

MDH Long Term Follow-up of Children Identified with Sickle Cell Disease (SCD) through Newborn Screening, 2013 – 2018

In 2013 the Minnesota Department of Health (MDH) Newborn Screening (NBS) Program began referring children with a confirmed hemoglobinopathy condition identified through newborn screening to the MDH Newborn and Child Follow-up Unit (NCFU) for public health long term follow-up (LTFU).

Hemoglobinopathy category	Number	Percent
Sickling hemoglobinopathy types (Sickle Cell Disease)		
Sickle Cell disease (Hb SS)	73	64%
Sickle-C disease (Hb SC)	25	22%
S-Beta thalassemia (Hb S β -thalassemia)	13	11%
Other sickling types (Sickle D, E, and O disease)	3	3%
Subtotal with Sickle Cell Disease	114	100%
Other hemoglobinopathy types	14	
Total of all hemoglobinopathies	128	

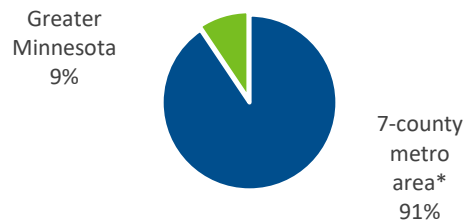
Types of Sickle Cell Disease (SCD)

Sickle Cell disease (Hb SS), Sickle-C disease (Hb SC), and S-beta thalassemia are the most common types of SCD. Sickle D, E, and O disease are rarer types of SCD. These sickling types of hemoglobinopathies are collectively known as Sickle Cell Disease (SCD). Subsequent data in this report are specific to children with SCD as identified through newborn screening.

Geographical Distribution

Although just over half of all children ages 0-4 in MN live in the 7-county metro area*, 91% of children with SCD live in the same metro area.

Distribution of Residence

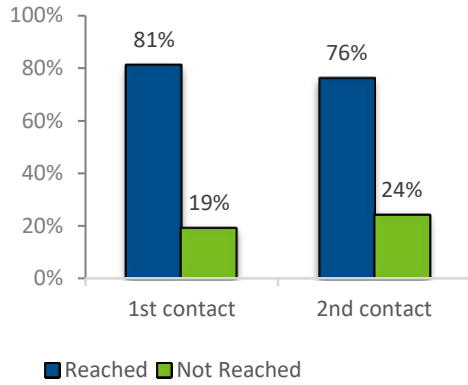


*Anoka, Carver, Dakota, Hennepin, Ramsey, Scott, and Washington counties

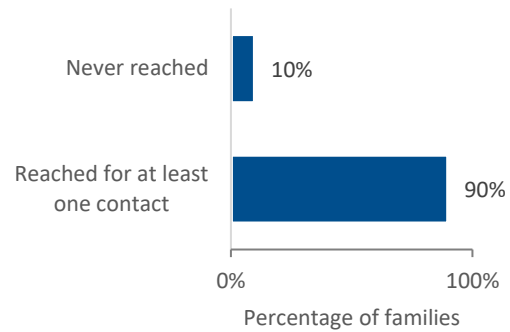
Assessments

Currently, MDH LTFU nurses attempt to reach families at two different points in early childhood. Nursing assessments are done over the phone with a parent or guardian shortly after diagnosis and again one year later. 90% of families were reached for at least one contact. 10% were never reached. The majority of data were obtained by parent/guardian self-report. If families were not reached, data were unknown.

Families Reached, percent by contact type

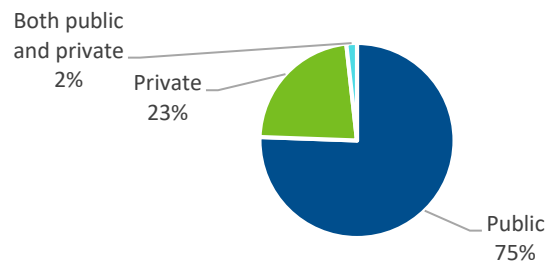


Families Reached, all contacts



Health Insurance Status

All children with known health insurance status were insured. Of those, the majority (75%) of children utilized public insurance programs. Insurance status was unknown for 18% of children.



Primary Care

Virtually all families who were reached (99%) had established care with a primary care provider and most (93%) were on track with preventive care. For families that could not be reached directly, MDH was able to obtain primary care status from other sources such as the initial referral, however the status for 8% of children was still unknown.

Specialty Care

Nearly all children received care at a hematology specialty clinic. Four hematology specialty clinics in MN provided care to children: Children's Minnesota - Minneapolis; University of Minnesota - Minneapolis; Mayo Clinic - Rochester; and Essentia Health - Duluth. Of families reached, 90% were seen in the previous 3 months and nearly all (99%) were seen in the last 6 months. Timing of last hematology visit was unknown for 24% of children.

