."³⁶⁻³⁸ When people with sickle cell disease do seek care, they often face long waits, treatment delays, and a lack of respect and empathy, and they are often denied effective medication for adequate pain relief.^{7,37-39} In addition, when compared with the general population seeking emergency department care, people with sickle cell disease are more likely to be admitted to hospital, often have a longer hospital stay, and experience higher rates of repeat emergency department visits within 30 days of being discharged from the emergency department.³⁹

Opportunities for improvement in Ontario exist to ensure that high-quality, timely care is delivered in the emergency department and other hospital settings for people experiencing acute complications of sickle cell disease. A survey of people with sickle cell disease found the following⁴⁰:

- 54% felt that the quality of care received was below their expectations
- For those presenting to the emergency department with pain, many waited more than 1 hour to see a nurse (31%) or physician (56%) and for the administration of pain medication (50%)
- Only 60% reported that the first person they met at triage was respectful, empathetic, and caring
- About 22% reported feeling stigmatized or afraid of dying during their hospital visit, and 44% reported feeling lonely or helpless
- 71% reported that their health care provider was not responsive or only somewhat responsive to their concerns
- Although 60% of respondents reported that their health care providers were very or extremely knowledgeable, 40% reported that their providers were not at all or only somewhat knowledgeable

People with sickle cell disease have also identified a lack of awareness and education about sickle cell disease among some health care providers who work outside specialist centres.^{31,41-43} In Ontario, gaps in provider knowledge of sickle cell disease and negative attitudes toward people with sickle cell disease are key barriers to accessing and receiving high-quality care.¹ Treatment advances have also led to people with sickle cell disease living longer; as a result, there is a crucial need to improve knowledge and capacity within the adult health care system to provide appropriate continuity of care for young people transitioning to adult care.³⁰

This quality standard includes eight quality statements that address areas identified by the Sickle Cell Disease Quality Standard Advisory Committee as having high potential to improve care for people with sickle cell disease in Ontario.

A quality standard on sickle cell disease strengthens Ontario Health's commitment to Black health and, through collaborations with the Black Health Plan Working Group, furthers the goals of Ontario Health's [Equity, Inclusion, Diversity and Anti-Racism Framework](#).

Measurement to Support Improvement

The Sickle Cell Disease Quality Standard Advisory Committee identified six overarching indicators to monitor the progress being made to improve care for people with sickle cell disease in Ontario.

Indicators That Can Be Measured Using Provincial Data

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

Indicators That Can Be Measured Using Only Local Data

- Percentage of people with sickle cell disease who report an improvement in their quality of life
- Percentage of people with sickle cell disease who report being satisfied with their interaction with their health care provider

Quality Statements to Improve Care

Racism and Anti-Black Racism

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.

Source: Advisory committee consensus

Definitions

Health care providers: Regulated professionals (such as doctors, nurses, and pharmacists), as well as people in unregulated professions, such as administrative staff, behavioural support workers, personal support workers, child life specialists, recreational staff, spiritual care staff, patient transport staff, and volunteers.

Health care system that is free from racism and anti-Black racism, discrimination, and stigma: A health care system that acknowledges the historic and current intersections of race and health care access and understands the systems of racism and anti-Black racism, discrimination, and stigma that have a negative impact on the way people with sickle cell disease access and receive health care and community and social services (see Appendix 4, Guiding Principles, *Social Determinants of Health*). Such a health care system ensures safe, accessible, and equitable care for people of Black and other racialized backgrounds, as well as their families.⁸ Health care practices validate the lived experiences of people with sickle cell disease. Health care providers take proactive steps to:

- Eliminate intrinsic systemic barriers to accessing care and services and the impact of bias on the care they provide

- Ensure equitable quality-of-life outcomes for all people

Racism and anti-Black racism: The systemic discrimination that harms racialized populations and groups living with health-related social needs and creates barriers to and disparities in accessing and receiving appropriate health care and community and social services.^{8,17,44} This type of racism often involves labelling, devaluation, judgment, and/or the social disqualification of a person based on their health condition, leading to negative health outcomes.³¹ Anti-Black racism is associated with policies and practices rooted in Canadian institutions such as the education, health care, social, and justice systems that mirror and reinforce beliefs, attitudes, prejudices, stereotyping, and discrimination toward people of African descent.^{17,45}

Culture that is compassionate, trauma informed, and respectful of people's racial/ethnic and cultural backgrounds: A culture in a health care setting that is:

- **Compassionate:** Care is provided by health care providers whose care is not influenced by racial/ethnic bias, who actively listen to their patients, and who work to understand their patients' needs^{46,47}
- **Trauma informed:** Care is provided by health care providers who understand the potential impact of past trauma on people with sickle cell disease and are able to provide them with the appropriate care⁴⁸ (see Appendix 4, Guiding Principles, *Trauma-Informed Care*)
- **Respectful of people's racial/ethnic and cultural backgrounds:** Care is provided by health care providers who look beyond preconceived notions and stereotypes of people with sickle cell disease to see the person for who they are as an individual. Providers respect the person's cultural or faith traditions, values, and beliefs; ensure that care is provided in the person's preferred language where possible; adapt their care as needed based on culturally relevant factors; and respect the person's wishes to involve family or community members in their care⁴⁹

Trust building: Trust is built between a health care provider and a person with sickle cell disease when the provider expresses attitudes and engages in behaviours that demonstrate to the person that they are respected and valued.⁵⁰ The person's experiences of those behaviours, as well as their perceptions and beliefs about their treatment, contribute to the degree of trust established. This degree of trust in turn influences the person's interpretation of subsequent provider behaviours, with a high degree of trust enabling them to seek care when needed in the future.

Remove barriers to accessing care: Health care providers and organizations should work toward removing intrinsic systemic barriers that hinder or deter people with sickle cell disease (and their families and caregivers) from accessing health care and community and social services. Such barriers include^{42,51-54}:

- Difficulties accessing a clinic or provider (e.g., lack of access to a primary care provider or comprehensive care [see quality statement 2], inability to contact providers or clinics, extended wait times, inconvenient clinic hours, travel/transportation)⁵⁵
- Patients' (and their families' and caregivers') difficulty navigating the health care system
- Patients' (and their families' and caregivers') limited knowledge of the disease
- Chronic pain (see quality statement 6)
- Frequent interactions with the health care system
- Negative provider attitudes toward people with sickle cell disease (e.g., implicit biases and prejudices, as well as providers' misperception of a person's need for pain medication as drug-seeking behaviour)
- Processes of care preventing patients from receiving needed treatments and high-quality care (e.g., perceived maltreatment or marginalization in the clinical setting, providers' lack of knowledge of sickle cell disease, difficulty communicating with providers [e.g., owing to language barriers or providers' inability to provide clear or sufficient information], difficulty accessing tools and/or care virtually through telemedicine or other technologies)

Equitable care: Equitable care requires that all people with sickle cell disease are provided an equal opportunity to attain their fullest health potential through barrier-free access to high-quality clinical care. Ensuring equitable care entails addressing barriers in and beyond health care settings, including addressing the social determinants of health (e.g., racism, discrimination, poverty).⁷ Equitable care is attained when people with sickle cell disease receive appropriate, timely interventions and no longer experience preventable complications or face stigma or discrimination.⁷

Rationale

Racism and anti-Black racism can have negative effects on a person's health. The traumatic impact of racism and anti-Black racism can also lead to the development of additional health issues (e.g., depression, anxiety).^{8,17} Frequent experiences of discrimination have also been associated with obesity and lower

self-rated health.¹⁷ Racism, particularly anti-Black racism, is the most significant source of stigma experienced by people with sickle cell disease. Racism and anti-Black racism create unsafe environments that prevent people with sickle cell disease from accessing care across all health care settings. Additionally, when people do seek care, racism and anti-Black racism can shape inequitable, unethical, and inadequate treatment and care.^{19,56}

In Ontario, gaps in provider knowledge of sickle cell disease and negative attitudes toward people with sickle cell disease are key barriers people with sickle cell disease experience in accessing and receiving high-quality care.¹ Some adults with sickle cell disease report reluctance to use health care services until their condition is severe owing to the discrimination they experience in the health care system.^{57,58} To improve health outcomes and the quality of life of people with sickle cell disease, the care they receive should be free of provider prejudice and bias and should address their mistrust in the health care system.^{57,58}

What This Quality Statement Means

For People With Sickle Cell Disease

Your health care providers should always treat you with respect, dignity, and compassion. You should be given the opportunity to be as healthy as possible. This means that you should be able to get high-quality health care when you need it, no matter where you seek care (for example, at your doctor's office or at the hospital).

For Clinicians

Treat people with sickle cell disease (and their families and caregivers, where appropriate) with respect, dignity, and compassion, and work to establish trust with them. Ensure that you and your health care team are equipped with the knowledge and skills needed to provide care in a culturally competent, anti-racist, and anti-oppressive way that recognizes the intersectional (see Appendix 4, Guiding Principles, *Intersectionality*) identities of people with sickle cell disease.⁴⁵ See the person for who they are as an individual, actively listen to them, work to understand their needs, and provide timely, high-quality care.⁵⁷ All health care providers, including administrators, should advocate for people with sickle cell disease (and their families and caregivers, where appropriate) who have historically been negatively affected by discrimination and stigma experienced when seeking and receiving health care.

For Organizations and Health Services Planners

At the provincial and local levels, ensure that health care and community and social services are provided by a knowledgeable workforce capable of addressing the many needs of people with sickle cell disease.⁵⁸ This includes engaging with other sectors such as education, employment, and housing.

Ensure that providers and teams across health care settings receive ongoing anti-racism and anti-oppression education and training and that the workforce represents the diversity of the population being served in terms of their racial/ethnic and cultural backgrounds.⁵⁷ Ensure that staff are supported to advocate for patients within anti-racist and social justice frameworks. Ensure that resources, including clinical space for trauma-informed and anti-racist care, are provided.

Ensure tailored services are developed in partnership with Black and other racialized communities to address their concerns and develop culturally competent health care and community and social services. This process should be accompanied by a review of policies and procedures that aims to remove intrinsic systemic barriers to accessing care and services; advance equity; address racism, anti-Black racism, and interlocking systems of social oppression; and recognize the intersectional (see Appendix 4, Guiding Principles, *Intersectionality*) identities of people with sickle cell disease.^{45,57}

For more information, please see Ontario Health's [Equity, Inclusion, Diversity and Anti-Racism Framework](#). To support the development of tailored services, consider using the Ministry of Health's [Health Equity Impact Assessment Tool](#) as a practical decision-making tool to support an equity analysis in addressing racism and anti-Black racism.

QUALITY INDICATOR:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- 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

Measurement details for this indicator, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Comprehensive Health Assessment and Care Plan

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.

Sources: American Society of Hematology, 2019⁵⁹ | American Society of Hematology, 2020⁶⁰ | National Heart, Lung, and Blood Institute, 2014²

Definitions

Comprehensive health assessment: This assessment includes but is not limited to^{2,61}:

- Screening for risk factors and early signs of complications of sickle cell disease
- Review of efforts to prevent infection (e.g., immunization, prophylactic antibiotic treatment)
- Clinical exam of the heart, lungs, liver, and spleen
- Assessment of blood pressure and oxygen saturation on room air
- For children, assessment of growth and development
- For children aged 2 to 16 years, annual screening for vasculopathies (e.g., stroke) using transcranial doppler⁶²
- Assessment of chronic pain caused by sickle cell disease (see quality statements 5 and 6) and a review of the person's history of pain medication and adverse medication effects
- Discussion of treatment options (e.g., hydroxyurea therapy,^{2,61} blood transfusion and support,^{2,61,63} stem cell transplantation^{61,64})

- Discussion of the impact of sickle cell disease and medications on sexual and reproductive health
- Screening for mental health issues (e.g., depression, anxiety) and psychosocial needs (see quality statement 7)
- Where appropriate, providing information, support, and/or referrals to address mental health issues and psychosocial needs
- Review of overall health and well-being (e.g., nutrition, dental health)
- Genetic counselling regarding family planning and management of at-risk pregnancy, where appropriate
- Identification of the person's needs, tasks, and goals
- For young people, a discussion of and planning for the transition to adult health care services (see quality statement 8)
- Where appropriate, providing education on:
 - Hydroxyurea therapy, including its potential benefits and side effects or risks^{2,61}
 - Self-management, including recognizing the signs and symptoms of acute complications (see quality statements 3 and 4) and chronic complications (see quality statement 5) to ensure timely access to medical care when needed¹

This assessment is ideally done in person but may be done through telemedicine or other technologies. It should include an assessment of patient experience and patient-reported outcome measures that are monitored over time.

At least annually: Adults should have a comprehensive assessment at least once a year, or more frequently if needed. Infants and children should have a comprehensive assessment more frequently, with the frequency determined by their age and health status.

Interprofessional care team: Includes physician specialists (e.g., hematology, internal medicine, pediatrics), a nurse, a social worker, a psychologist, and other medical and surgical specialists as appropriate, including but not limited to the areas of cardiology, nephrology, obstetrics, ophthalmology, and orthopaedic and general surgery.⁶¹ Where appropriate, additional support may be provided by care coordinators, patient navigators, providers working in home care and community support services, a geneticist or genetic counsellor, and any other relevant service providers. These providers work together with patients, and their families and caregivers where appropriate, to provide an integrated approach to care (see Appendix 4, Guiding Principles, *Integrated Care*).

Dedicated sickle cell disease centre: A centre that provides preventive and specialized care for people with sickle cell disease. This centre is connected to and integrated with the person's local health care team, which consists of the person's other sickle cell disease care providers (e.g., individual health care professionals and smaller centres), to provide support and collaborative care.

Individualized, person-centred care plan: A written document (printed or ideally digital) detailing the person's plan of care. The plan is individualized, based on the person's ongoing care needs, and linked to other plans they have with respect to care and support, such as education, employment, and housing. The care plan is updated regularly and accommodates the person's preferences in a culturally and linguistically appropriate manner.

Circle of care: The group of health care providers involved in a person's care who need to share information to provide that care. Consent to share information within the circle of care is generally implied; for example, when a patient accepts a referral to another health care professional.^{65,66} For young people capable of providing consent, however, it is important to explicitly ask them who they consent to share their information with. If the young person consents to sharing with their parents and caregivers, or if the parents and caregivers are the substitute decision-makers appointed under a "Power of Attorney for Personal Care," the care plan is also shared with them.⁶⁵

Rationale

The health and well-being of people with sickle cell disease is improved when care is coordinated throughout the lifespan and among health care settings.² People with sickle cell disease are at high risk of developing both acute and chronic multisystem conditions that are associated with significant disability and death.² Regular comprehensive health assessments provided at a dedicated sickle cell disease centre ensure that people with sickle cell disease receive preventive and specialized care from an interprofessional care team with expertise in treating people with sickle cell disease.² This assessment includes screening for risk factors and early signs of complications and providing early intervention to help prevent serious and life-threatening health conditions such as complicated infections, organ damage, and stroke.²

What This Quality Statement Means

For People With Sickle Cell Disease

You should be offered a complete health assessment at least once a year. This involves checking your physical health, your mental health, and your overall well-being. Your health assessment should be done at a health care centre that specializes in treating people with sickle cell disease. Your health care provider should use this health assessment to make a plan for your care. They should also share this plan with all your other health care providers so that everyone has the information they need to give you the best care for your sickle cell disease.

At your yearly complete health assessment, your health care provider should:

- Ask you about any pain you might be experiencing
- Provide education about the complications of sickle cell disease and tell you what early signs to watch out for
- Tell you about the treatment options available to you, including their benefits and risks
- Offer you information about other services or supports that might help you
- Tell you about any research studies you might be eligible for and help you find out how to participate if you would like to

For Clinicians

Interprofessional care team at a dedicated sickle cell disease centre: Perform and document a comprehensive health assessment at least annually for people with sickle cell disease to develop and manage individualized, person-centred care plans. For infants and children, perform and document a comprehensive health assessment more frequently, with the frequency determined by age and health status. Monitor patient experience and patient-reported outcome measures over time. Share the assessments and care plans with people's circles of care.

Check regularly for any research opportunities so that you can inform and invite people with sickle cell disease to participate if they are eligible and interested.

For Organizations and Health Services Planners

Ensure that training, systems, processes, and resources are in place at dedicated sickle cell disease centres to support the interprofessional care team in performing comprehensive health assessments at least annually for people with

sickle cell disease and developing and managing individualized, person-centred care plans.

Ensure that comprehensive health assessment services can be delivered virtually through telemedicine or other technologies in collaboration with a sickle cell disease specialist (e.g., a haematologist) when people are unable to travel to a dedicated sickle cell disease centre.

Ensure that dedicated sickle cell disease centres have systems, processes, and resources in place to document and share comprehensive health assessments and care plans with people's circles of care.

QUALITY INDICATORS:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- 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

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Vaso-occlusive Acute Pain Episodes

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.

Sources: National Heart, Lung, and Blood Institute, 2014² | National Institute for Health and Care Excellence, 2012⁵

Definitions

Vaso-occlusive acute pain episode: Also known as a vaso-occlusive crisis (VOC) or vaso-occlusive episode (VOE), a vaso-occlusive acute pain episode is an intermittent, recurrent acute severe pain episode. It is caused by vaso-occlusion (clumps of sickled red blood cells that cause blockages in blood vessels), most commonly in the bones or bone marrow. An episode presents as excruciating pain of sudden or gradual onset, most commonly in the extremities, chest, and/or back. This pain is often described as comparable to or worse than cancer pain, potentially because of the bone pain associated with some cancers and most vaso-occlusive acute pain episodes.^{1,2} An episode can also occur in the presence of other acute complications of sickle cell disease. When a vaso-occlusive acute pain episode occurs in other parts of the body such as the head or abdomen, it may be confused with other acute complications (see quality statement 4). Therefore, the etiology of the pain must be determined to rule out other potential causes.

Timely pain assessment and clinical assessment: People experiencing a vaso-occlusive acute pain episode should have their pain assessed with priority upon arrival using an age-appropriate pain scoring tool, and they should be assigned a Canadian Triage and Acuity Scale (CTAS) score of at least 2 (“emergent”).¹

A clinical assessment should include^{1,5,6,7}:

- Focused physical exam and history relating to the current episode, including an assessment of the following clinical signs:
 - Blood pressure
 - Oxygen saturation on room air
 - Pulse rate
 - Respiratory rate
 - Temperature
- Determination of whether the person's pain is caused by a vaso-occlusive acute pain episode, another acute complication of sickle cell disease (see quality statement 4), or an alternative diagnosis unrelated to sickle cell disease (particularly if the person reports their pain as atypical or if they do not respond to standard treatment for a vaso-occlusive acute pain episode)
- Consideration of laboratory and/or diagnostic imaging once appropriate pain management has been initiated, depending on the presenting signs and symptoms

Treatment begins within 30 minutes of triage or 60 minutes of presentation:

To achieve appropriate pain control as soon as possible, the initial treatment of a person experiencing a vaso-occlusive acute pain episode and appropriate pain management should be started within 30 minutes of triage or 60 minutes of presentation to the emergency department or hospital.

People experiencing a vaso-occlusive acute pain episode should receive the most effective analgesic therapy (e.g., opioids) with the least potential for adverse medication reactions. For further information on the use of opioids to treat acute pain, see Ontario Health's [Opioid Prescribing for Acute Pain](#) quality standard.

The severity of pain reported by people experiencing a vaso-occlusive acute pain episode must guide pain management.² Short-acting medications are preferable to long-acting alternatives, which are generally used to treat chronic pain¹ (see quality statement 6). Treatment response should be assessed regularly, and medication dosing should be titrated regularly to optimize pain control.^{2,5} Adverse reactions to any analgesics should be documented with an indication of the type

of reaction to inform the choice of alternative treatment when required in the future.^{1,61}

The [Clinical Handbook for Sickle Cell Disease Vaso-occlusive Crisis](#)¹ provides details on other pain management strategies (i.e., physical and psychological pain management techniques) and other treatments, as well as recommendations for the treatment of people who may be pregnant.

Before discharge: When the person with sickle cell disease feels ready to go home and their pain can be managed at home, health care professionals involve them (and their family and caregivers, where appropriate) in the development of a written comprehensive pain and symptom management plan for the person to continue managing their acute pain episode at home. Health care professionals at the hospital should also involve the person's primary care and home and community care providers (where appropriate) in the development of this plan.¹ The plan should account for the person's individual needs, preferences, and values and should be shared with the person's primary care providers and any other relevant physician specialists. This plan should be provided to the person (and their family and caregivers, where appropriate) and should include information on the following^{1,67}:

- How to use home symptom management strategies (e.g., self-report pain diaries, the use of opioid and nonopioid analgesics)⁶⁸⁻⁷⁰
- What to do and who to contact if pain becomes unmanageable
- How to obtain additional medication if needed, including considerations of cost, access, and education about its use
- How and when to obtain follow-up care and health care provider support (see definition below), as well as psychosocial information and support (see quality statement 7), as needed, including considerations of relevant cultural factors and language needs, where appropriate
- How to manage any potential adverse medication reactions

For additional information on the transition from hospital to home, see Ontario Health's [Transitions Between Hospital and Home](#) quality standard.

Follow-up care and support from health care providers: This care and support may be provided by members of the person's circle of care, such as their primary care provider, social worker, and/or physician specialists (e.g., hematology, internal medicine, pediatrics), as appropriate. The person may also need to be referred to a dedicated sickle cell disease centre for further assessment and management (see quality statement 2).

Rationale

Vaso-occlusive acute pain episodes are the most common presentation of sickle cell disease and the most common reason for emergency department visits and hospitalizations for people with sickle cell disease.^{1,39,61} These episodes have a significant impact on people's quality of life.⁶¹ People who undergo more than three hospitalizations for a vaso-occlusive acute pain episode within a year are at an increased risk of early death.² It has been reported that 30% of people with sickle cell disease have some degree of pain 95% of the time, whereas just 14% have pain less than 5% of the time.² In children, the first vaso-occlusive acute pain episode can occur as early as 6 months of age and often presents as dactylitis (a global swelling of a finger or toe giving it a clinical sausage-shape presentation).^{1,62} In a recent survey on the burden of sickle cell disease on patients and their unmet needs, health care professionals reported vaso-occlusive pain as the most common symptom reported by patients under 11 years of age, and the second most common symptom among those 12 to 17 years of age and those 18 years of age or older.³⁵ In the same survey, 71% of patients and 43% of caregivers rated vaso-occlusive acute pain episodes second among symptoms having the greatest impact on patients' lives (i.e., their ability to attend and be successful at school or work and their earning potential).³⁵

In Ontario, the highest volumes of vaso-occlusive acute pain episode-related emergency department visits and hospitalizations are observed among people 18 to 39 years of age.¹ A prompt and thorough assessment at presentation is needed to ensure that people receive an accurate diagnosis and are treated promptly. A pain assessment should be performed using an age-appropriate pain scoring tool to ensure that adequate analgesia is given and to inform future pain management.

When inadequately treated, repeated vaso-occlusive acute pain episodes can result in hypoxia (low levels of oxygen) in tissues.¹ Hypoxia damages the affected area and may result in life-threatening acute complications (see quality statement 4), chronic disease affecting multiple organs and limbs (see quality statement 5), and further pain management complications.⁶⁷ Inadequately treated vaso-occlusive acute pain episodes may require referral to and management by specialists such as chronic pain experts (see quality statement 6), which may have psychological and/or economic consequences for people with sickle cell disease (and their families and caregivers).

Before discharge from the emergency department or hospital, involving people (and their families and caregivers, where appropriate) in the development of a plan for continuing to manage their acute pain episode at home can significantly improve patient outcomes by reducing barriers to accessing care, which are often experienced after discharge, and reducing the likelihood of readmission.⁵¹

What This Quality Statement Means

For People With Sickle Cell Disease

If you have to go to the emergency department or hospital for treatment for pain caused by sickle cell disease, a health care professional should see you and start treatment quickly:

- Within 30 minutes of being assessed by a nurse *or*
- Within 60 minutes of arriving at the hospital

Before you leave the hospital, a health care provider should work with you to make a plan to continue managing your pain at home. This plan is called a discharge information sheet. It has information about:

- The treatment you received at the hospital, such as hydroxyurea therapy or pain medication
- How to continue managing your pain at home
- How to get more medication if you need it
- How to manage any medication side effects
- How and when to get a follow-up appointment if you need one
- What to do and who to contact if your pain becomes unmanageable

Your health care provider should give you a copy of your discharge information sheet. They should provide it in a language you understand or offer translation or interpretation services if you need them.

Your health care provider should also give your discharge information sheet to a health care professional you see regularly for your sickle cell disease, like your family doctor, your nurse practitioner, or a doctor who specializes in treating people with sickle cell disease.

Many things can cause an acute pain episode, things like not drinking enough water, being cold, being sick, having a fever, having surgery, or having stress in your life.

Some people with sickle cell disease might worry that physical activity can cause an acute pain episode. It is important to get exercise, so your health care professional should talk with you about this and help you understand how you can exercise safely.

For Clinicians

Treat a vaso-occlusive acute pain episode as an acute medical emergency. Assess the person's pain and clinical signs, and give appropriate hydration and appropriate pharmacological (e.g., pain management with analgesia) and nonpharmacological (e.g., massage, heat pad) treatment within 30 minutes of triage or 60 minutes of presentation.^{2,5,67} Throughout a vaso-occlusive acute pain episode, regard the person (and their family and caregivers, where appropriate) as an expert on their condition, acknowledge their pain, listen to what they say, and respect their views. Discuss with the person the following⁶⁷:

- The planned treatment for the current episode
- Treatments received for previous episodes
- Any concerns the person has about the current episode
- Any psychological and/or social support the person may need (see quality statement 7)

Involve the person (and their family and caregivers, where appropriate) in the development of a plan for continuing to manage their acute pain episode at home. Include information on home symptom management strategies and on follow-up care and health care provider support, as needed. Provide education on the triggers of vaso-occlusive acute pain episodes (e.g., dehydration, illness, fever, surgery, exposure to cold, psychological stress), as well as the impact of these episodes on one's health and quality of life.⁶¹ Encourage people with sickle cell disease to be as physically active as possible, and address any fears they may have about physical activity triggering a vaso-occlusive acute pain episode.

See the [Clinical Handbook for Sickle Cell Disease Vaso-occlusive Crisis](#)¹ for additional recommendations on treating vaso-occlusive acute pain episodes.

For Organizations and Health Services Planners

Ensure health care providers in the emergency department and in other units of the hospital receive sufficient education and training to provide high-quality care to people with sickle cell disease experiencing a vaso-occlusive acute pain episode. This education should include appropriate health care provider attitudes toward people with sickle cell disease.

Ensure health care professionals have sufficient resources to assess pain and clinical signs when providing care to people who present to the emergency department or hospital with a vaso-occlusive acute pain episode.⁶⁷ Ensure the presence of established medical directives, preprinted orders, and a culture of

communication between physicians and nurses regarding pain management to reduce the time to analgesic administration.¹

Ensure the availability of translation and interpretation services to support the language needs of people with sickle cell disease (and their families and caregivers, where appropriate).

QUALITY INDICATORS:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- 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 1 or 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 treatment 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

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Life-Threatening Acute Complications

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.

Sources: American Society of Hematology, 2020¹ | National Heart, Lung, and Blood Institute, 2014²

Definitions

Acute complication of sickle cell disease: An acute complication of sickle cell disease can be life threatening and can affect multiple organs. People with sickle cell disease can experience an acute complication without also experiencing a vaso-occlusive acute pain episode (see quality statement 3). Acute complications include^{1,2,61}:

- Acute anemia (a sudden drop in hemoglobin [red blood cell] concentration by 20 g/L or more below the person's baseline value)
- Acute chest syndrome (includes symptoms of chest pain and fever and/or signs and symptoms of lower respiratory tract disease, such as cough and shortness of breath)
- Acute ocular conditions (may occur as secondary to trauma, infection, or a vaso-occlusive acute pain episode [see quality statement 3], leading to occlusion of the eye structure or progression of proliferative sickle cell retinopathy)
- Acute renal failure (a rapid reduction in kidney function manifested by a rise in serum creatinine and a reduction in glomerular filtration rate)
- Acute stroke (presents as a sudden onset of weakness and/or aphasia, sometimes as a seizure or coma, and results in adverse motor and cognitive sequelae)

- Complications of other organ involvement
- Constipation from opioid toxicity
- Fever or sepsis (an extreme immune response that can cause organ damage) caused by an infection
- Acute hepatic or splenic sequestration (liver or spleen enlargement because of a blockage of sickled red blood cells)
- Multisystem organ failure (a severe and life-threatening complication usually associated with a vaso-occlusive acute pain episode [see quality statement 3], characterized by failure of the lungs, liver, and/or kidneys)
- Priapism (a sustained, unwanted, and often painful erection of the penis lasting 4 hours or more)

Have their condition and its severity identified through a prompt clinical assessment: People who present to the emergency department or hospital with or without pain associated with sickle cell disease should have their signs and symptoms assessed with priority upon arrival; that is, they should be assigned a CTAS score appropriate to the severity of their signs and symptoms. The assessment should include an evaluation of the following:

- Blood pressure
- Oxygen saturation on room air
- Pulse rate
- Respiratory rate
- Temperature
- Consideration of laboratory and/or diagnostic imaging depending on the presenting signs and symptoms

The prompt clinical assessment should be done to identify a potentially life-threatening acute complication, as well its severity.

Managed appropriately with an individualized treatment and monitoring plan: When a person is diagnosed as having an acute complication of sickle cell disease, their condition should be managed using established clinical guideline protocols for the complication(s) they are experiencing. An individualized, multimodal treatment and monitoring plan should be created for the person that addresses care in the emergency department as well as in inpatient and outpatient care settings; accordingly, it should be developed in consultation with

physician specialists or a dedicated sickle cell disease centre.¹ This plan should be shared with the person (and their family and caregivers, where appropriate) and the person's circle of care (see definition in quality statement 2). It should include:

- The person's unique needs, preferences, and values
- Specific treatment(s) to be given for the diagnosed acute complication(s)
- Risks and benefits of any medications, as well as documented adverse reactions to any medications

Rationale

People experiencing signs and symptoms of an acute complication of sickle cell disease should be assessed and treated promptly to reduce their risk of increased morbidity and mortality.² 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 (see quality statement 3), infection, acute chest syndrome, and cerebrovascular conditions (e.g., stroke).²

Acute complications of sickle cell disease can be life threatening. Acute stroke is one of the most common and devastating complications.² In children, sickle cell disease is the most common cause of pediatric stroke, with those aged 2 to 16 years being at highest risk.⁶² People with sickle cell disease are also particularly vulnerable to severe bacterial infections, as the disease causes people to be immunocompromised.²

What This Quality Statement Means

For People With Sickle Cell Disease

Call 9-1-1 or go to your nearest hospital if you suddenly feel weak or if you have a fever, chest pain, a cough, trouble talking, or trouble breathing—even if you are not in pain.

At the hospital, a doctor should see you quickly to check if you might be having a serious complication of sickle cell disease. Your doctor should talk with you about your treatment options and let you know the risks and benefits of each one. They should also ask if you have had any bad reactions to treatments or medications in the past. Your doctor should work with you to choose your treatment.

It is important to know your baseline hemoglobin value. Hemoglobin is a protein in your red blood cells that helps them carry oxygen from your lungs to other parts

of your body. Your baseline hemoglobin value is the amount of hemoglobin you usually have in your blood. A health care professional you see regularly for your sickle cell disease should tell you what your baseline hemoglobin value is. This information can help your health care professional at the hospital decide which treatment would be best for you.

For Clinicians

Ensure that people presenting to the emergency department or hospital with signs and symptoms of a potentially life-threatening acute complication of sickle cell disease are promptly assessed and treated, even in the absence of vaso-occlusive acute pain. The severity of a person's condition should be determined by the results of a thorough clinical assessment, rather than based on initial impressions of the person's physical appearance. Ensure that the diagnosed condition(s) is (are) managed appropriately with an individualized treatment and monitoring plan. Document this plan and share it with the person's circle of care. Most people with sickle cell disease experience chronic anemia; therefore, it is important for the person (and their family and caregivers, where appropriate) and their primary care provider to know the person's baseline hemoglobin value to inform ongoing monitoring and management of acute complications.²

For Organizations and Health Services Planners

Ensure health care professionals have the necessary training, knowledge, and skills to accurately assess, diagnose, and treat acute complications of sickle cell disease. Ensure the availability of diagnostic tools and resources required to promptly assess and treat acute complications of sickle cell disease.

QUALITY INDICATORS:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- 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

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Chronic Complications

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.

Sources: American Society of Hematology, 2019⁵⁹ | American Society of Hematology, 2020⁶⁰ | National Heart, Lung, and Blood Institute, 2014²

Definitions

Monitored: Monitoring involves a regular (or routine) review by the person's local health care team to ensure screening for chronic complications and prompt a referral to a dedicated sickle cell disease or other specialized centre for consultation and/or assessment and management, as needed. For people with additional health conditions, these should also be reviewed regularly. Monitoring is done in addition to the comprehensive health assessment (see quality statement 2) performed at a dedicated sickle cell disease centre.

Local health care team: This team includes primary care providers, home and community care providers, other individual physician specialists and health care providers, and smaller centres that provide care and support to the person with sickle cell disease outside their dedicated sickle cell disease or other specialized centre. The person's local health care team works in collaboration with the person's dedicated sickle cell disease or other specialized centre to monitor for signs and symptoms of chronic complications.

Chronic complications of sickle cell disease: Chronic complications of sickle cell disease can be both physical and mental.

Common physical health complications include but are not limited to²:

- Avascular necrosis (bone death due to compromised blood supply to the bone)
- Chronic pain
- Leg ulcers
- Ocular complications
- Prolonged or recurrent priapism
- Pulmonary hypertension (high blood pressure in the lungs) and chronic pulmonary disease
- Renal complications

Common mental health issues experienced by people with sickle cell disease (and their family and caregivers, where appropriate) include but are not limited to^{2,35}:

- Anxiety
- Caregiver fatigue or burnout
- Depression
- Fear
- Feelings of despair, loneliness, and/or helplessness
- Insomnia (poor sleep)
- Post-traumatic stress disorder

Dedicated sickle cell disease or other specialized centre: A centre that provides preventive and specialized care for people with sickle cell disease. This centre is connected to and integrated with the person's local health care team to provide support and collaborative care. While the centre may not be dedicated to treating people with sickle cell disease, it is capable of addressing the needs of people with chronic complications of sickle cell disease.

Rationale

Chronic physical complications of sickle cell disease can affect almost any organ in the body and can lead to severe illness.^{2,72} Despite the serious consequences of chronic complications, they are often dismissed or misdiagnosed in settings outside dedicated sickle cell disease or other specialized centres (advisory committee consensus). Close monitoring of symptoms and management of

chronic complications before they progress can improve health outcomes and lengthen lifespans for people with sickle cell disease.^{2,72}

Anxiety and depression are common mental health conditions among people with sickle cell disease, affecting up to one-third of people with the disease.^{2,72,73} These conditions are also associated with increased sensitivity to pain, greater health care use, and poor sleep quality.⁷²⁻⁷⁵ A survey of caregivers found that more than half felt their overall well-being (53%) and mental health (52%) were impacted by caring for someone with sickle cell disease.³⁵ However, mental health issues often go unrecognized and untreated in people with sickle cell disease and their families and caregivers.⁷⁴ Greater efforts need to be made by local health care teams with regard to the prevention, early diagnosis, and treatment of mental health issues to reduce the impact of these conditions on people with sickle cell disease and their families and caregivers and to improve their health-related quality of life.^{3,35,73}

Increased health care professional education and awareness of sickle cell disease outside dedicated sickle cell disease and other specialized centres is needed to ensure early recognition of chronic complications and access to appropriate care.^{1,41}

For additional information on chronic pain, anxiety, and depression, see Ontario Health's [Chronic Pain](#), [Anxiety Disorders](#), and [Major Depression](#) quality standards.

What This Quality Statement Means

For People With Sickle Cell Disease

Chronic complications of sickle cell disease can have a serious effect on your health. Your health care provider should tell you what to watch out for so you can get treatment quickly if you need it. Some things to watch out for are:

- Chronic pain (pain you have all the time)
- Leg ulcers (sores on your legs that take a long time to heal)
- Trouble with your kidneys, lungs, or eyes
- Anxiety (worrying a lot)
- Depression (feeling sad most of the time)
- Feeling lonely or helpless
- Not being able to sleep

If you are experiencing a chronic complication, your health care provider should talk with health care professionals at a health centre that specializes in treating people with sickle cell disease to make sure you get the best treatment possible. They may also arrange for you to have an appointment at this centre.

For Clinicians

Primary care providers and other local health care team members: Monitor people with sickle cell disease for signs and symptoms of chronic complications. For people with chronic complications, promptly consult with and/or refer them to a dedicated sickle cell disease or other specialized centre for assessment and management of their condition, as needed.

For Organizations and Health Services Planners

Ensure that training, systems, processes, and resources are in place for local health care teams to monitor people with sickle cell disease for signs and symptoms of chronic complications.

Ensure that systems and processes are in place for local health care teams to communicate signs and symptoms of chronic complications to people's dedicated sickle cell disease or other specialized centres, document the complications in people's health records, and consult with or refer people to a dedicated sickle cell disease or other specialized centre for assessment and management of their condition, as needed. Ensure that consultations with specialized centres can be provided virtually through telemedicine or other technologies.

QUALITY INDICATORS:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- 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

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Referral to Health Care Professionals With Expertise in Chronic Pain

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.

Sources: American Society of Hematology, 2020⁷¹ | National Heart, Lung, and Blood Institute, 2014²

Definitions

Chronic pain caused by sickle cell disease: Pain is considered chronic if it lasts more than 3 months.^{76,77} Chronic pain caused by sickle cell disease includes^{2,71}:

- Pain in a specific tissue or organ, commonly experienced in the chest, back, abdomen, extremities, neck, or head
- Neuropathic pain (pain caused by damage to nerves from poor blood supply or from persistent chronic pain and inflammation)
- "Breakthrough pain" (a flare-up of sudden pain that does not respond to usual treatment)
- Pain with an unknown cause, which may be an extension of recurrent vaso-occlusive acute pain episodes (see quality statement 3)

Pharmacological interventions: Pharmacological interventions used to treat chronic pain related to sickle cell disease include²:

- Nonsteroidal anti-inflammatory drugs (NSAIDs)
- Opioids (see Ontario Health's [Opioid Prescribing for Chronic Pain](#) quality standard)

- Antidepressants
- Anticonvulsant medications

In selecting pain-relieving medication, a stepped approach that considers risks, potential adverse medication reactions, efficacy, patient costs, and the person's needs and preferences should be used (see Ontario Health's [Chronic Pain](#) quality standard).

Nonpharmacological interventions: The management of all types of chronic pain related to sickle cell disease may be enhanced by adding nonpharmacological interventions, according to the preferences and responses of the person with sickle cell disease.² Examples include:

- Psychologically based interventions (e.g., cognitive and behavioural management strategies)⁷¹
- Physically based interventions (e.g., massage,^{2,71} acupuncture,^{2,71} mild to moderate exercise if tolerable,² aqua therapy²)

Rationale

Chronic pain caused by sickle cell disease develops with increasing age and affects up to 40% of young people and adults with sickle cell disease.⁷¹ Chronic pain is often associated with mental health conditions such as depression, anxiety, insomnia, post-traumatic stress disorder, and feelings of despair, helplessness, and loneliness.^{3,78} These conditions can worsen a person's chronic pain.

The management of chronic pain in people with sickle cell disease is complex and challenging.⁷¹ It is important that the person with sickle cell disease and their health care professionals work together to make decisions about the best plan for managing their chronic pain caused by sickle cell disease.⁷⁹ 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.^{2,71}

Chronic pain management, particularly in the midst of an opioid crisis, is an area of marked practice variation (advisory committee consensus). Believing the person's report of pain is critical to optimizing treatment outcomes, achieving adequate pain relief, and maintaining or improving functional outcomes and quality of life.²

What This Quality Statement Means

For People With Sickle Cell Disease

If chronic pain is having a negative effect on your life, your health care professional should arrange for you to have an appointment with a doctor or at a health centre that specializes in treating chronic pain caused by sickle cell disease.

For Clinicians

Refer people whose quality of life is significantly impacted by chronic pain caused by sickle cell disease, whose goals for pain control and function are not being met, or who have not benefitted from other multimodal pain treatments to individual health care professionals or to a chronic pain centre with expertise in treating people with chronic pain related to sickle cell disease. Or refer people to a dedicated sickle cell disease centre, which can then refer people to appropriate health care professionals or to an appropriate centre. Ensure that the health care professionals or centre is accessible to those being referred.

When starting treatment for chronic pain caused by sickle cell disease, help patients understand that improvements in daily functioning and quality of life are the primary goals and that improvement in these areas can be achieved when pain is still present.³

For additional information on chronic pain, see Ontario Health's [Chronic Pain](#) quality standard.

For Organizations and Health Services Planners

Ensure the availability of individual health care professionals or a chronic pain centre with expertise in treating people with chronic pain related to sickle cell disease. Individual health care professionals and chronic pain centres may be located in a variety of settings, including hospitals and community-based clinics. Services may also be delivered virtually through telemedicine or other technologies.

QUALITY INDICATORS:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- 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

- 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
- Local availability of health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Psychosocial Assessment, Information, and Support

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.

Sources: Advisory committee consensus | National Heart, Lung, and Blood Institute, 2014²

Definitions

Regular psychosocial assessments: These assessments should be done at least once a year as part of a routine clinical visit, or as part of the comprehensive health assessment (see quality statement 2), or when there are changes in psychosocial status (e.g., after a hospital admission). Validated assessment tools should be used where available. The following psychosocial factors should be assessed, as should their effects on the mood, activity, developmental needs, school performance (where applicable), employment status (where applicable), socioeconomic status, and overall quality of life of the person with sickle cell disease (and their family and caregivers, where appropriate)^{2,80}:

- Adverse medication reactions
- Anxiety (see Ontario Health's [Anxiety Disorders](#) quality standard)
- Caregiver fatigue or burnout
- Cognitive impairment
- Depression (see Ontario Health's [Major Depression](#) quality standard)
- Feelings of despair or helplessness
- Insomnia
- Post-traumatic stress disorder
- Social isolation or loneliness

The psychosocial assessment should also include an assessment of barriers to accessing in-person as well as digital or virtual supports.

Examples of validated psychosocial screening tools that can be used for children and adolescents with sickle cell disease (and their families and caregivers, where appropriate) include:

- The Psychosocial Assessment Tool (PAT), a parent-report screening instrument used to assess psychosocial risk in families of children with medical diagnoses^{81,82}
- The Pediatric Quality of Life Inventory (PedsQL), which measures health-related quality of life in healthy children and adolescents and those with acute and chronic conditions, providing a physical and psychosocial health summary score^{83,84}

Examples of validated psychosocial screening tools that can be used for adults with sickle cell disease (and their families and caregivers, where appropriate) include^{85,86}:

- The Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me), a patient-report outcome measurement system that assesses the physical, social, and emotional impact of sickle cell disease on adults^{87,88}
- The Patient-Reported Outcome Measurement Information System (PROMIS), a set of person-centred measures designed to assess how people with a chronic disease feel and function⁸⁹

Psychosocial needs: Psychosocial needs include but are not limited to those in the following areas^{11,80,90-92}:

- Accessibility and mobility (e.g., physical, developmental, intellectual, learning, visual, auditory, and emotional supports and services)
- Cognitive function
- Cultural identity (e.g., linguistic needs, health beliefs and behaviours, traditions, rituals, and cultural barriers to accessing health care)
- Education (e.g., required accommodations in schools, special needs funding, scholarships)
- Emotional well-being

- Employment (e.g., accommodations to maintain health, for example by staying hydrated or taking frequent breaks)
- Financial security
- Housing
- Mental health
- Social connectedness
- Spirituality

Information and support: The appropriate information and support needed from health care providers are identified and provided through regular psychosocial assessments. This includes developmentally appropriate information and support tailored to the individual psychosocial needs of the person to help them make informed decisions about their care or their child's care. Examples include:

- Informing them what services and supports are available (e.g., social workers, case managers, patient navigators, psychologists)
- Facilitating a connection with mental health services that provide psychologically based interventions (e.g., cognitive and behavioural management strategies)⁷¹
- Facilitating a connection with community and social services (e.g., counselling approaches such as solutions-focused^{93,94} and narrative therapy,⁹⁵ informal counselling, patient navigation services)^{93,94}
- Facilitating connections to services that offer health and social accommodations for those with disabilities or special needs (e.g., community-based services, supported educational and job training accommodations, housing)
- Facilitating connections to peer support if the person wants it. This may involve individual or group peer support, coaching and mentoring, and/or advocacy to support the person (and their family and caregivers, where appropriate) in navigating the systems and available resources. This may be through voluntary and community-sector organizations, such as specific support groups or charities⁹¹ (e.g., [Sickle Cell Association of Ontario](#), [Sickle Cell Awareness Group of Ontario](#))
- Facilitating connections to caregiver support (e.g., family and caregiver support services or groups, respite care) if family and caregivers want this support
- Informing them where they can get information about supports and services that they may be eligible for and how to apply and obtain

documentation to access these supports and services (e.g., adult developmental services accessed through [Developmental Services Ontario](#) and financial benefits such as the [disability tax credit](#), [Ontario Disability Support Program](#), and [Canadian Pension Plan disability benefits](#))

Rationale

Sickle cell disease is a chronic, often debilitating disease that presents physical, emotional, and social well-being challenges that begin at birth and continue throughout the lifespan.⁹⁶ As a genetic condition present from birth, sickle cell disease is likely to interact with developmental factors in infancy and early childhood with implications for cognitive and psychosocial functioning.⁹⁷ In addition, sickle cell disease can place a significant psychosocial burden (i.e., a broad range of stressors and associated psychological distress, behavioural difficulties, and challenges related to relationships and social functioning) on individuals and their families and caregivers across settings.^{98,99} These challenges can result in delayed puberty, reduced participation in recreational activities, increased levels of school or work absenteeism, limitations in social functioning, and a reduction in overall quality of life for people with sickle cell disease.⁹⁸

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.⁹⁶ Regular psychosocial assessments using a validated psychosocial screening tool during routine clinical visits are essential to ensuring that people with sickle cell disease (and their families and caregivers, where appropriate) have their psychosocial needs identified and addressed. Regular screening allows for early intervention and for appropriate information and support to be offered in a timely manner.⁸¹

What This Quality Statement Means

For People With Sickle Cell Disease

Living with sickle cell disease can be hard. So at least once a year, your health care provider should ask you about your mental health and your overall well-being. This includes asking if:

- You feel sad or worried a lot of the time
- You have trouble sleeping
- You feel lonely
- You are worried about school or work

Once your health care provider knows how you're feeling, they can let you know about services and supports that might help you if you would like that.

For Caregivers

You might also have difficulties from time to time. This means that a member of the health care team of the person with sickle cell disease should also ask you about your mental health and well-being at least once a year. They should also offer you information and support that might help you if you would like that.

For Clinicians

Ensure that 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 (see definition of *psychosocial needs*). Provide psychosocial assessments with compassion and respect for the person's (and their family's and caregivers', where appropriate) culture and racial/ethnic background. Foster an environment that builds trust (see definition of *trust building* in quality statement 1) with the person with sickle cell disease (and their family and caregivers, where appropriate). Showing a genuine interest in their health and well-being will enable them to open up during psychosocial assessments and ask for the help they may need. Incorporate any identified psychosocial needs into the person's care plan.

Support people with sickle cell disease (and their families and caregivers, where appropriate) to apply and obtain documentation for access to developmental services and financial benefits. Adopt a strengths-based practice by actively involving the person with sickle cell disease (and their family and caregivers, where appropriate) in working together to achieve their intended outcomes in a way that draws on the person's strengths (see Appendix 4, Guiding Principles, *Strengths-Based Practice*). Make referrals to support services where appropriate.

For Organizations and Health Services Planners

Ensure that health care providers have the necessary skills, tools, and resources to assess and address any unmet psychosocial needs of people with sickle cell disease (and their families and caregivers, where appropriate). Ensure relevant

information and support are available and accessible to people with sickle cell disease (and their families and caregivers, where appropriate); for example, access to team-based primary care models that include health care providers (e.g., social workers) able to provide psychosocial information and support. Ensure that health care providers, including social workers, have access to clinical space that facilitates trauma-informed care.

QUALITY INDICATORS:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- 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

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Transition From Youth to Adult Health Care Services

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.

Sources: Canadian Association of Pediatric Health Centres, 2016¹⁰⁰ | CanChild Centre for Childhood Disability Research, 2009¹⁰¹ | National Institute for Health and Care Excellence, 2016¹⁰²

Definitions

Young people: People aged 15 to 24 years.^{103,104} Some young people prefer to be referred to as “youths” or “young adults” (advisory committee consensus).

Designated health care provider for the transition from youth to adult health care services: One person from among the person's health care providers who gives care and support to the young person (and their parents and caregivers, where appropriate) and who agrees to take on the role of coordinating the young person's transition to adult health care services.¹⁰² This provider 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. The young person (and their parents and caregivers, where appropriate) helps decide who this provider will be. In some instances, it may be a nurse, social worker, or primary care provider. In other instances, this provider may have a job title such as “transition navigator,” “transition lead,” “transition coordinator,” “transition worker,” or “case manager.”

Although all of the person's health care providers have a shared responsibility for the young person's transition, the designated health care provider oversees and

coordinates the transition and provides transition support.¹⁰² They are the main link with other providers, particularly if a young person receives care from more than one service or provider. They arrange appointments for the young person, act as their support person and as an advocate, and guide them to other services and sources of support. They also provide support to the young person's parents or caregivers, where appropriate. Overall, they ensure there are no gaps in the transition process.

The designated health care provider is involved throughout the transition process, supporting the young person until a time agreed on with the young person (and their parents and caregivers, where appropriate). When the young person (and/or their parents and caregivers, where appropriate) agrees that the transition is complete, this provider (if they are based in youth-oriented services) hands over responsibilities to an adult health care service or other provider.¹⁰²

Transition: The purposeful, planned movement of adolescents and young adults requiring a change from child and youth health care services to adult health care services, with or without a transfer to a new provider.^{105,106}

Rationale

People with sickle cell disease should receive appropriate care throughout their lifespan and experience seamless transitions between services and health care providers. Advances in treatment have led to people with sickle cell disease living longer; as a result, there is a crucial need to improve capacity within the adult health care system to provide appropriate continuity of care for young people transitioning to adult care.³⁰

The transition to adult health care services is a critical and challenging time for young people with sickle cell disease and their parents and caregivers.⁶¹ The process is often complicated by health care 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 (advisory committee consensus).^{107,108} Having a designated health care provider whom the young person (and their parents and caregivers, where appropriate) knows and trusts to oversee transition planning and coordination can lead to a more positive experience, better attendance in adult health care services, and better outcomes.^{102,109}

Young newcomers to Canada who transition to adult health care services often face additional challenges because they lack the supportive network that is developed in child and youth health care services among those who have lived in Canada for all or most of their lives (advisory committee consensus).

For additional information on transitions from youth to adult health care services, see Ontario Health's [Transitions From Youth to Adult Health Care Services](#) quality standard.

What This Quality Statement Means

For Young People, Parents, and Caregivers

Your health care providers should involve you in choosing a single provider to be the designated health care provider for your transition from youth to adult health care services. This should be someone you know and trust. This person should work with you to coordinate your move to adult services. They should help arrange appointments and provide support until you feel your transition is complete. If this move takes a long while, over time you might have more than one designated health care provider.

For Clinicians

Work with the young person (and their parents and caregivers, where appropriate) to identify a designated health care provider to support the transition from youth to adult health care services. Then act as or work with this provider to coordinate care and provide support throughout the transition process until the young person (and their parents and caregivers, where appropriate) considers the transition is complete.

For Organizations and Health Services Planners

Ensure systems, processes, and resources are in place for young people who are transitioning out of youth-oriented health care services to have a designated health care provider to coordinate care and provide support throughout the transition process until the transition is complete.

QUALITY INDICATORS:

HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of young people with sickle cell disease who are 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 who are 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

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Appendices

Appendix 1. About This Quality Standard

How to Use This Quality Standard

Quality standards inform patients, clinicians, and organizations about what high-quality care looks like for health conditions or processes deemed a priority for quality improvement in Ontario. They are based on the best evidence.

Guidance on how to use quality standards and their associated resources is included below.

For People With Sickle Cell Disease

This quality standard consists of quality statements. These describe what high-quality care looks like for people with sickle cell disease.

Within each quality statement, we've included information on what these statements mean for you, as a patient.

In addition, you may want to download this accompanying [patient guide](#) on sickle cell disease, to help you and your family and caregivers have informed conversations with your health care providers. Inside, you will find information and questions you may want to ask as you work together to make a plan for your care.

For Clinicians and Organizations

The quality statements within this quality standard describe what high-quality care looks like for people with sickle cell disease. They are based on the best evidence and designed to help you know what to do to reduce gaps and variations in care.

Many clinicians and organizations are already providing high-quality evidence-based care. However, there may be elements of your care that can be improved. This quality standard can serve as a resource to help you prioritize and measure improvement efforts.

Tools and resources to support you in your quality improvement efforts accompany each quality standard. These resources include indicators and their definitions (Appendix 2). Measurement is key to quality improvement. Collecting and using data when implementing a quality standard can help you assess the quality of care you are delivering and identify gaps in care and areas for improvement.

There are also a number of resources online to help you, including:

- Our [patient guide](#) on sickle cell disease, which you can share with families and caregivers to help them have conversations with you and their other health care providers. Please make the patient guide available where you provide care
- Our [measurement resources](#), which include our measurement guide of technical specifications for the indicators in this quality standard, and our “case for improvement” slide deck to help you to share why this standard was created and the data behind it
- Our [placemat](#), which summarizes the quality standard and includes links to helpful resources and tools
- Our [Getting Started Guide](#), which includes links to templates and tools to help you put quality standards into practice. This guide shows you how to plan for, implement, and sustain changes in your practice
- [Quorum](#), an online community dedicated to improving the quality of care across Ontario. This is a place where health care providers can share information and support each other, and it includes tools and resources to help you implement the quality statements within each standard
- The [Health Equity Impact Assessment tool](#), which can help your organization consider how programs and policies impact population groups differently. This tool can help maximize positive impacts and reduce negative impacts, with an aim of reducing health inequities between population groups

How the Health Care System Can Support Implementation

As you work to implement this quality standard, there may be times when you find it challenging to provide the care outlined due to system-level barriers or gaps. These challenges have been identified and documented as part of the development of the quality standard, which included extensive consultation with health care professionals and lived experience advisors and a careful review of available evidence and existing programs. Many of the levers for system change fall within the purview of Ontario Health, and as such we will continue to work to address these barriers to support the implementation of quality standards. We will also engage and support other provincial partners, including the Ministry of Health or other relevant ministries, on policy-level initiatives to help bridge system-level gaps.

In the meantime, there are many actions you can take on your own, so please read the standard and act where you can.

Appendix 2. Measurement to Support Improvement

The Sickle Cell Disease Quality Standard Advisory Committee identified six indicators for this quality standard. These indicators can be used to monitor the progress being made to improve care for people with sickle cell disease in Ontario. Some indicators are provincially measurable, while some can be measured using only locally sourced data.

Using data from these indicators will help you assess the quality of care you are delivering and the effectiveness of your quality improvement efforts. We realize this standard includes a lengthy list of statement-specific indicators. These indicators are provided as examples; you may wish to create your own quality improvement indicators based on the needs of your population. We recommend you identify areas to focus on in the quality standard and then use one or more of the associated indicators to guide and evaluate your quality improvement efforts.

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*, for additional equity considerations.

Our [measurement guide](#) provides more information and concrete steps on how to incorporate measurement into your planning and quality improvement work.

Measuring the Success of This Quality Standard

Indicators That Can Be Measured Using Provincial Data

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

- Denominator: total number of people in Ontario with sickle cell disease
- Numerator: number of people in the denominator with an unscheduled emergency department visit for sickle cell disease
- Data sources: Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS)

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

- Denominator: total number of people in Ontario with sickle cell disease who visited the emergency department

- Numerator: number of people in the denominator who had a repeat unscheduled emergency department visit for sickle cell disease within 30 days
- Data sources: DAD, NACRS

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

- Denominator: total number of people in Ontario with sickle cell disease
- Numerator: number of people in the denominator who visited the emergency department for a mental health concern
- Data sources: DAD, NACRS

Percentage of people who were hospitalized for sickle cell disease

- Denominator: total number of people in Ontario with sickle cell disease
- Numerator: number of people in the denominator who were hospitalized for sickle cell disease
- Data sources: DAD, NACRS

Indicators That Can Be Measured Using Only Local Data

Percentage of people with sickle cell disease who report an improvement in their quality of life

- Denominator: total number of people with sickle cell disease
- Numerator: number of people in the denominator who report an improvement in their quality of life
- Data source: local data collection via patient survey

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

- Denominator: total number of people with sickle cell disease
- Numerator: number of people in the denominator who report being satisfied with their interaction with their health care provider
- Data source: local data collection via patient survey

How to Measure Improvement for Specific Statements

Quality Statement 1: Racism and Anti-Black Racism

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

- Denominator: total number of people with sickle cell disease
- Numerator: number of people in the denominator who report receiving care from health care providers and a health care system that is free from racism, anti-Black racism, discrimination, and stigma
- Data source: local data collection via patient survey

Quality Statement 2: Comprehensive Health Assessment and Care Plan

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

- Denominator: total number of people with sickle cell disease
- Numerator: number of people in the denominator who have a comprehensive health assessment annually from an interprofessional care team at a dedicated sickle cell disease centre
- Data source: local data collection via patient survey or electronic medical record

Percentage of people with sickle cell disease with a completed comprehensive health assessment who have an individualized, person-centred care plan

- Denominator: total number of people with sickle cell disease with a completed comprehensive health assessment
- Numerator: number of people in the denominator who have an individualized, person-centered care plan
- Data source: local data collection via patient survey or electronic medical record

Percentage of people with sickle cell disease who have their comprehensive health assessment and care plan shared with their circle of care

- Denominator: total number of people with sickle cell disease who have a comprehensive health assessment and care plan

- Numerator: number of people in the denominator who have had their comprehensive health assessment and care plan shared with their circle of care
- Data source: local data collection via patient survey or electronic medical record

Quality Statement 3: Vaso-occlusive Acute Pain Episodes

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 1 or 2

- Denominator: total number of people with sickle cell disease who present to an emergency department or hospital with a vaso-occlusive acute pain episode
- Numerator: number of people in the denominator who are assigned a CTAS score of 1 or 2
- Data source: NACRS

Percentage of people with sickle cell disease who present to an emergency department or hospital with a vaso-occlusive acute pain episode and have treatment started within 30 minutes of triage or 60 minutes of presentation

- Denominator: total number of people with sickle cell disease who present to an emergency department or hospital with a vaso-occlusive acute pain episode
- Numerator: number of people in the denominator who have treatment started within 30 minutes of triage or 60 minutes of presentation
- Data source: NACRS

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

- Denominator: total number of people with sickle cell disease who were discharged from hospital for a vaso-occlusive acute pain episode
- Numerator: number of people in the denominator who report receiving information on how to continue managing their acute pain episode and on follow-up care and health care provider support
- Data source: DAD, local data collection via patient survey

Quality Statement 4: Life-Threatening Acute Complications

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)

- Denominator: total number of people with sickle cell disease who present to an emergency department or hospital with a potentially life-threatening acute complication of sickle disease
- Numerator: number of people in the denominator who are assigned a 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)
- Data source: NACRS

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

- Denominator: total number of people diagnosed with a potentially life-threatening acute complication of sickle cell disease
- Numerator: number of people in the denominator whose condition is managed with an individualized treatment and monitoring plan
- Data source: local data collection via electronic medical record

Quality Statement 5: Chronic Complications

Percentage of people with sickle cell disease who are monitored by their local health care team for signs and symptoms of chronic complications

- Denominator: total number of people with sickle cell disease
- Numerator: number of people in the denominator who are monitored by their local health care team for signs and symptoms of chronic complications
- Data source: local data collection via electronic medical record

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

- Denominator: total number of people with chronic complications of sickle cell disease
- Numerator: number of people in the denominator who are referred to a dedicated sickle cell disease or other specialized centre for consultation and/or assessment and management of their condition
- Data source: local data collection via electronic medical record

Quality Statement 6: Referral to Health Care Professionals With Expertise in Chronic Pain

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

- Denominator: total number of people whose quality of life is negatively impacted by chronic pain caused by sickle cell disease
- Numerator: number of people in the denominator who are referred to health care professionals or a chronic pain centre
- Data source: local data collection via electronic medical record

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

- Denominator: total number of people with sickle cell disease
- Numerator: number of people in the denominator who report an improvement in their quality of life and who have received treatment from health care professionals or a chronic pain centre
- Data source: local data collection via patient survey

Local availability of health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease

- Data source: local data collection

Quality Statement 7: Psychosocial Assessment, Information, and Support

Percentage of people with sickle cell disease (and their families and caregivers) who report receiving psychosocial assessments annually

- Denominator: total number of people with sickle cell disease (and their families and caregivers)
- Numerator: number of people in the denominator who report receiving psychosocial assessments annually
- Data source: local data collection via patient survey

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

- Denominator: total number of people with sickle cell disease (and their families and caregivers)
- Numerator: number of people in the denominator who report receiving information and support to address any unmet psychosocial needs
- Data source: local data collection via patient survey

Quality Statement 8: Transition From Youth to Adult Health Care Services

Percentage of young people with sickle cell disease who are transitioning out of youth-oriented health care services who have a designated health care provider for the transition process

- Denominator: total number of young people with sickle cell disease who are transitioning out of youth-oriented health care services
- Numerator: number of people in the denominator who have a designated health care provider for the transition process
- Data source: local data collection via patient survey or electronic medical record

Percentage of young people with sickle cell disease who are 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

- Denominator: total number of young people with sickle cell disease who are transitioning out of youth-oriented health care services

APPENDIX 2 CONTINUED

- Numerator: number of people in the denominator who report feeling their care is being adequately coordinated by their designated health care provider
- Data source: local data collection via patient survey

Appendix 3. Glossary

Adults: People aged 18 years and older.

Caregiver: An unpaid person who provides care and support in a nonprofessional capacity, such as a parent, other family member, friend, or anyone else identified by the person with sickle cell disease. Other terms commonly used to describe this role include “care partner,” “informal caregiver,” “family caregiver,” “carer,” and “primary caregiver.”

Children and adolescents: People under 18 years of age.

Culturally appropriate care: Care that incorporates cultural or faith traditions, values, and beliefs; is delivered in the person's preferred language; adapts culture-specific advice; and incorporates the person's wishes to involve family or community members.⁴⁹

Dedicated sickle cell disease centre: A centre that provides preventive and specialized care for people with sickle cell disease. This centre is connected to and integrated with the person's local health care team, which consists of the person's other sickle cell disease care providers (e.g., individual health care professionals and smaller centres), to provide support and collaborative care.

Family: The people closest to a person in terms of knowledge, care, and affection; this may include biological family, family through marriage, or family of choice and friends. The person defines their family and who will be involved in their care.

Health care professionals: Regulated professionals, such as nurses, nurse practitioners, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, respiratory therapists, social workers, and speech-language pathologists.

Health care providers: Regulated professionals, as well as people in unregulated professions, such as administrative staff, behavioural support workers, personal support workers, child life specialists, recreational staff, spiritual care staff, patient transport staff, and volunteers.

Local health care team: This team includes primary care providers, home and community care providers, other individual physician specialists and health care providers, and smaller centres that provide care and support to the person with sickle cell disease outside their dedicated sickle cell disease or other specialized centre. The person's local health care team works in collaboration with the

person's dedicated sickle cell disease or other specialized centre to monitor for signs and symptoms of chronic complications.

Parents and caregivers, where appropriate: Those individuals who provide care and/or legal guardianship or whom the young person deems important in supporting their health.¹⁰⁰ In some instances, this may be a substitute decision-maker (see definition below). Young people should be asked regularly how they would like their parents and caregivers involved in their care. The involvement of parents and caregivers will vary depending on the young person's age and capacity to participate in their care.

Primary care: A setting where people receive general health care (e.g., screening, diagnosis, and management) from a regulated health care professional whom the person can access directly without a referral. This is usually the primary care physician, family physician, nurse practitioner, or other health care professional with the ability to make referrals, request biological testing, and prescribe medications.^{110,111}

Primary care provider: A family physician (also called a primary care physician), nurse practitioner, or community pediatrician.

Racism and anti-Black racism: The systemic discrimination that harms racialized populations and groups living with health-related social needs and creates barriers to and disparities in accessing and receiving appropriate health care and community and social services.^{8,17,44} This type of racism often involves labelling, devaluation, judgment, and/or the social disqualification of a person based on their health condition, leading to negative health outcomes.³¹ Anti-Black racism is associated with policies and practices rooted in Canadian institutions such as the education, health care, social, and justice systems that mirror and reinforce beliefs, attitudes, prejudices, stereotyping, and discrimination toward people of African descent.^{17,45}

Sickle cell disease: Refers to all sickle cell disease genotypes, including sickle cell anemia (which refers to the clinically similar disorders HbSS and HbS β o-thalassemia) and compound heterozygous disorders (such as HbSC, HbSD, and HbS β + -thalassemia). The carrier state for hemoglobin S (HbAS or sickle cell trait) is not a form of sickle cell disease.²

Substitute decision-maker: A person appointed to make decisions on behalf of another under a "Power of Attorney for Personal Care."

Vaso-occlusive acute pain episode: Also known as a vaso-occlusive crisis (VOC) or vaso-occlusive episode (VOE), a vaso-occlusive acute pain episode is an intermittent, recurrent acute severe pain episode. It is caused by vaso-occlusion (clumps of sickled red blood cells that cause blockages in blood vessels), most commonly in the bones or bone marrow. An episode presents as excruciating pain of sudden or gradual onset, most commonly in the extremities, chest, and/or back. This pain is often described as comparable to or worse than cancer pain, potentially because of the bone pain associated with some cancers and most vaso-occlusive acute pain episodes.^{1,2} An episode can also occur in the presence of other acute complications of sickle cell disease. When a vaso-occlusive acute pain episode occurs in other parts of the body such as the head or abdomen, it may be confused with other acute complications (see quality statement 4). Therefore, the etiology of the pain must be determined to rule out other potential causes.

Young people: People aged 15 to 24 years.^{103,104} Some young people prefer to be referred to as “youths” or “young adults” (advisory committee consensus).

Appendix 4. Values and Guiding Principles

Values That Are the Foundation of This Quality Standard

This quality standard was created, and should be implemented, according to the [Patient, Family and Caregiver Declaration of Values for Ontario](#). This declaration “is a vision that articulates a path toward patient partnership across the health care system in Ontario. It describes a set of foundational principles that are considered from the perspective of Ontario patients and serves as a guidance document for those involved in our health care system.”

These values are:

- Respect and dignity
- Empathy and compassion
- Accountability
- Transparency
- Equity and engagement

A quality health system is one that provides good access, experience, and outcomes for all people in Ontario, no matter where they live, what condition they have, or who they are.

Guiding Principles

In addition to the above values, this quality standard is guided by the principles outlined below.

Acknowledging the Impact of Colonization and Racism

Health care providers should acknowledge and work toward addressing the historical and present-day impacts of colonization and racism in the context of the lives of Black people, Indigenous people, and racialized people throughout Canada.⁴⁵ This work involves being sensitive to the impacts of intergenerational and present-day traumas and the physical, mental, emotional, and social harms experienced by Black people, Indigenous people, racialized people, families, and communities, as well as recognizing their strength and resilience. This quality standard uses existing clinical practice guideline sources that may not include culturally relevant care or acknowledge the traditional beliefs, practices, and models of care relevant to Black people, Indigenous people, and racialized people.

French Language Services

In Ontario, the *French Language Services Act* guarantees an individual's right to receive services in French from Government of Ontario ministries and agencies in [26 designated areas](#) and at government head offices.¹¹²

Integrated Care

People with sickle cell disease should receive care through an integrated approach that facilitates access to interprofessional services from multiple health care providers from different professional backgrounds and across health care settings to provide comprehensive services.^{96,113} Health care providers should work with patients, their families and caregivers, and communities to deliver the highest quality of care across settings. Interprofessional collaboration, shared decision-making, coordination of care, and continuity of care (including follow-up care) are hallmarks of this patient-centred approach.¹¹³

Intersectionality

Intersectionality refers to the differences in experiences with discrimination and injustice that people have based on social categorizations such as race/ethnicity, class, age, and gender, and the interaction of these experiences with compounding power structures (e.g., media, education system). These interconnected categorizations create overlapping and interdependent systems of discrimination or disadvantage.^{31,114-116} For example, the stigma experienced by people with sickle cell disease can vary depending on clinical and demographic characteristics such as racial/ethnic background and age, as well as other characteristics such as language barriers or perceived socioeconomic status. Understanding how the various aspects of people's identities intersect can provide insight into the complexities of the processes that cause health inequities and an understanding of how different people experience stigma and discrimination.³¹

Racism and Anti-Black Racism

Racism and anti-Black racism refer to the systemic discrimination that harms racialized populations and groups living with health-related social needs and creates barriers to and disparities in accessing and receiving appropriate health care and community and social services.^{8,17,44} This type of racism often involves labelling, devaluation, judgment, and/or the social disqualification of a person based on their health condition, leading to negative health outcomes.³¹ Anti-Black racism is associated with policies and practices rooted in Canadian institutions such as the education, health care, social, and justice systems that mirror and reinforce beliefs, attitudes, prejudices, stereotyping, and discrimination toward

people of African descent.¹⁷ Racism and anti-Black racism can have negative effects on a person's health such as triggering stress-coping behaviours (e.g., smoking). The traumatic impact of racism and anti-Black racism can also lead to the development of additional health issues (e.g., depression, anxiety).^{8,17} Frequent experiences of discrimination have also been associated with obesity and lower self-rated health.¹⁷ Racism, particularly anti-Black racism, is the most significant source of stigma experienced by people with sickle cell disease.

Social Determinants of Health

Poverty and social isolation are two examples of economic and social conditions that influence people's health, known as the social determinants of health. Other social determinants of health include employment status and working conditions, ethnicity, food security and nutrition, gender, housing, immigration status, social exclusion, and residing in a rural or urban area. Social determinants of health can have strong effects on individual and population health; they play an important role in understanding the root causes of poorer health. People with sickle cell disease often live under stressful social and economic conditions that may worsen their overall health and well-being, including social stigma, discrimination, and inadequate access to education, employment, income, and housing.^{6,31,32}

Strengths-Based Practice

A strengths-based practice actively involves the person and the care providers who support them in working together to achieve the person's intended outcomes in a way that draws on the person's strengths.^{102,117} The person is recognized and acknowledged as the expert of their own lived experience, while the clinician is recognized as an expert in their discipline and in facilitating a conversation that reinforces the person's strengths and resources.

Trauma-Informed Care

Trauma-informed care is health care that reflects an understanding of trauma and the impact that traumatic experiences can have on human beings.⁴⁸ This approach does not necessarily address the trauma directly; rather, the approach acknowledges that a person may have experienced a previous traumatic event that may contribute to their current health concerns and emphasizes understanding, respecting, and responding to the effects of trauma.¹¹⁸

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Ontario Health is an agency of the Government of Ontario. Our mandate is to connect and coordinate our province's health care system in ways that have not been done before to help ensure that Ontarians receive the best possible care. We work to support better health outcomes, patient experiences, provider experiences and value for money spent.

Equity, Inclusion, Diversity and Anti-Racism

Ontario Health is committed to advancing equity, inclusion and diversity and addressing racism in the health care system. As part of this work, Ontario Health has developed an [Equity, Inclusion, Diversity and Anti-Racism Framework](#), which builds on existing legislated commitments and relationships and recognizes the need for an intersectional approach.

Unlike the notion of equality, equity is not about sameness of treatment. It denotes fairness and justice in process and in results. Equitable outcomes often require differential treatment and resource redistribution to achieve a level playing field among all individuals and communities. This requires recognizing and addressing barriers to opportunities for all to thrive in our society.

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