

HELP US UNDERSTAND MORE ABOUT ADULTS AND CHILDREN WITH SICKLE CELL DISEASE



Thank you for being a part of the Pacific Sickle Cell Regional Collaborative (PSCRC) Minimum Data Set! Our goal was to understand more about adults and children with sickle cell disease seen in the seven Pacific Region states. Data was collected throughout ten clinical sites with 407 participants across Alaska, Arizona, California, Idaho, Nevada, Oregon, and Washington from May 2016 through August 2017.

WHAT?

We asked adults with sickle cell disease (18 years and older) and parents of children with sickle cell disease about experiences with hydroxyurea, and about any

concerns they might have with the medicine. Hydroxyurea is a medicine that can help children and adults with sickle cell disease by decreasing pain episodes, days in the hospital and episodes of acute chest syndrome.

WHO?

169 adults with sickle cell disease and 238 parents of children with sickle cell disease. Half were males and half were females. **93%** were African American and **74%** had the diagnosis of SS disease.



NEXT STEPS:

The PSCRC has expanded to 13 Western states. PSCRC providers are working together to figure out the best ways to support adults with sickle cell disease and parents of

children with sickle cell disease about hydroxyurea so that you fully understand the benefits of the medicine and any risks. We know that hydroxyurea is safe when you work closely with your health care provider. Your doctor or nurse will give you instructions about getting blood work, about how often to come into clinic and about the right dose for you or your child.

WHAT CAN YOU DO:

Talk with your doctor or nurse if you have any questions about whether or not hydroxyurea is right for you. If you were prescribed hydroxyurea but have any concerns or barriers to taking it, let your doctor or nurse know. You can come up with a plan together with your health care provider that will lead to your best health!

47% of adults and **67%** of children were on hydroxyurea

Adults said they had barriers to taking hydroxyurea more often, compared with parents of children (**81%** of adults said they had at least one barrier compared with **57%** of parents)

Adults were worried about side effects more often (**22%** compared with **13%** of parents)

Adults said that forgetting to take the medicine got in the way more often (**20%** compared with **8%** of parents)

Updated September 2020. For more information, visit: pacificscd.org or casicklecell.org

