Establishment of a Sickle Cell Registry in Louisiana: Feedback on Preliminary Recommendations – June 2023

The Louisiana Department of Health (LDH) has initiated the work to establish a Sickle Cell Disease (SCD) public health registry in the state as required by Act 647 of the 2022 Regular Session of the Louisiana Legislature. As highlighted by the 2020 National Academies of Sciences, Engineering, and Medicine report, *Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action*, patient registries and public health monitoring systems are foundational to improving clinical care and public policy that promotes health and quality of life. The LDH Office of Public Health (OPH) Bureau of Family Health is leading the development of the registry. This report summarizes the feedback on the preliminary recommendations related to defining the purpose, use, operations, and technical requirements of the state's future sickle cell registry.

Overview of Actions and Findings

In March 2023, the LDH OPH Bureau of Family Health published the Establishment of a Sickle Cell Registry in Louisiana: Preliminary Research, Findings, and Recommendations – February 2023. This report was drafted based on a scan of national best-practices and the elicitation of input from partners including the Louisiana Sickle Cell Commission (LSCC), the state's Sickle Cell Disease foundations, public health experts within LDH, and a Sickle Cell Disease Registry Steering Committee including clinicians and individuals with lived experience. This inquiry was conducted primarily between July 2022 and January 2023.

From March through mid-April 2023, a public input survey was posted on the BFH website to allow for additional feedback beyond the engaged process described above. The link was shared with partners and other relevant groups. The survey was built using REDCap and contained multiple choice and open-ended questions allowing respondents to share their comments. The final section of the survey allowed respondents to provide their contact information in case a response was requested.

At the end of the survey period, there was a total of eight completed responses. The respondents were from various backgrounds including state health department staff, healthcare providers, patient advocates, and other interested providers. All respondents agreed that they understood the rationale behind developing a Sickle Cell registry in Louisiana. Additionally, 7 out of 8 respondents agreed that a registry could be used to direct resources and services as well as help improve health outcomes. In the following section, there were three recommendations for next steps from the initial report that respondents commented on: 1) that the registry have a clear purpose, defined allowable uses, and safeguards, 2) hold additional discussions to explore what the registry should be able to do to help specific individuals who are diagnosed with Sickle Cell Disease and Sickle Cell Trait, and 3) analyze the currently available data in order to inform whether additional reporting will be necessary to be complete. The responses on the proposed recommendations were divided between "Completely On Track" and "Close But Not Quite", while none of the participants chose "Completely Missing the Mark".

Next Steps

The recommendations that emerged from the Bureau's initial planning and feedback processes align with national guidance for states developing sickle cell registries. Starting in July 2023, the LDH OPH Bureau of Family Health will initiate the more intensive planning steps for the registry. This work will address the recommendations in the preliminary report the Bureau of Family Health published in February 2023. The Bureau's most immediate next actions are to:

- Establish a formal multi-disciplinary guidance team
- Secure and orient personnel to lead the development of the registry
- Secure analytic support to conduct the nationally-recommended analyses and the analyses recommended by Louisiana partners
- Establish data use and data sharing agreements necessary to analyze data currently received or directly collected by LDH through newborn screening, Medicaid claims, hospital discharge (all payor), emergency room discharge, vital records, and patient-level data from contracted sickle cell disease clinics and foundations (community-based support providers);
- Memorialize the legal authorities (and restrictions) on using data for the registry; and,
- Link and analyze available data and publish a summary report of SCD and sickle cell trait (SCT) in the state based on available data with information about the timeliness, accuracy, completeness and feasibility of using data from the various existing data sources to achieve the required and proposed purposes of the registry.