

Sickle Cell Disease: 2022 Reading List

This brief bibliography contains a variety of resources focused on sickle cell disease. The list contains three sections: factsheets and toolkits for consumers, reports and recommendations for professionals, and peer-reviewed journal articles. All the resources in this list are available to read and download for free. For more resources on sickle cell disease, [contact the OMH Knowledge Center](#) or [browse the online catalog](#).

Consumer Materials

Do You Use the Emergency Department for Care of Sickle Cell Disease? What to Know Before You Go. Centers for Disease Control and Prevention (CDC), 2017.

- English version: [Click here to read](#)
- Spanish version: [Click here to read](#)

Toolkit for Living Well with Sickle Cell Disease. Centers for Disease Control and Prevention (CDC), 2014. [Click here to read](#)

Sickle Cell Disease: A Family Guide. (4th edition) Savage B., et al. New Jersey Department of Health; Division of Family Services; Newborn Screening and Genetic Services, 2017. [Click here to read](#)

Understanding Sickle Cell Disease. American Society of Hematology (ASH), 2019. [Click here to read](#)

Hydroxyurea for Sickle Cell Disease: Treatment Information from the American Society of Hematology. American Society of Hematology (ASH), 2020. [Click here to read](#)

A Century of Progress – Sickle Cell Disease: Milestones in Research and Clinical Progress. National Heart Lung and Blood Institute (NHLBI), 2018. [Click here to read](#)

Sickle Cell Disease: Hydroxyurea: What You Should Know. National Heart, Lung, and Blood Institute (NHLBI), 2018.

- English version: [Click here to read](#)
- Spanish version: [Click here to read](#)

Sickle Cell Disease: Managing Pain. National Heart, Lung, and Blood Institute (NHLBI), 2018.

- English version: [Click here to read](#)
- Spanish version: [Click here to read](#)

Reports

Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action. National Academies of Sciences, Engineering, and Medicine, 2020. [Click here to read](#)

2019-2021 ASH Clinical Practice Guidelines on Sickle Cell Disease (SCD): What You Should Know. American Society of Hematology (ASH), 2021. [Click here to read](#)

Characteristics of Inpatient Hospital Stays Involving Sickle Cell Disease, 2000–2016. Fingar K.R., et al. Agency for Healthcare Research and Quality (AHRQ), 2019. [Click here to read](#)

Strategies from the Field: Data Collection. National Center on Birth Defects and Developmental Disabilities, Division of Blood Disorders, 2018. [Click here to read](#)

Strategies from the Field: Health Promotion. National Center on Birth Defects and Developmental Disabilities, Division of Blood Disorders, 2018. [Click here to read](#)

Journal Articles

The State of Sickle Cell Disease Care in the United States: How Can Emergency Medicine Contribute? Giroir BP, et al. *Annals of Emergency Medicine*, v. 76, #3S, p. S1–S3, 2020. [Click here to read](#)

Barriers to Care and Quality of Primary Care Services in Children with Sickle Cell Disease. Jacob E., et al. *Journal of Advanced Nursing*, v. 72, #6 (June), p. 1417-1429, 2016. [Click here to read](#)

CDC Grand Rounds: Improving the Lives of Persons with Sickle Cell Disease. Hulihan M., et al. *Morbidity and Mortality Weekly Report (MMWR)*, v. 66, #46 (November), p. 1269–1271, 2017. [Click here to read](#)

Effective Recruitment Strategies for a Sickle Cell Patient Registry Across Sites from the Sickle Cell Disease Implementation Consortium (SCDIC). Masese R.V., et al. *Journal of Immigrant and Minority Health*, v. 23, #4 (August), p. 725-732, 2021. [Click here to read](#)

Family Engagement in Pediatric Sickle Cell Disease Visits. Cox E.D., et al. *Health Communication*, v. 32, #1 (January), p. 51-59, 2017. [Click here to read](#)

Lifespan Care in SCD: Whom to Transition, the Patients or the Health Care System? Minniti C.P., et al. *American Journal of Hematology*, v. 92, #6 (June), p. 487-489, 2017. [Click here to read](#)

Management of Chronic Pain in Adults Living with Sickle Cell Disease in the Era of the Opioid Epidemic: A Qualitative Study. Sinha C.B., et al. *JAMA Network Open*, v. 2, #5 (May): e194410, 2019. [Click here to read](#)

Reducing Health Care Disparities in Sickle Cell Disease: A Review. Lee L., et al. *Public Health Reports*, v. 134, #6 (November-December), p. 599-607, 2019. [Click here to read](#)

The Role of Patient-Physician Communication on the Use of Hydroxyurea in Adult Patients with Sickle Cell Disease. Jabour S.M., et al. *Journal of Racial and Ethnic Health Disparities*, v. 6, #6 (December), p. 1233–1243, 2019. [Click here to read](#)

Trends in Sickle Cell Disease-Related Mortality in the United States, 1979 to 2017. Payne A.B., et al. *Annals of Emergency Medicine*, v. 76, #3 Supplement (September), p. S28-S36, 2020. [Click here to read](#)

The OMH Knowledge Center contains a collection of over 70,000 documents, reports, books, consumer materials, and journal articles related to the health status of racial and ethnic minority populations. Knowledge Center staff can respond to requests from the public by providing selective bibliographies of articles and books in its collection.

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