Facilitators and Barriers to Scale-Up of Universal Newborn Screening for Sickle Cell Disease in Kalangala, Uganda

KALANGALA DISTRICT LOCAL GOVERNMENT, KALANGALA HEALTH CENTRE IV SICKLE CELL DEPARTMENT, P.O. BOX 2, KALANGALA, UGANDA

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BACKGROUND

- Uganda has the 5th highest sickle cell disease (SCD) burden globally, and an estimated 20,000 babies with SCD are born each year in Uganda, with an under-five mortality rate of 80%.
- SCD is an inherited blood disorder that can cause vaso-occlusive episodes, stroke, organ failure, and death.
- Kalangala Health Center IV (KHCIV) is located on Bugala Island, Uganda, the main island in an archipelago of 84 islands. The SCD clinic serves over 100 patients.
- KHCIV is officially recognized as “Hard to Reach” and “Hard to Stay,” indicating the difficulty of travel and clinic staff retention.
- In February 2024, Uganda’s Ministry of Health (MOH) initiated a new effort to reduce the burden of SCD through universal newborn screening (NBS) in all health centers.

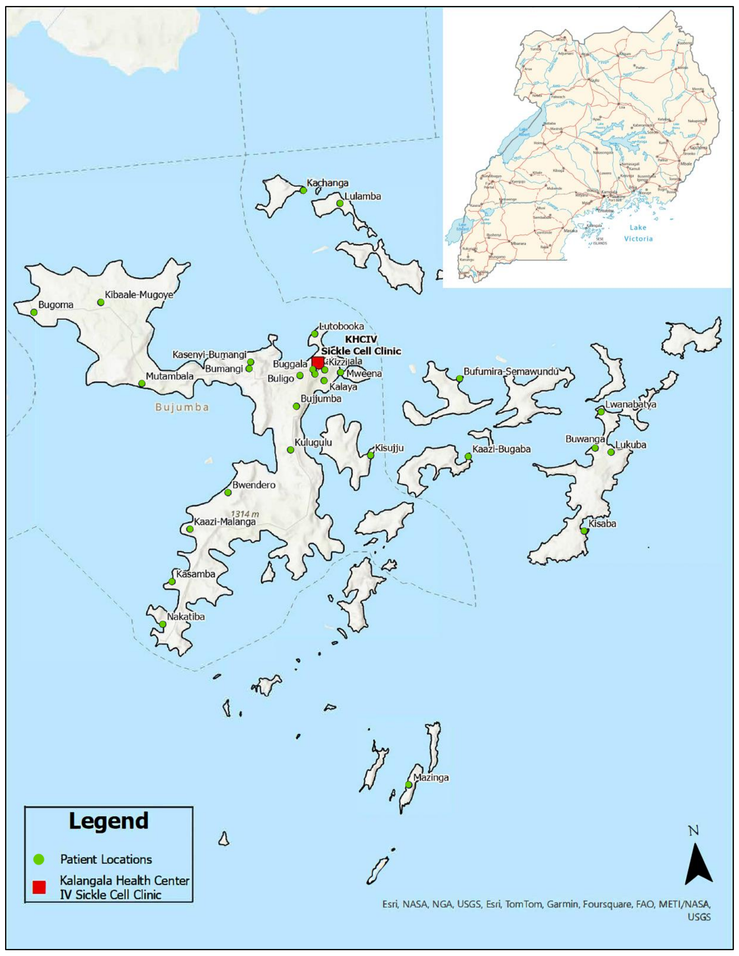
Labor and Delivery room at Kalangala Health Center IV

OBJECTIVES

- Explore parental perspectives of newborn screening for sickle cell disease to assess knowledge gaps and fears surrounding screening.
- Assess healthcare workers’ (HCW) perception of the feasibility and challenges of adopting universal NBS for SCD in local governmental health centers.

METHODS

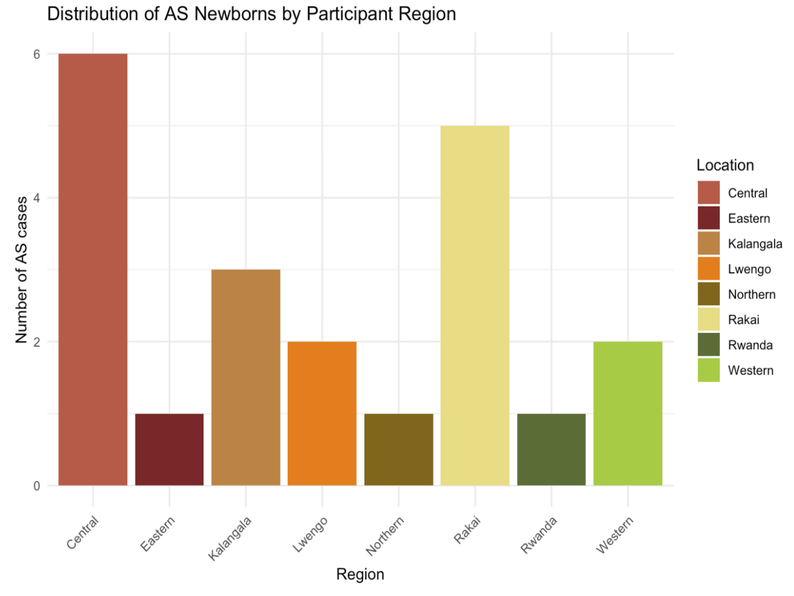
- **Surveys:** new parents at KHCIV, n=271, all parents of newborns at KHCIV will be invited to participate in a survey on SCD knowledge
- **In-depth interviews (IDI)**: 3 subgroups of new parents, (n=32)
  - IDI #1: child tests negative for SCD
  - IDI #2: child tests positive for trait or SCD
  - IDI #3: parent denied SCD screening
- **In-depth interviews**: n=18 HCW, at 3 different governmental health facilities across the island to prepare for scaling up NBS
  - Kalangala Health Center IV: 9 IDIs
  - Bwendero Health Center III: 5 IDIs
  - Mulabana Health Center II: 4 IDIs



Map of SCD clinic patient home locations in Lake Victoria

- With the remote location of KHCIV, the number of newborns varies due to the fishing patterns and seasonal changes which could impact our timeline.

RESULTS



- 223 participants received their newborns' SCD results, revealing a 9.4% prevalence of SCD trait.
- Participants urged HCWs to educate during antenatal care. This would benefit high-prevalence areas.
- HCW’s expressed concern for women with financial restraints that impede them from coming to the health centers.
- Children born outside of health centers are rarely screened, so SCD prevalence is hard to determine.

NEXT STEPS

- This work will support the Ugandan government’s initiative to reduce SCD by advocating for increased resource distribution, including workforce, to KHCIV and other government health facilities.
- We will present our findings to the SCD Clinic and the director of KHCIV to encourage the implementation of additional training and task shifting.
- Mobilize KHCIV staff for community outreach to encourage young adults to screen for SCD before they have children.
- Begin to integrate SCD education during antenatal visits and infant immunization.

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