



April 11, 2022

National Center for Injury Prevention and Control
Centers for Disease Control and Prevention
Re: Comments on the 2022 Revised Draft CDC Clinical Practice Guideline for Prescribing Opioids
Docket No. CDC-2022-0024

On behalf of the patients, providers, and advocates we work with across the country, Sick Cells would like to extend our sincere gratitude to the Centers for Disease Control & Prevention (CDC) for their efforts in updating the 2016 Opioid Prescription Guidelines. The 2022 updates show strides were taken to describe the nuances of opioid prescription and highlight the exclusion of sickle cell disease (SCD), among other conditions, from the standard approach to opioid pain management. We are grateful to the time and effort that went into updating the guidelines for 2022.

While the updated guidelines are not meant to apply to treatment for SCD, providers across the country will continue to reference them in their treatment of this population, as they did with the 2016 guidelines. Therefore, as dedicated members of the SCD community, we believe that the CDC should harness this moment as a teaching opportunity and strive to ensure the following measures are taken with future iterations of the guidelines:

- The CDC should specifically **request feedback from the SCD community**, both individuals and community-based organizations, during the initial public comment phase of updating guidelines.
- The CDC should **include the reasoning to exclude SCD**, among other conditions, from the guidelines to provide clinicians with an understanding of its uniqueness in treatment.
- The CDC should continue to **underscore how provider bias impacts interpretation** of the CDC guidelines and prescribing practices and can act as a major factor in poor treatment of SCD.

Sickle cell disease (SCD) is an inherited blood disorder that disproportionately affects Black and Brown populations in the United States, including 1 in 365 Black and African Americans, and 1 in 16,300 Hispanic Americans.¹ Recurrent pain crises are one of the most common symptoms of SCD. Many individuals with SCD rely on opioids for pain management throughout these crises and beyond. Due to racism and patterns of health inequities in the United States, the SCD population continues to be marginalized in the realms of research, data collection, education, and access to quality care across the healthcare continuum. Individuals seeking care are frequently labeled as drug seekers and are denied, either by their care team or by administrative opioid regulations, the level of pain management they require.

¹ American Society of Hematology. "Understanding the Impacts of Sickle Cell Disease." Retrieved March 17, 2022.
http://www.scdcoalition.org/pdfs/ASH_Infographic.pdf?_ga=2.174601826.1990484770.1602782758-1290231612.1584826769



The 2022 CDC Opioid Prescription Guidelines highlight that Black patients receive lower doses of opioid pain medication than white patients, and they are less likely to be given a referral to a pain specialist.² Studies have also found that providers undertreat SCD pain due to bias and stigma.³ Because of the negative impact past opioid prescription guidelines have had on the SCD community, **it is crucial that the SCD community is approached for comment and insight when developing updated opioid prescription guidelines.** The unique needs and attributes of individuals with SCD, along with continued patterns of bias, require a nuanced approach to research and the establishment of guidelines. Comments should be requested from individuals with SCD and community-based organizations representing the SCD community.

As members of the SCD community, we were pleased to see the new disclaimer state that the guidelines are not applicable to sickle cell disease, increasing the visibility of the document's limitations. We are hopeful that this will help undo some of the unintentional harm caused by the misapplication of the 2016 opioid guidelines to SCD treatment across the United States. In addition to this disclaimer, **we believe it would benefit providers to know why the listed conditions are excluded.** We find that there continues to be a knowledge gap in providers around treatment for, management of, and ongoing care for individuals with SCD.

Lastly, we are grateful to the many clinicians across the country who provide compassionate care to individuals with SCD. Supportive care teams are crucial to improving the patient experience and increasing quality of life for individuals with SCD. However, this is not the reality for many individuals with SCD, especially in rural areas, areas where there are provider shortages, or areas with low prevalence. Just as we recognize the persistence of provider bias, it is important that the **CDC continue to highlight how provider bias around patients' race, ethnicity, and/or socioeconomic status influences interpretation of the CDC guidelines and prescribing practices.** These biases lead to stigmatization of populations, like the SCD community and impact the quality of care individuals with SCD receive. Our supplemental materials cite relevant studies to use as guidance when writing about this issue in future guidelines.

The CDC plays a vital role in providing guidance to clinicians and filling gaps in knowledge surrounding the use of opioids to treat pain, and we thank them for their commitment to improving the lives of those seeking medical care across the country. Their initiative and humility in recognizing the shortcomings of the 2016 Opioid Prescription Guidelines shows empathy and willingness to learn, some of the most important aspects of medical care. Sick Cells looks forward to supporting the CDC in their dissemination of the 2022 Opioid Prescription Guidelines and continuing to offer our assistance and expertise in matters related to sickle cell disease.

² D. Dowell, K. Ragan, C.M. Jones, G. Baldwin, R. Chour. "CDC Clinical Practice Guidelines for Prescribing Opioids—United States, 2022." Retrieved March 17, 2022. <https://www.federalregister.gov/documents/2022/02/10/2022-02802/proposed-2022-cdc-clinical-practice-guideline-for-prescribing-opioids>

³ Zempsky. (2009). Treatment of Sickle Cell Pain: Fostering Trust and Justice. JAMA : the Journal of the American Medical Association, 302(22), 2479–2480. <https://doi.org/10.1001/jama.2009.1811>



We welcome the opportunity to meet with you to discuss the priorities of the sickle cell community and facilitate engagement with sickle cell disease nonprofits across the country for future initiatives. Please contact Ashley Valentine through the email included in this submission for inquiries related to the contents of this letter or to schedule a meeting. We look forward to working with the CDC to transform health outcomes for sickle cell disease patients across the country.

Respectfully,

A handwritten signature in black ink that reads "Ashley Valentine".

Ashley Valentine
Co-Founder & President
Sick Cells



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Listed below are suggested updates to the CDC [2022 Opioid Prescription Guidelines](#) (Docket No. CDC-2022-0024) submitted by Sick Cells, a national advocacy nonprofit for sickle cell disease (SCD). Please contact Ashley Valentine at Sick Cells through the email included with this submission for inquiries related to the contents of this letter or the suggested changes.

Line	Suggested Change
26	<p>Disclaimer Box: Include reasoning as to why sickle cell disease (and the other listed conditions/types of care) are excluded to increase provider understanding of the uniqueness of these conditions. An alternate resource should be cited to provide guidance, similar to the disclaimer provided in the 2016 for care, end-of-life, and palliative care.</p> <p><u>Suggested Statement for SCD:</u> “The guideline is not intended for patients with sickle cell disease because of the unique needs of this population and the individuality of the disease. The use of opioids for pain management remains an integral part of the care plan for many individuals with SCD and should be understood within this context. For further guidance, consult the American Society of Hematology’s “Management of Acute Complications of Sickle Cell Disease””</p>
157	<p>Include information from research showing the undertreatment of sickle cell disease due to stigma & racism, similar to research supporting the impacts of discrimination on wider minority populations in lines 135-164 . Suggested research:</p> <p>Zempsky. (2009). Treatment of Sickle Cell Pain: Fostering Trust and Justice. JAMA : the Journal of the American Medical Association, 302(22), 2479–2480. https://doi.org/10.1001/jama.2009.1811</p> <p>Phillips S, Chen Y, Masese R, Noisette L, Jordan K, et al. (2022) Perspectives of individuals with sickle cell disease on barriers to care. PLOS ONE 17(3): e0265342. https://doi.org/10.1371/journal.pone.0265342</p>
337-338	<p>Reiterate the reasoning to exclude conditions like sickle cell disease from the 2022 opioid prescription guidelines to improve provider awareness. Explanation should go beyond stating that the guidelines “might not be relevant” to these conditions (lines 396-398).</p>