DEVELOPING A DATA-DRIVEN SICKLE CELL DISEASE PUBLIC HEALTH SURVEILLANCE AGENDA IN CALIFORNIA

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Objective or Purpose

Sickle cell disease (SCD) is the most common severe genetic disease in the US, affecting approximately 7,000 people in California. Yet stakeholders know remarkably little about the people living with SCD as a whole. In contrast to some other genetic diseases, no national registry or tracking system has collected consistent information about the health and health care of people with SCD over the long term. Estimates of the prevalence of disease are not based on patient counts but rather on extrapolations of newborn screening data using statistics on life expectancy or are based on patient counts from hospital discharge databases.

Patients, advocates, clinicians, policymakers and other SCD stakeholders in California need accurate, up-to-date and longitudinal information to determine the healthcare needs of individuals living with SCD across the state and how well current systems of care are meeting needs, to inform the development of better care models, and to establish cost-effective practices that improve health and quality of life.

The California Sickle Cell Data Collection (SCDC) Project, a Center for Disease Control and Prevention (CDC) effort funded by the CDC Foundation, uses population-based surveillance methodology to identify a cohort of all persons with SCD living in the state with the goal of better understanding SCD at the population level. Its objective is to continue using and improve upon developed methods and data sources for understanding SCD at the population level in the state, as well as to analyze the data collected and disseminate results of these analyses to audiences who will drive policy and health care changes, in turn leading to improvements in quality of life, life expectancy and health among those living with SCD.

SCDC builds on California's earlier work on National Institutes of Health/CDC's Registry Surveillance System for Hemoglobinopathies (RuSH) and CDC's Public Health, Research, Epidemiology and Surveillance in Hemoglobinopathies (PHRESH) cooperative agreements. These earlier projects demonstrated the importance of a broad-based, long-term population-level surveillance effort for SCD.

Method

SCDC and earlier surveillance systems use data sources that include administrative data (hospital discharge data, emergency department data, and Medicaid claims), newborn screening case reports, vital records and clinical case reports. These data have been linked, de-duplicated and condensed to form a profile of the health conditions, health care and outcomes of the SCD population.

To determine the most important health related questions to ask of the data, SCDC created a participatory process for listening to the voices of stakeholders when setting priorities. Meetings with over 20 stakeholder groups in California and at the federal level in 2015 helped to identify data collection, analysis and dissemination areas that could inform best practices for policy and healthcare leading to improvements in quality of life, life expectancy and health among those with SCD. The SCDC team then conducted extensive research into the areas identified as most important by participants in these meetings to determine how best to address these information needs.

Results

Meetings with stakeholder groups led SCDC to select five target topics for analysis and dissemination using the data. We will present what is known about these topic areas and the information gaps identified.

- Patient geography – where in California to people with SCD live, and how does their location impact their access to care and health outcomes
- Transition to adult care – where do young adults in California receive the majority of their care after leaving the pediatric setting, and how does the site of their care impact their health?
- Hispanics with SCD – clinicians in Southern California noted that they are seeing a high number of previously undiagnosed SCD cases among immigrant populations, and Hispanic/Latino patients describe challenges accessing care – can we quantify and describe these problems?
- The aging SCD population – what are the specific healthcare needs and patterns among individuals with SCD who are over age 45, and are they being addressed?
- Emergency room utilization patterns – how are people with SCD using the emergency room and for what kinds of care, and what are the health outcomes of those most reliant on this form of care?

Conclusions

By determining the needs for information that can be addressed with a statewide and population based data collection effort over time, the SCDC has made important strides toward addressing SCD as a public health problem. With the inclusion of scores of stakeholders from the state and at the federal level, the California SCDC Project has aligned the analysis, distribution, and use of its data with the overall public health policy, education and outreach priorities of those who understand best the problems faced by those with SCD. SCDC is using collected data to support an array of efforts, from measuring the impact of a new SCD clinic in Los Angeles County on the health of its patients to raising awareness of the disease among state politicians. A number of collaborative publications are also in the pipeline describing findings on these target topics. SCDC will continue to use this successful participatory process to inform its priorities, with upcoming stakeholder meetings planned.