

Development and Implementation of a Longitudinal Study of Pregnant People and Their Children in the Appalachian Highlands Region, United States

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The Strong Longitudinal Initiatives for Newborns and Kids (Strong LINK) study, launched in April 2023, is a pioneering effort to assess maternal and child health outcomes in the Appalachian Highlands region of the United States. With 1397 HIPAA authorizations and 535 baseline surveys completed, the study is uncovering critical insights into recruitment and retention, data sharing, and cross-state collaboration.

BACKGROUND

Research Question: What are the social-related health needs and outcomes of families in the Appalachian Highlands, and how do these evolve over time from pregnancy through childhood?

Rationale: The Appalachian Highlands region is characterized by unique socio-economic and health challenges, including higher rates of poverty, limited access to healthcare, and significant health disparities compared to national averages. Despite these challenges, there is a lack of comprehensive, long-term research focused on understanding the factors affecting maternal and child health in this region.

Importance: The data collected through Strong LINK will be critical in informing healthcare policy, developing targeted interventions, and addressing the specific needs of families in this underserved region. The longitudinal nature of the study allows for a comprehensive analysis of how early life experiences and healthcare access impact long-term health outcomes, offering valuable insights that could improve maternal and child health not only in the Appalachian Highlands but also in similar rural settings.

METHODS

Population: Pregnant people aged 14 and older planning to deliver in the local health system facilities across 21 counties in two states.

Process: Recruitment by community health workers, HIPAA authorization, university contact for consent, and enrollment in the study.

Survey Timeline: Baseline, 4 postpartum surveys (3, 6, 9, and 12 months), and 7 surveys during specific developmental periods, totaling 12 surveys.

Data Collection: Surveys matched with electronic health record data on maternal and child health risk factors and outcomes.

RESULTS

- Enrollment Data:**
- 1397 HIPAA authorizations completed
 - 535 signed consents
 - 461 baseline surveys completed
 - 217 3-month postpartum survey completed
 - 109 6-month postpartum survey completed

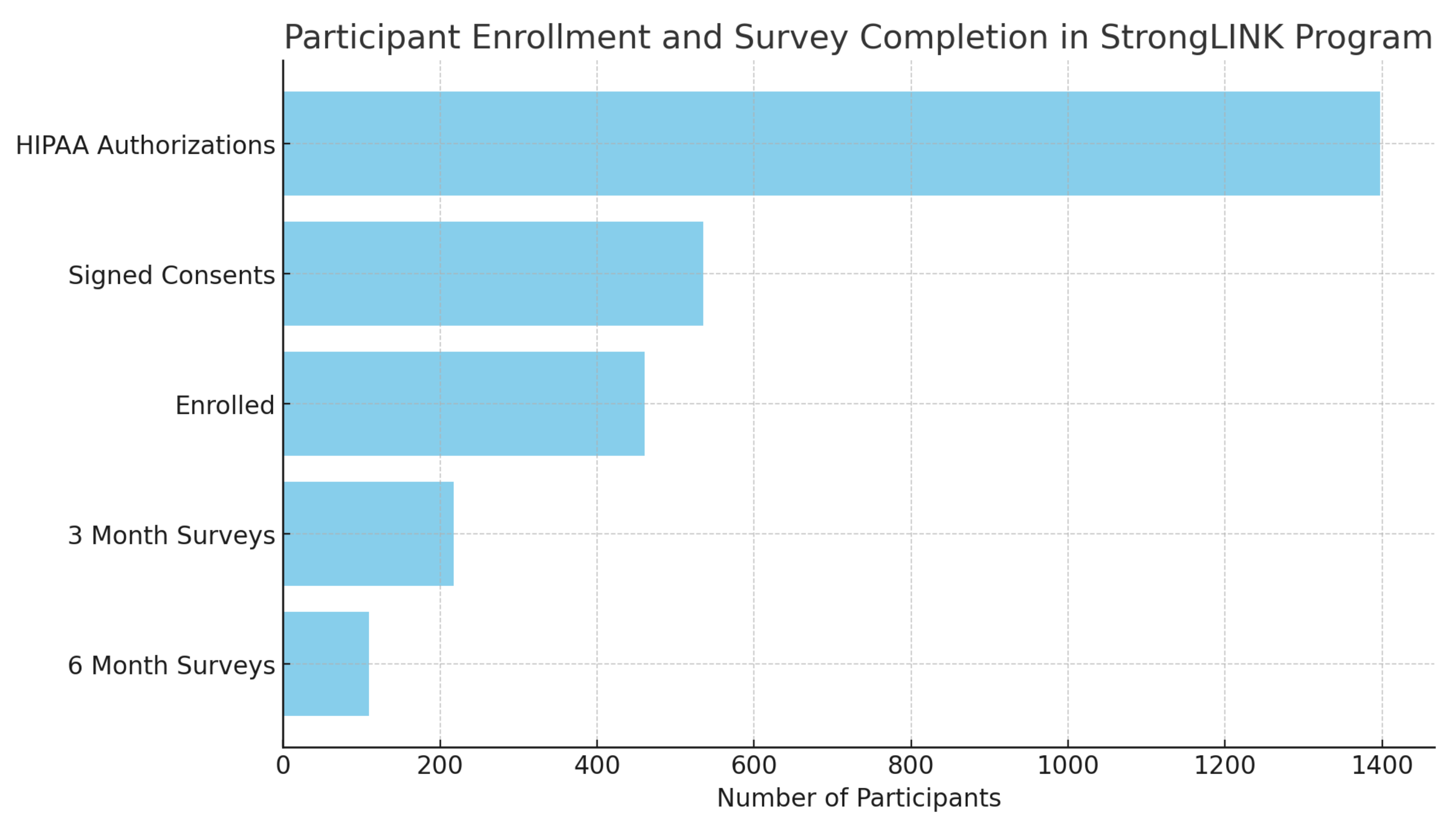
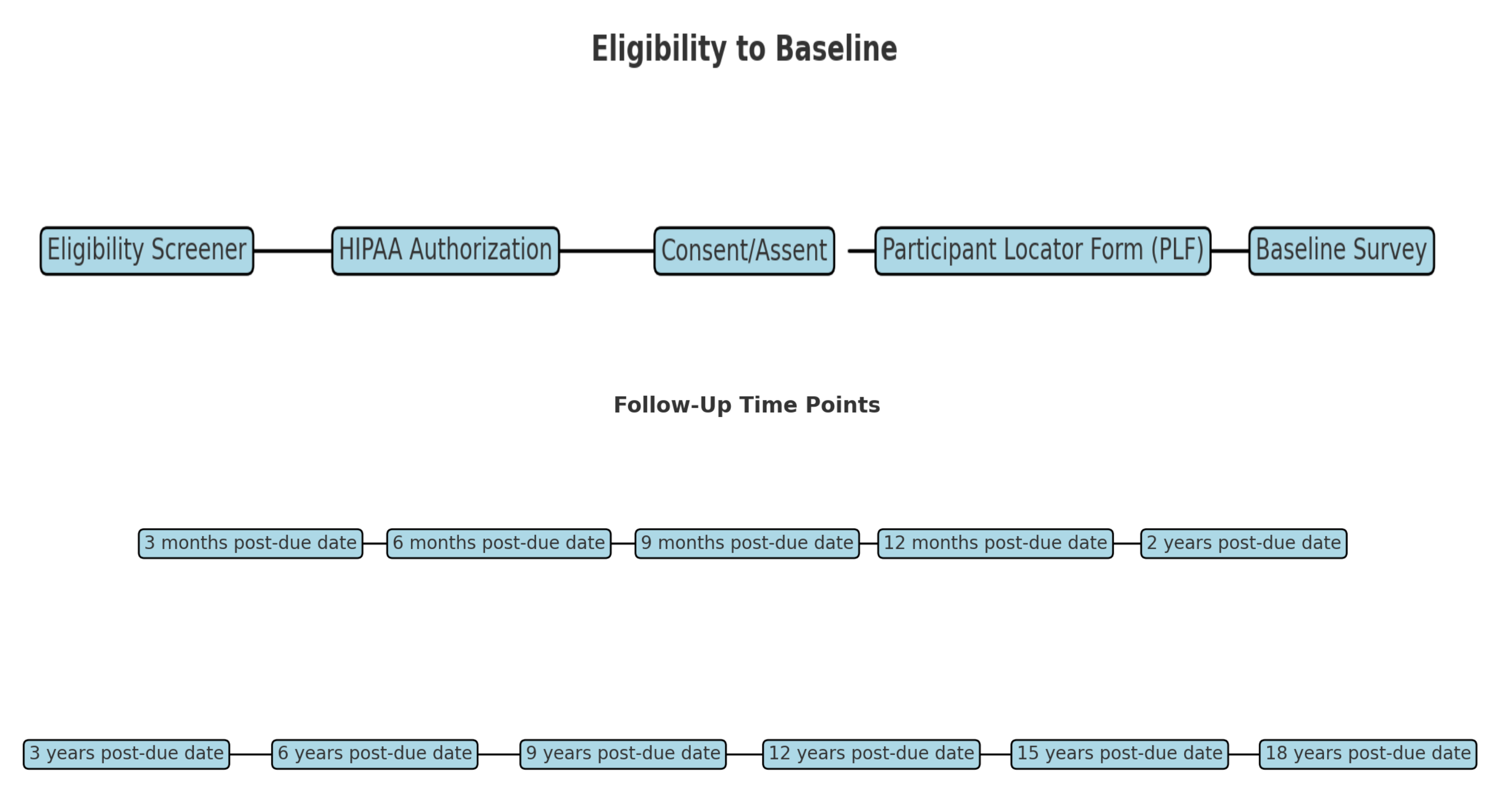
Challenges and Successes:

Recruitment and Retention: Effective community health worker engagement but challenges in participant retention.

Data Sharing: Successful cross-state collaboration but faced with complex data matching requirements.

Collaboration: Coordination between regional hospitals and university teams has been instrumental but requires ongoing effort.

RESULTS



CONCLUSIONS

Significance: This study represents a groundbreaking effort to address the unique and persistent health disparities in the Appalachian Highlands region. By focusing on a population historically underserved by research, Strong LINK is positioned to provide critical insights that are currently missing from the national discourse on rural health. The longitudinal design offers a rare opportunity to track the long-term effects of socio-economic and healthcare-related factors on maternal and child health outcomes in this region.

Implications: The early stages of the study highlight several key factors essential for its success, including the need for effective recruitment strategies tailored to rural populations, robust data-sharing agreements that facilitate cross-state collaboration, and a flexible approach to managing the logistical challenges inherent in long-term, multi-state research. These insights will not only enhance the study's impact but also inform future efforts to address health disparities in similar rural settings across the country.

ADDITIONAL KEY INFORMATION

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