

## Incorporating Stakeholder Input into Public Health Interventions

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In 2010, the State of California Department of Public Health (CDPH) was awarded a contract by the Centers for Disease Control and Prevention (CDC) to collect state-specific, population-based data on people with hemoglobinopathies or hemoglobin disorders. Hemoglobinopathies, including sickle cell disease (SCD) and thalassemia, affect a relatively small group of people in the U.S. but have been deemed a pub-

lic health issue due to poor access to quality care for those affected. CDC's Registry and Surveillance System for Hemoglobinopathies (RuSH) pilot project was implemented in six other states, with the goals of: providing estimates of the number of existing and new cases of SCD and thalassemia each year in the participating states; providing information on trends in medical care and about morbidity and mor-

tality for people with these disorders; and providing information to assist with planning public health interventions.

Unfortunately, individuals with SCD and thalassemia, also face significant barriers with regard to trust when accessing healthcare services and participating in public health and clinical research projects. These barriers are related, in part, to the cultural and linguistic diversity within the affected populations, as well as historic and current social and economic disparities. These barriers call attention to the need for increased sensitivity and communication surrounding the initiation of new projects such as RuSH that may unintentionally offend or stigmatize the affected population. As subcontractors with the CDPH, Children's Hospital & Research Center Oakland designed focus groups/stakeholder meetings to assess the impact of RuSH on the SCD and thalassemia communities. Our primary objective was to obtain input from community stakeholders on how to engage the SCD and thalassemia communities with the RuSH project; potential barriers to hemoglobinopathies surveillance;

appropriateness and appeal of the RuSH messaging tools; and identification of additional community stakeholders that should be engaged with the RuSH project.

We conducted the focus groups using standard qualitative methods. We invited representatives of community SCD organizations, health care providers and individuals directly affected by SCD or thalassemia. The focus groups were conducted at times and locations convenient to the participants and refreshments were provided. A group facilitator led the discussion and the session was recorded. Notes were reconciled with the recording transcripts immediately following the focus group.

We conducted four focus groups with a total of 34 individuals participating. Participants were briefly educated about public health surveillance and asked to respond to structured questions about barriers and facilitators to community participation in surveillance for hemoglobinopathies. They reviewed and critiqued written materials created for RuSH and identified other important groups to target, to share the RuSH message. Following the groups, team members reviewed notes and audio transcripts independently to identify common themes within and across groups.

Our focus groups identified common themes across providers, community members and patients around surveillance, which included concerns about who will have access to data and what will be done with

it. Focus group members emphasized the need for direct benefits of RuSH for patients and saw RuSH as a means for educating providers and the general community about hemoglobinopathies. They provided great input into the RuSH messaging and underscored the need to customize materials for different audiences (e.g., providers, patients, community), as well as the need for cultural and linguistic diversity in materials. Perhaps the most valuable information that we gained from the focus groups was about the potential barriers to surveillance and registry data for these populations. Group members noted that populations affected by SCD may have an historic mistrust of surveillance and cultural mores within the communities affected by thalassemia could lend to maintaining secrecy about the conditions. Participants also provided a diverse listing of regional community health, provider, faith-based, social and school groups that should be approached as potential supporters of RuSH.

In summary, we gathered information from focus groups/community stakeholders meetings to provide guidance to the RuSH project about potential barriers and perceived benefits to surveillance and participation in a registry program. We obtained invaluable insights to improve the design, marketing and execution of the project. The focus groups also allowed us to foster a relationship with affected communities, allowing our actions to be transparent and consumer-focused. A secondary benefit of the focus groups was the opportunity to pro-

vide basic education about the hemoglobinopathies to communities that had not been directly affected by the diseases, but who benefited from targeted education due to cultural groups served.

*Marsha Treadwell, PhD currently serves as the project director for the Northern California Network of Care for Sickle Cell Disease, funded by the Health Resources and Services Administration. In this capacity, her primary responsibilities include coordinating the efforts of health-care entities and community based organizations throughout the San Francisco Bay Area that provide services to individuals with SCD. Dr. Treadwell and her team have introduced initiatives to improve the quality of care for SCD, including acute pain management, transition from pediatric to adult care and self-management support. Dr. Treadwell was co-investigator on the California RuSH project and is co-investigator on the newly funded CDC Public Health Research, Epidemiology & Surveillance for Hemoglobinopathies in California.*

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