Designing a Solution Framework for a Sickle Cell Disease Registry in Kenya: Transforming Patient Care

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Abstract. Sickle Cell Disease (SCD) poses a significant healthcare challenge in Kenya, with about 14,000 new cases annually. Fragmented data collection hampers patient management, research, and resource allocation. This paper proposes a framework for a centralized SCD registry in Kenya, integrating with existing systems like KenyaEMR. Through stakeholder engagement and systematic design, we outline methods, system design, implementation strategies, and success metrics. The solution aims to enhance patient care, support research, and inform policy development.

Key terms. Sickle Cell Disease (SCD), Centralized Registry, DHIS2, Interoperability, Healthcare Outcomes

1. Introduction

Sickle Cell Disease affects about 14,000 newborns annually in Kenya [1], posing a significant healthcare challenge. Fragmented data systems hinder patient care, research, and resource allocation due to reliance on paper records and non-integrated electronic health records (EHRs), resulting in poor patient tracking and inconsistent treatment outcomes. Despite the high burden of SCD, especially in Western and Coastal Kenya [2,3], a coordinated data management system is lacking. While disease registries elsewhere have improved outcomes [4,5], Kenya lacks a nationwide SCD registry. Current fragmented systems fail to provide integrated care and robust data management needed to address this challenge. This manuscript presents a framework for developing a centralized SCD registry in Kenya to centralize patient data, improve care coordination, support research and advocacy, and enhance healthcare outcomes.

2. Methods and Solution Framework

We engaged 26 stakeholders, including patients, healthcare providers, policymakers, and digital health consultants, to shape the SCD registry framework by identifying system

requirements, challenges, and success factors. The SCD registry will be built on the DHIS2 platform for its interoperability and widespread use. The architecture includes web and mobile applications for data entry and retrieval, a data integration layer utilizing the DHIS2 API for exchange with existing EHR systems, and a cloud-based PostgreSQL database for secure storage. Healthcare providers without existing EHRs will enter data directly via the applications, while facilities using KenyaEMR will have patient data synchronized automatically, minimizing duplicate entry. The mobile application supports offline data entry, synchronizing when internet access is available. The pilot deployment will focus on Western and Coastal Kenya due to established SCD clinics and screening programs, with standardized data collection protocols and training provided for healthcare providers.

3. Implementation, Evaluation, and Discussion

The pilot phase requires an initial investment of USD 105,000 for system development, training, and infrastructure upgrades, with ongoing costs for maintenance. Funding sources may include government budgets, international organizations, and private donors. The evaluation aims for 80% adoption in pilot facilities within one year, 95% data accuracy, and user satisfaction scores averaging 4 out of 5 among other success metrics.

The centralized SCD registry addresses fragmented data challenges by enhancing patient care, provider efficiency, and policymaker decision-making. Patients benefit from accessible records across facilities, reducing repetitive tests. Providers enjoy streamlined data entry and quick access to patient histories, improving clinical decisions. Policymakers receive real-time aggregated data for evidence-based decisions and resource allocation. Challenges like implementation costs, data privacy concerns, and user adoption can be mitigated through partnerships, compliance with data protection regulations, robust security measures, and comprehensive training. Compared to alternative solution like a federated model, the centralized registry offers a faster, more cohesive approach to systemic gaps in SCD data management in Kenya.

In conclusion, implementing a centralized SCD registry is crucial for improving SCD management in Kenya. Success hinges on collective commitment, through stakeholder engagement, funding, and training, to enhance patient outcomes and strengthen the nation's healthcare infrastructure.

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