# Impact Assessment

## Provincial Implementation of the *Sickle Cell Disease* Quality Standard: Planning and Year 1

CLINICAL AND QUALITY STANDARDS PROGRAM | SEPTEMBER 2025

Ontario Health

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# Executive Summary

## Background

Sickle cell disease affects approximately 3,500 people in Ontario. It disproportionately impacts people from Black and racialized communities, who often face systemic and anti-Black racism in health care settings, as well as long wait times in the emergency department during vaso-occlusive acute pain episodes. Ontario Health's *Sickle Cell Disease* quality standard[1] was released in 2023 and is a key deliverable under the province's *A Black Health Plan for Ontario*.[2]

The vision for implementation of the quality standard is to ensure that everyone with sickle cell disease in Ontario has access to safe, equitable, high-quality care. This report aims to:

- Describe the components of Ontario Health's *Sickle Cell Disease* quality standard implementation plan, including the associated Integrated Quality Framework and implementation strategies
- Evaluate the impact of the implementation strategies, including clinical and implementation outcomes
- Examine lessons learned and opportunities for improvement

## Approach

This impact assessment uses the internationally recognized Organisation for Economic Co-operation and Development evaluation criteria[3] to conduct an analysis of the relevance, coherence, effectiveness, efficiency, impact, and sustainability of the implementation of the *Sickle Cell Disease* quality standard in 2023/24 and 2024/25.

The assessment draws on multiple data sources and reports on a review of the following implementation strategies:

- Implementation funding: targeted funding for new dedicated sickle cell disease centres, pediatric recovery, and one-time implementation projects
- Community of practice: an online platform that hosts webinar series and facilitates the sharing of information, resources, and tools, designed to foster collaboration and knowledge exchange among health care teams
- Implementation toolkit: resources and tools to help operationalize the quality standard and address barriers in care delivery
- eReport: an interactive dashboard for tracking hospital and regional data, enabling users to make informed decisions and monitor progress toward improvement
- Evidence2Practice: a provincial digital support program that integrates quality standards into health information systems and provides resources for change management

Overall, this impact assessment provides a comprehensive, data-driven review of *Sickle Cell Disease* quality standard implementation strategies to date, guiding ongoing quality improvement and sustainability efforts.

# Findings

Many high-level impacts have resulted from the implementation strategies described above:

- A 19% reduction in average time to physician initial assessment (PIA) for people with sickle cell disease experiencing vaso-occlusive acute pain episodes in the emergency department from 2023/24 to 2024/25
- Strengthened collaboration among health care teams with the establishment of the community of practice with 177 members
- Expanded use of data analytics to inform and drive quality improvement efforts
- Increased knowledge for more than 1,200 health care team members, supported by the implementation toolkit and resources from the community of practice
- Enhanced relationships and coordination with Ontario Health regional staff, empowering health care teams to deliver high-quality care
- Accelerated adoption of digital tools through the Evidence2Practice program, improving care delivery in acute care settings across 4 pilot hospital organizations, resulting in a median decrease of 27.5 minutes in time to first opioid dose across pilot organizations
- Strengthened implementation and coordination between health care teams and community partners through provincial clinical leadership

# Summary and Next Steps

Lessons learned include the following:

- Strategic funding plays a pivotal role in advancing equitable, high-quality care for sickle cell disease provincially, through:
  - Support for health service providers and community health centres, which enhances equitable access to care and addresses regional disparities
  - Investment in provincial leadership, fostering clinical relevance, partner engagement, and broader awareness of sickle cell disease
- Intentional partner engagement and structured collaboration are crucial for successfully implementing the *Sickle Cell Disease* quality standard and scaling best practices
- Leveraging digital tools and data-driven decision-making empowers health care teams to deliver consistent, evidence-based care for people with sickle cell disease
- Despite the profound impact made to date, province-wide coordination of care pathways is needed as care for sickle cell disease remains fragmented across care settings.

Overall, this impact assessment found improvement in clinical outcomes, system coordination and collaboration, and enhanced knowledge and awareness among health care teams, demonstrating a commitment to providing evidence-based care with continuous quality improvement for people with sickle cell disease in Ontario. To address persistent gaps in care and to support the delivery of high-quality care for people with sickle cell disease, we provide recommendations for establishing a provincial model of care.

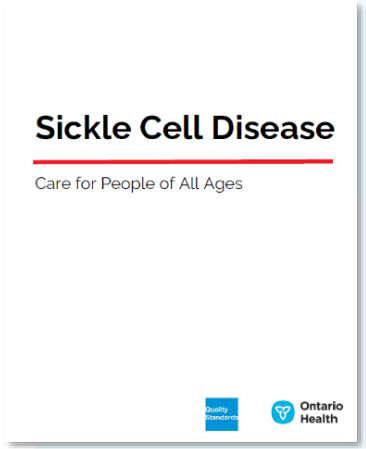
# Background

## The *Sickle Cell Disease* Quality Standard

Sickle cell disease affects approximately 3,500 people in Ontario and 6,500 people across Canada.[4] Prevalence is expected to increase as a result of immigration from regions where the disease is more common, births to parents who carry the sickle cell disease trait, and advancements in care that have improved life expectancy.[4-6] People of all races and ethnicities can have sickle cell disease, but it predominantly affects racialized people, particularly those who identify as Black.[7] Because of this, people with sickle cell disease frequently experience systemic racism and anti-Black racism in their interactions with the health care system, and this adversely affects the quality of the care they receive.[7,8]

Ontario Health has a legislated mandate to manage health service needs across Ontario (consistent with the strategies of the Ministry of Health) and to ensure the quality and sustainability of the Ontario health system. In support of this mandate, Ontario Health develops and supports the implementation of quality standards for populations or health care services for which there are substantial opportunities to improve clinical care and patient outcomes, enhance patient experiences, and reduce unwarranted variations in practice across Ontario.

The *Sickle Cell Disease* quality standard[1] was released in January 2023. It addresses care for children, young people, and adults with sickle cell disease. It addresses screening for and 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, and urgent care clinics, as well as primary care, specialist care, and home and community care settings).




The quality standard includes 8 quality statements on the following topics (see Appendix A for a summary of the quality statements):

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

The quality standard also aligns with Ontario Health's commitment to Black health: it is one of Ontario Health's deliverables in *A Black Health Plan for Ontario*[2] – the first provincial plan dedicated to advancing Black health.

# Implementation of the Quality Standard

## Implementation Vision and Goals

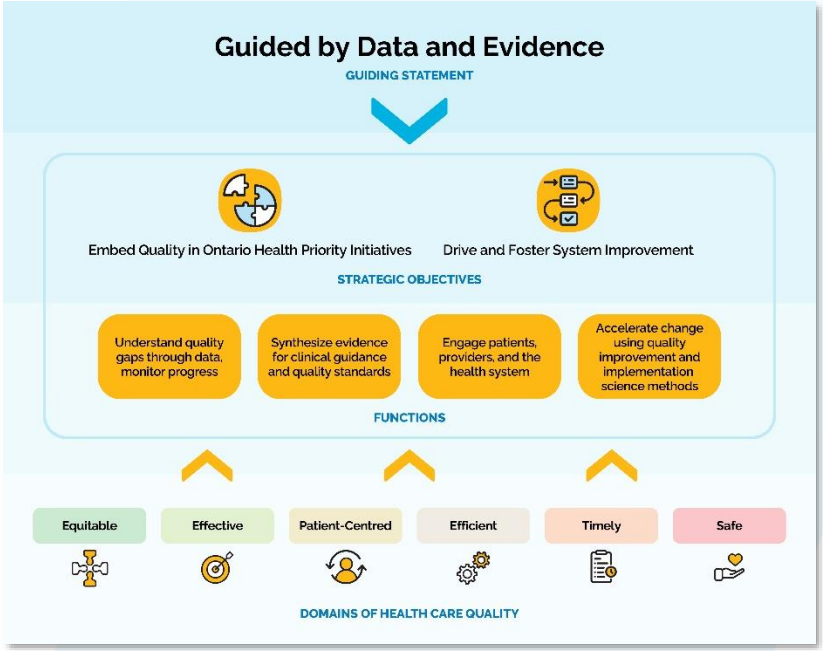
The vision for the implementation of the *Sickle Cell Disease* quality standard is to ensure that everyone with sickle cell disease in Ontario has access to safe, equitable, high-quality care.

The goals are to improve the quality of care for people with sickle cell disease in Ontario by addressing and challenging anti-Black racism; bridging the gap between the care described in the quality standards and real-world improvements made at the local, regional, and provincial levels; and adopting an integrated implementation approach that leverages the strengths of Ontario Health and its partners.

## Implementation Framework

In our approach to quality standard implementation, we have applied Ontario Health's Integrated Quality Framework, specifically its 4 key functions:

1) Understand quality gaps through data and monitor progress
2) Synthesize evidence for clinical guidance and quality standards
3) Engage patients, providers, and the health system
4) Accelerate change using quality improvement and implementation science methods




Ontario Health's Integrated Quality Framework. Guided by data and evidence, the strategic objectives of the framework are to embed quality in Ontario Health priority initiatives and to drive and foster system improvement. These strategic objectives are linked to 4 key functions: understand quality gaps through data and monitor progress; synthesize evidence for clinical guidance and quality standards; engage patients, providers, and the health system; and accelerate change using quality improvement and implementation science methods. Quality improvement efforts are aimed at ensuring that health care in Ontario is equitable, effective, patient-centred, efficient, timely, and safe.

Based on the 4 key functions, we identified 5 implementation strategies that could drive a provincial approach for the uptake and implementation of the *Sickle Cell Disease* quality standard. These strategies were selected based on input from key informants and partner organizations, lived experience advisors, the Sickle Cell Disease Quality Standard Advisory Committee, and public feedback. The strategies are aimed at removing barriers and leveraging enablers for implementation (related key functions from the Integrated Quality Framework are provided in parentheses):

- Implementation funding to establish accountability that will support implementation, including the involvement of regional leadership and provincial emergency department networks and tables (key functions 3 and 4)
- A community of practice to enhance engagement among partners and drive knowledge exchange by providing information, resources, and tools to guide quality improvement and implementation initiatives, including optional sickle cell disease indicators that can be included in Quality Improvement Plans (key functions 1, 3, and 4)
- An implementation toolkit to provide change ideas, resources (such as the Sickle Cell Awareness Group of Ontario education modules), tools, and measurement guidance to guide quality improvement and implementation initiatives (key functions 2 and 4)
- An eReport to provide data that can be used to understand regional and hospital variations and where high and low performance exist (key function 1)
- Inclusion of sickle cell disease in the Evidence2Practice program to translate evidence-based standards into digital clinical-decision support tools (key function 4)

## Implementation Journey

Implementation of the quality standard is a 3-year, iterative journey. This report provides a midstream assessment of the impact of implementation strategies from the planning phase and year 1.

### IMPLEMENTATION PLANNING (2023/24)

Following the release of the quality standard in January 2023, implementation began with early adopters and leaders in acute care hospitals. This included the development of the Sickle Cell Disease Quality Standard Implementation Toolkit, which focused on quality statements 1, 3, and 4 and addressed key areas for improving care in the emergency department. An implementation advisory group was created to provide guidance on planning and executing implementation. The Sickle Cell Disease eReport was launched to support data-driven, data-informed improvements, and sickle cell disease was identified as a use case for the Evidence2Practice program.

### YEAR 1 (2024/25)

The scope of the Sickle Cell Disease Quality Standard Implementation Toolkit was expanded to include change ideas and resources for the quality statements that had not been included in the initial version, and a Clinical Lead, Sickle Cell Disease, was recruited and onboarded.

Other activities included targeted webinars and resources for health care teams in acute care settings (through the Sickle Cell Disease Community of Practice), identification of key partners in the Ontario Health regions, and a provincial letter to emergency department chiefs that included a pathway for treating people with sickle cell disease who present to the emergency department, and resources to support Ontario emergency departments in delivering high-quality care to people with sickle cell disease (e.g., sample order sets). Later that year, the scope of the webinar sessions was broadened to include coverage of dedicated sickle cell disease centres and primary and community care settings. The eReport was redesigned, and ongoing education engagements took place across the province.

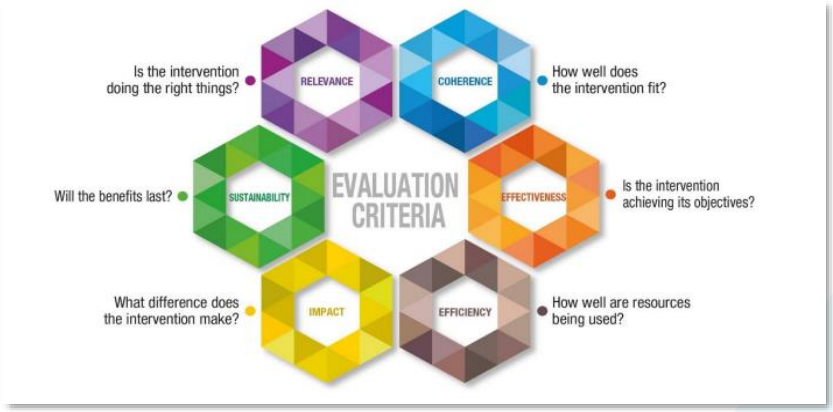
### YEAR 2 (2025/26)

So far this year, we have completed a series of regional engagements, participated in learning events hosted by new and established dedicated sickle cell disease centres, and presented implementation milestones and next steps at the annual summit of the Sickle Cell Awareness Group of Ontario. Further implementation strategies will be aimed at increasing engagement with primary and community care settings. We will focus on co-creating a provincial model of care for sickle cell disease, involving key partners and the implementation advisory group, with expanded representation across roles, settings, and regions.

# Impact Assessment: Approach

## Evaluation Criteria

We have structured this impact assessment using evaluation criteria from the Organisation for Economic Co-operation and Development (OECD).[3] These 6 internationally recognized criteria –relevance, coherence, effectiveness, efficiency, impact, and sustainability – can be used to evaluate interventions, understand challenges, and explore solutions. They are applicable to a range of interventions (e.g., strategies, policies, projects) and can be used in local, regional, national, and international contexts. Together, the evaluation criteria can be used to guide the consistent, high-quality, holistic assessment of an intervention.




Ontario Health's Quality division previously used the OECD criteria to evaluate the Ontario Surgical Quality Improvement Network (ONSQIN),[9] an Ontario Health community of practice for surgical teams from all hospitals and specialties across Ontario.

Applied to the implementation of the *Sickle Cell Disease* quality standard,[1] the evaluation criteria address the following questions:

- **Relevance:** Are the implementation strategies doing the right things?
- **Coherence:** How well do the implementation strategies fit into the context of Ontario's health system?
- **Effectiveness:** Are the implementation strategies achieving their objectives?
- **Efficiency:** How well are resources being used?
- **Impact:** What difference do the implementation strategies make?
- **Sustainability:** Will the benefits of implementation last?

## Implementation Strategies Evaluated

Using multiple data sources – including internal program work plans and documents, hospital data, and digital and Google analytics – we applied each of the evaluation criteria to the implementation strategies below. In this way, we provide a holistic impact assessment of *Sickle Cell Disease* quality standard implementation over the past 2 years.

### Implementation Funding

Three funding initiatives have been supported in fiscal years 2023/24 and 2024/25 to provide a data-driven and strategic allocation of financial resources to drive implementation of the *Sickle Cell Disease* quality standard:

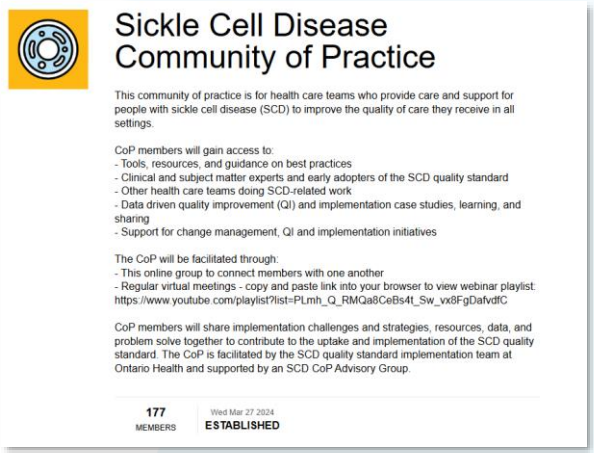
- Dedicated sickle cell disease centres: This base funding aims to provide funding for dedicated sickle cell disease centres for adult populations, pediatric populations, or both. The funding also aims to enhance the quality of care provided, alleviate

pressures on established dedicated sickle cell disease centres, and ensure delivery of specialized care closer to home for people with sickle cell disease

- Pediatric recovery: This base funding is part of a broader investment by the Ontario Ministry of Health specific to the implementation of the *Sickle Cell Disease* quality standard in pediatric settings, providing mental health supports for Black and 2SLGBTQIA+ children and youth. It aims to build health service provider capacity to meet the unique needs of pediatric patients, families, and care partners who are navigating sickle cell disease care – with a focus on reducing disparities for Black communities. This funding comes from the Pediatric Recovery Funding envelope and does not include reporting from other funding that Ontario Health manages to advance sickle cell disease outcomes
- *Sickle Cell Disease* quality standard implementation: This one-time funding is aimed at supporting quality standard implementation and recruiting a Clinical Lead, Sickle Cell Disease, to provide provincial leadership and coordinate implementation

## Community of Practice

Launched in May 2024, the Sickle Cell Disease Community of Practice addresses barriers to sickle cell disease care by fostering collaboration among health care teams. The community of practice is hosted on Quorum, an online community dedicated to improving the quality of health care across Ontario.




The community of practice supports the implementation of the *Sickle Cell Disease* quality standard across Ontario by providing a platform for knowledge exchange and capacity-building. Key features of the community of practice include the following:

- A discussion forum for peer exchange that enables health care teams and community members to share insights and solutions
- A document library that provides access to over 40 shared resources and tools addressing care challenges outlined in the quality standard
- A member directory that facilitates networking to strengthen community ties and provide interprofessional support
- Regular webinars and learning sessions featuring implementation stories that highlight innovative approaches to overcoming systemic care barriers
- Accredited continuing medical education that equips clinicians with updated knowledge and strategies to improve care delivery

The Sickle Cell Disease Community of Practice is guided by the implementation advisory group, which is made up of clinicians from across health care settings and people with lived experience. Surveys are conducted twice a year ensure that the activities of the community

of practice remain connected to the quality standard's goals and the community's needs. The community of practice emphasizes culturally safe approaches and addresses systemic and anti-Black racism in health care settings.

## Implementation Toolkit

The Sickle Cell Disease Quality Standard Implementation Toolkit[10] serves as a practical resource to help health care teams operationalize the quality standard and overcome barriers to providing high-quality care. Each component of the toolkit is designed to address challenges such as inconsistent care delivery and lack of standardized protocols.


The toolkit includes the following:

- Change ideas and concepts tailored to the 8 quality statements, offering actionable steps for improving care continuity and access
- Case studies and links to recorded webinars to facilitate local adaptation by sharing real-world experiences and evidence-based approaches
- Digital integration guidance that supports the embedding of order sets in hospital information systems such as Oracle, MEDITECH, and Epic, ensuring streamlined workflows.

By equipping teams with these resources, the implementation toolkit bolsters clinician confidence and establishes consistency in care delivery for sickle cell disease. The implementation toolkit also complements *A Black Health Plan for Ontario*[2] by fostering equity and culturally competent practices.

## eReport

The Sickle Cell Disease eReport is an interactive data dashboard that allows users to drill down into and understand regional and hospital-level variation and assess hospital performance on indicators that align with the *Sickle Cell Disease* quality standard. With continuous assessment for enhancements, the eReport enables Ontario Health to make data-informed decisions, identify where high and low performance exist, and provide targeted resources to support implementation. The eReport is also intended for use by regions and hospitals to support quality improvement initiatives by tracking quarterly progress at the system level using indicators adapted from the *Sickle Cell Disease* quality standard, such as:

- Sickle cell disease–related unplanned emergency department visits and the 30-day repeat visit rate
- Percentage of people with sickle cell disease presenting to the emergency department with a Canadian Triage and Acuity Scale (CTAS) score of 1 or 2
- Median wait time to physician initial assessment in the emergency department
- Inpatient hospitalization volumes for sickle cell disease

## Evidence2Practice

The Evidence2Practice program is a provincial initiative led jointly by the Centre for Effective Practice, Amplify Care, and North York General Hospital. Established as a central mechanism for advancing the adoption of quality standards, Evidence2Practice supports organizations and clinicians with digital enhancements, implementation supports, and change-management resources that are embedded in electronic medical records and health information systems.

Evidence2Practice also works to eliminate barriers to accessing high-quality care by supporting organizations in the development of robust clinician education and training and change management to support the adoption of digital tools. This work supports delivering care that is free from racism, anti-Black racism, discrimination, and stigma; enhancing clinical knowledge of sickle cell disease; and integrating evidence-based clinical guidelines into practice, particularly for pain management. Sickle cell disease training is embedded in onboarding for new staff and included in ongoing refresher courses to ensure that clinicians remain current with best practices.

# Impact Assessment: Findings

## Relevance

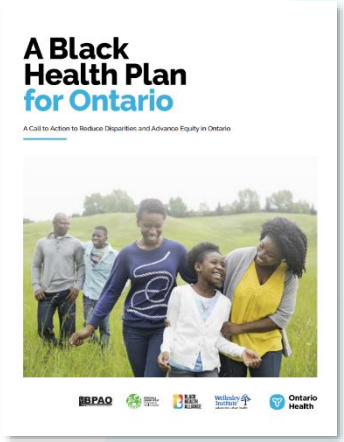
*Are the implementation strategies doing the right things?*

> *The implementation of the* Sickle Cell Disease *quality standard has been invaluable in guiding patient care in Windsor. It provides a clear framework for communicating care metrics both within our dedicated sickle cell team and across other departments, including the emergency department and inpatient clinical teaching units. Importantly, the tool also highlights and validates the historical inequities and substandard care experienced by individuals living with SCD, reinforcing the need for – and supporting the adoption of – trauma-informed approaches to care delivery.*
>
> *– Dr. Andrea Cervi, Hematology & Thrombosis Department Head, Windsor Regional Hospital*

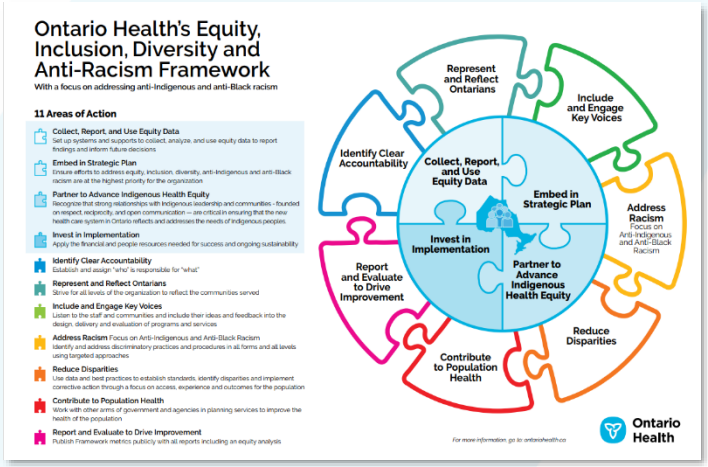
### Overall

Responsibility for the provincial implementation of the *Sickle Cell Disease* quality standard resides with Ontario Health's Quality division (part of the Acute and Hospital-Based Care portfolio), in collaboration with Ontario Health's Provincial Equity Office. Ontario Health remains committed to equitable health care access, experiences, and outcomes, and this commitment is embedded in key policy documents and plans.

Implementation of the *Sickle Cell Disease* quality standard[1] aligns with Ontario Health's commitment to Black health. It is also one of Ontario Health's deliverables in *A Black Health Plan for Ontario*[2] – the first provincial plan dedicated to advancing Black health.




*A Black Health Plan for Ontario* was developed and is stewarded by a diverse group of community members, health leaders, and academics. It seeks to build a health system that delivers sustained health equity for Black populations and furthers the goals of Ontario Health's *Equity, Inclusion, Diversity and Anti-Racism Framework*.[11]




Key partners, including clinicians, policymakers, lived experience advisors, and community organizations, have been involved in each step of the development and implementation of the *Sickle Cell Disease* quality standard. The members of the Sickle Cell Disease Quality Standard Advisory Committee are listed in Appendix B.

In addition, leaders from provincial sickle cell advocacy organizations – the Sickle Cell Awareness Group of Ontario, the Sickle Cell Association of Ontario, and the Black Health Alliance – met with the Clinical and Quality Standards team throughout the development of the quality standard and provided input on implementation to ensure alignment with community priorities.

## Implementation Funding

### DEDICATED SICKLE CELL DISEASE CENTRES

The Provincial Equity Office worked with Ontario Health regional leadership to identify 5 new sites for dedicated sickle cell centres and 3 established centres that would receive additional funding. The sites were chosen to address gaps in local availability of care and in collaboration with self-identified teams able to provide clinical expertise.

### PEDIATRIC RECOVERY

The Provincial Equity Office also worked with Ontario Health regional leadership to support implementation of the *Sickle Cell Disease* quality standard for pediatric populations. Submissions for base implementation funding were received from hospitals and community health organizations across all 6 Ontario Health regions and reviewed by regional and provincial equity teams. Proposals were further refined for scope with regional guidance and broader alignment with Ontario Health's equity programs. Selection was guided by regional needs, geographical gaps in care, and alignment with the *Sickle Cell Disease* quality standard.

### *SICKLE CELL DISEASE* QUALITY STANDARD IMPLEMENTATION

Submissions for one-time implementation funding were invited from hospital organizations across all 6 Ontario Health regions and reviewed by the regional quality and equity leads. The proposals were then reviewed by the Clinical and Quality Standards team, which provided feedback on scope and opportunities for alignment with other initiatives and existing programs. Selection was based on regional needs, eReport data indicating regions or hospitals with gaps in care, and alignment with the quality standard.

## Community of Practice

The Sickle Cell Disease Community of Practice includes representatives from key partner organizations across the province. It encourages active engagement and sharing of resources relevant to the implementation of the quality standard. The education plan for webinars and drop-in sessions is developed iteratively in response to feedback from each session and community input. The topics selected are designed to support ongoing implementation of the *Sickle Cell Disease* quality standard and to foster opportunities for connection between clinicians and community members across the province. The webinars held over the past year have included the following topics:

- Vaso-occlusive acute pain management using sublingual fentanyl
- Using and adapting order sets in pediatric and adult care settings
- Coordination between local health care teams and dedicated sickle cell disease centres
- Community health centres coordinating care to support implementation of the *Sickle Cell Disease* quality standard
- *Sickle Cell Disease* quality standard implementation success case study: Scarborough Health Network

## Implementation Toolkit

The Sickle Cell Disease Quality Standard Implementation Toolkit[10] provides practical change ideas and readily available resources to support implementation of the 8 quality statements. The toolkit was developed with input from health care teams and people with lived experience. It includes resources provided by key community partners, including the Sickle Cell Awareness Group of Ontario's education program.

## eReport

The Sickle Cell Disease eReport was created to support clinicians, policymakers, and community members in identifying opportunities for improvement in alignment with the quality standard. It includes key performance indicators such as time to physician initial assessment in the emergency department and hospital admission rates. Over the past year, the eReport has been made available to community partner organizations (the Sickle Cell Awareness Group of Ontario and the Sickle Cell Association of Ontario) to further empower them to advocate at the provincial level for high-quality sickle cell disease care.

The data in the eReport are refreshed each March, June, September, and December, allowing key partners to monitor trends and identify gaps or variations in care delivery using the most up-to-date information. The eReport will also be routinely reviewed by the provincial clinical lead and the project team; new indicators and insights will be continuously incorporated to ensure that the eReport provides a comprehensive picture of the quality of sickle cell disease care across the province.

## Evidence2Practice

To address care gaps and variability in the management of sickle cell disease in acute care settings, Evidence2Practice has partnered with 4 hospital organizations to pilot the streamlining, standardizing, and digitizing of clinical processes, including the following:

- Implementation of a comprehensive digital order set for vaso-occlusive acute pain episodes
- Development of standard operating procedures that prioritize prompt and effective pain management
- Delivery of targeted training to ensure that emergency department clinicians are prepared to efficiently identify, triage, and treat people with sickle cell disease

With freely available tools and services, hospital sites can apply health information system solutions to address gaps in sickle cell disease care. Hospital sites can self-identify to access these resources.

The applicability of Evidence2Practice to a variety of health information systems also makes it relevant to sites across the province, supporting implementation of the quality standard in day-to-day clinical practice.

# Coherence

*How well do the implementation strategies fit into the context of Ontario's Health system?*

## Overall

To achieve substantial change at the system level, a support system is needed to enable behaviour change at the local level. Coherence is exemplified by the ability of each implementation strategy to leverage existing Ontario Health programs and assets, including the Ontario Health regions and the Provincial Equity Office.

### INTEGRATED QUALITY FRAMEWORK

The implementation approach for the *Sickle Cell Disease* quality standard aligns with the Ontario Health Integrated Quality Framework (see page 7), which is guided by data and evidence and includes 2 strategic objectives: embedding quality in Ontario Health priority initiatives and driving and fostering system improvement. As noted in the Background, the implementation framework highlights 4 key functions that align with the domains of health care quality:

1) Understand quality gaps through data and monitor progress
2) Synthesize evidence for clinical guidance and quality standards
3) Engage patients, clinicians, and the health system
4) Accelerate change using quality improvement and implementation science methods

This framework provided a foundation for identifying and applying strategies to drive the provincial adoption and implementation of the *Sickle Cell Disease* quality standard.

### ONTARIO HEALTH REGIONS

The role of the Ontario Health regions is to fund, connect, and coordinate health care. Creating connections and relationships with the Ontario Health regional teams is another key step in creating a system of support for implementation of the *Sickle Cell Disease* quality standard. The regions monitor how the system is performing and provide evidence-based standards and improvements to address any gaps. The regions' scope includes primary care, community health centres, support services, home care, mental health and addiction agencies, long-term care, and hospitals. They have awareness of the local context in which clinicians and health care teams function.

In recognition of the important function of the regions as a lever for advancing integrated, high-quality, value-driven, efficient health system planning, connections between the Clinical and Quality Standards team and staff in each of the 6 regions were initiated in November 2023 and have continued via group meetings held approximately every 4 months.

This relationship-building has included the provision of region-specific data summaries, observations on hospital engagement in provincial work, and recommendations for the regions as they interact with emergency department or hospital leaders. Through relationships built over time, issues related to dedicated sickle cell disease centres and the flow or intake of patients have been identified and are being addressed collaboratively.

### PROVINCIAL EQUITY OFFICE

The Provincial Equity Office plays an integral role in fostering coherence by working closely and aligning priorities with Ontario Health regional leadership, the Clinical and Quality Standards team, clinical leadership, and people with lived experience to advance care for people with sickle cell disease across the province. This collaborative approach ensures that regional and provincial efforts remain harmonized, supporting the effective integration of equity considerations into planning, funding, and data collection. This alignment advances and promotes consistent and equitable care for everyone affected by sickle cell disease across the province.

## IMPLEMENTATION FUNDING

Implementation funding plays a critical role in supporting the coherence of efforts across strategies. By aligning financial resources with strategic priorities informed by data from the eReport, funding has ensured that Ontario Health regions, the Provincial Equity Office, the Clinical and Quality Standards team, and hospitals and community partners can act in concert. Consistent funding cycles will help synchronize data collection and reporting and accelerate improvement activities, reinforcing a unified and harmonized approach to care improvement for sickle cell disease across Ontario.

### Community of Practice

The Sickle Cell Disease Community of Practice is a hub of information. In addition to providing webinars and drop-in sessions, it has also been used to share information about the release of the new version of the Sickle Cell Disease Quality Standard Implementation Toolkit and make calls for participation for Evidence2Practice pilot sites – all with the goal of fostering meaningful engagement and building connections among people with lived experience, clinicians, and the broader health system.

### Implementation Toolkit

The Sickle Cell Disease Quality Standard Implementation Toolkit includes links to past webinar recordings from the Sickle Cell Disease Community of Practice. It also provides digital tools for clinical adoption (for example, Evidence2Practice) as sample resources for implementation of the *Sickle Cell Disease* quality standard. The toolkit serves as a central repository for all essential resources and tools, empowering and expediting meaningful change across the health care system.

### eReport

The Sickle Cell Disease eReport includes indicators selected to correspond directly with priority areas identified in the *Sickle Cell Disease* quality standard, reinforcing a unified approach to care and to the evaluation of implementation strategies. Quarterly refresh cycles help ensure that hospitals and key partners work with timely and comparable data, promoting coherent decision-making and action. Planned incorporation of new indicators and insights will ensure that the eReport remains aligned with emerging needs and evolving data needs, maintaining coherence with future directions in sickle cell disease care.

### Evidence2Practice

The Evidence2Practice team collaborates closely with the Ontario Health Quality team and provincial networks, leveraging data from the eReport and the Sickle Cell Disease Community of Practice to improve access to high-quality acute care. This includes alignment with discussions about order sets, education, indicators to measure progress, and workflow changes that are discussed in the community of practice and with Ontario Health teams and reflected in Evidence2Practice implementation. Evidence2Practice also aligns with Ontario Health's recommended Quality Improvement Plan initiatives to foster a systemic approach to change, supporting consistent progress across the health care system.

# Effectiveness

*Are the implementation strategies achieving their objectives?*

## Implementation Funding

### DEDICATED SICKLE CELL DISEASE CENTRES

The Provincial Equity Office has worked with Ontario Health regional leadership to fund new dedicated sickle cell disease centres across the province for adult populations, pediatric populations, or both. The funding also aims to enhance the quality of care provided, alleviate pressures on established dedicated sickle cell disease centres, and ensure delivery of specialized care closer to home for people with sickle cell disease.

About $2.2 million has been used to set up 5 new dedicated sickle cell disease centres across 5 of the 6 Ontario Health regions and to provide additional funding to 3 established centres. The funding has been used by interprofessional clinics to assess people with hemoglobinopathies, (including sickle cell disease) and to provide appropriate management of hemoglobinopathies in consultation with specialists. The centres have worked to develop plans for transitions in care and integrated comprehensive services for patients from pediatric to adult care. They have also improved access to clinical care and social supports, provided education, increased preventive care, and reduced the use of hospital-based services.

### PEDIATRIC RECOVERY

The Provincial Equity Office has worked with Ontario Health regional leadership to support implementation of the *Sickle Cell Disease* quality standard for pediatric populations. This initiative aims to build health service provider capacity to meet the unique needs of pediatric patients, families, and care partners navigating sickle cell disease care – with a particular focus on reducing disparities for Black communities.

About $2 million has been flowed to 11 health service providers across 5 Ontario Health regions and a range of settings, including dedicated sickle cell disease centres, emergency departments, community health centres, and family health teams.

### *SICKLE CELL DISEASE* QUALITY STANDARD IMPLEMENTATION

The Clinical and Quality Standards team has worked with Ontario Health regional leadership to support implementation of the *Sickle Cell Disease* quality standard. This funding initiative was aimed at facilitating implementation and recruiting a Clinical Lead, Sickle Cell Disease, who will provide provincial leadership and coordination.

About $1.3 million has been flowed to 14 health service providers across 5 Ontario health regions and a range of settings, including dedicated sickle cell disease centres, emergency departments, acute care centres, community health centres, and chronic pain clinics.

Dr. Jennifer Bryan has joined Ontario Health as Clinical Lead, Sickle Cell Disease. Dr. Bryan is an emergency physician at University Health Network who has a strong background in leadership, research, quality improvement, and advocacy for equity in health.

## Community of Practice

Over the past year, the Sickle Cell Disease Community of Practice has maintained sustained engagement, hosting 7 events with consistently strong participation. Two of these sessions stood out, achieving attendance rates of 86% and 89% and demonstrating substantial interest and engagement. The topics covered have been diverse and practical, ranging from clinical pain management to system-level coordination and the use of digital tools. Session content has also been responsive to the evolving needs of members, addressing priorities

such as support for newly funded centres and updating order sets to meet clinical care challenges.

The 5 webinars held over the past year covered a variety of topics on sickle cell disease care across settings:

- Vaso-occlusive acute pain management using sublingual fentanyl (May 2024): 186 registrations, 50% attendance
- Using and adapting order sets in pediatric and adult care settings (July 2024): 100 registrations, 71% attendance
- Coordination between local health care teams and dedicated sickle cell disease centres (November 2024): 99 registrations, 79% attendance
- Community health centres coordinating care to support implementation of the *Sickle Cell Disease* quality standard (April 2025): 126 registrations, 79% attendance
- *Sickle Cell Disease* quality standard implementation success case study: Scarborough Health Network (June 2025): 44 registrations, 89% attendance

The 2 informal drop-in sessions provided practical support and guidance for health care teams:

- Using Quorum, accessing eReports, and reviewing the June community of practice engagement survey results (August 2024): 29 registrations, 86% attendance
- Providing support and guidance for newly funded dedicated sickle cell disease centres (January 2025): 61 registrations, 75% attendance

### MEMBERSHIP

As of August 2025, the community of practice has 177 members. Of these, 30% are subscribers – a percentage considered excellent by comparative Quorum group trends and falling within the typical benchmark range of 30% to 50%. As well, 7% of members are classified as active participants – slightly below the usual benchmark of 10% but still representing a strong level of engagement.

### ENGAGEMENT

Since its launch, the community of practice has had a total of 72 posts and comments. On average, members have contributed 4 to 5 posts or comments per month. Engagement peaked in February 2025, with 16 posts and comments. Other months that saw notable engagement included July 2024, March 2025, and April 2025.

### PAGE VIEWS AND DOWNLOADS

The community of practice and its resources have recorded 7,441 page views, with an average of 480 page views per month. There have also been 965 downloads, with an average of 62 downloads per month. This trend in page views closely follows the pattern of posting activity, showing that members are especially likely to access and interact with content as it becomes available.

## Implementation Toolkit

The initial version of the Sickle Cell Disease Quality Standard Implementation Toolkit was released on Quorum in December 2023 and downloaded 115 times (106 English, 9 French). Quorum posts related to the toolkit received a combined total of 130 page views, suggesting that nearly everyone who accessed the posts proceeded to download the resource.

The second version of the toolkit was posted on the *Sickle Cell Disease* quality standard landing page in February 2025. As of July 2025, the landing page has had a total of 2,581 pageviews – 87 of those for the toolkit.

## eReport

The Sickle Cell Disease eReport is available to anyone with credentials for ONE ID, a platform that provides easy and secure access to digital health services. Users include clinicians, administrators, and quality program support staff in hospitals, dedicated sickle cell disease centres, and other health facilities. Reach can be tracked with the number of views. Via the Health System Reports portal, the eReport is also internally accessible to Ontario Health employees, including regional, equity, and clinical leadership.

Data from the eReport have been used by the Clinical and Quality Standards team to make informed decisions about where high and low performance exists with respect to quality indicators. These data have provided additional considerations for targeted funding to support implementation of the quality standard across the province.

The eReport has received a total of 730 views since its launch in January 2024. There were 469 views in 2024/25, with the highest number in the third quarter after its posting on the Health System Reports portal in November (113 views). In the fourth quarter, 43 distinct external users accessed the eReport using ONE ID. (See Appendix C for the number of eReport/Health System Report views.)

## Evidence2Practice

### DATA TO TARGET KEY AREAS FOR CHANGE

Evidence2Practice has used the Sickle Cell Disease eReport to identify organizations and prioritize implementation of the quality standard, ensuring that implementation efforts are both targeted and strategic.

Alignment with Ontario Health's recommended Quality Improvement Plan initiatives has fostered a systemic approach to change, supporting consistent progress across the health care system.

Evidence2Practice has partnered with various clinicians and digital health staff to drive change, including direct partnerships with 4 hospitals to address local issues. These partnerships have allowed for provincial and local integration (e.g., into existing clinical governance structures) to sustain change.

### DIGITIZING QUALITY STANDARDS

Evidence2Practice aims to enhance the provider experience and improve patient care by integrating evidence and quality standards directly into frontline digital clinical systems.

The program has integrated clinical decision support enhancements such as the Vaso-Occlusive Pain Order Set directly into health information systems (Epic, Meditech, Cerner), ensuring that evidence-based care is available at the point of care in the 4 partner hospital sites. Outside digital change, implementation has focused on appropriate education and change management, as well as on driving faster, more efficient, and more appropriate workflows to address patient concerns in the emergency department and inpatient settings.

### ENGAGEMENT AND ALIGNMENT

As part of its implementation evaluation, Evidence2Practice has enabled organizations to conduct timely, localized data collection to inform ongoing quality improvement efforts.

Engagement with networks such as the Sickle Cell Disease Community of Practice has further supported the dissemination and replication of effective strategies to hospitals and clinicians who have joined the program.

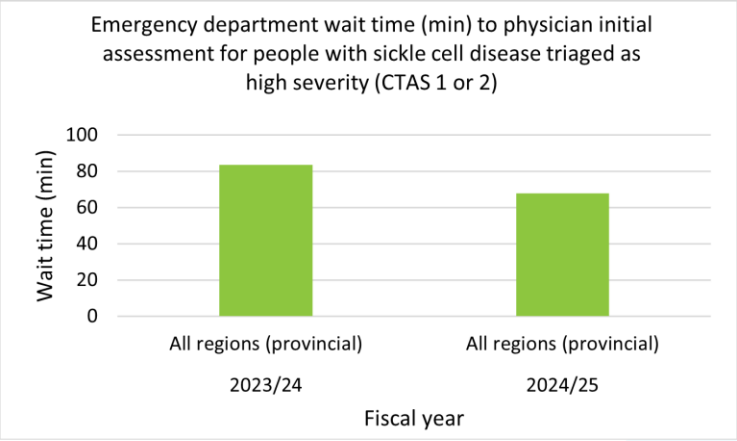
# Efficiency

*How well are resources being used?*

> *Early indicators show that people with lived experience of sickle cell disease are now reporting better access to timely, appropriate care. This progress is not only improving quality of life but also reducing hospital stays and alleviating pressure on the health care system, demonstrating a strong return on investment.*
>
> *– Lanre Tunji-Ajayi, President and CEO of the Sickle Cell Awareness Group of Ontario*

## Clinical Impact

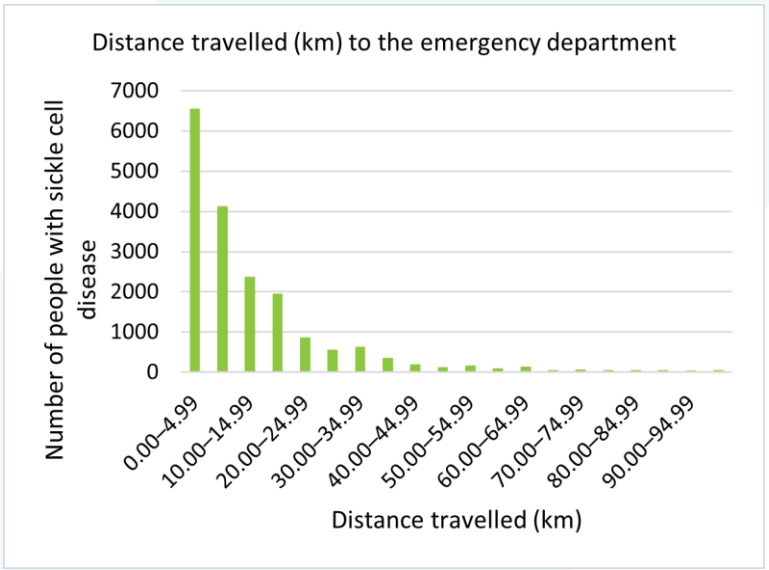
The average time to physician initial assessment in the emergency department was 68 minutes in fiscal year 2024/25, reflecting a 19% reduction compared to fiscal year 2023/24. This improvement suggests enhanced efficiency in patient flow and triage, potentially leading to faster clinical decisions.




Abbreviation: CTAS, Canadian Triage and Acuity Scale.
*Data source: National Ambulatory Care Reporting System, fiscal years 2023/24 to 2024/25.*

## Travel for Emergency Department Care

A key indicator of success for this initiative would be a reduction in the median distance people need to travel for emergency department care. A shorter median distance would show that people are finding care options closer to home, improving access and potentially leading to better health outcomes. In Ontario, people with sickle cell disease typically travel a median distance of 7.97 km to access care. However, median distance alone does not fully capture the extent of geographic disparities, as there is substantial regional variation in travel burden. In some areas, people with sickle cell disease travel considerably longer distances, highlighting that geographic barriers to accessing equitable emergency care remain.




*Data sources: National Ambulatory Care Reporting System, fiscal years 2018/19 to 2024/25; Postal CodeOM Conversion File (PCCF).*

# Impact

## *What difference do the implementation strategies make?*

> *The implementation of the Ontario Health quality standard for sickle cell disease, supported by strategic funding from the Ministry of Health, has marked a pivotal shift in care delivery. This investment has expanded the network of trained clinicians and equipped them with critical educational tools, such as the 13-module accredited e-course developed by the Sickle Cell Awareness Group of Ontario. These resources are directly enhancing provider competency and improving patient outcomes.*
>
> *– Lanre Tunji-Ajayi, President and CEO of the Sickle Cell Awareness Group of Ontario*

## Implementation Funding

### DEDICATED SICKLE CELL DISEASE CENTRES 2024/25

**Emergency Department Transformation**
Several centres have implemented targeted improvements in emergency department care for people with sickle cell disease. Time to first-dose analgesia has been reduced, and pain management strategies beyond the initial dose have been improved. Centres have addressed clinician bias through defined emergency department capabilities for sickle cell disease care.

Standardized order sets for both pediatric and adult patients in emergency departments have been implemented, and electronic medical record flags have been introduced for timely treatment. Self-identification kiosks for people with sickle cell disease have been introduced. Staff have been trained using Sickle Cell Awareness Group of Ontario education modules, and emergency department performance is being tracked through equity-focused indicators.

**Centre Development and Expansion**
New and expanded dedicated sickle cell disease centres have been launched to improve access to specialized care. Pediatric dedicated sickle cell disease centres have been expanded, and planning is underway for adult services, supported by community feedback from a town hall. Five new dedicated sickle cell disease centres have been planned and are in the process of phased implementation, including recruitment, internal alignment, and community engagement (see Appendix E).

A regional centre model has been proposed to address the lack of benign hematology services in the North East Region, aiming to reduce travel burden and improve continuity of care.

**Care Coordination and Transition Pathways**
Efforts have been made to ensure smoother transitions and integrated care, including the establishment of a working group with Ontario Health Teams and community partners (aligned with the *Black Health Plan*) and the creation of transition pathways between pediatric and adult services.

The need has been identified for a shared nurse practitioner to coordinate care across pediatric and adult dedicated sickle cell disease centres, addressing current gaps in continuity.

**Community Engagement and Partnerships**
Health service providers have strengthened ties with community organizations and advocacy groups. Achievements include improved referral pathways with a community health centre and other community partners and partnership with the Sickle Cell Awareness Group of Ontario to implement the Patient Wellbeing Program with physician oversight of patient interactions. The Central Region has seen the launch of outreach and engagement activities with the sickle cell disease community.

### Data and Quality Improvement

Data-driven approaches have been used to inform and improve care, including testing the collection of disaggregated data using the EPIC platform and tracking metrics such as emergency department wait times, time to pain management, and patient satisfaction to guide continuous quality improvement.

### Metrics

Across all dedicated sickle cell disease centres:

- 2,200+ adults and 2,800+ pediatric patients have been treated
- 80 patients have been transitioned from a pediatric sickle cell disease centre to an adult sickle cell disease centre
- 99+ patients have been transferred to care closer to home
- 2,900+ visits have been made to a dedicated sickle cell disease centre

Major successes include expanding access to care closer to home, improving the pediatric patient experience, enhancing medication access and clinic capacity, launching patient and family advisory councils, and strengthening interprofessional partnerships and community engagement.

Some centres are capturing racial group identity during intake, although most sites are not yet systematically collecting this information. Racial or ethnic groups served include:

- 895 Black patients
- 180 Middle Eastern, Arab, and West Asian patients
- 18 Latin American patients
- 18 East Asian patients
- 27 Southeast Asian patients
- 27 South Asian patients
- 36 White patients
- 72 clients from multiple racial groups

## PEDIATRIC RECOVERY 2024/25

### Clinical Care

Community-based sickle cell disease clinics (e.g., in Hamilton, Durham, Peel, and York–South Simcoe) have been established to provide primary and specialty care, including pain management, transfusions, and chronic illness support. More than 90 patients have been referred to these clinics.

Interprofessional teams (e.g., consisting of a nurse practitioner, registered nurse, hematologist, and social worker) have been created to deliver wraparound care. Emergency department protocols have been implemented for sickle cell disease vaso-occlusive acute pain episodes, and referral pathways to acute care and hospitals have been created.

### Education

Clinician training sessions and educational programs have been delivered on sickle cell disease management, including hydroxyurea therapy and pain protocols. More than 60 educational resources have been created to support patients, families, and care partners.

Evidence-based guidelines and best practices have been created and disseminated across regions, including Durham and Thunder Bay. Staff learning outcomes have been evaluated using pre- and post-training surveys, and qualitative feedback to date has demonstrated increased knowledge of and confidence in providing high-quality sickle cell disease care.

### Community Engagement

Community engagement activities across the province have included awareness campaigns and wellness education initiatives to empower people affected by sickle cell disease and their families, monthly support groups and health promotion activities (e.g., yoga, nutrition, stress relief), and partnerships with community ambassadors and elders to co-design culturally relevant services.

### Care Coordination

Enhancements to care coordination have included supporting transitions from pediatric to adult care through structured programs and patient-driven care plans; building partnerships across Ontario Health Teams, community health centres, and hospitals (including a collaborative table with 4 community health centres, 1 social service agency, and the Sickle Cell Awareness Group of Ontario) to ensure seamless care and communication; and facilitating access to primary care and specialist services, including navigation support for underserved populations (824 patients received patient navigation services).

### Support Services

Support services offered have included psychosocial support (such as counselling, respite care, and mental health services); addressing social determinants of health (such as food security, transportation, and employment support); wraparound services, including social worker, dietitian, and registered nurse support; and genetic counselling and family planning education.

## *SICKLE CELL DISEASE* QUALITY STANDARD IMPLEMENTATION

### Provincial Leadership and Coordination

Since December 2024, the Clinical and Quality Standards team has been working closely with Dr. Jennifer Bryan, Clinical Lead, Sickle Cell Disease, to facilitate the provincial implementation of the *Sickle Cell Disease* quality standard and associated necessary system transformation. Dr. Bryan has been active in 6 key areas:

- *Strengthening implementation through improved clinical relevance:* providing feedback on implementation projects to ensure clinical relevance and working directly with new and established dedicated sickle cell centres to identify barriers and facilitators to implementing the quality standard; collaborating with regional leads and supporting strategy development when a major centre paused on accepting new referrals
- *Enhancing collaboration between key partners:* strengthening communication across the 3 implementation funding streams; working with the Clinical and Quality Standards Data and Analytics team to refine the eReport, adding geographic distribution data to inform access to care and exploring the integration of mortality data as a balancing measure
- *Expanding data access to support local action:* building strong connections with community organizations, such as the Sickle Cell Awareness Group of Ontario, the Sickle Cell Association of Ontario, and the Black Health Alliance, to maintain momentum and alignment; promoting the quality standard at public events such as the Sickle Cell Awareness Group of Ontario Gala; ensuring key partners have access to the eReport
- *Building awareness and engagement:* encouraging participation in the community of practice, supporting its growth and visibility; contributing to the ongoing development of the platform as a space for shared learning and resource exchange
- *Supporting capacity building across the province:* delivering presentations at major events, including the Hamilton Symposium, the Windsor Regional Education Event, and the Black Health Summit; using these opportunities to advocate for the quality standard, share learnings, and increase provincial awareness of the initiative
- *Working toward a provincial model of care:* leading a needs assessment survey in June 2025 targeting health care teams that provide care for people with sickle cell disease, the results of which will be used to inform the development and establishment of a well-coordinated provincial model of care for consistent, evidence-based, and culturally responsive care for all people with sickle cell disease in Ontario; holding 4 virtual meetings and 1 in-person meeting between July and September 2025, all aimed at advancing the development of the provincial model of care for sickle cell disease in collaboration with system partners

### Education and Anti-Racism Training

> *There was previously little connection between emergency departments and people living with sickle cell disease. With the introduction of new education initiatives, I now feel safer seeking care at the emergency department – reassured that someone truly understands my needs. This growing relationship between sickle cell disease patients and emergency staff fosters a sense of safety, comfort, and trust in the care being provided and received.*
>
> *– Serena Thompson, Sickle Cell Disease Warrior & Advocate*

Investments in education and anti-racism training are fostering more inclusive and informed health care environments. As a result of funding for implementation of the *Sickle Cell Disease* quality standard:

- 976 health care team members have completed anti-Black racism training (e.g., the Toronto Academic Health Sciences Network's Anti-Black Racism eLearning module, other workshops)
- 241 health care team members have completed the Sickle Cell Awareness Group of Ontario education program
- 211 health care team members attended 2 regional symposia (held in Hamilton and Windsor) aimed at enhancing clinician knowledge and collaboration

### Equipment for Care Delivery

Funding has also allowed for the purchase of life-sustaining equipment, including 4 continuous ambulatory delivery device home infusion pumps for loan to patients for life-sustaining therapy and 15 iron chelation pumps to address backlogs in access to treatment. One organization has purchased vein viewers for every emergency department to support visibility across all skin tones, reducing pain and trauma during procedures (e.g., intravenous insertions).

### Regional Engagement

Regional engagement efforts are bringing local perspectives to broader initiatives, ensuring that diverse voices help shape outcomes across a range of settings in the province.

In collaboration with the Provincial Equity Office team, the Clinical and Quality Standards team is facilitating continuous coordination among and across regions (including the equity directors) to enable the provincial spread and use of resources, materials, and learnings. The use of provincial data and collaboration with Ontario Health regional partners have informed the review of proposals for sickle cell disease funding to target investments that maximize impact.

A regional sickle cell disease registry (165 patients enrolled) has been created in the East Region to support an organized data collection system that can be used to store and analyze data on people with sickle cell disease. Insights from the data may be used for research, to target interventions, and to inform strategies for care delivery.

## Community of Practice

The Sickle Cell Disease Community of Practice has had a substantial impact in terms of clinician engagement, knowledge exchange, equity, and practice change.

With 177 members, the community of practice has hosted multiple webinars and drop-in sessions, achieving strong participation and fostering a collaborative learning environment. The community acts as a virtual space for health care teams to share lessons learned, access clinical expertise, and support the implementation of the *Sickle Cell Disease* quality standard. Community webinars and drop-in sessions are focused on actionable topics such as pain management, care coordination, and adapting clinical tools, directly supporting improvements in frontline care. According to closing polls, most attendees felt that the topics discussed were highly relevant and that they were likely or extremely likely to apply what they had learned during the webinars to quality improvement.

Aligned with broader health equity goals, the community of practice has also played a role in addressing systemic disparities affecting people from Black and racialized communities, who are disproportionately impacted by sickle cell disease.

## Implementation Toolkit

The revised version of the Sickle Cell Disease Quality Standard Implementation Toolkit provides practical tools and implementation strategies that are aligned with all 8 quality statements from the *Sickle Cell Disease* quality standard. Use of the implementation toolkit has supported teams in documenting comprehensive assessments and improving care planning. It has also improved system integration, facilitating consistent, coordinated care across emergency department, primary care, and community health care settings.

## eReport

Organizations have used the Sickle Cell Disease eReport to track indicators and care outcomes. By tracking indicators such as time to physician initial assessment, the eReport has helped users identify delays and supported efforts to improve timely care for people with sickle cell disease.

Since its inception, the Sickle Cell Disease eReport has received 520 views on the eReport platform (external) and 210 views from the Health System Reports portal (internal), bringing the total number of views to 730. The availability of regularly updated data promotes transparency and accountability among clinicians, hospitals, and key partners, encouraging continuous quality improvement.

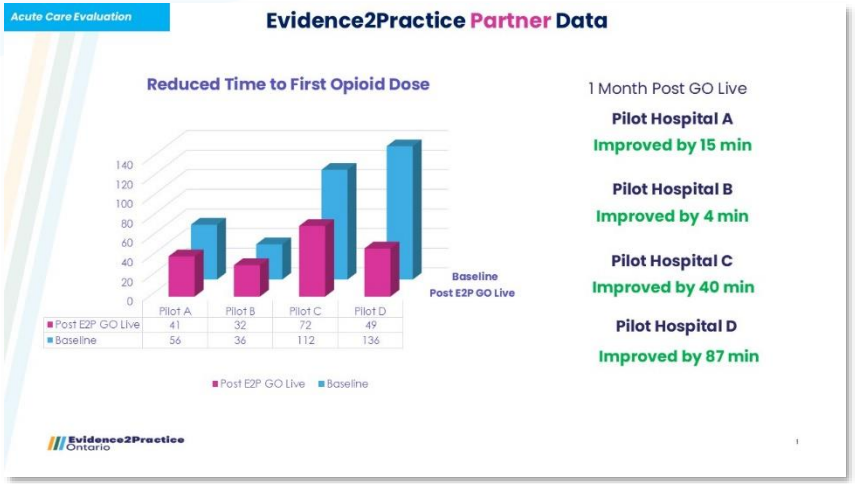
## Evidence2Practice

The Evidence2Practice program has acted as an enabler for accelerated change across 3 aspects of care: timely care delivery, pain management, and order sets. In March 2025, sites received tailored implementation strategies, clinical informatics guidance, and support to enhance project management expertise. Access to new tools and resources was also granted to 2,052 clinicians across 4 partner sites to assist with providing care for people with sickle cell disease in emergency department and inpatient settings.

Data from the partnership sites indicate measurable improvements in timely care delivery, including an increased percentage of CTAS 2 assignments; a reduction in time to first opioid administration for people experiencing vaso-occlusive acute pain episodes; and increased use of sickle cell disease–specific order sets.

| Aspect of care | Improved clinical metrics | Wide-scale adoption | Continuous quality monitoring | Partnerships driving change |
|---|---|---|---|---|
| Timely care delivery | Increased CTAS 2 assignments | Enhanced consistency in care | Real-time, localized data collection | Sustaining momentum across local, regional, and provincial levels |
| Pain management | Reduced time to first opioid administration | 2,000+ clinicians gained access to new E2P tools and resources | Monitoring the timing of opioid administration | Integration into clinical governance |
| Order sets | Increased use of sickle cell disease order sets | Access across 4 partner hospitals | Monitoring the use of order sets | Alignment with Ontario Health's *A Black Health Plan for Ontario* |

Abbreviations: CTAS, Canadian Triage and Acuity Scale; E2P, Evidence2Practice.
*Source: Evidence2Practice Ontario, 2025.*




Abbreviation: E2P, Evidence2Practice.
Bar graph showing reductions in time to first opioid dose from baseline to 1 month after the launch of the Evidence2Practice program ("post go live"). Time to first opioid dose was reduced by a median of 27.5 minutes across 4 pilot hospitals: by 15 minutes at pilot hospital A, by 4 minutes at pilot hospital B, by 40 minutes at pilot hospital C, and by 87 minutes at pilot hospital D.
*Source: Evidence2Practice Ontario, 2025.*

# Sustainability

*Will the benefits of implementation last?*

> *Continued policy support and sustained funding are essential to build on this momentum, close remaining care gaps, and ensure that all Ontarians living with sickle cell disease receive equitable, high-quality care.*
>
> *– Lanre Tunji-Ajayi, President and CEO of the Sickle Cell Awareness Group of Ontario*

Since provincial implementation of the *Sickle Cell Disease* quality standard was initiated, data have shown measurable improvements in clinical care and implementation outcomes, including a reduction in time to physician initial assessment for people with sickle cell disease and management of vaso-occlusive acute pain episodes in the emergency department and time to first opioid dose in hospital sites implementing the Evidence2Practice program. Implementation activities have also led to an increase in the number of trained health care teams involved in sickle cell disease management.

## Implementation Funding

A cornerstone of provincial implementation of the *Sickle Cell Disease* quality standard is the availability of base funding for dedicated sickle cell disease centres and pediatric recovery, as well as one-time funding to support implementation of the quality standard. This has led to the establishment of new dedicated sickle cell disease centres, as well as a psychosocial supports pilot. For adult populations, 14 health service providers across the Ontario Health regions (encompassing diverse care settings) have been supported in implementing the quality standard. For pediatric populations, 10 health service providers (primarily community health centres and some hospitals) have been similarly supported. Collectively, these efforts will advance regional capacity to deliver care to all people with sickle cell disease, regardless of location.

## Community of Practice

The Sickle Cell Disease Community of Practice serves as a central forum for engaging key partners, including clinicians from a range of health disciplines, quality improvement specialists, administrators, and people with lived experience. This collaborative environment encourages knowledge sharing, mentorship, and the identification of best practices that can be scaled across the province.

## Implementation Toolkit

The Sickle Cell Disease Quality Standard Implementation Toolkit has been instrumental in providing a central repository of targeted change ideas, along with tools, resources, and measurement guidance to facilitate implementation of each quality statement in the *Sickle Cell Disease* quality standard. The implementation toolkit is readily available online to health care teams and can be used to support their implementation and quality improvement efforts related to sickle cell disease care.

## eReport

A key component of provincial implementation is the availability of data from the eReport for decision-making and care delivery. The evolving nature of the eReport – with planned additions of new indicators – positions it as a foundational tool for long-term planning and the evaluation of sickle cell disease care across Ontario.

> *Strengthening partnerships between hospitals and primary care ensures that patients gain vital connections to teams in the community who truly understand and can address their needs.*
>
> *– Dr. Madeline Verhovsek, Cofounder and Hematologist, McMaster Hemoglobinopathy Clinic, Hamilton Health Sciences*

## Evidence2Practice

The success of provincial implementation is also rooted in intentional partner engagement and structured collaboration, leveraging digital tools through the Evidence2Practice program. Incorporating existing digital tools better prepares hospital sites to adopt new or emerging technologies and evidence-based practices to advance the delivery of sickle cell disease care.

Ensuring the long-term sustainability of these benefits will rely on the ongoing support of key partners through the Sickle Cell Disease Community of Practice, mapping clinical pathways, and providing mentorship across health care teams. Defining roles throughout the care continuum and developing a robust framework for integration at the regional and provincial levels will further reinforce lasting change. These initiatives must be coupled with targeted support, primarily for primary care and community health care, to maintain and build on the positive outcomes already observed.

# Summary and Next Steps

## Provincial Implementation: Planning and Year 1

Provincial implementation of the *Sickle Cell Disease*[1] quality standard represents a significant advancement in standardized, equitable, and integrated health service delivery for people with sickle cell disease in Ontario. Key outcomes include the following:

- Emergency department transformation, including a 19% reduction in average time to physician initial assessment for people with sickle cell disease experiencing vaso-occlusive acute pain episodes in the emergency department from 2023/24 to 2024/25
- More health care teams trained on sickle cell disease management and anti-racism
- Expanded specialized sickle cell disease care through funding for 5 new dedicated sickle cell disease centres across Ontario Health regions
- A virtual space for almost 180 clinicians, people with lived experience, and community advocates to engage in knowledge exchange, increase collaborations across care settings, share lessons learned, and access clinical expertise and resources
- Recruitment of a Clinical Lead, Sickle Cell Disease, providing provincial leadership and coordination for implementation and working toward establishing a provincial model of sickle cell disease care

Establishing dedicated sickle cell disease centres and piloting psychosocial supports have enhanced care across regions. Fourteen health service providers for adults and 11 for pediatric populations have been supported in implementing the *Sickle Cell Disease* quality standard. These initiatives mark a decisive step toward consistent and evidence-based care for all people with sickle cell disease in Ontario.

Collaboration and partner engagement are central to provincial implementation, including leveraging digital tools and data for decision-making and care delivery. The Sickle Cell Disease Community of Practice serves as a central forum for engaging key partners (i.e., clinicians from a range of health disciplines, quality improvement specialists, administrators, and people with lived experience). This online forum supports knowledge sharing, mentorship, and the spread of best practices across the province.

Key partners – including representatives from both new and established dedicated sickle cell disease centres and regional leads – have also noted opportunities for greater coherence in the implementation of the quality standard. An agreed-upon provincial model of care is needed to support patients and clinicians in accessing available resources. Further, funding efforts could be directed more effectively if there were a shared provincial framework for how to navigate care across settings for people with sickle cell disease.

# Establishing a Provincial Model of Care: Year 2

The impact of the provincial implementation of the *Sickle Cell Disease* quality standard has been profound, touching every element of the care continuum. With expanded access to dedicated centres, standardized care through quality standards, and enhanced system integration, people with sickle cell disease are better supported than ever before.

However, gaps still exist because care delivery is fragmented between care settings and across the province. The establishment of a provincial model of care, building on current initiatives, will continue to drive improvements in health outcomes, patient experience, and overall system performance.

Next steps include the following:

- Continuing to engage key partners through the community of practice
- Conducting a needs assessment survey to map current clinical pathways
- Facilitating a series of group discussions to collaboratively develop and iteratively revise and enhance a provincial model of care for regional and provincial integration of care

Through these efforts, Ontario is charting a clear path toward equitable, high-quality, sustainable care for people with sickle cell disease in Ontario.

# Appendices

## Appendix A: Summary of the *Sickle Cell Disease* Quality Standard

### 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.

*See the Sickle Cell Disease quality standard web page for the full text and accompanying resources.*

# Appendix B: Sickle Cell Disease Quality Standard Advisory Committee

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# Appendix C: One-Time Implementation Funding – Summary of Work Plans (Goals and Planned Activities)

### *Sickle Cell Disease* Quality Standard Implementation: Summary of Funded Projects 2024/25

| Ontario Health region* | Health service provider | Sample deliverables across health service providers |
|---|---|---|
| Central | Oak Valley Health<br>Orillia Soldiers' Memorial Hospital<br>William Osler Health System | Clinician education<br>Dedicated registered nurse navigation<br>Patient support groups |
| East | Lakeridge Health<br>The Ottawa Hospital | Bilingual digital patient portal<br>Sickle cell disease patient registry<br>Sickle cell disease mobile clinic |
| North East | Health Sciences North | Social worker community outreach<br>Clinician education module |
| Toronto | Humber River Health<br>Michael Garron Hospital<br>Scarborough Health Network<br>University Health Network | Emergency department nursing education<br>Sickle cell disease centre of excellence<br>Reductions in emergency department wait times and improvements in pain management |
| West | Hamilton Health Sciences<br>Hamilton Urban Core Community Health Centre<br>London Health Sciences Centre<br>Windsor Regional Hospital | Hosting of a hemoglobinopathy symposium to build province-wide capacity<br>Provision of home infusion pumps<br>Launch of patient resource hub<br>Clinician education |

*No projects were funded in the North West region.

# Appendix D: Sickle Cell Disease eReport Views Since Launch

| Month | External views (ONE ID eReports) | Internal clicks (HSR) | Internal views (HSR) | Number of views (ONE ID eReports + HSR) |
|---|---|---|---|---|
| January 2024 | 24 | NA | NA | 24 |
| February 2024 | 19 | NA | NA | 19 |
| March 2024 | 59 | NA | NA | 59 |
| April 2024 | 59 | NA | NA | 59 |
| May 2024 | 10 | NA | NA | 10 |
| June 2024 | 23 | NA | NA | 23 |
| July 2024 | 9 | NA | NA | 9 |
| August 2024 | 18 | NA | NA | 18 |
| September 2024 | 10 | NA | NA | 10 |
| October 2024 | 66 | NA | NA | 66 |
| November 2024 | 28 | 266 | 83 | 111 |
| December 2024 | 25 | 87 | 30 | 55 |
| January 2025 | 40 | 153 | NA | 40 |
| February 2025 | 33 | 140 | NA | 33 |
| March 2025 | 35 | 136 | NA | 35 |
| April 2025 | 16 | 392 | 128 | 144 |
| May 2025 | 23 | 121 | 58 | 81 |
| June 2025 | 23 | 58 | 24 | 47 |
| **Total** | **520** | **1,353** | **210** | **730** |

Abbreviations: HSR, Health System Reports portal; NA, not available.
Note: *Views* refers to instances of distinct user access to a report, whereas *clicks* refers to individual interactions with the report. A single view may result in multiple clicks. For example, if a user accesses both the Summary tab and a data tab within the Sickle Cell Disease eReport on the same day, it will count as 2 clicks. A higher click count may reflect greater engagement with the report because it suggests that users are navigating across multiple pages and exploring various types of content.

# Appendix E: Spotlight – Dedicated Sickle Cell Disease Centres

## Spotlight: Sickle Cell Awareness Group of Ontario – Psychosocial Pilot at London Health Sciences Centre and Windsor Regional Hospital

The Sickle Cell Awareness Group of Ontario launched a pilot Patient Wellbeing Program with London Health Sciences Centre, later expanding to Windsor Regional Hospital to meet growing regional needs. The program delivered culturally safe, timely, and community-informed support, improving appointment adherence, clinical integration, and access to psychosocial care. Despite a staffing gap, the Sickle Cell Awareness Group of Ontario maintained service continuity through virtual support and collaborative hiring with hospital partners. The program's demonstrated impact underscores its value as a scalable model for equitable care, with plans underway to expand across Ontario.

## Spotlight: Scarborough Health Network Sickle Cell Disease Clinic

Scarborough Health Network's Sickle Cell Disease Clinic has demonstrated measurable progress in improving access, experiences, and outcomes for people with sickle cell disease. The clinic reports the lowest emergency department wait times (22 minutes) and 30-day readmission rates (15%) in Ontario. Success is driven largely by community engagement, interprofessional collaboration, evidence-based interventions, and a strong commitment to dismantling anti-Black racism.

## Spotlight: Health Sciences North Sickle Cell Disease Clinic

Health Sciences North has successfully launched the first hemoglobinopathy clinic in Northern Ontario, serving 6 patients and receiving resoundingly positive feedback. Patients highlighted the clinic's culturally responsive care, language accessibility, and support for family planning as key strengths. Clinicians reported smooth operations and identified opportunities to enhance follow-up care. The clinic has demonstrated a strong early impact and is positioned to improve patient journeys further through workflow refinements and patient advocacy.

The opening of Northern Ontario's first dedicated sickle cell disease clinic in June 2025, bringing specialized care closer to home for people of Black, Caribbean, Middle Eastern, and South Asian backgrounds living in the Sudbury area.

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# About Us

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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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