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## Sickle Cell Data Collection Program Brief

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# SICKLE CELL DATA COLLECTION PROGRAM BRIEF

May 2018

## BETTER ACCESS TO OUTPATIENT CARE MAY DECREASE EMERGENCY VISITS AND COSTS



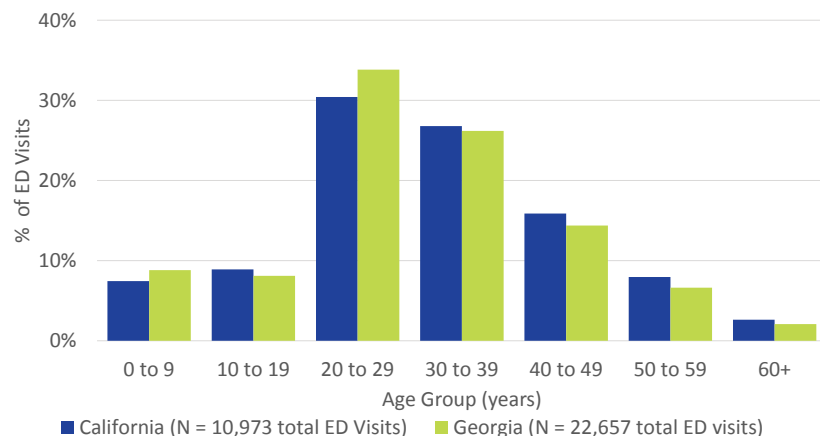
For patients with sickle cell disease (SCD) who lack access to specialists or primary care physicians informed about their condition, health care is often limited to the emergency department (ED). New data from the Sickle Cell Data Collection programs in California and Georgia shows that public payers are responsible for the majority of costs associated with these ED visits. An increased focus on access to high-quality, coordinated care — both preventive and SCD-related — may decrease ED visits and costs, while improving quality of life for this population.

### ED USE IS COMMON FOR SICKLE CELL PATIENTS

In 2016, there were a total of 33,630 SCD-related visits to EDs in California and Georgia, including a marked increase in ED visits among patients in early adulthood, as they transition from pediatric to adult care. ED visits for those aged 20 to 39 years accounted for more than half of all ED visits by SCD patients.

While some negative effects of the disease are more likely as patients age (e.g., organ damage and stroke-related disability), this increase in ED visits may also be related to the lack of insurance and access to comprehensive care that adults with SCD commonly experience.

Percentage of All SCD-Related ED Visits  
In California and Georgia by Age Group, 2016

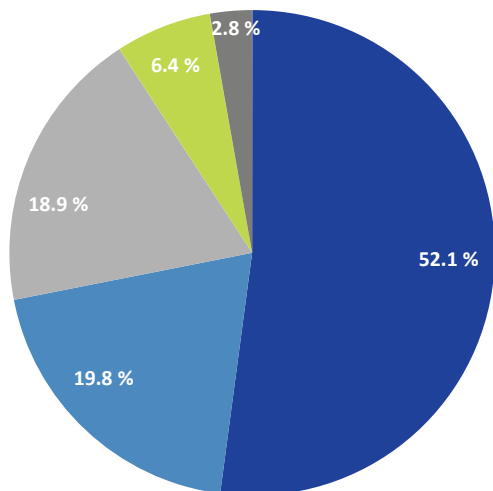


## PUBLIC PAYERS FUND MAJORITY OF SCD-RELATED EMERGENCY VISITS

Over the three-year period from 2014 to 2016, data from the Sickle Cell Data Collection programs shows that in both California and Georgia, public payers — Medicare and Medicaid — paid for more than 70% of SCD-related ED costs.

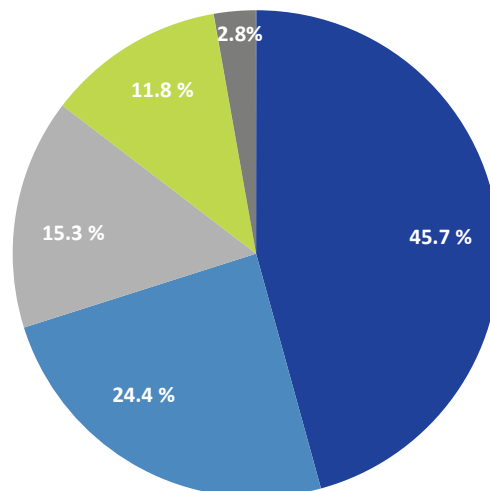
California Payer Mix for SCD-Related ED Visits, 2014-2016

■ Medicaid ■ Medicare ■ Private ■ Self-pay ■ Other



Georgia Payer Mix for SCD-Related ED Visits, 2014-2016

■ Medicaid ■ Medicare ■ Private ■ Self-pay ■ Other



Previous studies have shown that medical expenditures for patients with SCD are considerably higher than similarly insured and similarly aged patients without SCD.<sup>1</sup> Lifetime medical costs for patients with SCD are substantial — \$1 million for an SCD patient reaching 45 years of age.<sup>1</sup> Given the high-cost of care, payers are incentivized to find cost-effective means to reduce costly ED visits due to disease crises.

## POLICY IMPLICATIONS

It has been shown for other chronic conditions that having a regular doctor and coordinated care — which might include case management, home visits, or telemedicine consultations — can reduce ED visits and cut total medical costs.<sup>2-4</sup> If the same holds for patients with SCD, these findings suggest a potential for significant savings. Better access to SCD-specific outpatient care that follows evidence-based practice recommendations may improve overall disease management of SCD and decrease reliance on expensive ED services.<sup>5</sup> Policymakers may find these data from the Sickle Cell Data Collection programs helpful as they consider ways to improve SCD patients' access to outpatient care, to develop coordinated care models for patients with SCD, and to increase SCD expertise among health care providers (through education, workforce incentives, and telemedicine).

<sup>1</sup> Kauf, T. L., Coates, T. D., Huazhi, L., Mody-Patel, N., Hartzema, A. G. (2009). The cost of health care for children and adults with sickle cell disease. *American Journal of Hematology*, 84(6), 323-327.

<sup>2</sup> van dan Berg, M.J., van Loenen, T., Westert, G.P. (2015). Accessible and continuous primary care may help reduce rates of emergency department use. An international survey in 34 countries. *Family Practice*, 33(1), 42-50.

<sup>3</sup> Darkins, A., Kendall, S., Edmonson, E., Young, M., Stresell, P. (2015). Reduced cost and mortality using home telehealth to promote self-management of complex chronic conditions: a retrospective matched cohort study of 4,999 veteran patients. *Telemedicine and e-Health*, 22(1).

<sup>4</sup> Ruiz, S., Snyder, L.P., Rotondo, C., Cross-Barnet, C., Colligan, E.M., Giuriceo, K. (2017). Innovative home visit models associated with reductions in cost, hospitalizations, and emergency department use. *Health Affairs*, 36(3), 425-432.

<sup>5</sup> Yawn, B. P., Buchanan, G. R., Afenyi-Annan, A. N., Ballas, S. K., Hassell, K. L., James, A. H., ... John-Sowah, J. (2014). Management of sickle cell disease: summary of the 2014 evidence-based report by expert panel members. *Journal of the American Medical Association*, 312(10), 1033-1048.