Performed during Screening period to confirm eligibility. Testing should be completed at this time regardless of whether newborn screening was performed. Testing should be performed at least 12 weeks after most recent exchange transfusion. Some diagnostic methods may only capture a subset of hemoglobin genotypes; if this is the case, a secondary method must be completed to obtain a complete dataset. Core data elements should be collected on all clinical research studies.

\*Hemoglobin Analysis

\*Method Used:

High performance liquid chromatography (HPLC) - ***preferred***

Isoelectric focusing (IEF) - ***preferred***

Capillary zone electrophoresis (CZE)

Gel electrophoresis

Point of Care (consideration for low resource geographies)

Other

\*Results (%):

HgS

HgC

HgF

HgA

HgA2

Genetically modified HgA variant

Other, specify

\*Parent testing:

α- and β-thalassemia Testing Results

GENERAL INSTRUCTIONS and NOTES

* Performed during Screening period to confirm eligibility. Testing should be completed at this time regardless of whether newborn screening was performed.
* Testing should be performed at least 12 weeks after most recent exchange transfusion.
* Some diagnostic methods may only capture a subset of hemoglobin genotypes; if this is the case, a secondary method must be completed to obtain a complete dataset.
* The questions Supplemental unless they are indicated with \* to be Core. Core data elements should be collected on all clinical research studies.
* Reference doc: <https://www.aphl.org/aboutAPHL/publications/Documents/NBS_HemoglobinopathyTesting_122015.pdf>