

Statewide Sickle Cell Disease Registry Statement

July 15, 2024

Background

On April 4, 2024, Governor Glenn Youngkin signed into law [HB 252](#) which mandates the creation of a statewide registry for sickle cell disease, including the collection of disease case information. The law has been enacted as [Chapter 437 of the 2024 Acts of Assembly](#).

The statewide registry of sickle cell patients will be maintained by the Virginia State Health Commissioner. The new law adds Sections 32.1-73.22 through 32.1-73.27 to the Code of Virginia. The law includes information about who shall report data to the registry, the purpose of the registry, parameters for the collection of the data, confidentiality of the registry data, penalties for unauthorized use of the registry data, and patient rights. The law specifically stipulates that patients with sickle cell disease may self-report and may opt out of having their data reported to the statewide sickle cell disease registry. Finally, the law requires the Board of Health to promulgate regulations pertaining to on-site data collection and requires the State Health Commissioner to submit an annual report on the status of the registry to the Governor and General Assembly.

Status Update

Per the Code, the Virginia Department of Health (VDH) is responsible for establishing and maintaining the statewide sickle cell registry. HB 252 became effective July 1, 2024.

As of July 1, VDH has begun engaging in work to design the registry and establish its infrastructure, pursuant to the Code. This includes identifying the processes through which data will be collected, selecting the data elements the agency will collect, and drafting regulations. VDH plans to seek stakeholder input on the design of the registry.

Once VDH has finalized the plans for the design of the registry, VDH will determine a timeline for each phase of implementation to communicate to stakeholders.

Given this, hospitals, clinics, laboratories, and physicians are not yet required to collect data on patients with sickle cell. VDH will keep stakeholders informed of updates related to the status of the registry, including when providers will be expected to begin collecting data and the guidelines for collection and reporting. VDH will provide informative materials and technical assistance to support providers in collecting this information at that time.

What This Means for Providers

Hospitals, clinics, laboratories, and physicians should wait for further outreach from VDH to begin collecting this data. If you are interested in staying updated on the agency's progress on the registry, you can fill out this [form](#) to join our outreach list.
