Quality-Based Procedures
Clinical Handbook for Sickle Cell Disease Vaso-occlusive Crisis

Provincial Council for Maternal and Child Health & Ministry of Health and Long-Term Care

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Quality-Based Procedures Clinical Handbook: Sickle Cell Disease Vaso-occlusive Crisis

1.0 Purpose

This Clinical Handbook has been created to serve as a compendium of the evidence-based rationale and clinical consensus driving the development of the policy framework and implementation approach for Sickle Cell Crisis QBP.

This document has been prepared for informational purposes only. This document does not mandate health care providers to provide services in accordance with the recommendations included herein. The recommendations included in this document are not intended to take the place of the professional skill and judgment of health care providers.
2.0 Introduction

The Ministry of Health and Long-Term Care (Ministry) established Health System Funding Reform (HSFR) in Ontario in 2012 with a goal to develop and implement a strategic funding system that promotes the delivery of quality health care services across the continuum of care, and is driven by evidence and efficiency. HSFR is based on the key principles of quality, sustainability, access, and integration, and aligns with the four core principles of the Excellent Care for All Act (ECFAA):

- Care is organized around the person to support their health;
- Quality and its continuous improvement is a critical goal across the health system;
- Quality of care is supported by the best evidence and standards of care; and
- Payment, policy, and planning support quality and efficient use of resources.

Since its inception in April 2012, the Ministry has shifted much of Ontario’s health care system funding away from the current global funding allocation (currently representing a large portion of funding) towards a funding model that is founded on payments for health care based on best clinical evidence-informed practices.

Principles of ECFAA have been further reinforced first by Ontario’s Action Plan for Healthcare in January 2012, and recently with Patients First: Action Plan for Healthcare in February 2015, which signals positive transformational activity which will require adaptive responses across sectors and organizational levels at a time of accelerated change. The Ministry’s commitment is to make Ontario the best healthcare system in the world.

The 2012 Action Plan identified HSFR as a lever to advance quality and ensure that the right care gets provided at the right place and at the right time. HSFR focuses on delivering better quality care and maintaining the sustainability of Ontario’s universal public health care system. Ontario is shifting the focus of its health care system away from one that has primarily been health care provider-focused, to one that is patient-centred. The 2015 Action Plan continues to put patients at the heart of the health care system by being more transparent and more accountable to provide health care in a way that maximizes both quality and value.

HSFR comprises 2 key components:

1.0 Organizational-level funding, which will be allocated as base funding using the Health-Based Allocation Model (HBAM); and
2.0 Quality-Based Procedure (QBP) funding, which will be allocated for targeted activities based on a “(price x volume) + quality” approach premised on evidence-based practices and clinical and administrative data.

2.1 ‘Money follows the patient’

Prior to the introduction of HSFR, a significant proportion of hospital funding was allocated through a global funding approach, with specific funding for select provincial programs, wait times services and other targeted activities.
However, a global funding approach may not account for complexity of patients, service levels and costs, and may reduce incentives to adopt clinical best practices that result in improved patient outcomes in a cost-effective manner. These variations in patient care evident in the global funding approach warranted the move towards a system where ‘money follows the patient’.

Under HSFR, provider funding is based on: the types and quantities of patients providers treat, the services they deliver, the quality of care delivered, and patient experience/outcomes. Specifically, QBPs incent to health care providers to become more efficient and effective in their patient management by accepting and adopting clinical best practices that ensure Ontarians get the right care, at the right time and in the right place.

QBPs were initially implemented in the acute care sector, but as implementation evolves, they are being expanded across the continuum of care, including into the community home care sector, in order to address the varying needs of different patient populations.

Internationally, similar models have been implemented since 1983. While Ontario is one of the last leading jurisdictions to move down this path, this positions the province uniquely to learn from international best practices and pitfalls, in order to create a sustainable, efficient and effective funding model that is best suited for the province and the people of Ontario.

### 2.2 What are Quality-Based Procedures?

QBPs are clusters of patients with clinically related diagnoses or treatments that have been identified using an evidence-based framework as providing opportunity for process improvements, clinical re-design, improved patient outcomes, enhanced patient experience, and potential health system cost savings.

Initially developed in the acute (hospital) sector, QBPs were defined as “procedures.” However, as implementation evolved since the introduction of QBPs in 2012, so too has the approach. Currently, the expanded focus is on care provided in other parts of the health care sector with a focus on a more functional/programmatic/population-based approach. As a result, the definition of QBPs is expanding to include Quality-Based Procedures, Programs and Populations.

QBPs have been selected using an evidence-based framework. The framework uses data from various sources such as, but not limited to: the Discharge Abstract Database (DAD) and National Ambulatory Care Reporting System (NACRS) adapted by the ministry for its HBAM repository. The HBAM Inpatient Grouper (HIG) groups inpatients based on the diagnosis or treatment responsible for the majority of their patient stay. Additional data has been used from the Ontario Case Costing Initiative (OCCI), and Ontario Cost Distribution Methodology (OCDM). Evidence published in literature from Canada and international jurisdictions, as well as World Health Organization reports, have also assisted with the definition of patient clusters and the assessment of potential opportunities (e.g. reducing variation, improving patient outcomes, sustainability).

The evidence-based framework assesses patients using five perspectives, as presented in Figure 1. It is this evidence-based framework that has identified QBPs that have the potential to improve quality of care, standardize care delivery across the province and show increased cost efficiency.
2.2.1 Practice Variation

Practice variation is the cornerstone of the QBP evidence-based framework. A demonstrated large practice or outcome variance across providers or regions in clinical areas, where a best practice or standard exists, represents a significant opportunity to improve patient outcomes through focusing on the delivery of standardized, evidence-informed practices. A large number of ‘Beyond Expected Length of Stay’ and a large standard deviation for length of stay and costs were flags to such variation.

2.2.2 Availability of Evidence

A significant amount of research has been conducted and collected, both nationally and internationally, to help develop and guide clinical practice. Working with clinical experts, best practice guidelines and clinical pathways can be developed for QBPs and establish appropriate evidence-informed indicators. These indicators can be used to measure the quality of care and help identify areas for improvement at the provider level, and to monitor and evaluate the impact of QBP implementation.

Clinical leaders play an integral role in this process. Their knowledge of the identified patient populations, and the care currently provided and/or required for these patients, represents an invaluable element in the assessment of much needed clinical delivery and clinical process improvements. Many groups of clinicians have already developed care pathways to create evidence-informed practice. There is now an opportunity for this knowledge to be transferred provincially.

2.2.3 Cost Impact

The provincial footprint from a financial perspective also impacts the selection of the QBP. This may include QBPs that are high volume and low-cost, as well as those that are low-volume and high costs (i.e. specialized procedures that demonstrate opportunity for improvement).
A selected QBP should have, as a guide, no less than 1,000 cases per year in Ontario and represent at least one percent of the provincial direct cost budget. For patient cohorts that fall below these thresholds, the resource requirements to implement a QBP can be restrictive. Even where the patient cohorts represent an opportunity for improvement, it may not be feasible, even if there are some cost efficiencies, to create a QBP.

2.2.4 Impact on Transformation

The *Action Plan for Health Care* was launched in January 2012 and is already making a difference to Ontarians and our health care system:

- We’ve bent the cost curve since 2011/12
- We’re improving the health of Ontarians
- We’re enhancing the experience of Ontarians when they use the health system
- We’re working with our health sector partners to improve the quality of health care

The next phase of Transformation will build on and deepen implementation of the Action Plan. HSFR is a key element of the Health System Transformation Agenda by ensuring sustainability and quality.

Selected QBPs should, where possible, align with the government’s transformational priorities. In addition, the impact on transformation of certain patient populations hitherto not prioritized by the framework can be included as QBPs. This will ensure that QBPs are wide ranging in their scope e.g. paediatric patient populations or patients requiring community care. QBPs with a lesser cost impact but a large impact on the provincial health care system may still be a high priority for creation and implementation.

2.3 How will QBPs encourage the delivery of high quality, evidence-based care and innovation in health care delivery?

The QBP methodology is driven by clinical evidence and best practice recommendations from the Clinical Expert Advisory Groups (Advisory Groups). Advisory Groups are comprised of cross-sectoral, multi-geographic and multi-disciplinary membership, including representation from patients. Members leverage their clinical experience and knowledge to define the patient populations and recommend best practices.

Once defined, these best practice recommendations are used to understand required resource utilization for QBPs and will further assist in the development of evidence-informed prices. The development of evidence-informed pricing for the QBPs is intended to incent health care providers to adopt best practices in their care delivery models, maximize their efficiency and effectiveness, and engage in process improvements and/or clinical re-design to improve patient outcomes.

Best practice development for QBPs is intended to promote standardization of care by reducing inappropriate or unexplained variation and ensuring that patients get the right care, at the right place and at the right time. Best practice standards will encourage health service providers to ensure that appropriate resources are focused on the most clinically and cost-effective approaches.
QBPs create opportunities for health system transformation where evidence-informed prices can be used as a financial lever to incent providers to:

- Adopt best practice standards;
- Re-engineer their clinical processes to improve patient outcomes;
- Improve coding and costing practices; and
- Develop innovative care delivery models to enhance the experience of patients.

An integral part of the enhanced focus on quality patient care is the development of indicators to allow for the evaluation and monitoring of actual practice and support on-going quality improvement.

In addition, the introduction of additional QBPs such as outpatient and community-based QBPs will further help integrate care across sectors and encourage evidence-based care across the continuum.
3.0 Description of Sickle Cell Disease, the Vaso-occlusive Acute Pain Episode and Current State in Ontario

Sickle Cell Disease

Terminology
Sickle cell disease (SCD) causes intermittent and recurrent acute pain episodes as a result of vaso-occlusion. These episodes have been referred to as ‘vaso-occlusive crises’ (VOC). While some have advocated that the term ‘crisis’ be changed, patients still use the terminology. So, for consistency, the term VOC will be used in this handbook. VOCs are the most common reason for emergency department (ED) visits and hospitalizations for patients with SCD. Ensuring that patients receive timely, effective pain relief is one of the most important elements of delivering high quality care to individuals with SCD in the ED.

SCD is one of the most common genetic disorders. It results in the predominant production of an abnormal/mutant hemoglobin called hemoglobin S (Hb S) in red blood cells. Affected patients usually have at least one S gene inherited from one parent and another abnormal gene S, C, D, E or beta-thalassemia from the other parent. Thus, genotypes of the disease include SS, SC, S-beta thalassemia, SD and SE. Usually, parents who pass on these genes are healthy as they produce more normal hemoglobin called hemoglobin A (Hb A) than abnormal hemoglobins (Hb S, Hb C, Hb D, Hb E). Persons who carry one normal hemoglobin gene and the S gene are known as having sickle trait (AS), and are usually healthy and haematologically normal.

SCD occurs in people of African, Arabic and Indian racial backgrounds. Normally red blood cells are spherical shaped discs. In people with SCD some of the red blood cells are shaped like a ‘sickle’, hence the name SCD. The hemoglobin in the red blood cells carries oxygen to all tissues of the body. Sickle shaped red cells, which form when hemoglobin offloads oxygen to the tissues, are more rapidly removed from the circulation by the body (a process called hemolysis) leaving much less hemoglobin circulating (anemia).

The Vaso-occlusive Acute Pain Episode
Normal spherical red cells flow smoothly through the blood vessels while the misshapen (sickled) red cells are sticky and can clump together or stick to the inside of blood vessels causing blockages (vaso-occlusive), in the smaller blood vessels. The blockages result in oxygen deprivation to tissues. The National Health Lung and Blood Institute’s Expert Panel Report on the Management of Sickle Cell Disease describes the vaso-occlusive episode:

“VOCs are typically associated with excruciating pain of sudden onset, some people experience gradual onset of a VOC. Nearly all individuals affected by SCD will experience a VOC during their lifetime. The first VOC may occur as early as 6 months of age, often presenting as dactylitis, but thereafter VOCs
occur with variable frequency. VOCs and their accompanying pain most commonly occur in the extremities, chest, and back. When they occur in other sites, they can be confused with, or can be the prodromal stage of, other acute complications e.g., head (stroke), flank (papillary necrosis), and abdomen (hepatic or splenic sequestration, constipation from opioid toxicity, or another hepatobiliary complication). The etiology of the pain must be determined in order to rule out potential causes of pain. A VOC is the hallmark acute complication for persons with SCD and manifests as acute severe pain. VOC can still occur in the presence of other complications. There are no tests to rule in or to rule out a VOC; there are only tests that potentially rule out other causes of pain. Persons with the genotypes HbSS or HbSβ^0-thalassemia are likely to experience more frequent VOCs. Persons with HbAS (commonly referred to as sickle cell trait) do not experience typical VOCs.”

VOC has been described as comparable to or worse than cancer pain, a comparison perhaps arising from bone pain which is associated with some types of cancer and most VOCs. Over time repeated blockages causing hypoxia to the tissues leads to damage to the area, thus SCD becomes a chronic disease with multiple organs and limbs affected to varying degrees. Recurrent episodes of pain, especially if inadequately treated can present further pain management challenges that may require management by chronic pain experts. Thirty percent of people with SCD have some degree of pain 95% of the time, while fourteen percent have pain less than 5% of the time\textsuperscript{1, ii}.

Very few disease-modifying therapies exist for use in the treatment of SCD. Hydroxyurea, the most easily available, decreases the frequency of VOCs and reduces organ damage with improved lifespan of people with SCD. It is unknown how many people with SCD are offered or take the medication, or if they or their providers fully understand the benefits. Hydroxyurea does not treat acute pain, rather it reduces the frequency and severity of VOCs. Contraindications to its use are very few. Regular laboratory monitoring of blood is required with the use of hydroxyurea.
Figure 2. Is a schematic of the **typical profile of the events that develop during the evolution of a severe SCD VOC in an adult in the absence of overt infection or other complications**. Such events are usually treated in the hospital with an average stay of 5-7 days. Pain becomes most severe by day 3 of the crisis and starts decreasing by day 6 or 7.

*Figure 2. Typical profile of an SCD VOC.*
Current State In Ontario

Prevalence Unknown
The number of people living in Ontario who have SCD is not known. Using CIHI data, the number of unique individuals was identified who had SCD and over three years had an encounter, for any reason, with the acute care system and their SCD status documented in NACRS or DAD in the time period from April 01, 2011 and March 31, 2014.

This group is described as follows:
- 59% are aged 18 and over
- 25% are 0 to 9 years
- 55% are female
- Roughly 78% live in the GTA (LHINs 5 to 9)
- 4 communities with over 100 people with SCD
  - Toronto with 698 people (39% of the total patients)
  - Brampton with 270 people (15% of total patients)
  - Ottawa with 179 people (10% of total patients)
  - Mississauga with 163 people (9% of total patients)

Figure 3. Three year acute care encounter volume in Ontario LHINs
The distribution of the SCD population is mirrored in the newborn screening data, which demonstrates that the number of people with SCD in Ontario is growing. (Appendix 1) What is not available is the volume contributed by people from other countries who emigrate or have some length of stay in Canada (often for post-secondary education). ED clinicians in paediatric centres and adult centres, particularly in the GTA, Ottawa and Hamilton will encounter people with VOCs. The colour coding of the boxes was simply done to identify common volume ranges by LHIN. LHIN abbreviations: ESC- Erie St Clair; SW-Southwest, WW-Waterloo Wellington; HNHB- Hamilton, Niagara, Haldimand, Brant; CW-Central West; MH- Mississauga Halton; TC-Toronto Central; C-Central; CE-Central East; SE-Southeast; Chmp – Champlain; NSM- North Simcoe Muskoka; NE- North East; NW- North West

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Ranked ED Volumes</th>
<th>Ranked Hospital Admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brampton William Osler</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>SickKids</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Toronto General</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Trillium Credit Valley &amp; Mississauga</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Humber River Regional</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Rouge Valley (Toronto)</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>The Ottawa Hospital</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Scarborough Hospital</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>North York</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>CHEO (Ottawa)</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Toronto East General</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>Hamilton Health Sciences</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Mount Sinai (Toronto)</td>
<td>10</td>
<td>16</td>
</tr>
</tbody>
</table>

Further detail regarding ED visits / revisits and admissions / readmissions in high volume hospitals is provided in Appendix 2.
Table 2. Average number and per patient encounters to the ED and hospitalizations for VOC episodes for all Ontarians with SCD, by age category

<table>
<thead>
<tr>
<th>Patient age</th>
<th>Unique individual acute care encounters all reasons (3 year)</th>
<th>ED Visits Yearly average (2011-13/14) (ED visits/encounters)</th>
<th># Hospitalizations Yearly average (2011-13/14) (Hospitalizations/encounters)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 00-09</td>
<td>440</td>
<td>242 (0.55)</td>
<td>200 (0.45)</td>
</tr>
<tr>
<td>2. 10-17</td>
<td>288</td>
<td>191 (0.66)</td>
<td>190 (0.66)</td>
</tr>
<tr>
<td>3. 18-25</td>
<td>302</td>
<td>430 (1.42)</td>
<td>264 (0.87)</td>
</tr>
<tr>
<td>4. 26-39</td>
<td>382</td>
<td>557 (1.46)</td>
<td>268 (0.70)</td>
</tr>
<tr>
<td>5. 40+</td>
<td>356</td>
<td>192 (0.54)</td>
<td>82 (0.23)</td>
</tr>
</tbody>
</table>

ED visits and hospital admissions per person increase with age, with 18-39 years olds having the highest average of ED visits / admissions per person. Above the age of 40 years, increased mortality in those with severe disease and better experience with managing and living with pain may account for reduced ED visits and hospitalizations.

**CTAS Level 2013/14**

The Canadian Emergency Department and Triage Acuity Scale is used by triage nurses to determine in a 2 to 5 minute assessment how quickly a patient needs to be seen by a physician on arrival at the ED. CTAS level is a guide and compliance with adhering to time frames is relative to the CTAS levels of other patients in the ED. The highest CTAS is level 1 and the patient must be seen immediately. Level 2 is for patients who are considered ‘emergent’ and the expected time to physician assessment is less than or equal to 15 minutes; the 15 minute interval also guides the frequency with which a nursing reassessment should occur while awaiting physician assessment if there is a delay. CTAS level 3 is considered ‘urgent’ and requires that the patient is seen in less than or equal to 30 minutes.

“When I was a kid my mom used to call my doctor and we would take a cab to the hospital and they would be waiting for me with a bed and IV and pain medication. My first crisis as an adult after I turned 18 was like a slap in the face… it was brutal. It took four hours until they gave me anything.”
Adults with SCD are more often assigned the lower CTAS level of 3 compared to those less than 18 years old (Table 3) and even when they are assigned a CTAS level of 2, adults typically wait longer to be seen by a physician and have a longer length of stay in the ED (Table 4).

Table 3. Percent of patients assigned CTAS level 3 of all assigned level 2 or 3 by age category

<table>
<thead>
<tr>
<th>Fiscal 2013/14</th>
<th>Percent Urgent of (Urgent + Emergent )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Group</strong></td>
<td>*<em>L3/(L3+L2)<em>100</em></em></td>
</tr>
<tr>
<td>1. 00-09</td>
<td>13</td>
</tr>
<tr>
<td>2. 10-17</td>
<td>9</td>
</tr>
<tr>
<td>3. 18-25</td>
<td>28</td>
</tr>
<tr>
<td>4. 26-39</td>
<td>26</td>
</tr>
<tr>
<td>5. 40+</td>
<td>47</td>
</tr>
</tbody>
</table>

Table 4. Comparing paediatric and adult CTAS levels and ED wait measures in fiscal 2013/14

<table>
<thead>
<tr>
<th>Fiscal 2013/14</th>
<th>*Ages 00-17</th>
<th>Ages 18 and up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CTAS Level 2 –Time (in hours) from triage to initial physician assessment</strong></td>
<td>cases*</td>
<td>405</td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>P90**</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>Time (in hours) from triage to Disposition Decision in ED</strong></td>
<td>cases*</td>
<td>469</td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>4.7</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>4.3</td>
</tr>
<tr>
<td></td>
<td>P90**</td>
<td>7.7</td>
</tr>
<tr>
<td><strong>Time (in hours) from triage to patient leaving the ED</strong></td>
<td>cases*</td>
<td>469</td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>6.8</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>6.2</td>
</tr>
<tr>
<td></td>
<td>P90**</td>
<td>10.7</td>
</tr>
</tbody>
</table>

*Number of cases does not include those with negative wait times, missing date/time information and cases where the patient left without being seen or died.

**P90 is the time by which 90 percent of patients have been seen.

“I am afraid to go to a hospital now. I will not step foot in a hospital.”

“It is a fear of how you will be treated.”

“I am afraid I will be sent home when I don’t feel well.”
Barriers to Care
The first measure in table 4 is the time the triage nurse sees the patient (time 0) to the time the physician interview or assessment (PIA) takes place. The many potential enablers and barriers in this aspect of care reflect the complexity of the ED environment:

Tools and processes as enablers and barriers:
- A medical directive or other “protocol” mechanism will enable the nurse to initiate an intravenous (IV) ASAP
- Once the physician sees the patient and decides to order opioids, other barriers to quick administration can include CPOE, (computerized physician order entry) dispensing cabinets, limits on dose/rate at which the narcotic can be given, needs of other patients
- Establishing medical directives, pre-printed orders and developing a culture of MD-RN communication regarding pain control can reduce the time to analgesic administration.

Clinical challenges
- IV access can be challenging (children, dark skin, lots of IVs in the past so no easy sites)
- SCD patients with a VOC often do not exhibit painful distress; which is what ED staff respond to when providing early analgesia

Nurses’ role
- Once the nurse determines that the patient is likely having a VOC and has asked about symptoms of complications, they may attempt to obtain an order for opioids even prior to physician initial assessment (PIA)

Physicians’ Role
- Some physicians would see a patient experiencing substantial pain and/or note their sickle cell history, begin an assessment with ABCs and then move to pain and find a nurse to administer analgesia.
- Others would complete a full assessment and then leave written orders for analgesia and investigations for the RN to complete.
- Being seen by a junior trainee in a teaching hospital or by an ED physician in a community hospital with little experience managing SCD patients can easily delay treatment further after PIA
- In a community hospital a paediatrician may be the expert consulted for a paediatric patient with VOC.

Patient - Provider Barriers to Care
- Patients experience negative provider attitudes of distrust, inconsistencies in care and attitude, lack of respect, etc.
- Patients arrive at ED in pain and with the trepidation about whether they will receive timely, adequate and compassionate care.
- The net result can be a confrontational environment.
**Patients with High ED / Hospital Utilization**

“Individuals with more than three hospitalizations for a VOC in a year are at an increased risk of early death.” (NHLBI 2014)

A small number of people with the disease are the highest users of ED visits. Provincially, over the three fiscal years from 2011/12 to 2013/14, 2.7 percent of patients accounted for 27.5 percent of visits and 17 percent of patients accounted for 53 percent of visits for VOC. (Table 5) As previously stated the disease becomes chronic over time and with unpredictable episodes of acute pain and chronic disease, there are psychological consequences and economic consequences. A small percentage of patients make up a large percentage of ED visits.

<table>
<thead>
<tr>
<th>ED Visits SCD VOC /Fiscal Year</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>3 year average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unique patients with ED visits</td>
<td>602</td>
<td>596</td>
<td>627</td>
<td>608</td>
</tr>
<tr>
<td>Number of visits</td>
<td>1692</td>
<td>1597</td>
<td>1597</td>
<td>1629</td>
</tr>
<tr>
<td>People &gt; 4 visits</td>
<td>89 (15%)</td>
<td>100 (17%)</td>
<td>93 (15 %)</td>
<td>17%</td>
</tr>
<tr>
<td>Number of visits by people ≥ 4 visits</td>
<td>921 (54%)</td>
<td>871 (55 %)</td>
<td>806 (50 %)</td>
<td>53%</td>
</tr>
<tr>
<td>People with &gt; 10 visits</td>
<td>15 (2%)</td>
<td>17 (3%)</td>
<td>18 (3%)</td>
<td>2.7%</td>
</tr>
<tr>
<td>Number of visits by people ≥ 10 visits</td>
<td>525 (26%)</td>
<td>422 (26%)</td>
<td>399 (25%)</td>
<td>27.5%</td>
</tr>
</tbody>
</table>

A systematic review demonstrated that provider knowledge and attitudes toward people with SCD are among the barriers to care. The waits for care in the various measures in the ED together with the experiences described by the focus group participants suggest that this is generalizable to Ontario.

“My brother was 33 years old when he went to ED with a crisis. They saw a black male and told him he was looking for drugs not having a crisis. Despite that comment they gave him 40 dilaudid and sent him home. I called him and told him I would go over the next day as he lived alone in an apartment. My aunt called in the morning and told me not to come. They found him dead. He had a pill sitting on his tongue. When you are in a crisis you don’t know what’s two hours or four hours...”

“You have to speak very calmly and yet be assertive. You have to make sure you are presentable. Even if it is two in the morning and your child is screaming in pain take a moment to brush your hair and dress well. I’ve coached my son on how to speak to nurses and doctors, not to look down but look them in the eye when you speak to them.”

“It is all about strategy. Figuring out what you will say to them and how to say it to get them to help you. It is like a game of chess.”

“One time a young doctor put her hand on my son’s arm and said to him “You don’t need to manage your mother’s anger’. I was standing right there.”

“It takes a lot to put yourself in the place (mentally) to go to the hospital. It is like a week in a battle zone for minimal release.”
Table 6. SCD Expert Panel Members Contextualize the Current State Data

<table>
<thead>
<tr>
<th>Metric</th>
<th>Adults</th>
<th>Paediatrics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volume of ED visits (as a percentage of all acute care encounters)</td>
<td>ED visits rise in the 18-39 year old group. This is also identified in published literature. Factors thought to include: - Increasing severity of disease - Increasing chronic component of disease - More adults receive care outside of tertiary comprehensive programs - Suboptimal transition from paediatric to adult health services</td>
<td>Paediatric patients presenting to ED are most likely to be assigned CTAS level 2. Paediatric patients are accompanied by parents.</td>
</tr>
<tr>
<td>CTAS Level and physician interview / assessment (PIA)</td>
<td>CTAS level 3 is more often assigned to adults than children. Greater number of competing priorities in adult ED. Patients may present without an advocate present. Patient response to pain variable; ranges from stoic and not communicative to outraged and calling out for pain medications. Higher percentage of children use ED at tertiary centre medical home, whereas adults use community ED closer to home.</td>
<td>Children are more likely to be assigned CTAS level 2 and are seen more quickly.</td>
</tr>
<tr>
<td>Triage to physician interview / assessment (PIA)</td>
<td>The recommended time increment is linked to the CTAS assignment. Even when CTAS level 2 is assigned, adults wait longer for PIA, the time by which 90% (P90) of people are seen is very high for both CTAS level 2 and 3. For this metric, the goal should be that 90 percent of people meet the target. P90 is the first metric to look at to reduce variation, and then to improve overall. Setting goals based on the ideal care is the only way to push improvement.</td>
<td>As with time from triage to PIA, the paediatric metrics are better on this, however there is room for improvement at the P90 measure.</td>
</tr>
<tr>
<td>Triage to disposition</td>
<td>The patient needs intensive treatment and monitoring to have a reasonable chance of getting the pain under control. Once the intensive treatment has been provided the decision can be made if the VOC severity is such that the patient feels they can continue with home management or if they need to be admitted. Setting targets for the disposition is consistent with the recommendations of prompt intensive treatment and a decision based on that care having been delivered. Improvement across this measure is needed at all points; P90 mean and median all high.</td>
<td></td>
</tr>
<tr>
<td>Admitted patients: Discharge disposition to time patient leave ED</td>
<td>If triage to disposition time is good and there is a long wait to leave the ED for patients who are admitted, that is outside of the ED team’s control (mostly), as patients often need to wait for a bed.</td>
<td>The same pattern of variation is seen with paediatric measures - better than adult, worse from 10 to 17 than 0 to 9 years old.</td>
</tr>
<tr>
<td>Metric</td>
<td>Adults</td>
<td>Paediatrics</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Percentage of patients who attend ED that are admitted</td>
<td>Variable across organizations and may not be a valuable metric given the tendency for sicker patients to seek care in tertiary centres and for the high rates of revisits associated with low rates of admission. As knowledge and care processes improve across the system this may be a metric to reconsider. Data currently available does not allow for explanation but highlights variations across institutions.</td>
<td>Higher percentage of pediatric patients are admitted from ED. This may reflect more frequent fever or concern for fever in pediatrics.</td>
</tr>
<tr>
<td>Repeat ED visit or inpatient admission ≤ 14 days</td>
<td>This is a key target of the QBP recommendations. Rapid, aggressive treatment, appropriate discharge disposition and adequate discharge preparation / planning are core guidelines to reduce ED revisits and inpatient readmissions. Adequate discharge preparation and planning will include individualized intensive case management for the small group of patients who are frequent users of acute care.</td>
<td>Much lower in pediatric cases and particularly in tertiary and existing satellite centres. A higher percentage of children are linked to comprehensive care centres as medical homes.</td>
</tr>
<tr>
<td>Length of inpatient stay</td>
<td>LOS is longer in adults, which may reflect the increasing complexity of the disease and pain presentations with aging and cumulative end-organ damage, although other factors are likely also at play. This has also been reported in the literature. When looking at the LOS, look mostly at the median, which is quite consistent across the board, and is similar for pediatric and adult. P90 LOS likely reflects patients with more complex pain or medical issues.</td>
<td></td>
</tr>
<tr>
<td>Repeat ED visit or inpatient admission ≤ 30 days</td>
<td>The data show that for the bulk of patients who return to ED or are readmitted this occurs within the first 14 days, however there is a group that do so &gt; 14 days and &lt; 30 days. This is believed to be a failure of care and coordination between the hospital and community based providers and / or ambulatory clinics. Again, the small number of high users of acute care is thought to make up a significant portion of this group.</td>
<td></td>
</tr>
<tr>
<td>High users of acute care</td>
<td>It has been identified that use of acute services is higher between the ages of 18 and 39 years. However, it is a small proportion of users who use a high proportion of resources. The chronic care models with intensive case management will be essential to curbing the ongoing high use of acute care. This subset of patients requires additional interventions.</td>
<td></td>
</tr>
</tbody>
</table>
Table 7. Issues and Gaps cross the Care Path Identified by Expert Panel Members

<table>
<thead>
<tr>
<th>Presentation/Location/Seeking help</th>
<th>Triage</th>
<th>Initiation</th>
<th>Monitoring</th>
<th>Decision making: Admission vs Discharge and planning</th>
<th>Follow-up</th>
<th>Prevening unplanned ED, unplanned visits, Repeat visit</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Home-based management</td>
<td>Chronic pain and opioid use</td>
<td>Challenge getting IV access</td>
<td>Support person</td>
<td>Does patient feel ready to go home?</td>
<td>Priority on attending routine follow-up</td>
<td>If unplanned visit to ED: (probe) psychosocial circumstances</td>
</tr>
<tr>
<td>Patient education</td>
<td>Subjectivity of pain (Lack of) outward manifestations of pain</td>
<td>Socioeconomic status / area</td>
<td></td>
<td></td>
<td>Cultural issues</td>
<td>Tools for prevention eg. stress reduction</td>
</tr>
<tr>
<td>Awareness of phone advice options</td>
<td>Past experiences with acute care</td>
<td></td>
<td></td>
<td></td>
<td>Language barriers</td>
<td>Geographic location</td>
</tr>
<tr>
<td>Adherence to care plan/medical advice follow-up</td>
<td>Self care plans</td>
<td></td>
<td></td>
<td></td>
<td>Access to meds and education about their use</td>
<td></td>
</tr>
<tr>
<td>Past experiences with acute care</td>
<td>Acceptance of SCD diagnosis</td>
<td></td>
<td></td>
<td></td>
<td>Access to meds and education about their use</td>
<td></td>
</tr>
<tr>
<td>Self care plans</td>
<td>Availability of transportation / Mode of transportation-public, car, EMS</td>
<td></td>
<td></td>
<td></td>
<td>Cultural issues</td>
<td></td>
</tr>
<tr>
<td>Social circumstances</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Prevented travel</td>
<td></td>
</tr>
<tr>
<td><strong>Provider</strong></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Knowledge of SCD</td>
<td>Education of triage</td>
<td>Timing of dose</td>
<td>Involving patients SCD provider(s)</td>
<td>Pain plan for discharge</td>
<td>Preventing un-planned visits</td>
<td>Local physician champions needs ED culture / communication</td>
</tr>
<tr>
<td>Education to patients</td>
<td>Hesitation about narcotic doses</td>
<td>Appropriate dose</td>
<td>Early initiation of discharge planning</td>
<td>Role of SCD clinic vs. family physician</td>
<td>Preventing un-planned visits</td>
<td>Social work support</td>
</tr>
<tr>
<td>Inquire about opioid supply at routine visits</td>
<td>Evaluation of response</td>
<td>Route of administration of opioids</td>
<td>Incentive spirometry &amp; Psychosocial history / monitoring</td>
<td>Communication with clinic</td>
<td>Preventing un-planned visits</td>
<td>Team-based settings</td>
</tr>
<tr>
<td>Access to expert advice</td>
<td>Citizens adequate history of opioid use/dose requirement</td>
<td>Criteria for step down</td>
<td>ED social worker</td>
<td>Prevention</td>
<td></td>
<td>Practice / primary care / community hospitals</td>
</tr>
<tr>
<td>Availability of providers</td>
<td>Judgment based on how patient is behaving</td>
<td>Additional testing</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Consider other causes of pain</td>
<td>Mobilization</td>
<td></td>
<td></td>
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<tr>
<td><strong>System</strong></td>
<td></td>
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<tr>
<td>Community vs academic setting-expertise, accessibility, patient volumes, and patient file directions for ED</td>
<td>Patient passport / SCD cards</td>
<td>Evaluation / benchmarks for appropriate time of first dose</td>
<td>Fast track to admission / short stay</td>
<td></td>
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<tr>
<td>Access to services</td>
<td>EMTs / ODI, clinical records</td>
<td>Patient specific pre-printed unit</td>
<td>Patient specific pre-printed unit</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Communication with clinical providers eg. fix</td>
<td>Standard care pathways / algorithm</td>
<td>Short stay unit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient experience in acute care setting</td>
<td>Triage guidelines (CTAS)</td>
<td>SCD pain order sets</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Phone resources: telescreen, SCD clinic / nurse, on call physician</td>
<td>Inconsistent triage triage-centre dependent (eg patient volume)</td>
<td>Create a calm environment</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Self care plans/see to date, accessible</td>
<td>Lack of access to narcotics at triage</td>
<td>Culture of care</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Access to opioid prescriptions (eg no phone prescriptions)</td>
<td>Delay in triage due to patient volumes</td>
<td>Availability of PCA pumps</td>
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<tr>
<td>Family physician</td>
<td></td>
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<tr>
<td>Walk-in clinic</td>
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<tr>
<td>Day treatment area</td>
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<td></td>
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<tr>
<td>Hours of operation of outpatient services</td>
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</tbody>
</table>
Focus of QBP

VOCs are the most common reason for emergency department (ED) visits and hospitalizations for patients with SCD. Ensuring that patients receive timely, effective pain relief is one of the most important elements of delivering high quality care to individuals with SCD in the ED.

The patient’s journey in this QBP begins with presentation to the ED, with some patients proceeding to admission to hospital, and ends with successful discharge home and a further period of 30 days after leaving hospital (ED or inpatient unit). In other jurisdictions (Florida, Georgia) and in one Ontario pilot project, care that meets best practices has been delivered in environments other than an ED setting. However, the vast majority of initial care in Ontario is delivered in an ED setting. Many hospitals require that any unplanned admission of a patient to hospital occur via the ED. Throughout the best practice recommendations the ED is referred to frequently as that is the current state in Ontario. However it is emphasised that these recommendations are applicable to whatever setting is able to provide the assessment, treatment and monitoring required to treat patients with VOC.

Cohort Selection

The focus of this QBP will be uncomplicated moderate to severe VOC, as VOC without complications of fever/sepsis, acute chest syndrome, splenic sequestration, stroke or other organ involvement is the most common presentation to the ED. Initial assessment and treatment for VOC occur in the ED, where patients may either be discharged home or admitted to hospital inpatient unit for continuing care.

There is no specific ID coding for SCD with uncomplicated VOC. The ICD code D 57.0, sickle cell anaemia with crisis (Includes: Hb-SS disease with crisis) is defined to include VOC, acute chest syndrome and splenic sequestration. Most cases coded D 57.0 will be VOC without acute chest syndrome or splenic sequestration. A further CIHI e-query identifies that the code D 57.0 includes other SCD genotypes (Hb-SC, Hb-SD, Hb-SE, Hb S-β thalassaemia) in addition to Hb SS.

To validate the criteria for cohort selection, a process was designed to request that a group of panel members ‘test’ the criteria in their home institutions. Working with their decision support units in two iterations, these panel members used the developed criteria to pull a cohort at their organizations and then review the cohort to see if it captured the target patient population i.e. SCD with uncomplicated VOC. The process helped to further refine the inclusion criteria for this QBP.
Table 8. Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Data Set</th>
<th>Data field</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
</table>
| NACRS    | Visit reason     | D57.0 Sickle-cell anaemia with crisis  
Includes: Hb-SS disease with crisis | None      |
| DAD      | Diagnosis type   | ‘M’- Most responsible diagnosis  
D57.0 Sickle-cell anaemia with crisis  
Includes: Hb-SS disease with crisis | None      |

**CIHI e-query support the use of this code**

**Query #35230** – When crisis is present, ensure crisis is captured as well as type of sickle cell disorder; e.g. Sickle cell-thalassemia with crisis code D57.0 as the main diagnosis and D57.2 as secondary type 3.

**Query #33903** – Sickle cell crisis with acute chest syndrome (ACS) D57.0 crisis code includes ACS so no additional code needed for the ACS.

**Discussion:**

‘Crisis’ includes patients with VOC, ACS and splenic sequestration. It is not possible with current diagnostic codes available to capture only the SCD patients with uncomplicated VOC. However, the capture of the patients with ACS and splenic sequestration will represent a small proportion of the patients in crisis and there may also be overlap with these ‘crises’ and VOC. The algorithm recommended in the care of patients presenting with VOC will include assessments to rule out or rule in ACS or splenic sequestration.

Children with SCD often present with pain and fever and when pain is present the code 57.0 should be used (even if other codes are used to identify fever), however if only fever is present D57.0 should not be used and thus ‘SCD with fever only’ will not be included in the cohort. This decision is not intended to minimize the emergent need for assessment and management of the person (especially children) with SCD who presents with fever, rather, to capture for the purposes of the QBP, the most homogeneous cohort possible with the coding available.

If a person presents with a VOC and then another complication develops and that complication is most responsible for the length of hospital stay then D 57.0 will not be the most responsible diagnosis for the hospitalization and should not be charted as such and is not intended to be included in the cohort.

Through the iterative testing of the criteria, instances of incorrect coding were uncovered. A communication to health records coders and physicians will be required with the implementation of this QBP.

**Implementation recommendation number 1:**

A communication plan is developed to clarify for coders and physicians the intended use of the sickle cell crisis code D 57.0.
Figure 4. Recommendations for best practices and their implementation will be described and the following schematic provides the high level view and context for the detailed recommendations.

A person with SCD has a history of positive and negative experiences from past encounters with ED doctors and nurses and other clinicians both in acute care and in primary or community care. The past experiences influence their confidence in seeking help as they experience increasing pain with a VOC.

Where can they get help when they cannot tolerate the pain?

ED visit +/- admission to hospital

Rapid assessment and aggressive treatment?

Yes

Discharged when pain manageable for patient

- Patient and SCD provider are in contact within 48 hours of discharge
- Patient leaves hospital with pain manageable and appropriate opioid prescription to get through crisis

- Decrease 14 day revisits
- Decrease readmissions within 14 days

No

- Patient receives assessment and management plan in Centre of Excellence comprehensive clinic
- Patient receives regular management in satellite clinic closer to home

- Increased use of hydroxyurea
- Decreased number of VOCs
- Appropriate monitoring and assessment of end organ damage
- Decreased 30 day revisit to ED
- Decreased readmission to hospital within 30 days

VOC is the most common reason for a person with SCD to go to ED.

Optimal VOC management opens the opportunity to build trust and influence future management choices.

Colour Legend
- Premise
- Pre-hospital factors
- Focus of QIP
- To be avoided
- Aims
4.0 Recommending QBP best practices\(^1\) in the management of SCD VOC

Preamble:

1. Team based care in supportive communities and patient/family education in self-care to prevent and effectively treat VOCs is essential to minimize the use of acute care services.

2. The severity (phenotype) of SCD varies from person to person and some VOCs will not be adequately managed without hospital admission.

Prior to the development of best practices, the Expert Panel members developed a comprehensive overview of the system-, provider- and patient-related issues and gaps across the care pathway of a patient presenting to the ED with a VOC. This mapping process revealed three overarching themes needing addressed to bridge the gaps in the care pathway: education, communication and coordination. (Table 7)

The work of the panel to recommend clinical best practices has been aided by the availability of recent guidelines. The recommendations for best practices for the care of SCD patients with VOC are taken from the following sources:


2. Sickle cell acute painful episode: management of an acute painful sickle cell episode in hospital, National Institute for Health and Care Excellence (NICE) Guideline [CG 143], June 2012

3. Consensus Statement on the Care of Patients with Sickle Cell Disease, Canadian Haemoglobinopathy Association (Unpublished) 2014

4. Expert Panel Members

5. Additional evidence based publications as needed

The recommended best practices are presented as:

- a numbered algorithm for care from triage in the ED to discharge (Figure 5)
- a table of recommendations corresponding to the algorithm numbers (Table 9)
  - a focus on the “Principles of Vaso-occlusive Acute Pain Management” (Figure 6)
  - an expanded section related to pain management principles and approaches

Excellent algorithms that can be used as clinical tools have been created by others. Such algorithms tend to be brief, use few words and often just address one section of the care path. (Appendix 3) The algorithm created by the SCD VOC QBP Expert Panel was designed to provide a broader view of care and the context within which the care is provided.

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\(^1\) Best practice refers to a combination of best available evidence and clinical consensus as recommended by the Clinical Expert Advisory Groups
Figure 5. Algorithm of Care for SCD VOC

Management of a Sickle Cell Related Acute Painful Episode (Vaso-occlusive Crisis ICD: DS7.0)

Self-management techniques have not been effective Telephone consultation or ambulatory care options exhausted. Pertinent information gathered for ED visit

1. Triage time ‘0’ seen by RN

2. Triage nurse classifies patient as CTAS level 2

3a. RN does focused history and physical exam of this episode. Age-appropriate pain scoring tool used.

3a. Is the patient’s pain likely due to an uncomplicated sickle cell pain episode? Be aware of signs of other SCD complications such as stroke, acute chest syndrome, fever, splenic sequestration, etc.

3b. No

3b. Acknowledge severity of pain to patient. Initiate supportive therapy ASAP (oral fluids, warming, stress reduced environment). Developing pain is essential.

3b. Yes

4a. Determine institution and patient-specific directives and orders to facilitate care.

4a. Implement medical directives

5a. RN quickly reviews case with ED doctor to get PPD/S signed to initiate early opioids. MD may wish to assess patient before ordering if so, CTAS 2 timeline should be met.

5a. Initiate opioid treatment

6a. QLS: 30 minute monitoring for pain relief, respirations, O2 sat, sedation and other side effects

7a. Are there complications related to SCD?

7a. No

7a. Adjust treatment plan

7a. Manage complications as appropriate

7a. Consider admission to inpatient unit

8a. Admit to a unit/MRP familiar with SCD; engage social work if required to address trigger or precipitant of pain

9a. Discharge home with supports

9a. Determine patient’s capacity to fill opioid prescription

9a. Review with patient ACTION PLAN if crisis pain should become unmanageable again

9a. Discharge fact sheet to include: Treatment provided at hospital, plus any discharge prescription of opioids for crisis coverage

9a. Current phone number for patient/family; Notation on whether patient receives hydroxyurea

9a. Copy of fact sheet: Give to patient or family; sent to primary care provider, SCD provider if different

9a. Patient advised to contact or visit SCD provider within 48 hours of discharge

9a. SCD provider requested to contact patient with 48 hours of patient discharge
<table>
<thead>
<tr>
<th>Instruction</th>
<th>Recommendations</th>
<th>Source</th>
<th>Grading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assign patient CTAS level 2</td>
<td>Treat as an acute medical emergency.</td>
<td>CCS</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>Patients should be assessed with priority upon arrival, and appropriate management (with opioids) should be started within 30 minutes</td>
<td>NICE</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NHLBI</td>
<td>√</td>
</tr>
<tr>
<td>RN Does a focused physical exam and history relating to this episode. Ask the patient:</td>
<td>Is the pain similar to prior vaso-occlusive crises? Does this feel like your usual sickle pain?</td>
<td>CCS</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>What are the characteristics, location and intensity of the pain? Any associated symptoms?</td>
<td>NICE</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NHLBI</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>Assess pain and use an age-appropriate pain scoring tool for all patients presenting at hospital with a VOC.</td>
<td>CCS</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>Patients with SCD VOC should be cared for in an age-appropriate setting.</td>
<td>NICE</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NHLBI</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>Identify when the pain started and what the patient did to manage the pain? Did they take medications, and if so, record medications, dosage and timing?</td>
<td>CCS</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>Does the patient take opiates for chronic pain management related to SCD?</td>
<td>NICE</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NHLBI</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>Clinically assess all patients presenting at Hospital with a VOC including monitoring of:</td>
<td>CCS</td>
<td>√</td>
</tr>
<tr>
<td></td>
<td>- blood pressure</td>
<td>NICE</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- oxygen saturation on room air by pulse oximetry (if oxygen saturation is 95% or below, offer oxygen therapy to maintain oxygen saturation above 95%)</td>
<td>NHLBI</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- pulse rate</td>
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<tr>
<td></td>
<td>- respiratory rate</td>
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<tr>
<td></td>
<td>- temperature.</td>
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</tr>
</tbody>
</table>

Table 9. Recommendations to correspond with care path algorithm.
<table>
<thead>
<tr>
<th>Instruction</th>
<th>Recommendations</th>
<th>Source</th>
<th>Grading</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Be aware of other SCD complications. Is the pain likely a VOC?</td>
<td>For pregnant women with a VOC, seek advice from the obstetrics team and refer when indicated. Any women 20 weeks gestation or greater should be referred to a high risk obstetrical centre. For patients with abdominal pain, examination of the spleen (through palpation) is absolutely necessary to ensure that the pain is not due to acute splenic sequestration.</td>
<td>QBP Panel consensus</td>
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<td></td>
<td>Parents of children with SCD must be taught how to palpate for enlargement of the spleen.</td>
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<td>Be aware of other possible complications seen with a VOC, at any time from presentation to discharge, including: - acute stroke - aplastic crisis - priapism - myocardial ischemia</td>
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<td>Patients should be evaluated for constipation upon admission, and appropriate preventative measures should be provided.</td>
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<td>3a</td>
<td>Assess for causes of pain unrelated to SCD</td>
<td>Those with atypical pain or symptoms should be evaluated for an alternative etiology for the pain that may not be directly caused by SCD</td>
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<td>3b</td>
<td>Acknowledge pain and implement supportive measures</td>
<td>Acknowledge the pain. Place patient in quietest space possible, away from drafts (and don’t forget to check on them) Provide warm blanket or heat pad Developing trust is essential; engage social work if required</td>
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<tr>
<td>Throughout a VOC, regard the patient (and/or their care-giver) as an expert in their condition, listen to their views and discuss with them:</td>
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<td>QBP Panel consensus</td>
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<td>- planned treatment regimen for the episode</td>
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<td>- treatment received during previous episodes</td>
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<td>- any concerns they may have about the current episode</td>
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<td>- any psychological and/or social support they may need.</td>
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<td>Encourage the patient to use their own coping mechanisms (for example, relaxation techniques) for dealing with acute pain.</td>
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<td>QBP Panel consensus</td>
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<td>Determine institution specific and patient specific directives and orders to facilitate care</td>
<td>General medical directives should be in place in the ED to facilitate rapid assessment and preparation for treatment. Additional medical directives specific to VOC events are recommended. Order sets developed collaboratively by clinician experts in SCD, pain management and emergency are recommended to guide best practices. Triage files specific to the patient are recommended for people who attend ED frequently, or in situations where the volume of SCD patients is very low and care is dependent upon the shared knowledge of the SCD provider with the treating physicians. (example: hospitals that have less than 20 ED visits per year for SCD VOC)</td>
<td>QBP Panel consensus</td>
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<tr>
<td>Patients should be started on hydration</td>
<td>Patients should be started on hydration (preferably oral, if tolerated) to ensure that they are not dehydrated. In euvolemic adults and children with SCD</td>
<td>QBP Panel consensus</td>
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<td>and a VOC who are unable to drink fluids, provide intravenous hydration at no more than maintenance rate to avoid overhydration.</td>
<td>CCS</td>
<td>NICE</td>
<td>NIHLB</td>
</tr>
<tr>
<td>Order sets and medical directives, patient specific care plans and triage files</td>
<td>Once appropriate pain management has been initiated, and depending upon the presenting symptoms, laboratory and/or diagnostic imaging investigations may be considered. Septic work up if fever or symptoms of infection present. No role for chest x-rays or other imaging studies for an uncomplicated VOC. Risk of frequent radiation exposure should be kept in mind. Routine measurement of oxygen saturation by pulse oximetry (SpO2). If further assessment of hypoxemia is indicated (e.g. SpO2 &lt;95%), ABG or capillary blood gases may be performed. Patients should be treated with the most effective therapy with the least potential side effects in each individual patient. The response to treatment should be recorded in each patient’s chart so it can be reviewed upon future admissions.</td>
<td>QBP Panel consensus</td>
<td>✓</td>
</tr>
<tr>
<td>Rapidly initiate treatment with opioids in a VOC with severe pain.</td>
<td>QBP Panel consensus</td>
<td>✓ ✓ ✓</td>
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<td>The initial treatment should be chosen to achieve appropriate pain control as soon as possible. Patients who have moderate to severe pain or those who were treated with oral morphine without successful pain relief at home should be given intravenous morphine after evaluation. Long-acting oral opiates should be considered for basal pain control once an appropriate dose can be approximated if patients do not have a continuous IV opioid</td>
<td>QBP Panel consensus</td>
<td>✓</td>
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<td>For breakthrough pain, short-acting medications are preferable over long-acting alternatives. An equi-analgesia chart should be available and used to determine appropriate dosing. Long-acting opioids are generally used for pain that is chronic in nature.</td>
<td>CCS</td>
<td>√ QBP Panel consensus</td>
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<td>Patients with adverse reactions to any analgesics should be provided with a written document indicating the type of adverse reaction, so that, in the future, an alternative treatment can be provided as soon as required.</td>
<td>CCS</td>
<td>√ QBP Panel consensus</td>
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<td>Hydroxyurea should not be discontinued during a vaso occlusive event unless laboratory results (as per hydroxyurea protocol –) or other indications are present, such as active infection, neutrophils &lt;1.0 x 10⁹/L, reticulocytes &lt; 80 x 10⁹/L, platelets &lt; 80 x 10⁹/L</td>
<td>CCS</td>
<td>QBP Panel consensus</td>
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<td></td>
<td>The response to treatment should be regularly evaluated, and analgesia dose should be reassessed on a regular schedule to titrate the medication dosing to optimize pain control. Step-down therapy should not be attempted until the pain is well controlled.</td>
<td>CCS</td>
<td>√ QBP Panel consensus</td>
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<td></td>
<td>The respiratory status of all patients on infusion of analgesics should be monitored. All patients, especially those with chest or back pain and those with supplemental oxygen requirement, should be started on age-appropriate incentive spirometer.</td>
<td>CCS</td>
<td>QBP Panel consensus</td>
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<tr>
<td>7a</td>
<td>Reassess for complications, seek support form and SCD specialist, adjust</td>
<td>CCS</td>
<td>QBP Panel consensus</td>
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<td></td>
<td>If the patient does not respond to standard treatment for a VOC, reassess them for the possibility of an alternative diagnosis.</td>
<td>CCS</td>
<td>√ QBP Panel consensus</td>
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<td>For those patients whose pain is not controlled upon infusion of analgesics, a team that is expert in the management of pain (e.g., anesthesia, acute pain service) should be consulted, and PCA or nurse controlled analgesia (NCA) should be started. Once sufficient pain control is achieved, de-escalation of therapy can be attempted.</td>
<td>CCS</td>
<td>(Moderate Recommendation, Low-Quality Evidence) NHLBI plus QBP Panel consensus</td>
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<tr>
<td></td>
<td>Optimal treatment of VOC requires a combination of pharmacological, psychological and physical therapeutic approaches and may require expertise from a SCD pain specialist.</td>
<td>NICE</td>
<td>QBP Panel consensus</td>
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</table>
|             | Be aware of other possible complications seen with a VOC, at any time from presentation to discharge, including:  
  - acute stroke  
  - aplastic crisis  
  - infections  
  - osteomyelitis  
  - splenic sequestration (see number 3).                                                                                                                                                                                                                       | NHLHB          | QBP Panel consensus                                                                           |
| 7           | Within 4 to 6 hours of arrival discuss discharge disposition with patient.  
  Patients are best able to identify when they are ready to go home and the pain is such that they can manage it.                                                                                                                                                                                      | QBP Panel       | consensus                                                                                     |
| 8           | Maintain best practices on general medical inpatient unit  
  - Admit to inpatient unit most familiar with SCD VOC management  
  - SCD provider advised of admission  
  - Inpatient most responsible physician to contact SCD expert (if patient’s SCD provider not available to discuss ED care)  
  Incentive spirometry recommended during inpatient stay to prevent evolution of acute chest syndrome.                                                                                                                                                           | QBP Panel       | consensus                                                                                     |
### Instruction

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<td>Pain medication to be ordered at regular intervals <em>(not only as required)</em> with appropriate drug/dosing.</td>
<td>CCS</td>
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<tr>
<td>Provide non-pharmacological measures such as massage, heat pad, and distraction. Involve a pediatric life specialist for children. Encourage activities as tolerated.</td>
<td>NICE</td>
<td>QBP Panel consensus</td>
</tr>
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#### 9

**Discharge summary to include:**
- Treatment provided at hospital, plus any discharge prescription of opiates for VOC coverage
- Current phone number for patient / family
- Notation on whether patient receives hydroxyurea

**Copy of summary:**
- Given to patient or family
- Sent to primary care provider, SCD provider if different
- Determine patient’s capacity to fill opioid prescription

**Review with patient what to do if pain should become unmanageable again**
- Patient advised to contact or visit SCD provider within 48 hours of discharge; SCD provider requested to contact patient within 48 hours of patient discharge

### Not recommended

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<td>Do not offer pethidine (demerol) for treating pain in a VOC</td>
<td>QBP Panel consensus</td>
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<tr>
<td>Inhaled nitric oxide, corticosteroids, or magnesium sulfate have not been shown to be effective during VOC.</td>
<td>QBP Panel consensus</td>
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<td>Transfusion of episodic packed red blood cells for the management of uncomplicated VOC not recommended; however, it can be given for the management of symptomatic anemia.</td>
<td></td>
<td>CCS NICE NIHBL</td>
</tr>
<tr>
<td>Red cell transfusions do not have a beneficial role in the management of VOC in SCD. The benefit of chronic transfusion therapy for the management of chronic sickle cell pain is controversial</td>
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<td>Transfuse only with the approval of haematologist</td>
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<tr>
<td>Antibiotic therapy has no role in the management of a simple VOC, and when there is no fever or any other findings suggestive of infection. Physicians should be aware that patients with SCD may have a high baseline WBC count, and leukocytosis in isolation may not be due to infection. Nucleated red blood cells can also be erroneously counted as WBCs on automated CBCs – manual WBC count and WBC differential are often required.</td>
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<tr>
<td>No routine intravenous fluid bolus in patients with VOC unless clinically indicated.</td>
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Expanding on Algorithm point 5a: Initiate Opioids

Figure 6. Principles of Vaso-occlusive Crisis Management

**Enablers**

**Organization and clinician**
- Medical directives
- Order sets
- Metrics
- RN and MD SCD education

**Patient-centred**
- Triage files
- Pain Scoring Tools
- Options for routes of opioid administration including intravenous, subcutaneous injection, oral, including sublingual or intranasal if IV access challenging
- Bolus titration of opioids until pain tolerable with monitoring and frequent assessment for side effects; manage side effects

**Treatment Aim**

Manage pain so patient can go home

**Principles**

3 P’s of pain management:
1. Physical strategies
2. Psychological strategies
3. Pharmacological strategies

Rapid:
- Assessment of recent analgesia use (opioid and non-opioid)
- Evaluation and initiation of opioid analgesic within 30 minutes of triage
- Titrate dose to effect

Patient-centred prescribing of opioids
Multimodal analgesia (opioids, NSAIDs, acetaminophen)

- Titrate parenteral opioids down as vaso-occlusive pain is managed
- Transition to oral
- Pain must be well controlled on oral analgesics for more than one hour before decision to discharge from ED
- Sometimes admission will be required

---

Home with education and plan (see algorithm)

Decision made to admit
Transfer care to inpatient service ASAP
Pain consult for patient controlled analgesia if modality is required

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Pain Management Best Practices

Analgesic history:
✓ The patient should be well prepared with education in self-management and should have a care plan for managing early stage VOC.
✓ The patient should bring their medications and record of self-administration with them to ED.

3 P's of Pain Management:
✓ Physical pain techniques (e.g., massage, warm blankets / heat packs to the affected area, stretcher adjusted to position of comfort, quiet surroundings, etc.).
✓ Psychological techniques (e.g., emotional support, behavior management, distraction with music, video games, TV, etc); minimization of psychological stress related to provider interactions/environment (e.g., behaviours that are not empathetic add to psychological stress which makes it more difficult to manage pain).
✓ Pharmacological treatment and hydration are the cornerstones of the management of VOC.

Principles of Acute Pain Management
✓ Rapid assessment to establish that the patient is having a VOC.
✓ Aggressive treatment with opioids at the right dose, the latter to be determined by: (a) whether the patient has taken opioids at home to manage this episode, (b) whether the patient has chronic pain managed by opioids, and (c) the dosages that the patient has had in the ED in the past to manage their pain.
✓ Titrate opioids until effective pain relief has been achieved, as measured by a validated pain assessment tool. Intravenous bolus delivery is optimal to initiate treatment and achieve rapid pain relief, with repeat doses every 15-20 minutes (while assessing for pain relief and sedation). Can initiate opioid therapy using any other route (eg. Oral, SC, intranasal) if immediate IV access not available
✓ Patient-centred pain management is reflected by rapid, aggressive use of the ‘opioid of choice’ for the patient. Base analgesia selection on pain assessment, associated symptoms, outpatient analgesic use, patient knowledge of effective agents and doses, and past experience with side effects. There is NO standard drug, dose, route or frequency of administration that is applicable to/effective for ALL patients.
✓ Multimodal pain management. “This approach simultaneously administers two or more analgesic agents with different mechanisms of action. Combination therapy using drugs with distinct mechanisms of action may add analgesia or have a synergistic effect and allow for better analgesia with the use of lower doses of a given medication than if the drug were used alone”(Pasero 2011)
Analgesics and adjuvants

The effectiveness of analgesics varies from person to person. Treatment should include a standard opioid approach with options available for patients who have had reactions to one opioid or have had better results from one opioid over another. Non-steroidal anti-inflammatory medications (NSAIDs) such as ibuprofen at home and ketorolac (parenterally) in hospital are recommended as adjuvant medications in the absence of contraindications. Acetaminophen can be added as well if there are no contraindications. Over time people with SCD develop chronic disease related to tissue and organ damage; some medications will not be recommended when specific organ damage is present. Manage side effects, most commonly nausea, pruritus and sedation. Be aware of further sedative effect from medication used to manage side effects e.g. dimenhydrinate, diphenhydramine.

Dose

Titrated intravenous bolusing of opioids to effect is recommended. Delivering frequent (every 15-20 minutes) boluses in the initial phases of treatment in acute care (usually the ED) provides a rapid systemic effect. The patient should be monitored as per organization policy following the administration of opioids. The goal for patient care is that they receive prompt attention, safe and effective pain management. Once pain control has been achieved, opioids can then be given in regularly scheduled doses aimed to provide longer-term analgesia (e.g. oral long-acting formulations, transdermal patches or continuous IV infusions) with appropriate orders for breakthrough dosing. The evidence supports this aggressive management of acute pain\(^ \text{v} \). Attention must be given to equivalence when converting route or drug. Emergency department length of stay among those with SCD VOC has been shown to be reduced with rapid, aggressive pain management with opioids. Dose ranges should be standardized for the opiate naïve. People with SCD can develop chronic pain and their requirements might be much higher than with opioid naïve patients.

Route

Options for route of administration should be identified for analgesics. Intravenous delivery of opioids is optimal for the initial management of acute pain in the ED; however at times difficulties starting an intravenous can occur. This should not delay opioid administration. Alternate delivery can provide bridge dosing while a clinician with the expertise to place the intravenous catheter is located and arrives at the bedside. Intranasal, subcutaneous and oral, including sublingual routes should all be considered.

Patients may present with central venous access catheters in place; ED clinicians must have access to clinicians with expertise in working with these lines. While waiting for support, alternate routes of opioid administration should be used to provide bridge dosing.

Patient controlled analgesia (PCA) is recommended for patients who are competent to manage PCA and are in environments where clinicians are competent and able to initiate PCA. Oral PCA has been used in the appropriate environments with patients who are carefully selected for their ability to take their analgesic as required\(^ \text{vi} \) and to record their utilization. Both of these patient controlled options require careful patient selection, clinician education, resources and processes in place to ensure safety.
Organizations that have long waits from discharge disposition to transfer to an inpatient bed should ensure transfer of care to an inpatient physician/service as quickly as possible. In the interim, the emergency physician should write standing orders for analgesia during waiting time of transfer of care to in-patient consultant to avoid lengthy times of no analgesia. A process should be developed to support patients with the delivery of pain medication and monitoring in the least noisy and stressful environment possible, reducing negative environmental impact on the patient’s ability to rest and sleep while awaiting consultation and transfer to an in-patient bed.

Many clinical pathway algorithms, order sets and medical directives (both adult and paediatric) have been developed for the management of SCD patients with a VOC. Organizations are encouraged to liaise with their nearest Centre of Excellence or Satellite Centre to obtain examples.

**Patient Self-Management**

People with SCD, and their families, need education on how to recognize the onset of a VOC as well as the physical, psychological and pharmacological self-management measures to take. Understanding one’s own pattern and experiences in order to manage them is a critical component of living with SCD. Patients are encouraged to keep a pain diary and have an action plan should the pain become unmanageable at home. Patients should be educated about common triggers for VOC, and work with members of the healthcare team to develop prevention strategies.

All patients with SCD should have a home care/action plan developed in conjunction with their SCD provider. The plan should include:

- A reminder of warning symptoms that should prompt urgent ED/SCD team care (fever, chest pain, shortness of breath, signs of stroke, splenic enlargement, etc.)
- Steps to manage pain, analgesia type, dose and frequency, hydration, warm blankets or warming pads, quiet and a stress free environment
- Support of family member or advocate
- Contact information for a SCD provider for advice and consultation
- Plan on how to travel to their regular hospital
- Details of the VOC, including what treatments have been implemented (i.e. the name, dose and timing of oral pain medications at home), should be documented and brought to hospital if it becomes necessary.

Providers should understand that VOC can and will occur despite informed and conscientious self-management.
5.0 Implementation of best practices

The relatively small population of Ontarians who have SCD live for the most part in the Greater Toronto Area (GTA), Ottawa and Hamilton. The rates of ED visits, repeat ED visits, hospital admissions with return to ED or readmissions after discharge are high. Literature demonstrates that prompt and aggressive treatment decreases the length of stay in the ED. Fourteen day ED revisits or readmissions to hospital are associated with care received during ED visit or admission while 30 day revisits or readmits are associated with care received in the community.

Achieving best practices for the management of acute pain of a VOC, for all patients, no matter where they live will require a system level strategy with multiple approaches to strengthen the performance of all actors within the system. These approaches must tap into the existing health resource capacity and address the system-, provider- and patient-related gaps at all points of care delivery with measurable indicators by which performance will be monitored.

Literature on process and models that impact frequency of ED visits and hospital admissions

Paediatric 30 day readmission to hospital related to SCD VOC is related most strongly to lack of outpatient follow up with haematologist, as well as a diagnosis of asthma or having been on room air for less than or equal to 24 hours after having required supplemental oxygen to maintain oxygen statusvi.

Studiesviii,ix also show that readmission rates for patients with SCD further rise with age, peaking in the 18-30 year age range with rates of 40%. This very age group, when transition to adult care usually occurs in North America, is associated with increased mortality within this patient populationx.

In adults, a before and after evaluation of the provision of care within a clinic employing a chronic care model2 showed a significant increase in the use of hydroxyurea, a trend toward decreased hospital admissions per patient per year and a decrease in 30 day readmissions. This evaluated intervention took place in a tertiary setting with comprehensive educational efforts across ED and inpatient units by all team members. The care team included a medical internist expert in the care of people with SCD, a nurse practitioner, a social worker and patients had 24/7 telephone access to a knowledgeable care provider for coaching through the early stages of a VOCxi.

The evidence is endorsed by the QBP experts on the need to see a SCD provider soon after hospital encounter for VOC and the use of the chronic/comprehensive care model is required as chronicity sets in.

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2 The chronic care model, as described by Wagner, has 6 components including: (1) community resources and policies, (2) health care organization, (3) self-management support, (4) delivery system design, (5) decision support, and (6) clinical information systems.
Evidence continues to indicate that quality improvements that further reduce ED revisits, frequency of VOC, admissions and readmissions include the implementation of individualized, multimodal treatment plans that cross ED, inpatient and outpatient care settings\textsuperscript{ix}. Even for the higher users in the 18 to 30 year old age group, which a large population based study across eight American states identified as having a readmission rate of 41.1 percent within 30 days and 28.4 percent within 14 days\textsuperscript{x}, reductions in acute care utilization can be achieved.

**System Level Tactics to Enable Best Practices**

**Implementation recommendation number 2**

Formalize ‘Centres of Excellence’ with dedicated funding, at the following paediatric and adult Academic Health Science Centres:

- a. McMaster / Hamilton Health Sciences Centre
- b. SickKids
- c. University Health Network / Toronto General
- d. The Ottawa Hospital
- e. Children’s Hospital of Eastern Ontario

**Implementation recommendation number 3**

Develop adult and paediatric satellite centres at high volume hospitals within the GTA, modelled on the existing paediatric satellite Centres at William Osler and Scarborough Hospitals. The newborn screening data indicate that these volumes will continue to grow.

**Implementation recommendation number 4**

Formalize a hub and spoke relationship between the Centres of Excellence and Satellite Centres. A schematic (Figure 3) has been developed to illustrate of GTA hospitals, existing Centres of Excellence, existing and recommended Satellites and other high volume sites (Humber River and Mississauga) where both paediatric and adult satellite centres should be developed.
Figure 6. Hub and Spoke of Centres of Excellence and Satellite Centre

The numbers are the yearly average of ED visits at hospitals in LHINs 5 to 9 (FY 2011-2013)

The numbers are the yearly average of ED visits at hospitals in LHINs 1-4 and LHINs 10 and 11 (FY 2011-2013)
A hub and spoke model provides the structure to support knowledge translation and care delivery closer to home. In order for the hub and spoke model to successfully create the conditions to drive and sustain best practices the roles (structures and processes) that each organization fulfills must be clearly articulated.

Centres of Excellence

- All people with SCD linked to a C of E.
- Participates in and facilitates basic and clinical research
- Participates in research and evaluation to improve quality of care
- Liaises with all providers involved in the care of people with SCD within the region served
- Develops and delivers education aimed at providers who care for people with SCD, with particular emphasis on Satellite teams as partners
- Provides on call SCD expertise to support physicians caring for people with SCD within the C of E or at another acute care facility within the region; promotes service to low to moderate volume hospitals
- Develops and shares educational materials for patients and families

Roles

- Haematologist
- Clinician focused on pain management (could be Nurse Practitioner supported by pain team)
- Social worker
- Neuropsychologist
- Nurse Practitioner / Nurses

Resources

- Emergency Departments
- Pain services
- Critical care services
- Located in or has access to diagnostic capabilities to monitor organ damage related to SCD

Centre of Excellence Approach

- Models organization wide standardization in care
- Developed order sets in collaboration with ED, haematology, inpatient service, pain services (including pharmacy)
- Identifies validated age appropriate pain measurement tools and ensures they are integrated into practice in all care settings
- Formalizes transition from paediatrics to adult health services preparation
- Individualized case management approach for people who are high users of acute services; partner with team-based community providers to enhance community supports (CHCs, CCACs, HealthLinks)
- Clinical expertise 24/7 provided in-house and available to community specialists
- Automated red cell exchange
- MRI
- Other specialists with understanding of SCD
Regional Paediatric and Adult Centres of Excellence Relationships with Each Other:

- Collaborate on regional quality initiatives and outreach activities
- Collaborate to develop regional strategies to resolve issues affecting both adult and paediatric populations (e.g. central access, uptake of hydroxyurea treatment)
- Includes satellite teams in development and delivery of clinician CMEs (rounds, conference sessions, seminars)

Implementation recommendation number 5
Implement a formal transition process using evidence-based readiness and (when available) risk assessment tools\textsuperscript{vii}

- Collectively the C of E’s and Satellites in Ontario formalize a Network Relationship/Community of Practice to increase the quality of care for people with SCD across Ontario; specifically develop communication materials to be provided to patients at any point of contact in the health care system regarding:
  - hydroxyurea therapy
  - self-care measures to be taken at the earliest awareness of onset of a VOC.

Satellite Centres

- Serve high volume communities
- Link to C of E for shared care, consultation, education
- Designated Satellites to offer both paediatric and adult programs
- Satellites formally appointed program leads (both clinical and administrative)
- SCD teams developed and lead practice within the organization
- Teams to include ED MDs and RNs, paediatricians, haematologists, anaesthetists/pain clinician, social worker, case manager for intensive support where needed (some team members consult as needed)
- Participate in CME/all clinician education locally and with C of E (consider OTN access)
- Maintain patient referral and physician consult relationship with C of E and encourage all people with SCD to be seen in a C of E at least annually.
- Cross-setting (ED, inpatient) protocols, medical directives, order sets, access to SCD expertise
- Monitor metrics and indicators; QI and process improvement to meet indicator targets

System level approaches to link the many organizations that provide care is essential to ensure sustainable quality care for VOC and SCD more broadly. Relationship building between providers, programs and organizations is the first step and must be formalized in a network of SCD provider-leaders. Shared educational resources and collaboration to develop educational resources will provide some economy of scale and allow Satellite Centres to benefit from the capacities of Centres of Excellence. Most community hospitals in the GTA have ED visit and admission volumes to suggest that the organization should develop a Satellite Centre or at the very least formalize a programmatic approach and leadership to implement best practices.
e-Health
System level electronic solutions for and communication of patient disease state and medication history across organizations have been tried but have not made a significant and sustainable difference in quality of care.

The ease and speed of use and resulting acceptance by clinicians limit the degree to which current electronic solutions are significant levers in quality improvement immediate to the point of care. They do provide data capture monitoring of quality and improvement. In the future the regional Electronic Health Records may be a useful tool.

Organization level
Implementation recommendation number 6
Assign leadership and resources to the Centre of Excellence, Satellite Centre or Sickle Cell Program as appropriate to the role your organization should take within the hub and spoke system of sickle cell care.

Implementation recommendation number 7
Determine the quality improvement approach that the organization will take to enable best practices to be delivered.

Inter-disciplinary collaboration among the ED clinicians, haematologists (adult and paediatric) and pain specialists is essential to developing solutions that incorporate the expertise of each discipline in the clinical solutions (evidence based and organizationally practical).

Implementation recommendation number 8
Approaches to deliver best practice must coordinate care across ED and the inpatient unit.

The clinical processes and clinical flow pathways that must be put in place to achieve the rapid and effective treatment of VOC must be identified within each organization. The barriers to care (knowledge, physical space, policy, interdisciplinary silos) must be identified and solutions developed.

Enabling VOC Management Best Practices

Implementation recommendation number 9
Expedite care with medical directives that enable nurses to fast-track assessment and prepare for pain management.

Implementation recommendation number 10
Implement best practices beginning with pre-printed order sets that guide clinicians to order and carry out evidence-based care. Hospitals that care for both adults and children with SCD should have separate order sets for adult and paediatric care. Interdisciplinary development of order sets is highly recommended.

Implementation recommendation number 11

Pain assessments should always be made with age appropriate validated pain tools. (Appendix4)

Patient-centred care will require that when patients need specific opioids that are not the opioids most commonly used, these medications are available and administered in the right dose and through the best available route. All EDs should have an ‘Opioid Equianalgesic Chart’ available, supported and endorsed by the organization’s pharmacy and pain team\textsuperscript{xvii}.

Implementation recommendation number 12

Patient-specific order sets and triage files are recommended, especially for the frequent users of ED care, people with underlying chronic pain or any other condition that makes their VOC pain treatment vary from the norm. Also consider using patient-specific order sets in hospitals with very low volume of SCD patients.

Implementation recommendation number 13

Set targets and monitor quality improvement metrics internally. In addition to provincially available quality indicators developed using data submitted to Canadian Institute for Health Information, organizations wanting to monitor and improve the quality of acute pain management for patients experiencing a SCD VOC are advised to focus on the three organization level metrics:

a. The length of time from triage to administration of the first dose of opioids.

b. The time to an initial reduction of pain score that is meaningful to the patient, e.g. 2 points on a 0 to 10 scale

c. The length of time from triage to a pain score reduction that is sufficient for the patient to be able to manage the pain at home.

d. Patient experience data, specifically if available, the three questions in the Picker instrument related to pain management.

For all aspects of care from assessment to treatment and monitoring, the importance of medical directives to expedite care and preprinted order sets to guide best practices have been strongly recommended. These are not simple ‘make them and forget them’ solutions. The medical directive developed by CHEO for the ED nurses to expedite care, “Investigation/initiation of intravenous access on immune-compromised patients with fever by nurses in the Emergency Department” documents the following quality management process within the directive:

- All RNs will be educated by the clinical educator or delegate about the purpose, indications and contraindications of initiating the investigations and interventions outlined in this medical directive.
- All incident reports related to initiating investigations under this medical directive will be reviewed by the Clinical Manager, Medical Director and physician involved with care of the patient.
- Audits will be conducted periodically to ensure that the medical directive is being used appropriately.
Likewise, preprinted order sets need to be developed and owned by the end users and medical and clinical supervisors, and be part of a multi-modal intervention to improve care. A publication (Frei-Jones, 2009) on a multi modal intervention for patients admitted with SCD VOC showed reduced rates of readmission within 30 days. The interventions included a nurse who educated family and caregivers, preprinted orders and a third intervention, the addition of regular physician education on SCD and how to use the orders. When the regular physician education was discontinued the 30-day readmission rates increased.

Quality measures such as use of PCA analgesia, greater change in pain scores by the time of discharge and the booking and keeping of a follow-up haematology appointment were improved with the use of the preprinted orders xviii.

Patients who attend ED frequently, most often have chronic disease related to damage from SCD and/or chronic pain treated with opioids. They attend ED for VOC and are best served during the VOC with individualized patient-specific orders or triage files. These documents may include a description of the patient’s disease state, identify the medications and dosages that have worked for that patient in the past and recommend that their haematologist or the acute pain team and social work or a case manager be contacted immediately upon the patient’s presentation at ED. Organizations may need to develop referral relationships for chronic pain management to chronic pain management programs.

Research in the physiology of chronic pain of musculoskeletal origin has demonstrated that ‘normal’ physiologic responses to pain such as peaks in blood pressure and heart rate may not occur and endogenous opioids may not have the same pain relieving effects. Adults with SCD often note that the nurses and doctors do not believe they have the level of pain they are reporting, particularly because they may not be showing physical signs of painful distress. Believe the patient’s identification of pain severity.

**Implementation recommendation number 14**

Clinicians must be educated that in this population the best assessment of severity of pain is the patient’s.

Intensive disease and chronic pain management and social work interventions are required to mitigate the need for ED visits in the high user group. For many patients with SCD, repeated poorly treated VOC results in deteriorating quality and quantity of life.

Medical directive and pre-printed orders should be in place to expedite care and support best practices across the organization and personalized plans are recommended for the high users of acute services.

One pre-hospital enabler is recommended to expedite rapid ED triage and treatment: the paramedics call the hospital where the patient will be taken to notify the ED that a SCD patient with acute pain is en route.

In summary, the clinical protocols, medical directives, preprinted orders, patient-specific orders or triage files are essential enablers for best practice. But, to make the desired impact, these enablers must be combined with clinician education and practice monitoring and evaluation through focused audits. These clinical process improvements should be designed to work within the existing work-flow and process to ensure consistent and sustainable quality care delivery. Process or work-flow redesign, where required, must include all involved, from registration clerk, to ED nurses and doctors and any others in or beyond the ED involved in the care of the patient with a VOC.
Several approaches including Day Units and other models based on inter-professional collaboration between ED staff, haematologists and pain service staff have been developed and implemented in other jurisdictions (Example- Appendix 5). In Ontario, the University Health Network (UHN) are piloting and evaluating a program in which the patient calls the SCD Program Nurse Practitioner (NP) when they develop a VOC. The NP uses a protocol to assess them to ensure the VOC is not associated with related complications and if not, directs them to the Acute Care Ambulatory Unit (ACAU) who relays it to the nurses to expect the patient. The UHN leadership provided education on the assessment and management for people having a VOC to the staff of the ACAU.

The assessment service is available from Monday to Thursdays from 8:00 – 16:00, but upon arrival at the ACAU the patient can remain overnight if needed. While early metrics on patient satisfaction, treatment outcomes and length of stay are positive, a considerable number of patients prefer to attend an ED in their own community

A simple guide that aligns with the recommendations of this report and follows the principles of quality improvement has been recently released by The National Institute of Child’s Health Quality, “Sickle Cell Pain in the Emergency Department: A Guide to Improving Care”

**Provider level**

**Implementation recommendation number 15**

It should be recognized that patients with SCD presenting with acute pain from VOC should be assigned and treated as CTAS level 2 and be given emergent care for their pain. This is a fundamental right of the patient.

**Implementation recommendation number 16**

Extensive education on best practices for nurses and doctors who work in hospitals with high volumes of ED visits of people in acute pain from a SCD VOC will be required.

**Educate To Overcome Attitudinal Barriers to Care**

Education for providers must also address attitudes that are barriers to care. Information must be shared to help providers understand the strength of evidence in support of the unacceptably long wait times for analgesia by people with SCD VOC. Timeliness of initiation of analgesic therapy should be paramount in recommendations to implement best practices within hospital settings.

Clinicians and administrators recognize that racism towards patients with SCD does exist and must be addressed in education for clinicians. Racial bias, whether the clinician is aware of it or not, negatively impacts patient-provider communications.
The potential for a reinforcement cycle between the illness, racism and providers is well depicted in the following graphic:

```
"Speaking of black male.....When I had my first major crisis as an adult I fell into a major depression. I've been to the ED and been told I wasn't having a crisis. They didn't believe me until I threw up on myself. It turns out I had a blood clot and the vein was twice the normal size. One time I pushed the call bell 50 times in two hours before they came. One time I was yelling for help and they called security and security threatened to call the cops because I was irate about a lack of care"
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While clinicians cannot control all of the factors that negatively affect people with SCD, they can recognize and avoid contributing to the ‘reinforcement cycle’ of negative experiences and responses.
<table>
<thead>
<tr>
<th>Number</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A communication is developed to clarify for coders and physicians the intended use of the sickle cell crisis code D 57.0.</td>
</tr>
<tr>
<td>2</td>
<td>Formalize ‘Centres of Excellence’ at the recommended paediatric and adult Academic Health Science Centres.</td>
</tr>
<tr>
<td>3</td>
<td>Develop adult and paediatric satellite centres at high volume hospitals with in the GTA, modelled on the paediatric satellite Centres at William Osler and Scarborough Hospital.</td>
</tr>
<tr>
<td>4</td>
<td>Formalize a hub and spoke relationship between the Centres of Excellence and Satellite Centres.</td>
</tr>
<tr>
<td>5</td>
<td>Implement a formal transition process using evidence based readiness and (when available) risk assessment tools.</td>
</tr>
<tr>
<td>6</td>
<td>Assign leadership and resources to the Centre of Excellence, Satellite Centre or Sickle Cell Program as appropriate to the role your organization should take within the hub and spoke system of sickle cell care.</td>
</tr>
<tr>
<td>7</td>
<td>Determine the quality improvement approach that the organization will take to enable best practices to be delivered.</td>
</tr>
<tr>
<td>8</td>
<td>Coordinate approaches to deliver best practice across ED and the inpatient unit.</td>
</tr>
<tr>
<td>9</td>
<td>Expedite care with medical directives that enable nurses in fast tracking assessment and preparing for pain management.</td>
</tr>
<tr>
<td>10</td>
<td>Implement best practices beginning with preprinted order sets that guide clinicians to order and carry out evidence based care.</td>
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<td>Pain assessments should always be made with age appropriate validated pain tools.</td>
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<td>Patient-specific orders sets and triage files are recommended, especially for the frequent users of ED care, people with underlying chronic pain or any other condition that makes their VOC pain treatment vary from the norm.</td>
</tr>
<tr>
<td>13</td>
<td>Set targets and monitor quality improvement metrics internally.</td>
</tr>
<tr>
<td>14</td>
<td>Clinicians must be educated that in this population the best assessment of severity of pain is the patient’s.</td>
</tr>
<tr>
<td>15</td>
<td>Recognize the right and validity of people with acute pain from a VOC to be treated as CTAS level 2, emergent care needed.</td>
</tr>
<tr>
<td>16</td>
<td>Extensive education on best practices for nurses and doctors who work in hospitals with high volumes of ED visits of people in acute pain from a SCD VOC will be required.</td>
</tr>
<tr>
<td>17</td>
<td>Formally create a network of provider leaders, many that are currently in the QBP Expert Panel, as an advisory body within PCMCH (or another secretariat or agency), mandated by the Ministry to oversee and monitor implementation of quality improvement initiatives to enable best practices.</td>
</tr>
</tbody>
</table>
6.0 What does it mean for multi-disciplinary teams?

ED/Inpatient Care

Nurses and physicians must

- be provided and take educational opportunities to increase their knowledge and skill in delivering care to the patient having a VOC.
- receive education to understand the behaviours that reflect prejudice or any lack of caring to people having a VOC.

Nurses

- must have medical directives to expedite assessment and early treatment measures. Nurse educators must provide the front-line nurses with the education to knowledgeably execute the medical directives.
- through education and the use of clinical supports (tools), demonstrate knowledge and competence in assessing and expediting care so that physicians trust their assessments and can expedite the physician component of timely care.

Physicians

- must through education and through the use of clinical supports (tools) demonstrate knowledge and competence in providing care that adheres to best practices
- adult and paediatric physicians from ED, haematology and pain services must collaboratively develop order sets (different for children and adults).

Nurses, physicians, administrators and ED registration staff must participate in the development of processes that eliminate barriers and are manageable within current work flow processes. Where teams feel this is not possible or desirable to achieve the standards of care in the existing work flow, then new approaches must be developed.

Relationships must be developed between internal disciplines across units in an organization. ED physicians and nurses must collaborate with haematologists and the most responsible physicians on inpatient medical units where the patients are admitted to develop coordinated order sets so that treatment approaches are consistent. If patients receive care in haematology clinics in the organizations, the team from those clinics should also be part of developing and ensuring consistent treatment approaches.

Transition

The paediatric team, the patient and their family and the adult SCD team must develop formal transition preparation processes for handing over paediatric patients to adult receiving teams. This piece of work will be critical in building knowledge capacity among adult providers and raising the standards of care in the adult settings.
7.0 Service capacity planning

This component will be more fully developed within the planning and costing of formalizing structures and roles within a hub and spoke model. Much of the care is being delivered with existing capacity, improving front end quality of care in the ED or inpatient unit will reduce care through revisits and readmits. Local leadership and education will require new resources, however much that has already been developed can be shared across organizations through hub and spoke relationships and joint activities.

ED and inpatient clinicians must have increased capacity through higher levels of knowledge and clinical tools.

In many EDs social work support is lacking. Patients linked to a Centre of Excellence do or will have access to social work support.

Outpatient care capacity to deliver care using the chronic care model must exist across all Centres of Excellence and Satellite Centres. In turn, these centres must work to build bridges with community settings to improve primary care for people with SCD across the entire lifespan.
8.0 Performance evaluation and feedback

The advisory body that works under the auspices of a lead LHIN (with the support of the Network of Experts) will monitor indicators and develop organization specific targets in consultation with the organizations and LHINs.

- A schedule and process of reviewing and interpreting quarterly metrics will be developed, approved and implemented.
- Outreach will take place with organization and LHIN performance leads as required

In introducing the QBP the ministry has a strong interest in:

1. Supporting monitoring and evaluation of the impact (intended and unintended) of the introduction of QBP
2. Providing benchmark information for clinicians and administrators that will enable mutual learning and promote on-going quality improvement
3. Providing performance-based information back to Expert Panels to evaluate the impact of their work and update as required in real time

There was recognition that reporting on a few system-level indicators alone would not be sufficient to meet the ministry’s aim of informing and enabling quality improvement initiatives at the provider-level. Therefore measures meaningful to hospitals and clinicians that are interpretable and have demonstrable value in improving the quality of care provided to patients are also of utmost importance.

To guide the selection and development of relevant indicators for each QBP, the ministry, in consultation with experts in evaluation and performance measurement, developed an approach based on the policy objectives of the QBP and a set of guiding principles. This resulted in the creation of an integrated scorecard with the following six quality domains:

- Effectiveness (including safety)
- Appropriateness
- Integration
- Efficiency
- Access
- Patient-centeredness

The scorecard is based on the following guiding principles:

- **Relevance** – the scorecard should accurately measure the response of the system to introducing QBP
- **Importance** – to facilitate improvement, the indicators should be meaningful for all potential stakeholders (patients, clinicians, administrators, LHINs and the ministry)
- **Alignment** – the scorecard should align with other indicator-related initiatives where appropriate
- **Evidence** – the indicators in the integrated scorecard need to be scientifically sound or at least measure what is intended and accepted by the respective community (clinicians, administrators and/or policy-decision makers)
A set of evaluation questions was identified for each of the QBP policy objectives outlining what the ministry would need to know in order to understand the intended and unintended impact of the introduction of QBPs. These questions were translated into key provincial indicators resulting in a QBP scorecard (see table below).

<table>
<thead>
<tr>
<th>Quality Domain</th>
<th>What is being measured?</th>
<th>Key provincial indicators</th>
</tr>
</thead>
</table>
| Effectiveness  | What are the results of care received by patients and do the results vary across providers that cannot be explained by population characteristics as well as is care provided without harm? | 1. Proportion of QBP patients with improved outcomes  
2. Proportion of QBPs that reduced variation in outcome  
3. Proportion of QBP patients who avoided adverse events and infections |
| Appropriateness | Is patient care being provided according to scientific knowledge and in a way that avoids overuse, underuse or misuse? | 4. Proportion of patients who received care aligned with standard QBP pathway  
5. Proportion of QBP patients that saw a substitution from inpatient to outpatient/day surgery (where appropriate)  
6. Proportion of QBP patients who received less invasive procedures (where appropriate)  
7. Proportion of QBP patients that saw an increase in discharge dispositions into the community (where appropriate)  
8. Proportion of QBP patients with reduced lengths of stay |
| Integration     | Are all parts of the health system organized, connected and work with another to provide high quality care? | 9. Reduction in 30-day readmissions rate (if relevant)  
10. Improved access to appropriate primary and community care (e.g. psychosocial support) following discharge if deemed appropriate  
11. Improved access to appropriate primary and community care including for example psychosocial support (e.g. personal, family, financial, employment and/or social needs)  
12. Coordination of care (TBD)  
13. Involvement of family (TBD) |
<p>| Efficiency      | Does the system make best use of available resources to yield maximum benefit ensuring that the system is sustainable for the long term? | 14. Actual costs vs. QBP price |</p>
<table>
<thead>
<tr>
<th>Quality Domain</th>
<th>What is being measured?</th>
<th>Key provincial indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>Are those in need of care able to access services when needed?</td>
<td>15. Increase in wait times for QBPs / for specific populations for QBP</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16. Increase in wait times for other procedures</td>
</tr>
<tr>
<td></td>
<td></td>
<td>17. Increase in distance patients have to travel to receive the appropriate care related to the QBP</td>
</tr>
<tr>
<td></td>
<td></td>
<td>18. Proportion of providers with a significant change in resource intensity weights (RIW)</td>
</tr>
<tr>
<td>Patient-Centeredness</td>
<td>Is the patient/user at the center of the care delivery and is there respect for and involvement of patients’ values, preferences and expressed needs in the care they receive? (TBC)</td>
<td>19. Increased rate of patients being involved in treatment decision</td>
</tr>
<tr>
<td>(to be further developed)</td>
<td></td>
<td>20. Coordination of care (TBD)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21. Involvement of family (TBD)</td>
</tr>
</tbody>
</table>

It should be noted that although not explicitly mentioned as a separate domain, the equity component of quality of care is reflected across the six domains of the scorecard and will be assessed by stratifying indicator results by key demographic variables and assessing comparability of findings across sub-groups. Where appropriate, the indicators will be risk-adjusted for important markers of patient complexity so that they will provide an accurate representation of the quality of care being provided to patients.

The ministry and experts recognized that to be meaningful for clinicians and administrators, it is important to tie indicators to clinical guidelines and care standards. Hence, advisory groups that developed the best practices were asked to translate the provincial-level indicators into QBP-specific indicators. In consulting the advisory groups for this purpose, the ministry was interested in identifying indicators both for which provincial data is readily available to calculate and those for which new information would be required. Measures in the latter category are intended to guide future discussion with ministry partners regarding how identified data gaps might be addressed.

In developing the integrated scorecard approach, the ministry recognized the different users of the indicators and envisioned each distinct set of measures as an inter-related cascade of information. That is, the sets of indicators each contain a number of system or provincial level measures that are impacted by other indicators or driving factors that are most relevant at the Local Health Integration Networks (LHINs), hospital or individual clinician level. The indicators will enable the province and its partners to monitor and evaluate the quality of care and allow for benchmarking across organizations and clinicians. This will in turn support quality improvement and enable target setting for each QBP to ensure that the focus is on providing high quality care, as opposed to solely reducing costs.

It is important to note that process-related indicators selected by the expert panels will be most relevant at the provider level. The full list of these measures is intended to function as a ‘menu’ of information that can assist administrators and clinicians in identifying areas for quality improvement.

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For example, individual providers can review patient-level results in conjunction with supplementary demographic, financial and other statistical information to help target care processes that might be re-engineered to help ensure that high-quality care is provided to patients.

Baseline reports and regular updates on QBP specific indicators will be included as appendices to each QBP Clinical Handbook. Reports will be supplemented with technical information outlining how results were calculated along with LHIN and provincial-level results that contextualize relative performance. Baseline reports will also be accompanied by facility-level information that will facilitate sharing of best practices and target setting at the provider-level.

The ministry recognizes that the evaluation process will be on-going and will require extensive collaboration with researchers, clinicians, administrators and other relevant stakeholders to develop, measure, report, evaluate and, if required, revise and/or include additional indicators to ensure that the information needs of its users are met.
9.0 Support for Change

Implementation recommendation number 17

Recommend a network of provider leaders, many that are currently in the QBP Expert Panel, formally create an advisory body within PCMCH (or another secretariat or agency), mandated by the Ministry to oversee and monitor implementation of quality improvement initiatives to enable best practices. The advisory, through PCMCH’s (or other) program development and management capacity will provide mentorship and coaching to support sites in quality improvement initiatives to meet indicator targets through best practices. The advisory will interpret performance metrics to support PCMCH in performance monitoring.

- The advisory should develop a comprehensive plan with costing to develop and sustain a hub and spoke system that will include 5 to 7 additional adult Satellite Centres and 2 to 3 additional paediatric Satellite centres.
- The paediatric and adult Centres of Excellence will formalize collaborative efforts in achieving comparable standards of care that are reflective of best practice recommendations and make transitions in care from paediatric to adult health services less distressing.
- Centres of Excellence and Satellite centres shall establish provider leader relationships and collaboratively plan shared education and share educational materials and resources

The ministry, in collaboration with its partners, will deploy a number of field supports to support adoption of the funding policy. These supports include:

- Committed clinical engagement with representation from cross-sectoral health sector leadership and clinicians to champion change through the development of standards of care and the development of evidence-informed patient clinical pathways for the QBPs.

- Dedicated multidisciplinary clinical expert group that seek clearly defined purposes, structures, processes and tools which are fundamental for helping to navigate the course of change.

- Strengthened relationships with ministry partners and supporting agencies to seek input on the development and implementation of QBP policy, disseminate quality improvement tools, and support service capacity planning.

- Alignment with quality levers such as the Quality Improvement Plans (QIPs). QIPs strengthen the linkage between quality and funding and facilitate communication between the hospital board, administration, providers and public on the hospitals’ plans for quality improvement and enhancement of patient-centered care.

- Deployment of a Provincial Scale Applied Learning Strategy known as IDEAS (Improving the Delivery of Excellence Across Sectors). IDEAS is Ontario’s investment in field-driven capacity building for improvement. Its mission is to help build a high-performing health system by training a cadre of health system change agents that can support an approach to improvement of quality and value in Ontario.

We hope that these supports, including this Clinical Handbook, will help facilitate a sustainable dialogue between hospital administration, clinicians, and staff on the underlying evidence guiding QBP implementation. The field supports are intended to complement the quality improvement processes currently underway in your organization.
10.0 Frequently Asked Questions
Afterword: Beyond the walls of acute care: home and community

Home
When one family member has SCD the whole family is impacted. Unplanned visits to ED, hospitalizations, and chronic pain impact school and the work place and bring chronic and intermittent peaks of stress to families. Strong family, community and health team supports both in primary and specialty care settings are essential to help people with SCD, and their families optimize their health and overall quality of life.

Community Care
In Ontario, the establishment Community Health Centres (CHCs), in both rural and urban settings has been associated with reduced ED visits\textsuperscript{xix}. CHCs are designed to promote wellness and serve populations that have traditionally faced barriers to accessing health services. TAIBU is one CHC in the GTA devoted to serving the black population that operates a SCD program one day per week where a haematologist sees patients with SCD. The haematologist prepared for this work by attending for 3 weeks in the GTA adult Centre of Excellence at the UHN, and by regular communication/consultation with the Centre’s Medical Director. Patients receive evidence based care and there is a strong relationship between the CHC haematologist and the Centre of Excellence team. Patients with treatment challenges that cannot be met at the TAIBU are quickly referred to the UHN\textsuperscript{xx}. TAIBU is reaching out to two other CHCs in the GTA regarding the care of people with SCD\textsuperscript{xxi}. These are examples of initiatives that can strengthen the education, social supports and overall management of SCD. CHCs are well positioned to improve the primary care of people with SCD and liaise with satellite centres and centres of excellence to support individualized care coordination, particularly for the small percentage of people with SCD who require more intensive clinical and social supports.

Advocacy groups
There are three advocacy groups, two provincial and one national that advocate for lifelong medical care and social supports for people with SCD in Ontario\textsuperscript{xxii}. 

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### 11.0 Membership

Sickle Cell Quality Based Procedure Expert Panel

<table>
<thead>
<tr>
<th>LHIN</th>
<th>Member Name</th>
<th>Job Title and Organization</th>
<th>Chair/Co-Chair</th>
<th>Area of Expertise</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Dr. Mark Awuku</td>
<td>Community Paediatrician, Windsor Associate Professor of Paediatrics, Department of Paediatrics, Schulich School of Medicine &amp; Dentistry, Windsor Program, Western University</td>
<td>-</td>
<td>Physician</td>
</tr>
<tr>
<td>2</td>
<td>Ms Jill Craven</td>
<td>Director of Children’s Care, Children’s Hospital London Health Sciences Centre</td>
<td>-</td>
<td>Executive Administration</td>
</tr>
<tr>
<td>4</td>
<td>Dr. Uma Athale</td>
<td>Associate Professor, Department of Paediatrics, McMaster</td>
<td>-</td>
<td>Physician</td>
</tr>
<tr>
<td>4</td>
<td>Ms Danielle McKinlay</td>
<td>Information Controller, Decision Support Services McMaster Children’s Hospital - Hamilton Health Sciences</td>
<td>-</td>
<td>Decision Support/Health Information Management</td>
</tr>
<tr>
<td>4</td>
<td>Dr. Madeleine Verhovsek</td>
<td>Assistant Professor of Medicine, Division of Hematology and Thromboembolism, Consultant Laboratory Hematologist, Red Cell Disorders Laboratory, Hamilton Regional Laboratory Medicine Program, St. Joseph’s Healthcare, Hamilton</td>
<td>Co-Chair</td>
<td>Physician</td>
</tr>
<tr>
<td>5</td>
<td>Dr. Sanjeev Luthra</td>
<td>Staff Pediatrician, Pediatric Sickle Cell Clinic, William Osler Health System</td>
<td>-</td>
<td>Physician</td>
</tr>
<tr>
<td>6</td>
<td>Ms Shauna Dowsley</td>
<td>Laboratory Manager, Hematology and Transfusion Medicine, Trillium Health Partners</td>
<td>-</td>
<td>Executive Administration</td>
</tr>
<tr>
<td>7</td>
<td>Dr. Isaac Odame</td>
<td>Haematologist, Division of Haematology/Oncology, SickKids. Professor, Department of Paediatrics, University of Toronto</td>
<td>Co-Chair</td>
<td>Physician</td>
</tr>
<tr>
<td></td>
<td>Ms Jacqueline Flowers</td>
<td>Mother of child with SCD; involved with SCAGO</td>
<td></td>
<td>Patient Advocate</td>
</tr>
<tr>
<td>7</td>
<td>Ms Colleen Johnson</td>
<td>Nurse Practitioner, University Health Network, Red Blood Cell Disorders Program</td>
<td></td>
<td>Clinician</td>
</tr>
<tr>
<td>7</td>
<td>Dr. Carolyn Beck</td>
<td>Director of Inpatient Units, Division of Paediatric Medicine, SickKids</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>7</td>
<td>Ms. Marina Strzelecki</td>
<td>Clinical Pharmacist, SickKids</td>
<td></td>
<td>Clinician</td>
</tr>
<tr>
<td>7</td>
<td>Dr. Jennifer Stinson (Nurse Practitioner)</td>
<td>Mary Jo Haddad Nursing Chair in Child Health, Scientist, Child Health Evaluative Science; Associate Professor in the Faculty of Nursing, Institute of Medical Science and Institute of Health Policy Management and Evaluation at the University of Toronto, SickKids</td>
<td></td>
<td>Clinician</td>
</tr>
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<td>Member Name</td>
<td>Job Title and Organization</td>
<td>Chair/Co-Chair</td>
<td>Area of Expertise</td>
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<tr>
<td>7</td>
<td>Dr. Matthew Hodges</td>
<td>Emergency Physician, Mount Sinai Hospital</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>7</td>
<td>Dr. Dominick Shelton</td>
<td>Emergency Physician, Sunnybrook Health Sciences Centre</td>
<td></td>
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</tr>
<tr>
<td>7</td>
<td>Christiane Gray-Schleiauf</td>
<td>Registered Nurse, Addiction Medicine and Chronic Pain, Centre for Addiction and Mental Health</td>
<td></td>
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</tr>
<tr>
<td>7</td>
<td>Dr. Richard Ward</td>
<td>Director, Red Blood Cell Disorders Program, Toronto General Hospital Associate Training Program Director, Adult Hematology</td>
<td></td>
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<tr>
<td>7</td>
<td></td>
<td>Associate Program Director, Adult Hematology</td>
<td>Assistant Professor, University of Toronto</td>
<td>Physician</td>
</tr>
<tr>
<td>8</td>
<td>Dr. Olaniyi Ajisafe</td>
<td>Family Physician, North York, Ontario</td>
<td></td>
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</tr>
<tr>
<td>9</td>
<td>Dr. Muhammad Akhter Hamid</td>
<td>Paediatrician, Rouge Valley Centenary Health Centre</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>9</td>
<td>Dr. Paks Madikiza</td>
<td>Paediatrician, Rouge Valley Centenary Health Centre</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>9</td>
<td>Dr. Larry Grossman</td>
<td>Haematologist, TAIBU Community Health Centre</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>11</td>
<td>Dr. Ewurabena Simpson</td>
<td>Assistant Professor, Division of Hematology/Oncology, Department of Pediatrics, Children’s Hospital of Eastern Ontario</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>11</td>
<td>Ms. Fatiha Rochelle</td>
<td>Social Worker, Ottawa Hospital</td>
<td></td>
<td>Clinician</td>
</tr>
<tr>
<td>11</td>
<td>Dr. Ken Farion</td>
<td>Paediatric Emergency Medicine, CHEO</td>
<td></td>
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</table>

With, Mary Ellen Salenieks, Senior Project Manager, Provincial Council for Maternal and Child Health
<table>
<thead>
<tr>
<th>Name</th>
<th>Role and Affiliation</th>
</tr>
</thead>
</table>
| Dr. Jennifer Stinson       | Jennifer Stinson, RN-EC, PhD, CPNP  
Mary Jo Haddad Nursing Chair in Child Health  
Peter Lougheed CIHR New Investigator  
Scientist, Child Health Evaluative Sciences  
Nurse Practitioner, Chronic Pain Program  
The Hospital for Sick Children  
Associate Professor, Lawrence S. Bloomberg, Faculty of Nursing, University of Toronto  
Member QBP Expert Panel                                                                 |
| Dr. Isaac Odame            | Haematologist, Division of Haematology/Oncology, SickKids. Professor, Department of Paediatrics, University of Toronto  
Co-chair QBP Expert Panel                                                                                                                      |
| Dr. Madeleine Verhovsek    | Assistant Professor of Medicine, Division of Hematology and Thromboembolism, Consultant Laboratory Hematologist, Red Cell Disorders Laboratory, Hamilton Regional Laboratory Medicine Program, St. Joseph's Healthcare, Hamilton  
Co-chair QBP Expert Panel                                                                                                                      |
| Ms. Lorraine Bird          | Clinical Nurse Specialist, Acute Pain Management, SickKids                                                                                                                                                    |
| Ms. Salima Ladak           | NP, Toronto General Hospital Acute Pain Service Coordinator, UHN Pain APN Committee                                                                                                                              |
| Dr. Larry Grossman         | Community Hematologist, member QBP Expert Panel                                                                                                                                                                  |
| Dr. Guy Petroz             | Anaesthetist, Anesthesia and Pain Medicine, SickKids  
Assistant Professor, Department of Anaesthesia, University of Toronto                                                                                                                                          |
| Ms. Mary Ellen Salenieks   | Senior Project Manager, Provincial Council for Maternal and Child Health                                                                                                                                         |
Screening for Sickle Cell Disease

Newborn Screening Ontario screens for 29 diseases including Sickle Cell Disease (SCD).

Screening for Sickle Cell Disease (SCD) in Ontario began November 24, 2006.

Early detection permits improved health outcomes through early treatment and care:
- Preventive antibiotic treatment can be started
- Education of family regarding medical management:
  - Fever, enlarged spleen, sickling crisis, aplastic crisis preventative measures
- Monitoring for stroke
- Avoids misdiagnosis
Since 2006, 359 infants with Sickle Cell Disease have benefited from newborn screening.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>SS disease</td>
<td>210</td>
</tr>
<tr>
<td>SC disease</td>
<td>103</td>
</tr>
<tr>
<td>S-Beta thalassemia</td>
<td>40</td>
</tr>
<tr>
<td>HbS/HPFH</td>
<td>6</td>
</tr>
<tr>
<td>Grand Total</td>
<td>359</td>
</tr>
</tbody>
</table>

The birth prevalence in Ontario, Canada is 1:2814.

* Incidence of new SCD diagnoses is likely slightly higher due to net immigration into Ontario. Dr. Ewurabena Simpson at CHEO has initiated a project that will help quantify this.

Total # of infants screened: 1,010,159

The Central and Central West LHINs have the highest proportion of newborns with Sickle Cell Disease or who are carriers.

<table>
<thead>
<tr>
<th>LHIN</th>
<th>Affected 2006-2013</th>
<th>Carrier 2010-2014</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>Percent of Total</td>
</tr>
<tr>
<td>CENTRAL WEST (5)</td>
<td>81</td>
<td>23%</td>
</tr>
<tr>
<td>CENTRAL (8)</td>
<td>73</td>
<td>21%</td>
</tr>
<tr>
<td>CENTRAL EAST (9)</td>
<td>62</td>
<td>17%</td>
</tr>
<tr>
<td>TORONTO CENTRAL (7)</td>
<td>43</td>
<td>12%</td>
</tr>
<tr>
<td>CHAMPLAIN (11) – GATINEAU</td>
<td>42</td>
<td>12%</td>
</tr>
<tr>
<td>MISSISSAUGA HALTON (6)</td>
<td>26</td>
<td>7%</td>
</tr>
<tr>
<td>HAMILTON NIAOARDIA HALDIMAND BRANT (4)</td>
<td>14</td>
<td>4%</td>
</tr>
<tr>
<td>WATERLOO WELLINGTON (3)</td>
<td>&lt;6</td>
<td>1%</td>
</tr>
<tr>
<td>SOUTH WEST (2)</td>
<td>&lt;6</td>
<td>1%</td>
</tr>
<tr>
<td>ERIE ST CLAIR (1)</td>
<td>&lt;6</td>
<td>1%</td>
</tr>
<tr>
<td>NORTH WEST (14)</td>
<td>&lt;6</td>
<td>0%</td>
</tr>
<tr>
<td>SOUTH EAST (10)</td>
<td>&lt;6</td>
<td>0%</td>
</tr>
<tr>
<td>NORTH SIMCOE (12)</td>
<td>&lt;6</td>
<td>0%</td>
</tr>
<tr>
<td>NORTH EAST (13)</td>
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<td>0%</td>
</tr>
<tr>
<td>Grand Total</td>
<td>359</td>
<td>100%</td>
</tr>
</tbody>
</table>

1 LHIN was determined by the Forward Sortation Area (FSA) – first 3 digits of the maternal postal code submitted to NSO on the requisition form (i.e. maternal address at the time of birth).
Brampton is the community with the highest proportion of newborns with Sickle Cell Disease or who are carriers.

### Named Community

<table>
<thead>
<tr>
<th>Name</th>
<th>Affected (2006-2013)</th>
<th>Carrier (2010-2014)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BRAMPTON</td>
<td>53</td>
<td>855</td>
</tr>
<tr>
<td>NORTH YORK</td>
<td>49</td>
<td>775</td>
</tr>
<tr>
<td>SCARBOROUGH</td>
<td>40</td>
<td>670</td>
</tr>
<tr>
<td>TORONTO</td>
<td>38</td>
<td>391</td>
</tr>
<tr>
<td>ETOBICOKE</td>
<td>28</td>
<td>401</td>
</tr>
<tr>
<td>OTTAWA/GATINEAU</td>
<td>25</td>
<td>393</td>
</tr>
<tr>
<td>MISSISSAUGA</td>
<td>24</td>
<td>577</td>
</tr>
<tr>
<td>YORK</td>
<td>13</td>
<td>199</td>
</tr>
<tr>
<td>AJAX</td>
<td>10</td>
<td>167</td>
</tr>
<tr>
<td>HAMILTON</td>
<td>7</td>
<td>195</td>
</tr>
<tr>
<td>NEPEAN</td>
<td>6</td>
<td>92</td>
</tr>
<tr>
<td>ORLEANS</td>
<td>&lt;6</td>
<td>62</td>
</tr>
<tr>
<td>PICKERING</td>
<td>&lt;6</td>
<td>71</td>
</tr>
</tbody>
</table>

1. **Named community was determined by the maternal postal code submitted to NSO on the requisition form and Canada Post’s community name associated with that postal code.**

Toronto is the region in Ontario with the highest proportion of newborns with Sickle Cell Disease.

### Region

<table>
<thead>
<tr>
<th>Name</th>
<th>Affected (2006-2013)</th>
<th>Carrier (2010-2014)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TORONTO</td>
<td>171</td>
<td>1437</td>
</tr>
<tr>
<td>PEEL</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>OTTAWA/GATINEAU</td>
<td>42</td>
<td>575</td>
</tr>
<tr>
<td>DURHAM</td>
<td>19</td>
<td>389</td>
</tr>
<tr>
<td>YORK</td>
<td>11</td>
<td>312</td>
</tr>
<tr>
<td>HAMILTON</td>
<td>10</td>
<td>231</td>
</tr>
<tr>
<td>HALTON</td>
<td>7</td>
<td>168</td>
</tr>
<tr>
<td>OTHER</td>
<td>22</td>
<td>1151</td>
</tr>
</tbody>
</table>

1. **Region was determined by the maternal postal code submitted to NSO on the requisition form and the Association of Municipalities of Ontario’s regions listing at [www.amo.on.ca/YLG](http://www.amo.on.ca/YLG).**

2. Regions with 5 or less affected individuals are shown as ‘Other’. 
Limitations of NSO Data

The data presented here only measures Ontario-born infants who had a newborn screen.

The geography is calculated through self-reported maternal address at time of birth and does not necessarily reflect the current location of these infants.
## Appendix 2: ED visits and revisits, inpatient discharges and readmission for fiscal years 2011/12 and 2014/15

| LHIN | Hospital | FY2011/12 | | Inpatient | | FY2014/15 | | Inpatient |
|------|----------|-----------|-----------|-----------|-----------|-----------|-----------|
|      |          | ED Visit | Revisit ≤ 14 days | Revisit ≤ 30 days | Admission rate | Inpatient Discharges | Revisit ≤ 14 days | Revisit ≤ 30 days | Admission rate |
|      |          |          |          |          |           |                   |          |          |                   |
| 7    | HOSPITAL FOR SICK CHILDREN (THE) | | | | | | | |
| 8    | ADULT | 1 | 100% | 100% | 0 | | | |
| 9    | PEADES | 1 | 0% | 0% | 0 | | | |
| 11   | OTTAWA HOSPITAL (THE) - GENERAL SITE | | | | | | | |
| 8    | ADULT | 1 | 100% | 100% | 100% | | | |
| 9    | PEADES | 1 | 0% | 0% | 0 | | | |
| 11   | CHILDREN'S HOSPITAL OF EASTERN ONTARIO | | | | | | | |
| 8    | ADULT | 1 | 100% | 100% | 100% | | | |
| 9    | PEADES | 1 | 0% | 0% | 0 | | | |
| 11   | ROUGE VALLEY HEALTH SYSTEM-CENTENARY | | | | | | | |
| 8    | ADULT | 1 | 100% | 100% | 100% | | | |
| 9    | PEADES | 1 | 0% | 0% | 0 | | | |
| 11   | SUNNYBROOK HEALTH SCIENCES CENTRE | | | | | | | |
| 8    | ADULT | 1 | 100% | 100% | 100% | | | |
| 9    | PEADES | 1 | 0% | 0% | 0 | | | |
| 11   | UNIVERSITY HEALTH NETWORK-GENERAL SITE | | | | | | | |
| 8    | ADULT | 1 | 100% | 100% | 100% | | | |
| 9    | PEADES | 1 | 0% | 0% | 0 | | | |
Appendix 3: Algorithms from other jurisdictions

Pain Management Algorithm

Moderate/Severe Pain

Patient Very Uncomfortable, Pain Score ≥ 5

Give IN Fentanyl Immediately

IV placed or Patient Refuses IN Fentanyl

Reassess pain 20 min

IV Opioid #1: Loading Dose
Ketorolac (within 30 min arrival)

Reassess pain 20 min

IV Opioid #2: 50% Loading Dose

Reassess pain 20 min

IV Opioid #3: 25-50% Loading Dose

Pain Not Well Controlled

Reassess
Determine Disposition

Persistent Pain

Pain Controlled
Patient’s Comfortable

PO Opioid #1: Oxycodone

Patient Comfortable
Pain Well Controlled
Pain Score ≤ 5

Discharge

Reassess pain hourly
Continue IV Opioid every 1-2 hours as needed

Persistent Pain

IV Opioid #4: 25-50% Loading Dose

Admit
Hematology Consultation
ED Pathway for Evaluation/Treatment of Children with Sickle Cell Disease and Pain

**Goals and Metrics**

**Sickle Cell Disease Patient with Pain**

**Triage Criteria (Critical/Acute)**

**MD/CRNP/RN Rapid Assessment**
- IV Access
- CBC with Differential
- Reticulocyte Count
- History and Physical

**MILD / MODERATE PAIN**
- Minimal Pain Management at home

**Oral Analgesia**
- Codeine
  - < 6 yrs: 0.15 mg/kg up to 2.5 mg
  - 6-12 yrs: 0.15 mg/kg up to 5 mg
  - > 12 yrs: 0.2 mg/kg up to 10 mg
- AND
- ibuprofen: 10 mg/kg
  - (If no NSAIDS in preceding 6 hrs)

- Assess
  - 0-60 minutes after po dose
  - pain adequately controlled, discharge at 1 hour
  - pain not adequately controlled, proceed to IV analgesia

**Pain Management Algorithm**

**IV/IN Analgesia**
- Fentanyl
  - 2 mg/kg administered with MAD
  - Consider as bridge if severe pain to ease IV access
  - Does not replace need for IV morphine
- Morphine
  - 0.1-0.15 mg/kg/dose IV (max 7 mg/dose)
  - Order 1st pm dose (50% of initial dose at the same time)
- Hydromorphone
  - 0.015-0.02 mg/kg/dose IV (max 2 mg/dose)
  - Order 1st pm dose (50% of initial dose at the same time)
- Ketorolac
  - 0.5 mg/kg/dose IV (max 30 mg/dose)
  - (If no NSAIDS in preceding 5 hours)

- Assess
  - Every 20-30 minutes
  - Document pain score using age-appropriate scale
  - Monitor for side effects and complications

**Titration of Opioid Therapy**
- Administer 25-50% of initial Morphine or Hydromorphone loading dose every 20-30 minutes as patient tolerates until pain adequately controlled

**After 3rd PRN morphine or hydromorphone dose**
- Pain not adequately controlled – Admit to Hematology Service
- Pain adequately controlled, or consider transition to PO, possible discharge

**Hematology Consultation**

**MACU Admission**
- Patients with the following:
  - ≥ 6 months of age
  - Non-toxic
  - Uncomplicated vaso-occlusive pain event requiring multiple IV doses of analgesics

**Inpatient Admission Criteria**
- Patients with the following:
  - < 6 months of age
  - Focal neurologic findings
  - Acute chest syndrome
  - Splenic sequestration
  - Fever
  - Reticulocyte count < 1 % (unless Hgb > 10 g/dL)
  - Severe anemia (Hgb < 5 g/dL)

**Posted**: July, 2010
**Revised**: October 2011, October 2014
**Authors**: A. Ellison, MD, Lisa Payne, RN, C. Norris, MD, K. Smith-Whitley, MD, C. Jacobstein, MD, J. Lavalle, MD

ED SCD Pain Management Algorithm

RN informs LIP
LIP available to write order? NO
YES
LIP enters order into ED information system
RN obtains verbal order for pathway initiation from LIP
Has patient taken opioids within the last 24 hours?
YES
NO
RN enters order into ED information system
LIP cosigns order

If patient has a history of pruritis
with opioid analgesia, give diphenhydramine 25 mg IV x 1.
Do not give Ketorolac to patients with a history of kidney or peptic ulcer disease.

LIP / RN administers: Hydromorphone 2 mg IV or SQ or Morphine Sulfate 10 mg IV x 1 and Ketorolac 30 mg IV x 1
Reassess pain and sedation scores in 15 minutes

LIP evaluates patient
Pain at acceptable level to patient? NO
YES
Continue to assess pain, sedation & vitals q15 minutes x one hour

Three doses administered?
NO
YES
Pain at acceptable level to patient?
NO
YES
Consider discharge with hematology follow-up
Discharge patient

LIP/RN administers appropriate dosage depending upon opioid use in last 24 hours
Consideration admission / PCA

http://www.ctscts.org/seed.html
Clinic/Office Setting
SC Pain

Are there signs of other complications (e.g., aplastic crisis, neurological event, sepsis, pulmonary, abdominal, or orthopedic event)?

Yes

- Transfer to emergency department (ED).
- Triage as high priority (ESI 2).
- Evaluate for complications on arrival.
- Begin analgesic management within 30 minutes of triage or within 60 minutes of registration.

No

Can the pain be managed in the clinic, day hospital setting, or other short-term stay hospital setting?

Yes

Treat pain in clinic, or transfer to alternative setting.

- Treat pain aggressively and promptly. Administer 1st dose prior to transfer if possible within 30 minutes of arrival (administer 2nd dose if delay in transfer to alternate care site).
- Administer opioids (morphine sulfate or hydromorphone) per patient-specific protocol. IV route, subcutaneous when IV not available.
- Reassess for pain and sedation every 15–30 minutes and readminister analgesic doses until pain relief is obtained. Maintain or consider escalation of the dose by 25 percent until pain is controlled.
- Use nonpharmacologic approaches such as heat. Manage pain for 6–8 hours. If unable to control pain, consider admission to short-term observation unit or hospital.
- Begin PCA in the ED when possible and once admitted if not initiated in the ED.

No
Appendix 4: Pain Scoring Tools


word scale.pdf  revised-flacc tool with instructions.fdoc

Appendix 5: Implementation of a Community Hospital-Based Fast Track Pathway for the Treatment of Acute Pain Episodes in Adults with Sickle Cell Disease

Richard Lottenberg, MD1, Robert Krywicki, MD2, Gurinder Doad, MD3, Witemba Kabange, MD3, Monisola Modupe, MD3, Gregory Steele, APRN2, Zeretta K McGriff, RN, BS4, James A Sirleaf, MD4, Abdullah Kutlar, MD5, Robert Gibson, PhD6, Betsy Clair6 and Matthew L Lyon, MD6

1Department of Medicine, Division of Hematology/Oncology, University of Florida, Gainesville, FL
2Phoebe Cancer Center, Albany, GA
3Southwest Georgia Family Medicine Residency Program, Albany, GA
4Phoebe Memorial Hospital, Albany, GA
5Sickle Cell Center, Georgia Regents University, Augusta, GA
6Department of Emergency Medicine, Georgia Regents University, Augusta, GA

Background: A growing number of adult patients with sickle cell disease (SCD) receive care in a community setting and often lack access to physicians with sickle cell expertise. To address this healthcare disparity we are testing a co-management medical home model with Hematology/Oncology (H/O) and Family Medicine (FM) physicians to facilitate evidence-based acute and chronic care. An Emergency Department (ED) Observation Unit based pathway for treatment of sickle cell pain developed at an academic medical center with a Comprehensive Sickle Cell Center (CSCC) has been adopted and modified to fit the needs of a community multi-specialty hospital with an unopposed FM residency program. The hospital serves a large sickle cell population in a predominantly rural setting with the closest CSCC 180 miles away.

Methods: Pathway development was facilitated by having a formal meeting for the community hospital physicians and staff at the academic medical center and sickle cell experts providing ongoing on site consultation at the community hospital. Protocols for the community hospital were produced with input from physicians, nurses, advanced practice providers, and support services at multiple meetings. Adult patients with SCD presenting to the ED with pain are triaged at Emergency Severity Index Level 2 for evaluation by the ED physician. The ED protocol uses specific criteria to identify patients with uncomplicated pain. Patients presenting with abnormal vital signs (other than mild tachycardia), fever, pregnancy, or apparent other sickle cell-related complications are excluded.
Patients qualifying for the pathway are directly admitted to the SCD unit (a hospital room with 4 infusion chairs on the H/O floor exclusively designated for care of sickle cell patients). Following intake evaluation by the nurse, a clinician is notified to evaluate the patient and provide orders for intravenous fluids and opioid patient controlled analgesia (PCA) which is administered according to hospital guidelines. PCA by the subcutaneous route is used if intravenous access is not readily available. A CBC is obtained whereas other laboratory testing and imaging studies are ordered based on clinical indications. H/O physicians and nurse practitioners cover the unit weekdays 8:00am-5:00pm and FM residents cover nights and weekends with back up by the on call H/O physician. Patients can be treated in the SCD unit up to 23 hours. For patients discharged home a follow up phone call by an H/O nurse will be placed within 3 days and an outpatient clinic appointment is scheduled to be within 7 days. Monthly quality assurance meetings are attended by H/O, FM, and ED physicians as well as nursing, pharmacy and administrative staff from the ED and H/O inpatient service to review process issues and patient outcomes. Consultation is provided by academic physicians with sickle cell expertise (H/O and ED) who attend each meeting in person or by conference call.

**Results:** From March 5-June 30, 2014, 67 patients accounted for 271 visits to the SCD unit. The mean time in the unit was 13.6 hours. The mean pain score on admission was 8.7/10 and reduced to 4.9 upon discharge. PCA drug, pump setting, and dosage are recorded to be used for future visits. Over the 4 months 91.1% of the patients were discharged home from the unit. Six patients accounted for 31% (84) of the visits with only 4 hospital admissions.

**Conclusions:** A fast track pathway for the treatment of acute sickle cell pain coordinated between ED, H/O, and FM physicians has been implemented at a community hospital using an Observation Unit based treatment program. During the entire initial experience the majority of patients have been discharged home with adequate pain relief. In the future the impact of the program will be evaluated including effect on frequency of hospitalizations, outpatient follow up, patient satisfaction, and cost effectiveness. The pathway can be adapted to other community hospital settings where sickle cell expertise is not locally available.
References


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x Quinn C et al. Blood 2010; 115(17):3447-3452


xii Manwani, D., Carullo, V., Rinke, M., Choi, S., Driscoll, C., Reducing Health Care Utilization in Sickle Cell Disease Patients By Implementation of an Individualized, Multimodal Care Plan during Hospital Admission and at Inpatient to Outpatient Discharge, Blood, December 06, 2014

xiii Brousseau, DC, Owens, PL, Mosso, AL, Panepinto, JA, Steiner, CA., Acute Care Utilization and Rehospitalizations for Sickle Cell Disease, JAMA. 2010;303(13):1288-1294


xvi Link to transition tool on PCMCH website

xvii Opioid Equianalgesic Tables: Are They All Equally Dangerous? Philip E. Shaheen, MD, Declan Walsh, MSc, FACP, FRCP (Edin), Wael Lasheen, MD, Mellar P. Davis, MD, FCCP, and Ruth L. Lagman, MD, MPH. J Pain Symptom Manage 2009;38:409e417. 2009 U.S. Cancer Pain Relief Committee.


xix Personal communication Mary Ellen Salenieks with Colleen Johnson,, NP UHN


xxii Information obtained through Expert Panel Members L. Grossman MD and Colleen Johnson NP.

xxiii Personal communication M. E. Salenieks and Ulysse Guerriere, Sickle Cell Support Group Coordinator, TAIBU