Sickle Cell Pain in the Emergency Department:
A Guide to Improving Care

NICHQ
National Institute for
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Executive Summary

Pain episodes are the most common reason for emergency department (ED) visits and hospitalizations for patients with sickle cell disease.[1-4] Ensuring that patients receive timely, effective pain relief is one of the most important elements of delivering high quality care to individuals with sickle cell disease in the ED. This implementation guide was developed to share strategies and lessons learned about the management of sickle cell pain episodes from the experiences of multidisciplinary teams that worked between 2010 and 2015 to improve care for individuals with sickle cell disease.

Strategies for Improving Care → Jump to section

> **Use quality improvement methods to improve care**
> *Start with small tests of a change, and move to implementation only with changes that prove to be successful.*

> **Measure progress**
> *You can't improve what you don't measure: make sure to set up a system for data collection and data analysis, and use data to guide improvement efforts.*

> **Form a multidisciplinary team**
> *A diverse team that includes multiple perspectives and all key stakeholders will be most effective at creating and sustaining improvement.*

> **Include the patient perspective**
> *Patients and families understand the patient experience, and bring an invaluable perspective to improvement efforts.*

> **Facilitate multi-site collaborative sharing**
> *Accelerate progress by sharing and learning from other organizations pursuing similar aims.*

Key Facilitators and Key Barriers → Jump to section

Key facilitators of success	Key barriers to success
Senior leadership support	Low priority for leadership
Physician champions and nurse champions in the ED	Lack of adequate staffing
Robust involvement of nursing staff	Staff turnover
Alignment of goals	Low frequency of individuals with sickle cell disease
Adequate staffing	High utilizers
Access to quality improvement expertise	Difficulties with electronic health record systems
Regular and robust education for all staff	
Data collection with timely review and feedback	
Electronic health record documentation	

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Recommendations and Change Ideas → Jump to section

- **Assess intensity and location of pain**

  Change idea: Pain assessment charts

  ➡ These charts are especially effective when patient feedback is used to develop them. Education for patients and staff is essential to ensure they are used effectively.

- **Use a sickle cell disease-specific pain protocol**

  Change idea: Standard order sets

  ➡ Standard order sets reduce confusion, increase confidence and facilitate consistent care. When developed carefully, they are easy to use and can be a great resource for staff.

- **Use an individualized prescribing and monitoring protocol**

  Change idea: Pain action plans

  ➡ Individualized pain action plans facilitate faster and more effective pain relief. They can improve care and increase patient satisfaction.

- **Consider initiating around-the-clock opioid administration**

  Change idea: Patient-controlled analgesia

  ➡ Initiating patient-controlled analgesia in the emergency department can facilitate effective pain treatment for admitted patients and improve patient satisfaction. Patients should be educated about all available pain medication options.

- **Rapidly initiate analgesic therapy**

  Change idea: Intranasal fentanyl

  ➡ Intranasal fentanyl is effective at delivering rapid pain relief for patients. When used as a first line pain medication, it can reduce the time that patients wait to receive treatment.

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Acknowledgments

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Introduction

The importance of timely, effective treatment for pain episodes

Sickle cell disease is characterized by unpredictable episodes of extreme pain, known as acute vaso-occlusive episodes (VOE) or pain episodes, caused when sickled red blood cells are unable to move freely through blood vessels. In addition to pain, these changes at the cellular level can also lead to organ damage, stroke and even death. Pain episodes are the most common reason for emergency department (ED) visits and hospitalizations for patients with sickle cell disease.[1-4] Detailed guidelines and quality indicators for the management of pain episodes currently exist, but both pediatric and adult patients with the disease often experience prolonged periods of waiting for treatment in the emergency department and ineffective treatment of their pain.[5-9]

Delays in treatment are often due to systemic factors, such as the lack of a clear treatment protocol or limited provider experience in treating sickle cell disease-related pain. Prolonged waits for effective pain relief can lead to unnecessary suffering, hospitalizations, chronic pain syndromes, other complications and increased health care costs.[1,8,10-12] Ensuring patients receive timely, effective pain relief is one of the most important elements of delivering high quality care to individuals with sickle cell disease in the emergency department.

"Sickle cell crises can happen anywhere and anytime. Therefore, the first place we go is the emergency room. Sadly, I would have to wait anywhere between an hour to three hours [for pain medication]."

– Sickle cell disease patient

Patient voices: Experiencing pain episodes

- ▶ CRISIS: Experience of People with Sickle Cell Disease Seeking Health Care for Pain [video]
- 📄 Voices of Adults Living with Sickle Cell Disease Pain [article]
- 📄 Pain, Persistence, Family: Sickle Cell Disease [article + audio]

About this guide

This implementation guide was developed for health care providers who care for individuals with sickle cell disease in hematology programs and acute care settings such as the emergency departments and day hospitals. It provides insights and lessons learned from multidisciplinary teams across the country that have succeeded in improving the management of pain episodes in emergency departments or day hospitals for both pediatric and adult patients. This guide provides:

Part 1: Five strategies for improving care that can help to ensure that improvement efforts are successful:

- Use quality improvement methods to improve care
- Measure progress
- Form a multidisciplinary team
- Include the patient perspective
- Multi-site collaborative sharing

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Part 2: Key facilitators and key barriers that can affect the success of an improvement effort

Part 3: Five recommendations for improving care and five corresponding change ideas, along with links to relevant tools, which these teams have found to be effective:

- Assess intensity and location of pain | *Pain assessment charts*
- Use a sickle cell disease-specific protocol | *Standard order sets*
- Use an individualized prescribing and monitoring protocol | *Pain action plans*
- Consider initiating around-the-clock opioid administration | *Patient-controlled analgesia pumps*
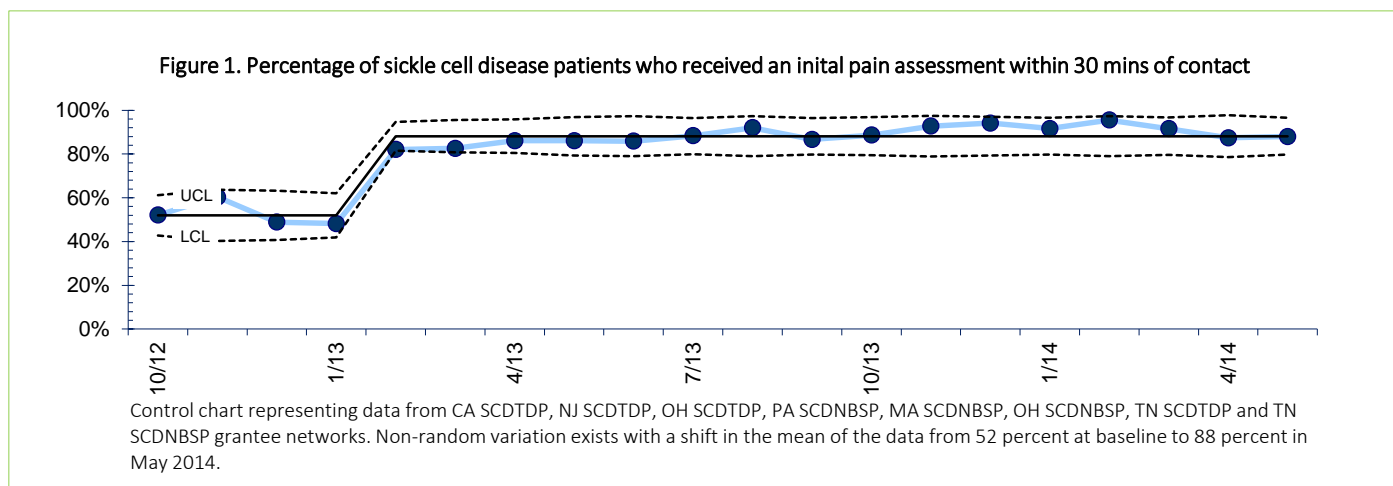- Rapidly initiate analgesic therapy | *Intranasal fentanyl*

The recommendations presented here align with the expert panel report released in 2014 from the National Heart, Lung, and Blood Institute, "Evidence-Based Management of Sickle Cell Disease."[7]
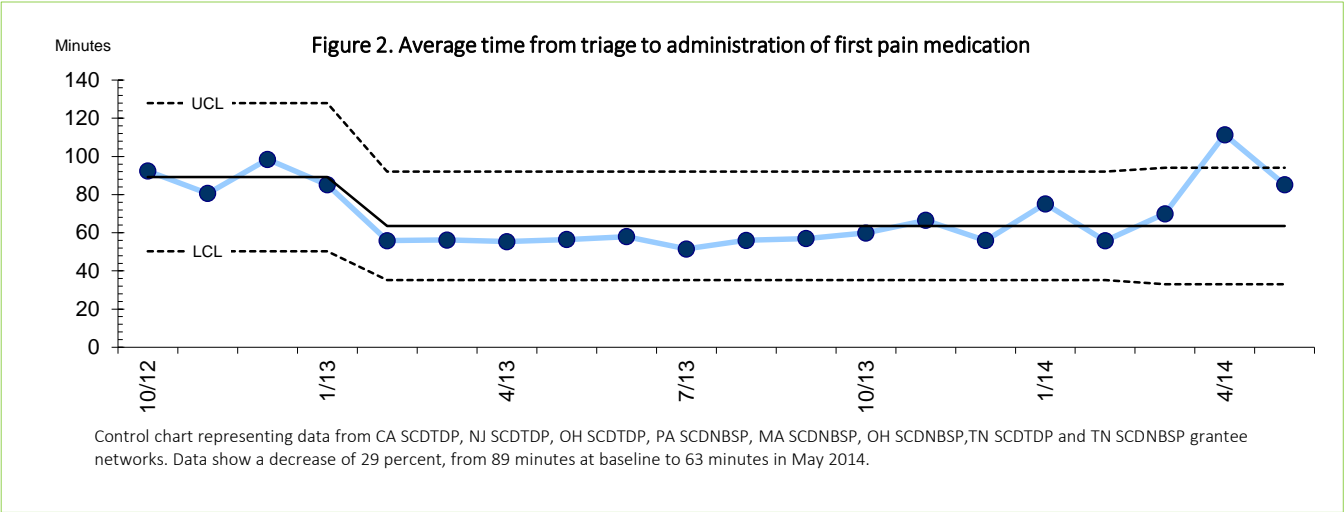
The strategies, lessons learned and change ideas detailed here are drawn from the experience of grantees of the Sickle Cell Disease Treatment Demonstration Program (SCDTDP) and the Sickle Cell Disease Newborn Screening Program (SCDNBSP), two federally-supported programs administered by the Health Resources and Services Administration of the Department of Health and Human Services, between 2010 and 2015.[13] Each grantee consisted of a multidisciplinary team that worked on several dimensions of care for individuals with sickle cell disease and trait; a listing of these grantees can be found here. During this five-year period, NICHQ (the National Institute for Children's Health Quality) served as the national coordinating center for both programs. More information on this work can be found here.

Teams tested many change ideas, selected based on the specific resources and needs of their institutions, using quality improvement methods. Acute care was one of the main areas of focus, and many teams met regularly to share and discuss data through the Acute Care Affinity Group. These teams achieved significant reductions in the amount of time sickle cell disease patients waited to have their pain assessed and to receive their first dose of pain medication (see Figures 1 and 2).

> *"I would dread going to the emergency room because I was afraid of how I would be treated by the doctors and how long I would have to wait. Now I am not afraid to go to the emergency room when I am in pain because my doctor and the emergency room representatives were able to come together and develop a great treatment plan for us. It is amazing to be able to walk in the emergency room and know what the protocol is because you were a part of implementing it and to know that there are people out there who care and want us to be treated fairly and not suffer in pain."*
>
> – Sickle cell disease patient

Figure 1. Percentage of sickle cell disease patients who received an inital pain assessment within 30 mins of contact

Control chart representing data from CA SCDTDP, NJ SCDTDP, OH SCDTDP, PA SCDNBSP, MA SCDNBSP, OH SCDNBSP, TN SCDTDP and TN SCDNBSP grantee networks. Non-random variation exists with a shift in the mean of the data from 52 percent at baseline to 88 percent in May 2014.

Figure 2. Average time from triage to administration of first pain medication

Control chart representing data from CA SCDTDP, NJ SCDTDP, OH SCDTDP, PA SCDNBSP, MA SCDNBSP, OH SCDNBSP,TN SCDTDP and TN SCDNBSP grantee networks. Data show a decrease of 29 percent, from 89 minutes at baseline to 63 minutes in May 2014.

Outcomes from the SCDTDP and SCDNBSP teams' work in acute care can be found here:

- Excerpt from the Sickle Cell Disease Treatment Demonstration Program Congressional Report [NICHQ]
- A Quality Improvement Initiative to Improve Emergency Department Care for Pediatric Patients with Sickle Cell Disease [article]
- Using Quality Improvement Methods to Implement an Individualized Home Pain Management Plan for Children with Sickle Cell Disease [article]

The Acute Care Affinity Group expects to publish a manuscript detailing outcomes from its work in 2015 or 2016.

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Part 1: Strategies for Improving Care

STRATEGY: Use quality improvement methods to improve care

Quality improvement is a helpful framework for achieving improved outcomes for patients with sickle cell disease and their families and has been used extensively in the healthcare field. This approach allows organizations to test many ideas, identify which are effective and which are not, and implement robust processes to support those ideas that yield the greatest results.

There are several models for applying quality improvement techniques. In this work, NICHQ employed the Model for Improvement, a simple yet powerful tool that has been used successfully by hundreds of healthcare organizations to improve a variety of different healthcare processes and outcomes. The model involves addressing three fundamental questions and engaging in iterative tests of change while measuring the impact of those changes on key process and outcome measures.

The three fundamental questions are:

What are we trying to accomplish?

Develop a specific, time-limited, and measurable aim statement

How will we know if a change is an improvement?

Identify process and outcome measures to collect over time in order to track improvement and evaluate progress

What changes can we make that will result in improvement?

Identify ideas to try out that are supported by evidence

Tips for applying quality improvement:

- ✓ When considering a new change idea, start with very small tests involving just a few patients or just one staff member, which minimizes risk and limits resistance.
- ✓ If the initial tests show promise, gradually expand them to more patients, more providers, longer time periods, and different conditions.
- ✓ Measure and assess progress throughout to ensure that the change continues to be effective.
- ✓ If this testing process reveals that a change is no longer effective, reevaluate and, if needed, abandon the change. Some ideas are promising at first but do not result in improvement once tested more broadly.
- ✓ Refine changes after each cycle based on what was learned during the previous test.
- ✓ Continue testing until confident that the change is leading to improvement and should be adopted widely.
- ✓ Spread effective changes throughout the system.
- ✓ Continue to monitor data to ensure that gains are sustained over time.

STRATEGY: Measure progress

A vital component for any improvement effort is a data collection strategy to monitor progress in meeting goals. Measuring progress allows an organization to determine whether a change is actually leading to improvement (in which case it should be tested further and expanded) or not (in which case it should be modified or abandoned). When undertaking a quality improvement project, organizations should:
- Select measures that are feasible to collect and relevant to the goals of the improvement project.
- Develop systems to collect and monitor data.

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- Provide data in real time so that the impact of changes that have been tested can be assessed quickly.
- Use run charts – graphs of data over time – to monitor progress, guide the improvement process, and communicate the impact achieved to internal and external audiences.[14]

In the quality improvement process, data collection is used for learning, rather than for judgment. In fact, using data to judge the performance of individuals, teams, departments or even an entire organization can greatly inhibit the improvement process by making people less open to sharing and learning from the data.

SCDTDP and SCDNBSP teams working on acute care management collected data monthly on several measures that tracked timeliness in delivering care to patients experiencing pain episodes. Typically, this data collection required chart review, although some teams built data collection capacity into their electronic health record systems. See here for a description of the measures collected by these teams.

STRATEGY: Form a multidisciplinary team

Effective systems change requires a team approach and a shared vision. Relying on a single person within an organization to move improvement work forward is rarely successful. Ideally, this team will be multidisciplinary, with members reflecting different perspectives, expertise and resources. Additionally, senior leadership buy-in is essential to the success of any improvement initiative.

For improving care in the emergency department, a team should include the following members:
- Patients and family members
- Providers from the emergency department
- Providers from the hematology program
- Other physicians, nurses, nurse practitioners, physician assistants, psychologists, pharmacists
- Also consider including lay health professionals such as community health workers and patient navigators

Everyone on this team should have regular opportunities to review progress, provide input, and suggest change ideas such as a new protocol or a new pain assessment tool. A subset of the team should manage the improvement process on a day-to-day basis.

STRATEGY: Include the patient perspective

Patients and families bring an invaluable perspective to any healthcare improvement project. In this work, patients and families understand the experience of seeking care for sickle cell disease-related pain, and can translate this understanding into strategies and ideas for improving care. Including patient and family partners as part of the multidisciplinary improvement team enables them to provide input at every stage of the process.

Patients and family members, along with representatives from community-based organizations and key staff members from the hematology and emergency departments, can also form an advisory board that provides periodic feedback on patient experience of care on an ongoing basis.

In addition, teams may find it helpful to seek the input of all patients who receive care in the emergency department. Since the goal is to improve care for patients, their experience of care is as important a measure of success as process data, such as showing reduced wait times. One way to obtain this input is through patient satisfaction surveys, which allow teams to prioritize areas for improvement and give patients and families much-appreciated opportunities to be heard. If implemented consistently over time, these surveys can provide data on the progress of the improvement effort and identify particularly effective practices. A streamlined survey that patients can fill out quickly, in their primary language, is easiest to sustain over time.

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STRATEGY: Facilitate multi-site collaborative sharing

Collaboration with other organizations that are pursuing similar improvement projects can yield valuable ideas and knowledge, reduce duplication of efforts, and provide peer support and encouragement.

The Acute Care Affinity Group was active between 2012 and 2014 and played an integral role in participating teams' success (the group expects to publish its results in the coming year; a summary of results can be found [here](#)). Participants decided early on to collect and share data each month on a small set of measures that would track progress in improving care for sickle cell disease pain episodes. Each month, the group's leaders facilitated a discussion based on the data.

Lessons learned from the Acute Care Affinity Group:

- ✓ Designate one or two leaders who will organize calls. These leaders should collect and aggregate data and facilitate discussion.

- ✓ Agree on vision, objectives, expectations, roles and responsibilities, and meeting format. Write these down and adapt them as needed over time.

- ✓ Schedule meetings at a consistent time. This reduces administrative work and makes it easier for participants to remember and attend calls.

- ✓ Ensure the calls are useful to participants. Ask them what format and content are most useful to them, and assess periodically for feedback.

- ✓ If the group will be sharing improvement data, define a set of measures that all members will report on for each call. Keep the focus narrow; the Acute Care Affinity Group found that focusing on four to six measures was useful and feasible. Designate a data lead to collect data from all sites before each meeting, so participants can see the trends in each site's data and discuss what led to those trends. A webinar format works well, with a few simple slides displaying the data.

- ✓ Hold calls regularly so that experiences are fresh in participants' minds. The Acute Care Affinity Group met monthly, and for a period of time several members also met on a weekly basis.

- ✓ Freely share tools and allow members to adapt them as needed for their sites.

- ✓ Seek outside inspiration and help when needed by inviting experts to join calls and seeking help with facilitation.

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Part 2: Key Facilitators and Key Barriers

In the course of their work, SCDTDP and SCDNBSP teams reflected on which contextual factors influenced their progress both positively and negatively. These are summarized below.

Key facilitators of success

- *Senior leadership support*
  Support from the ED director, hospital leadership, and hospital quality improvement leadership – such as acknowledgement from leadership about the importance of the project – can encourage more people to join the effort and make it easier to sustain changes over time.

  💻 [Engaging Leadership in Quality Improvement Work](#) [NICHQ]

- *Physician champions and nurse champions in the emergency department*
  Ideally, these leaders combine clinical expertise, organizational influence, persistence, commitment and the ability to motivate the rest of their team.

- *Robust involvement of nursing staff*
  Nurses play a critical role in managing sickle cell disease pain episodes and should be involved in designing, testing, evaluating, and implementing change ideas.

- *Alignment of goals*
  When department-specific improvement efforts align with hospital-wide efforts (to improve e.g., quality, patient satisfaction, readmission rates), it is often easier to engage staff members to participate in tests of change and modify their practices.

- *Adequate staffing*
  Improving care takes time and effort, which can be a challenge when hospitals are busy and staff members have many competing priorities. When planning an improvement effort, it is essential to allocate adequate staffing to support data collection, performance monitoring, and the planning and execution of the improvement process (such as systematic PDSA testing).

- *Regular and robust education for all staff*
  Developing a process for ongoing training opportunities that reach all staff members is key to long-term success, especially when there are frequently new staff members in the emergency department (e.g., interns/residents). Examples of effective training strategies include offering videos and other online resources, holding regular in-service trainings (which can be made more appealing by offering food), and holding a yearly provider/patient event that provides an opportunity for patients to share their experiences outside of a medical setting. Education is most effective when it includes both *why* it is important to improve care for patients experiencing sickle cell disease pain episodes and *how* staff can offer high-quality care to those individuals.

  💻 [Emergency Department Sickle Cell Disease: Crisis Management and Beyond](#) [Duke University]

- *Data collection with timely review and feedback*
  It is important to review data frequently and identify problems shortly after they occur, when the circumstances are still fresh in everyone's minds. For example, instances in which patients waited an unacceptably long time to have their pain assessed should be identified quickly and examined.

- *Access to quality improvement expertise*
  Having access to experts in quality improvement – people who have substantial experience in these methods and specific training in how to use data to drive clinical improvement – can accelerate progress.

- *Electronic health record documentation*
  Electronic health record (EHR) systems can help the improvement process immensely. Harnessing this benefit takes time and resources, since these systems usually require extensive customization, but they can help in

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many ways. Programming measures into an EHR system makes data collection and analysis much easier. Building process changes into an EHR system – for example, making an order set easily available electronically – can make it much easier to test and spread these changes.

Key barriers to success

Teams also identified several barriers to their success. While these barriers can present significant challenges, a committed and creative team can achieve meaningful improvement even while facing many of them.

- *Low priority for leadership*
  When improving care in a specialty area is not a priority for departmental or organizational leadership, it can be challenging to find adequate time and resources for the improvement process, for the staff training that is needed to test and adopt new practices, and for changes that require multidisciplinary solutions.

- *Lack of adequate staffing*
  Sometimes, improvement efforts struggle not because of lack of interest or commitment, but because no resources have been designated to sustain it. For example, when data collection and analysis are done entirely on a volunteer basis, they can be inconsistent due to other demands on the volunteers' time.

- *Staff turnover*
  Changing practices within a department is difficult, and gains can be lost over time if new staff members are not educated on the newly adopted practices.

- *Low frequency of individuals with sickle cell disease*
  In some areas with lower frequency of sickle cell disease patients, hospitals receive few visits for uncomplicated pain episodes. This can make it challenging to test change ideas on an adequate number of patients, and with few data points, it can be difficult to see trends in the data.

- *High utilizers*
  In some health systems, a small number of patients account for a high proportion of health care use. Caring for these patients ("high utilizers") is a challenge because there is often a complex interplay between psychosocial needs and health needs. As a result:
    - Improving care for these patients may require a multifaceted approach.
    - Because these patients can influence data trends, it is important not only to review data in aggregate but also to examine patient-level data.
    - Dismissive attitudes toward these patients can make it difficult to improve care for them, and can affect staff members' perception of all patients with sickle cell disease. These attitudes hinder efforts to improve care and increase understanding between providers and patients.

- *Difficulties with electronic health record systems*
  While EHR systems can be powerful tools, it can be difficult to use them effectively. Waiting for technical help can be frustrating, and ensuring that electronic tools are easy to use may require repeated fine-tuning.

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Part 3: Recommendations, Change Ideas and Tools

Most of the changes tested by SCDTDP and SCDNBSP teams aligned with the guidelines for the management of sickle cell disease that were included in the expert panel report published in 2014 by the National Heart, Lung, and Blood Institute (NHLBI). Below, we have indicated which NHLBI recommendation is associated with each change idea. The level of evidence for each recommendation indicated in the NHLBI expert panel report is detailed in parentheses.

RECOMMENDATION: Assess intensity and location of pain

NHLBI Expert Panel Report: In adults and children with sickle cell disease and a vaso-occlusive crisis (VOC): Determine characteristics, associated symptoms, location, and intensity of pain based on patient self-report and observation. If the VOC pain is atypical, investigate other possible etiologies of pain. (Consensus–Adapted)

CHANGE IDEA: Pain assessment charts

Pain assessment charts help patients describe the level of pain they are experiencing. Numerical and picture-based charts allow patients to communicate their pain more clearly, so interventions can be planned accurately.

Outcomes and lessons learned

- Since pain assessment charts are tools that patients interact with directly, it is helpful to get feedback on them from patients and families and refine them accordingly.
- Patients can be involved in refining existing pain assessment charts. The Illinois SCDTDP team's patient partner developed a new pain chart that combines descriptions of pain with drawings of faces and diagrams showing where in the body the patient feels pain. This full-body, color-coded chart was reviewed by medical professionals and a patient advisory board, and early feedback has been promising. In addition to being a standard assessment tool within an emergency setting, it is also a tool that patients can bring with them to the ED to communicate their level of pain.
- Educating both patients and providers about these tools is important. Teams found it helpful to discuss how to use the tools with patients and to provide frequent staff trainings to ensure that they are being used consistently.

> Tools:
>
> 📄 Illinois SCDTDP Pain Assessment Chart
> 🖥️ Wong-Baker FACES Pain Rating Scale©
> 📄 New York SCDNBSP Pain Assessment Chart

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RECOMMENDATION: Use a sickle cell disease-specific pain protocol

NHLBI Expert Panel Report: In adults and children with sickle cell disease and a VOC: Use an individualized prescribing and monitoring protocol (written by the patient's sickle cell disease provider) or a sickle cell disease-specific protocol whenever possible to promote rapid, effective, and safe analgesic management and resolution of the VOC. (Consensus–Panel Expertise)

CHANGE IDEA: Standard order sets

A standard order set is a group of medical orders used to standardize diagnosis and treatment for specific medical conditions, such as sickle cell-related pain, based on clinical practice guidelines. These order sets can be paper based or embedded in an electronic health record. A sickle cell pain order set standardizes the timeframes for triage, assessment of pain, medication administration, and reassessment of pain. The ultimate goal is to expedite patient care and decrease delays in administration of pain medication.

Outcomes and lessons learned

- For staff, standard order sets reduce confusion and hesitation and make it easier to offer consistent care. For patients, knowing that they will receive fast, effective treatment at each visit builds trust and decreases uncertainty. The California SCDTDP team's implementation of a standard order set led to reports of decreased pain intensity over time and significant reductions in the time that patients waited to receive a first dose of analgesic.
- The Massachusetts SCDNBSP team found that the standard pain dose calculator that was placed on the ED intranet as part of the standard order set was very helpful to staff. The calculator ensured that patients received consistent treatment even with rapid turnover of rotating residents within the ED, and the team received very positive feedback from families.
- The Pennsylvania SCDNBSP team found that a standard order set improved the process of determining patients' pain dosing and increased residents' and nurses' confidence in treating sickle cell disease patients.

> Tools:
>
> - California SCDTDP Sickle Cell Initial Order Set
> - Massachusetts SCDNSBP Pediatric ED VOE Protocol
> - New Jersey SCDTDP ED Algorithm
> - Tennessee SCDNBSP Checklist for Pain

RECOMMENDATION: Use an individualized prescribing and monitoring protocol

NHLBI Expert Panel Report: In adults and children with sickle cell disease and a VOC: Use an individualized prescribing and monitoring protocol (written by the patient's sickle cell disease provider) or a sickle cell disease-specific protocol whenever possible to promote rapid, effective, and safe analgesic management and resolution of the VOC. (Consensus–Panel Expertise)

CHANGE IDEA: Pain action plans

Individual pain action plans list pain medication and doses that have been previously effective for that individual. Tailoring pain treatment to the individual facilitates faster and more effective pain management. Care plans should be developed and finalized with patients and their families based on their desired level of engagement.

Outcomes and lessons learned

- The Pennsylvania SCDNSBP team set up a database with patients' personalized care plans that was independent of the EHR system, though plans were scanned into the system for easy access. The team

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found that using these plans reduced confusion in prescribing pain medication, reduced the number of errors in treatment and increased patient satisfaction.

- For the Massachusetts SCDNBSP team, paper-based individualized pain plans were successfully used in the adult ED. While staff found these plans helpful, care was needed to ensure that new patients who do not have a plan receive consistent care as well.
- The Ohio SCDNBSP team created individualized home pain management plans that enable patients and families to treat pain more effectively at home, reducing pain-related visits to the ED. The plans are developed collaboratively with input from the patient and his or her family members, are updated regularly, and are documented in the EHR system. Families have a copy and discuss how to use it with the care team.

> Tools:
>
> 📄 California SCDTDP (English and Spanish) Pain Action Plan
> 📄 Massachusetts SCDNBSP Adult ED Individualized Pain Plan
> 📄 Pennsylvania SCDNBSP Pain Action Plan

RECOMMENDATION: Consider initiating around-the-clock opioid administration

NHLBI Expert Panel Report: In adults and children with sickle cell disease and a VOC associated with severe pain: Initiate around-the-clock opioid administration by patient-controlled analgesia (PCA) or frequently scheduled doses versus "as requested." (Moderate Recommendation, Low-Quality Evidence)

💡 CHANGE IDEA: Patient-controlled analgesia

Patient-controlled analgesia pumps (PCAs) allow patients to control the timing of intravenous administration of their own pain medication, resulting in timely pain relief.

Outcomes and lessons learned
- The Massachusetts SCDNBSP team worked with the ED director and nurse manager to initiate PCA use in the pediatric ED rather than waiting until admission. This was sometimes a challenge due to equipment availability, so the team added PCAs to the start-of-shift checklist. Staff noted they no longer needed to administer IV pain medication at frequent intervals, and the PCA order set was easy to use (see above for more information on standard order sets). Patients and families were happy to have PCAs started earlier during hospital stay.
- The Pennsylvania SCDNBSP team also found that patients appreciated PCAs in the ED: patient satisfaction scores increased and no concerns were raised.
- Teams have found that while patients and their families appreciate having this option, they want to understand all pain management options and have a voice in which one they are given. One team developed a brief fact sheet on pain medication options to give to patients.

> Tools:
>
> 📄 Massachusetts SCDNBSP PCA Handout

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RECOMMENDATION: Rapidly initiate analgesic therapy

Teams also tested innovative approaches to initiate treatment rapidly. One change that they tested is not included in the NHLBI expert panel report: the use of intranasal fentanyl for pediatric patients.[15] Teams that tested this intervention found it enabled them to initiate analgesic therapy very quickly, thereby achieving the NHLBI recommendation to initiate therapy within 30 minutes of triage or 60 minutes of registration. Because of these teams' success, NICHQ recommends that sites consider the use of intranasal fentanyl as a short-term intervention to relieve pain when intravenous access is difficult or until intravenous access is obtained. Additional research on intranasal fentanyl is in progress.[16]

CHANGE IDEA: Intranasal fentanyl

Opioid analgesic administered intranasally (a squirt into the nose) to allow for rapid administration of first dose of pain medication. This medication comes in a liquid preparation and is not available over the counter.

Outcomes and lessons learned

- The Massachusetts SCDNBSP team tested intranasal fentanyl extensively in the pediatric ED as the first line pain treatment for sickle cell pain episodes. Using intranasal fentanyl led to a significant decrease in the time patients waited for the first dose of pain medication, since there was no need to wait for IV placement. The team found that intranasal fentanyl was very successful for younger patients, some of whom were able to avoid IV placement entirely. Some older and heavier patients could not receive a sufficient dose because of concentration limits, so it did not relieve their pain as effectively. Higher concentrations, if available, might be able to benefit these patients.
    - The team encountered many challenges, including nurses' discomfort in administering the medication, but overcame them with a relentless education effort that included charts in the ED, training sessions during which food was offered, and leadership from the nurse ED champion.
    - Patients also had concerns. Initially there was resistance to having a medication squirted into the nose, which can be uncomfortable, especially when patients did not know why it was being used. Patients and families received ongoing education about this new treatment.
    - Over time, the results were positive and both patients and staff became more comfortable with this approach.
- The Pennsylvania SCDNBSP team has begun to test intranasal fentanyl in the pediatric ED. Initial feedback suggested that patients liked the quick pain relief but do not always like the intranasal administration. Patients and families had a lot of questions and the team developed strategies for ongoing education of patients/families about this new approach.

Tools:

📄 [Massachusetts SCDNBSP Intranasal Fentanyl handout](#)
📄 [California SCDTDP ED Protocol for IN Fentanyl](#)

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