

Sickle Cell Disease Stakeholders Meeting Meeting Summary

On Wednesday, August 22, 2012 federal and community stakeholders met at the American Society of Hematology (ASH) headquarters in Washington, DC with the two primary goals: 1) identify priorities and the corresponding activities that should be addressed in sickle cell disease (SCD) and 2) determine which activities would be most appropriately accomplished by the Centers for Disease Control and Prevention (CDC) in partnership with other stakeholders. Stakeholders attending the meeting included representatives of ASH, SCDA, CDC, AHRQ, FDA, OMH, MCHB, NHLBI, NICHQ, Children's Hospital of Chicago, Children's Hospital of Philadelphia, Mount Sinai Hospital, Children's Hospital of Michigan, Children's Hospital of Pittsburgh, University of Miami, National Medical Association, and Destiny Sickle Cell and Wellness Center.

Dr. Althea Grant, Acting Division Director of the Division of Blood Disorders at CDC began the meeting by summarizing CDC's mission and the mission and the organization of the Division of Blood Disorders. CDC's mission is to *create the expertise, information, and tools that people and communities need to protect their health – through health promotion, prevention of disease, injury and disability, and preparedness for new health threats*. The Division of Blood Disorders' mission is to *reduce morbidity and mortality from blood disorders through comprehensive public health practice* and seeks to support this mission through surveillance and epidemiologic research, prevention and health services research, and laboratory sciences. Recent and on-going CDC activities in SCD have included establishing systems for data collection and monitoring, tracking emerging threats through blood safety surveillance, developing resources for people living with SCD, providers, and families, and fostering collaboration among state and local partners.

To distinguish CDC's role within public health from that of other agencies, federal agency representatives from HRSA, NHLBI, FDA, and AHRQ each gave a brief synopsis of the function of their agency and summary of their activities in the area of SCD.

- The Health Resources and Services Administration (HRSA) is the primary federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable. HRSA is involved in several programs to improve sickle cell care. HRSA funds the Sickle Cell Disease Treatment Demonstration Program, the Sickle Cell Disease Newborn Screening Program, and the Hemoglobinopathy Uniform Medical Language Ontology Project. HRSA is also partnering with other agencies of the Department of Health and Human Services to create and monitor objectives in the Healthy People 2020 initiative in sickle cell.
- The Division of Blood Diseases and Resources of the National Heart, Lung and Blood Institute (NHLBI) funds basic, translational and clinical research in hemoglobinopathies by academic investigators across the U.S. and internationally. It also funds training of physician scientists and other scientists to gain expertise in this field. NHLBI has recently created a new strategic plan for hemoglobinopathies that provides detail about strategies to achieve these two goals. In

ASH – American Society of Hematology; SCDA – Sickle Cell Disease Association of America; AHRQ – Agency for Healthcare Research and Quality; FDA – Food and Drug Administration; OMH – Office of Minority Health; MCHB – Maternal and Child Health Bureau; NHLBI – National Heart, Lung and Blood Institute; NICHQ - National Initiative on Children's Healthcare Quality

addition, within NHLBI the Division for the Application of Research Discoveries (DARD) develops medical and research information for physicians and consumers based on validated research, including creation and dissemination of sickle cell guidelines across for the nation.

- The FDA was not able to provide a written statement for this summary.
- The Agency for Healthcare Research and Quality (AHRQ) as an active partner of the HHS initiative on sickle-cell disease will be involved in supporting research and promoting evidence based best practices to improve health care services and outcome for all Americans with SCD, which is aligned to its mission of improving quality, safety, efficiency and effectiveness of healthcare by improving healthcare outcomes through research, and transforming research into practice. AHRQ is presently supporting a project entitled ‘Improving Sickle Cell Transitions of Care through Health Information Technology’. Another demonstration and dissemination project presently underway is ‘Improving Emergency Department Management of Adults with SCD.’

Overall Public Health Needs in SCD

In the first sessions of the day, attendees engaged in a discussion about the public health priorities for various sickle cell disease stakeholders including people with SCD and their families, medical care providers, community-based organizations and federal agencies.

People with SCD and their Families. Education, awareness and access to care emerged as topics of high priority for people living with SCD and their families. In particular, the group articulated a need to develop credible educational resources for people living with SCD and families on the benefits and side effects of hydroxyurea, resources on trait education and reproductive issues, resources on attaining education and vocational training, materials on navigating developmental transitions/what families need to know as children get older, and decision support tools for people living with SCD (e.g., helping people living with SCD to become more active participants in their care, recognizing that every health event is not related to SCD, identification of appropriate providers). Access-to-care topics that were high priority issues included the need for comprehensive care systems across the life span, continuity of care across geographic regions, access to mental health services, integration of care (between emergency room use and primary care), access to high quality care, and defining what a medical home should look like for people living with SCD. Participants stressed the need for a clearinghouse of resources for people living with SCD and families that could include information beyond medical support. For instance, there is a great need for information on social services particularly in geographically isolated communities. Also, there continues to be a gap in mental health services for people living with SCD.

Medical Care Providers. SCD specific training emerged as a priority area for providers. A majority of attendees agreed that generally, providers are ill-equipped to care for the SCD patient over the lifespan. Attendees agreed that there are gaps in provider knowledge around management of pain in SCD (especially among emergency room clinicians), cultural sensitivity (e.g. assumption that all people living with SCD are drug seeking), and understanding that every medical encounter is not necessarily related to SCD. The overall number of providers and provider knowledge of SCD management were highlighted as ideas where change could have a significant impact on the SCD community. Participants noted the need for fellowship programs that focus lifespan issues in caring for people living with SCD as a

pipeline to increase the number of frontline clinicians that become experts in SCD management (e.g., education repayment programs for medical students who will serve in underserved areas). SCD curriculum should also be developed as part of CME and CEUs. Thus, a list of providers who should have access to continuing education and training in SCD patient care was nominated -- physicians (ER and primary care), nurses, physician assistants, social workers, case managers, and mental health professionals. A parallel discussion arose about best practice for people living with SCD. Attendees posed the following questions: 1) Are primary care providers the best type of provider for people living with SCD? 2) Should there be designated treatment centers that are strategically placed throughout the country? 3) What does high quality care look like for people living with SCD (i.e., how do we measure the effectiveness of care and what should outcome measures be)? 4) Is there an ideal model for managing SCD? Finally, the attendees acknowledged that under the current system of care, reimbursement practices should be re-evaluated if a primary medical home model for SCD is to be implemented and more creative/innovative care models should be developed as a bridge (e.g., co-location of services or incentivize telemedicine) until more comprehensive systems are in place.

Community Based Organizations (CBO). CBOs should be recognized as valued partners in the SCD community that links people living with SCD, researchers, and clinicians. Attendees identified the need for a clear, consistent message around improving care for people living with SCD from CBOs and suggested a few ways to develop their niche. First, CBOs have to find ways to collaborate, allowing member organizations to have a unique contribution to the national organization's priorities. A collaborative effort could begin by encouraging larger CBOs to provide technical assistance to emerging CBOs in communities where no other services exist. SCD specific CBOs should also reach out to non-disease specific organizations to learn from their successes and failures. Second, CBOs should create stronger relationships with local and state entities around the areas of research and surveillance. Similarly, CBOs have the opportunity to lead the interagency dialogue on research, public health and health care services. In addition, CBOs could develop a database that supports community participation in clinical trials. CBOs could also be integral to the development of toolkits that are tailored to specific communities (e.g., the incarcerated population emerged as a group that is in need of SCD education). Additionally, CBOs are widely recognized for their extensive knowledge around case management and should be tapped for that knowledge to inform interventions (e.g., decreasing Medicare costs and helping people with SCD to live productive, healthy lives). The attendees recognized the need for more consistent, stable funding for CBOs and the need to develop support from others beyond the SCD community. It was also acknowledged that staff within CBOs could benefit from continuing education and training.

Other Federal Agencies, including State Health Departments. Attendees noted that states and other federal agencies could play a vital role in SCD research, patient education, and shaping a system of care for people living with SCD. By aiding our understanding of the epidemiology of SCD, Registry and Surveillance System for Hemoglobinopathies (RuSH) was highlighted as a major step in advancing the SCD research agenda. Participants discussed the need for continued funding of surveillance and registry activities and suggested that RuSH data and future surveillance activities be used to spur new research on SCD management and patient care. For example, investigations on factors that contribute to variation in the receipt of high quality care (e.g., what are appropriate performance and outcome metrics?) and evaluations of different models of care that currently being utilized can be informed by surveillance data. Secondly, governmental agencies could develop a patient-friendly website that houses SCD education for people living with SCD, families, and providers. A government sponsored website

could house credible information on sickle cell trait, places to go to get treatment, strategies to improve uptake of treatments, and instructions on how to enroll in clinical trials. Also, people living with SCD, families and researchers need information on the role of governmental agencies that have programs related to SCD and how their work supports the SCD community. The SCD community should also be given a forum to express their opinions about how governmental entities could provide more support. Third, governmental entities should begin to explore the impact of ACA on people living with SCD (e.g., what are the provisions that benefit people living with SCD most?). In addition, state and federal agencies should use the ACA as a means to develop a system of care for people living with SCD with comparable guidelines across regions/states. Fourth, some attendees suggested that a technology infrastructure could be developed around social media that would allow CBOs and physicians to engage clients for tracking, monitoring, and education. Similarly, electronic health records systems could facilitate collaboration between governmental agencies and organizations while encouraging a more streamlined cohesive healthcare system. Attendees also posed questions related to determining the role of the state in developing a coordinated healthcare system and whether there should be designated SCD treatment centers. A final suggestion included finding opportunities to connect newly immigrated people with SCD to healthcare.

Prioritization of Needed Activities

Gaylon Morris, the facilitator, organized activities identified by participants into priority areas and asked participants individually to identify three areas of greatest importance to addressing the public health needs in the SCD community. The priority areas listed below are the top four priority areas and the order reflects the number of votes received, with number one being the area prioritized by the highest number of participants.

The priority areas (listed from highest to lowest rank) included the following:

- 1) Develop a comprehensive, high quality care model with uniform access
 - Determine gaps in services, including mental health
 - Develop innovative care models informed by health services utilization data (e.g., RuSH)
 - Leverage the Affordable Care Act (ACA) to develop an ideal model of care
 - Define “centers of excellence” (e.g., What standards and measurements are used to define a center of excellence?)
- 2) Provide patient and family education
 - Hydroxyurea
 - Child to adult care transition; life span model
 - Parent awareness
 - Trait education
 - Role of federal agencies
- 3) Identify appropriate care, for people living with SCD
 - Assess the need for SCD treatment centers
 - Assess who sickle cell experts are (not always hematologists)
 - Use NIH guidelines to examine healthcare outcomes
- 4) Provide education and training for clinicians working with people living with SCD (e.g., doctors, nurses, social workers, etc.)
 - Cultural sensitivity
 - Pain management
 - Co-morbidities

Needs to be Addressed by CDC

In the third session of the day, access to care, the practice of care, and patient education emerged as themes that CDC should prioritize within their SCD science agenda.

Access to Care: surveillance, evaluation, and data needs. The attendees suggested that with RuSH data, CDC could determine areas/regions where people living with SCD are concentrated and where providers are located to figure out whether people living with SCD have access to and are receiving the kind of care that they need. CDC and partners should assist in developing strategies to bridge gaps in services in geographic locations where they do not exist or are inadequate. Participants also nominated ideas for how CDC could become involved in evaluating the quality of SCD care. For example, CDC should leverage newborn screening (NBS) data to track quality measures and outcomes for SCD, determine the criteria for minimal care that people living with SCD should receive, determine the minimum criterion to be deemed a Center of Excellence for sickle cell care, and examine who should be considered qualified sickle cell care providers. The attendees also noted the need for CDC to explore ways of incorporating SCD-related items into national surveys including questions on access to care. Patient access survey items should include traditional barriers as well as non-traditional barriers (e.g., children's mental health issues, education, employment, family engagement, etc.). Any questions that CDC develops should take advantage of the experience of case managers/community navigators who typically work with people living with SCD.

Practice of Care: evaluating professional standards and training needs. Attendees indicated that it will be important to look at who determines the standards for professionals providing services to people living with SCD and to think of ways to expand uniform genetic education and counseling certification. To accomplish goals in improving patient care, CDC should partner with organizations like the Joint Commission.

Patient education: resource needs. Participants reiterated the need for a standard set of educational resources for providers (physicians and non-physician training modules) and families around general SCD knowledge (i.e., inheritance, penicillin prophylaxis, transcranial Doppler [TCD], and hydroxyurea) and navigating/accessing educational support systems (e.g., school-based accommodations and the Family Medical Leave Act [FMLA]). Participants encouraged CDC to disseminate their educational messages using innovative, multimedia campaigns. CDC should also leverage idle or existing activities, including the national "know your family history" awareness campaign and following up on the NICHQ gap analysis.

Partnerships and Collaboration

In the fourth session of the day, attendees nominated a list of partners that could be included in future discussions on SCD. The following list was generated: the Department of Education, school-based health clinics, Association of American Medical Colleges, American Medical Association, nurse practitioners, mental health provider networks, African American physician networks, various cultural alliances, ethnically based alliances (e.g., Historically Black Colleges and Universities, Hispanic alliances, Arab alliances, etc.), Robert Wood Johnson Foundation, faith-based organizations, international health groups, state health information exchanges, national civic organization (e.g., NAACP, Urban League, etc.), Commonwealth Fund, California Endowment, Gates Foundation, Clinton

Foundation, community health charities, media outlets (e.g., public service announcements and C-SPAN), and pharmaceutical companies.

Closing comments

“Be Bold”

During the stakeholder discussion, the consensus of opinion was that people living with SCD experience highly variable quality of care within communities, across states, and across regions. The implementation of the Affordable Care Act offers us a prime opportunity to develop a “medical home” model of care for people living with SCD that could also serve as template for how healthcare should work for all Americans. An overarching goal reiterated by the stakeholders included helping people with SCD lead quality, productive lives by making “best practices” – in mental health services, pain management, uptake of pharmacotherapies, and provision of social services – more available through the system of healthcare.

Prior to adjourning, center director Coleen Boyle posed the question “What would you want high quality care to look like for individuals living with SCD in the next 3-5 years?” She then charged us to “Be BOLD!” -- develop innovative methods and ideas in our efforts to build a model public health infrastructure for people living with SCD.

Conclusion

In summary, to align with CDC’s mission as a public health entity, efforts should be focused on bridging the gap between the community and providers by developing educational tools, providing technical assistance, and collaborating on research and surveillance activities that are informed by those living with SCD and those caring for individuals living with SCD. Existing data (e.g., newborn screening, RuSH, etc.) and models of care should be leveraged by CDC. Finally, some of the work suggested by attendees will require interagency collaboration at the federal and state level.

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