

Johns Hopkins University SiNERGe Project ECHO Implementation Profile

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It was amazing how ECHO grew on its own.”*

SiNERGe (Sickle cell Improvement across the NorthEast ReGion through Education) and the Johns Hopkins Sickle Cell Disease (SCD) ECHO were part of a study, led by Diffusion Associates and funded by the Robert Wood Johnson Foundation. The purpose of this study was to document and share how ECHO is adopted, implemented and sustained across ECHO hubs and programs in the United States and Canada. This study was separate from, but endorsed by, the ECHO Institute.

This profile is based on an interview conducted in November 2020 by R. Sam Larson, PhD, director of Diffusion Associates, and Trisha Calabrese, then the Senior Director of Pediatric Population Health American Academy of Pediatrics and a 2020 implementation fellow working with Diffusion Associates.

We begin this profile by sharing unique implementation insights from the Project ECHO from SiNERGe and the Sickle Cell Disease ECHO program

ECHO Implementation Insights

Creating an ECHO “Bank”

Building an inventory or library of didactics and “banking” cases streamlined the work of the Sickle Cell Disease (SCD) ECHO. Didactics followed a recurring cycle and panel experts tended to take the lead on the same topics over time. Experts were “pretty well rehearsed” and while content was updated, they had a solid library of presentations to draw from. As the program was weekly, there was a high demand for cases. If a spoke did not come forward with a case, the panel used a case from their practice. However, if a spoke came forward, “we bank the case if we don’t need it.” This strategy—of creating an inventory of didactics and “banking” cases—was especially important given the SCD ECHO was weekly and there was little time to develop new content between sessions.

Discontinuing an ECHO Program

Although not the focus of our study, respondents discussed a discontinued ECHO program. The program, STAMP (Sickle Cell Disease Training and Mentoring Program), was sponsored by the Office of Minority Health in the U.S. Department of Health and Human Services. The STAMP ECHO was focused on providing primary care providers with the knowledge, skills, and co-management support to care for adults living with sickle cell disease. STAMP was a collaborative effort across multiple regions. Primary care physicians were spokes, but they were not highly engaged. Said one respondent, “It was not ECHO. It was didactics. It was us presenting cases and then discussing them. The primary care physicians weren’t necessarily engaging in the conversation.” In addition, “a lot of time was taken up answering questions from people who weren’t treating patients.” The STAMP ECHO missed the major metric—engaged primary care providers who were treating adults with sickle cell disease. Choosing not to continue this ECHO allowed SiNERGe to focus on work that would help them meet their goal.

ECHO Model Adoption

SiNERGe

The Health Resources and Services Administration (HRSA) funded five regional teams from across the country to improve conditions and service delivery for individuals living with sickle cell disease, enhance access to services, and expand patient and provider education. The Northeast Region included the District of Columbia, Delaware, Maryland, New Jersey, New York, Pennsylvania, Virginia, West Virginia, Puerto Rico, and the US Virgin Islands. Collaborative efforts in the Northeast Region were coordinated at Johns Hopkins University School of Medicine. The collaborative was known as SiNERGe—Sickle cell Improvement across the NorthEast ReGion through Education (SiNERGe).

ECHO came to the attention of Sophie Lanzkron, MD, a professor of medicine at Johns Hopkins University School of Medicine, and a primary investigator on the HRSA grant that funded SiNERGe. Lanzkron was encouraged by HRSA staff to include ECHO in the proposal “as a way to spread knowledge and help other people understand sickle cell disease.” Lanzkron said that SiNERGe had limited funds to help clinicians treating patients with sickle cell disease and ECHO was a way to “help people with sickle cell disease high-quality care.” SiNERGe was the first HRSA-funded region to implement Project ECHO for sickle cell disease. Lanzkron and Bailey House, MPH, the SiNERGe regional collaborative coordinator, attended immersion training at the University of New Mexico where they learned how to implement ECHO and saw its potential for expanding knowledge about treating sickle cell disease.

Johns Hopkins University did not have a center or office to oversee or coordinate ECHO work and SiNERGe fulfilled this role as they had “the most experience in Hopkins using ECHO, so people are often coming to us and wanting direction and our thoughts on using ECHO.” SiNERGe worked with institutions within the HRSA Northeast Region to support the adoption of sickle cell disease–focused ECHO programs. Lanzkron commented: “We have a very large region and one ECHO wasn’t going to be enough. It was amazing how ECHO grew on its own.” Boston Medical Center started a Pediatric Sickle Cell Disease ECHO and New York City Health & Hospitals started a Quality Improvement ECHO. As medical centers expressed interest in sickle cell disease ECHOs, SiNERGe provided funding, through the HRSA grant, to send members to the ECHO Institute at the University of New Mexico for immersion training.

Johns Hopkins Sickle Cell Disease (SCD) ECHO

SiNERGe launched the Johns Hopkins Sickle Cell Disease (SCD) ECHO in 2015. The SCD ECHO met weekly. Sessions were led by four key faculty including Lanzkron, two psychiatrists, and a pediatric hematologist. The ECHO Model was easy to implement as it was similar to grand rounds and clinic conferences that were part of the regular practice of the faculty and participants. Participants, or spokes, were primarily hematologists who were in practice in and beyond the Northeast Region. House initially provided administrative support for ECHO but much of the day-to-day work transitioned to a project coordinator. The SCD ECHO recruited cases and didactic presenters from Johns Hopkins University and its broader network.

When the SCD ECHO first launched, Lanzkron and House relied on cases being presented by a local hospital team that joined sessions. Members of the hospital team were “consistent participants, and always had cases. Having that one group committed to those sessions helped us to have enough time to recruit more participants and to get us fully launched. It was pivotal to have the one group committed to

attending.” As the program matured, they attracted about 40 participants per session, most of whom regularly attended sessions. The ECHO program ran “like a tight ship” to ensure sufficient time for the didactic, case presentations, and discussion.

ECHO Model Implementation

The ECHO Model seeks to build a learning community where “all teach, all learn.” This is done by leveraging technology, sharing best practices, through case-based learning, and using data. We asked respondents to tell us what “all teach, all learn” meant to them. Lanzkron described it as “all of us learning from one another and all of us teaching one another.” She shared, “I might lead the discussion, but I am more than happy to have someone else who knows more lead the discussion.” “All teach, all learn” was encouraged, said House, by a “very open environment where people feel comfortable sharing and inputting on the cases or asking questions during the didactic.” Lanzkron said, “We create an environment where people feel free to raise their hand and say, ‘Oh, I don’t do it this way,’ or, ‘This is what I think.’ And if nobody raises a hand, I ask, ‘Are you following this guideline? Does it make sense to you?’ I call on people to give their point of view and relate how they might approach it and what they might do.”

The SCD ECHO was described as a “support group” among a community that could be isolated because few people treat sickle cell, which is a rare disease. Lanzkron described the community as a place where you can say, “Golly, that is one tough case and I would have done everything the way you did it and I’m sorry you had this bad outcome,” or “Keep doing what you’re doing; we think that’s the right thing to do.” Lanzkron went on to say that ECHO “offers a lot of reassurance.”

SCD ECHO didactics focused on topics that “everyone should know about. If there are new guidelines, we focus on presenting new guidelines. We go back to previous topics that we haven’t discussed recently and redo those.” Didactics were selected and presented by the lead faculty although they did have guest speakers, including a community health worker. New presenters were invited to an ECHO session to see how it worked and provided simple guidelines, such as limiting the number of slides to 10 to 15.

SCD ECHO sessions typically included two cases. Sessions were weekly, so many cases were needed. The coordinator sent out emails every week asking for cases from participants. If no participant submitted a case, one of the lead faculty would present a case based on their own practice, drawing from a previous patient encounter. Lanzkron reminded participants that the sessions were “much more interactive and enlightening when it’s someone else’s case versus their own cases.” Getting cases became “easier because we have a bigger crowd. I think a lot of it is getting people to overcome being shy and nervous presenting to us. But I think we’re beyond that.” Lanzkron shared that they sometimes had “residents and interns present cases, often with the whole team attending or a couple members of the team attending” who had little knowledge of how to treat sickle cell disease and it was “really nice to have a mechanism to educate people who know little about sickle cell disease.”

Factors Influencing Implementation

Studies of program implementation identify contextual factors that can shape how a program was implemented. These factors include leaders and champions, state and federal policies, funding,

partnerships, and internal organizational structures and processes, monitoring for quality and fidelity, and staffing—including how people were trained and the characteristics of the people leading and supporting the program.

Not all of these factors may play a role in how ECHO was implemented here or elsewhere, and some factors were more important than others. Below, we identify factors that emerged during interviews which influence how SiNERGe implemented Project ECHO.

Quality and Fidelity Monitoring

SiNERGe valued fidelity to the ECHO Model. Initially, participants did not submit cases in advance. Lanzkron commented that “being off the cuff” meant she lost an opportunity to invite someone into the ECHO to speak to the specifics of a “curious case.” The process shifted to encourage participants to submit cases in advance so Lanzkron and House could review them. Lanzkron also “pays attention to the presentation,” she wasn’t multi-tasking. By paying attention and being in the moment, the program moved forward on time and with participant engagement. Quality and fidelity were also monitored through semi-annual surveys and regular post-session evaluations.

Organizational Characteristics

Being associated with the Johns Hopkins University Medical School provided the advantage of having a “world of expertise” at hand. Lanzkron said, “We’re lucky to be at Hopkins where we have a wide diversity of expertise around us that we can call on to help us.” Another advantage was for the university—which received indirect costs from grants that SiNERGe received, including the HRSA grant that funded the ECHO work.

Partnerships and Networks

SiNERGe drew on multiple networks to create a vibrant ECHO community. They were influenced early on by a Sickle Cell Adult Provider Network formed for providers to discuss what to do when there were no guidelines and you “learned what to do from the person who did it before you.” HRSA funded five regional teams to improve conditions and service delivery for individuals living with sickle cell disease. They met once a year to share best practices and “present ECHO every year because it’s the best part of what we do.” This larger network stayed in touch and would “call one another and ask, ‘Can you present?’ or ‘Here are my slides.’ We try to share.” SiNERGe leads also attended and presented at a MetaECHO conference where they met others and exchanged ideas. Beyond the sickle cell and ECHO networks, SiNERGe was also embedded in the Johns Hopkins University network, where they had access to experts to present didactics and discuss cases. They also had a local community network of hospitals and physicians providing direct care.

Funding

The multiyear HRSA grant created a stable funding base for SiNERGe. These funds were used to pay for coordinators, facilitators, and experts so they could devote time to ECHO. Funds also supported travel for partners to attend immersion training at the University of New Mexico. Although these funds were not guaranteed beyond the life of the grant, the funds were multiyear and expected to continue into the near future.

ECHO Vision and Sustainability

When asked about the vision for the hub in the next several years, respondents focused on how to meet the need of patients. Lanzkron wanted to use ECHO as a resource—as a way to “spread care to people who don’t have access to an expert around the corner from them.” She anticipated that their work would continue and expand to include new types of participants. She wanted to extend the ECHO program to advanced practice providers. Lanzkron said, “We have a long-term vision of how ECHO is going to help us improve care for people with sickle cell disease. This includes training APPs [advance practice providers]. We want to train the APPs and send them out into the community as spokes with the ECHO hub providers as their back-ups. But they need to have ongoing participation with ECHO to present their cases and engage in ongoing learning.” House agreed with Lanzkron and shared that ECHO was a “great tool for education providers and for establishing a community that supports those caring for individuals with sickle cell. I don’t want to see it going away.”

To achieve this vision, they needed continued funding for the hub and possibly funding for participants. Lanzkron notes, “If we want to go deeper and deeper into the community, we’re going to run into this problem more and more. It’s one thing when you have a bunch of academics on the call who can take the hour to do this. But it’s much more difficult when you get into the community. We have to figure out how to compensate those people for their time.”

Respondents

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