

Sickle Cell Care Coordination Initiative

Thank you for being a part of the Needs Assessment!

In 2017-18, we surveyed and interviewed 58 people with sickle cell disease ages 15 – 48 years and 56 of their healthcare providers and community leaders, all from Alameda, Contra Costa, Sacramento, San Francisco and Solano counties.

Our goal was to understand more about healthcare barriers for adolescents and adults with sickle cell disease, so that we can work on making real and long lasting improvements.

What we found . . .

84% of adolescents and adults surveyed said that they just tried to take care of their severe pain at home, rather than going to the emergency room at all.

Some Challenges Discussed:

- Pain, fatigue, emotional burden of sickle cell disease
- **Bad** experiences with the healthcare system
 - Being accused of drug seeking
 - **Long** waits in emergency departments
 - Being questioned about pain level
 - Feeling emergency **providers do not really care**
- **Trouble** finding knowledgeable or experienced providers for care
- Transportation, insurance, support systems
- **Struggle** finding places to go where they can learn how to stay well and to manage pain so that it does not interfere so much with their daily life.

Positive Results:

- Adolescents and adults were **most comfortable** with their sickle cell providers.
- Adolescents and adults with **more confidence** in their ability to manage their sickle cell disease had **lower pain ratings**.

Providers' feedback:

- They **want** to take care of people with sickle cell disease.
- But they need access to guidelines for care and care coordinators who can help individuals with sickle cell disease deal with insurance and transportation issues.
- Sickle cell and primary care providers were concerned that the behavioral and mental health needs of individuals with SCD were not being met.



What's Next?

- Regular meetings and better paths of communication between sickle cell providers, primary care providers, emergency department providers, and adolescents and adults with sickle cell disease in Northern California
- Educational opportunities for providers in the area, that includes patient presentations that can give the providers first hand accounts of patients' healthcare experiences and the impacts of those experiences on their lives
- Meetings with administrators and policy makers to strategically improve sickle cell care coordination

What you can do . . .

- Stay tuned for studies that will be rolled out in Northern California and around the U.S. to
1) improve emergency department care and 2) support providers and individuals with sickle cell disease in using hydroxyurea.
- Please be a part of our Registry, that tracks the health and healthcare of adolescents and adults with sickle cell disease from around the U.S. The Registry will allow us to know how effective our strategies are.

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Other Resources:

Sickle Cell Community Advisory Council

Contact Name: Wanda Williams

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Sickle Cell Anemia Awareness of San Francisco Foundation

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Sickle Cell Community Health Network

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