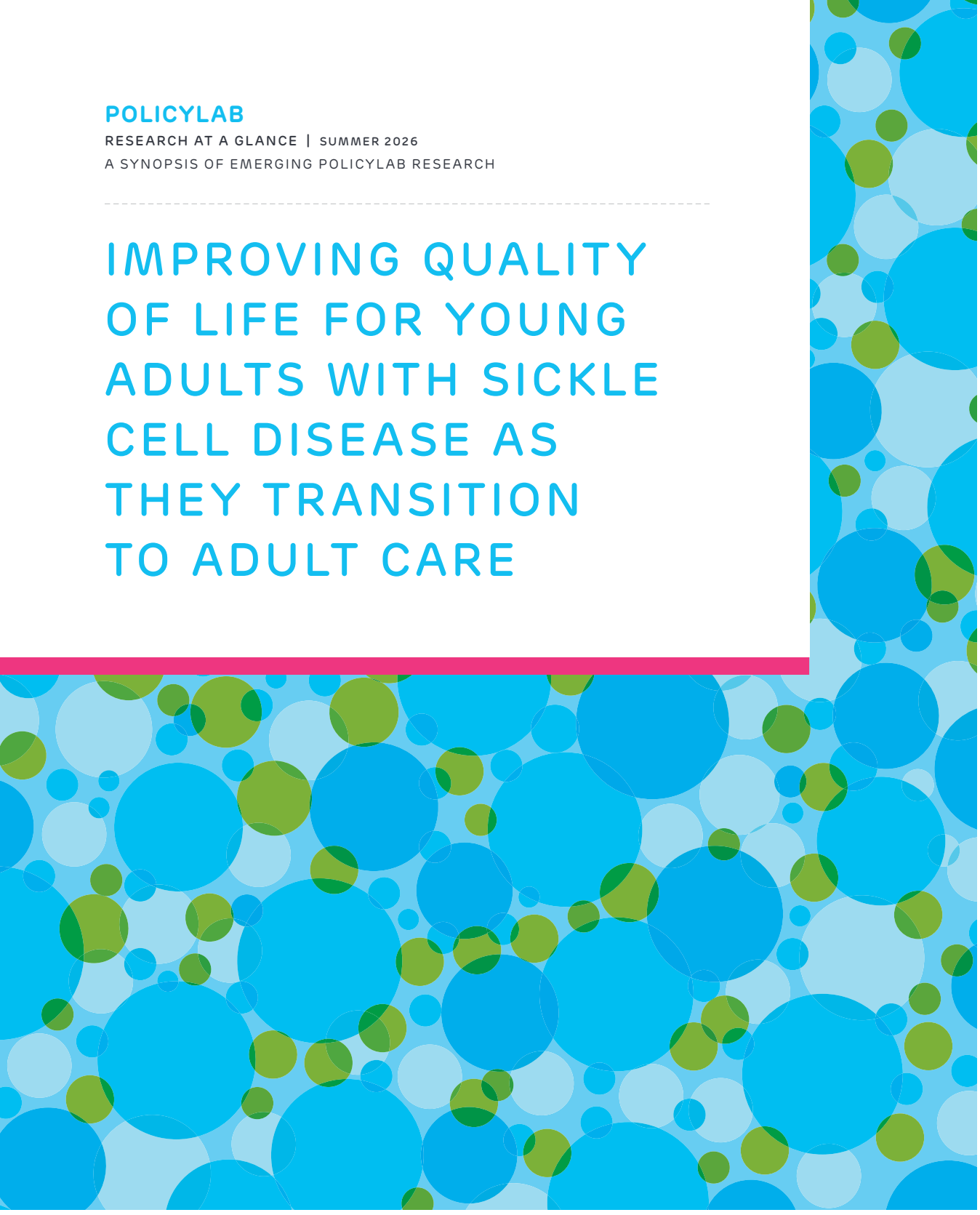
POLICYLAB

RESEARCH AT A GLANCE | SUMMER 2026

A SYNOPSIS OF EMERGING POLICYLAB RESEARCH

IMPROVING QUALITY OF LIFE FOR YOUNG ADULTS WITH SICKLE CELL DISEASE AS THEY TRANSITION TO ADULT CARE



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WHAT IS THE PROBLEM:

The transition to adult care is a critical and vulnerable period for youth with sickle cell disease, as even small breakdowns in care coordination can have long-term impacts on health and quality of life.

Youth with special health care needs face many challenges when moving from pediatric to adult care, including gaps in health care coverage, a shortage of adult health care providers and poor care coordination between health systems. This is the case for the 100,000 Americans living with sickle cell disease[1]—a group of genetic red blood cell disorders that causes severe pain and anemia—as even brief gaps can disrupt medication regimens, specialist care and monitoring.

The transition to adult care is one of the highest-risk periods for young adults with sickle cell disease, with notable increases in mortality.[2] This period[3] can also have lasting impacts on these young adults' health and quality of life.[2]

Among the promising interventions to support young adults with special health care needs as they make the transition to adult care are community health worker[4] and mobile health programs.[5] But to date, no clinical trial has compared interventions aimed at improving this transition among young adults with sickle cell disease.

WHAT WE ASKED:

Do community health worker and mobile health interventions improve the health-related quality of life for young adults with sickle cell disease transitioning to adult care?

Which strategy (CHW, mobile health or enhanced usual care) best supports young adults with sickle cell disease transitioning to adult care?

How do these interventions improve young adults' knowledge of sickle cell disease, transition readiness and perceived social support?

WHAT WE DID:

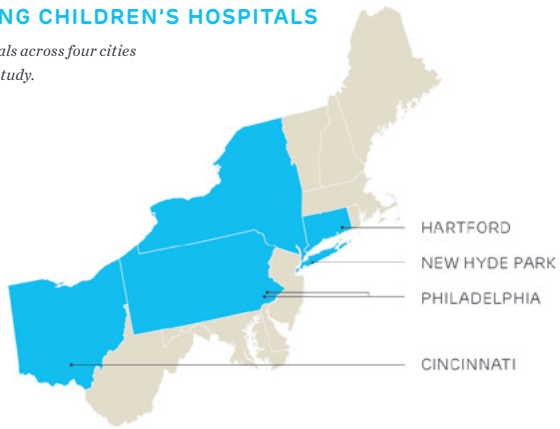
In a randomized clinical trial[6] involving 375 young adults across five children's hospitals, we compared how two support interventions and enhanced ususal care impacted the health-related quality of life of young adults with sickle cell disease aged 17 and older. Participants were randomly assigned to one of the six-month support interventions:

1. **Enhanced usual care** to help young adults prepare for the transition to adult care using standardized transition planning and support
2. **Community health worker support** to help the young adult set goals and create action plans for their care transition
3. **Mobile health support** that allowed participants to connect with peers and track their goals and symptoms

We then compared changes in self-reported health-related quality of life over time (at 6, 12 and 18 months) across groups, and whether the programs helped with things like knowing more about sickle cell disease, feeling ready to move to adult care, and feeling supported during the transition to adult care.

PARTICIPATING CHILDREN'S HOSPITALS

Five children's hospitals across four cities were included in the study.



WHAT WE FOUND:

For young adults living with sickle cell disease, both the community health worker support and the mobile health intervention modestly improved health-related quality of life after six months.

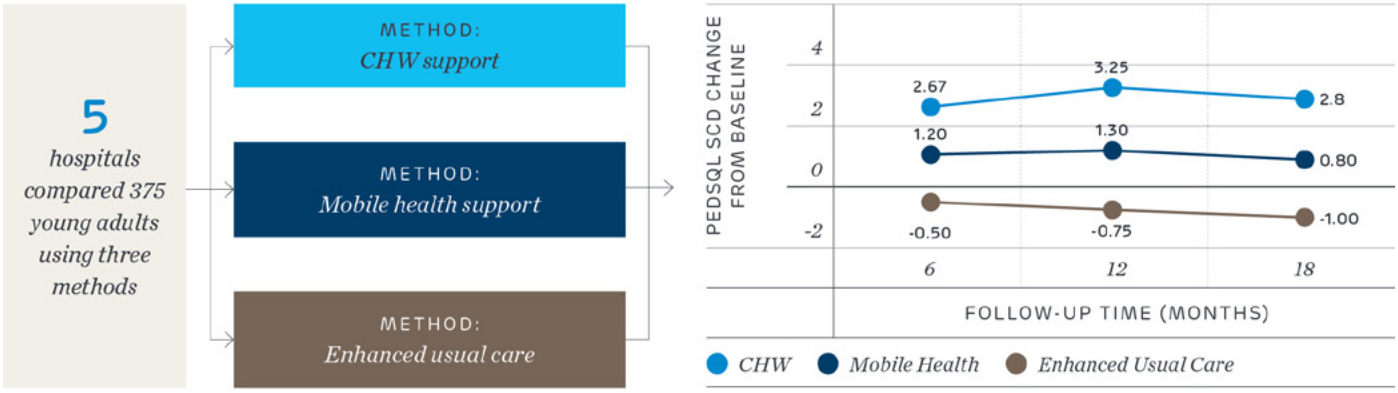
Among young adults receiving **community health worker support**, health-related quality of life increased over time, with Pediatric Quality of Life Sickle Cell Disease (PedsQL SCD) scores peaking at 12 months. Improvements in health-related quality of life for this group were sustained through 18 months. Compared with enhanced usual care, the CHW group had a higher health-related quality of life at each follow-up point.

The **mobile health intervention** group also experienced improvements relative to enhanced usual care, but gains were smaller than those seen with CHW support and were not sustained as clearly over time.

Among those who received **enhanced usual care support alone**, health-related quality of life slightly declined over the same period.

Beyond findings on health-related quality of life, young adults were **highly engaged** with the community health worker intervention, with frequent and meaningful contact over the study period. Typically, participants had a median of 25 contacts with the community health worker. However, neither the community health worker nor the mobile health intervention improved transition readiness, sickle cell disease knowledge or perceived social support.

HEALTH-RELATED QUALITY OF LIFE IMPROVED MOST WITH COMMUNITY HEALTH WORKER SUPPORT:
YOUNG ADULTS WITH SICKLE CELL DISEASE



WHAT IT MEANS:

CHW support can meaningfully improve health-related quality of life for young adults with sickle cell disease as they transition to adult care, with benefits lasting beyond the active intervention period.

Mobile health programs may provide short-term benefits, but additional strategies are needed to maintain engagement and sustain improvements over time.

Health systems should consider integrating CHWs into transition programs for young adults with chronic conditions while continuing to develop and evaluate scalable approaches that combine personalized support with mobile health tools.

STUDY METHODS

We conducted a prospective, randomized clinical trial across five children's hospitals comparing three interventions for young adults with sickle cell disease transitioning to adult care. Participants were randomly assigned to standard transition support, community health worker support, or a mobile health intervention over a six-month period. We collected self-reported data on health-related quality of life at baseline, 6, 12, and 18 months and analyzed changes over time across groups using longitudinal models to compare mean differences and assess within-group improvements. We also examined transition readiness, sickle cell disease knowledge, and social support as secondary outcomes. Outcomes were measured at baseline, 6, 12, and 18 months to determine whether improvements lasted beyond the intervention. More information on our study recruitment and retention strategies is available in the study protocol.[7]

RELATED POLICYLAB WORK

Identifying Best Practices for Transitioning Youth with Sickle Cell from Pediatric to Adult Care. *https://policylab.chop.edu/project/identifying-best-practices-transitioning-youth-sickle-cell-pediatric-adult-care*.

PUBLICATION

Jan S, Steinway CM, Belton TD, et al. Community Health Worker and Mobile Health Interventions for Quality of Life Among Young Adults With Sickle Cell Disease: A Randomized Clinical Trial. *JAMA Netw Open*. 2025;8(11):e2543571. *doi:10.1001/jamanetworkopen.2025.43571*.

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6. Belton TD, Steinway CM, Teng O, et al. The Community Health Workers and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS) Trial: Protocol for a Randomized Controlled Trial. *JMIR Research Protocols*. 2025;14(1):e69239. *doi:10.2196/69239*
7. Belton TD, Carbaugh L, Stevens E, et al. Recruitment and retention of young adults with sickle cell disease. *Health Care Transitions*. 2026;4:100133. *doi:10.1016/j.hctj.2026.100133*

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The mission of PolicyLab at Children's Hospital of Philadelphia (CHOP) is to achieve optimal child health and well-being by informing program and policy changes through interdisciplinary research. PolicyLab is a Center of Emphasis within the Children's Hospital of Philadelphia Research Institute, one of the largest pediatric research institutes in the country.

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