



March 26, 2026

The Executive Director,

FS Digital.

Dear Sir,

**Re: Requirements for Development of the TSCA Sickle Cell Screening Registry System**

I hope this letter finds you well. It outlines the comprehensive requirements for the development and implementation of a **digital registry system** to support our sickle cell screening program at Tackle Sickle Cell Africa. Please take some time to read through.

The goal of this system is to ensure accurate data capture, secure storage, efficient retrieval, and meaningful reporting of all individuals screened through our outreach activities.

**1. Purpose of the Registry.**

The registry is intended to systematically capture demographic, clinical, and programmatic data of individuals screened for sickle cell disease under our program. It will support longitudinal tracking, enable follow-up and referrals, and provide reliable data for reporting, research, and strategic planning.

**2. Core Functional Requirements.**

*A. Patient Registration Module:* The system must allow entry and storage of unique individual records, including:

- ✓ Full name (first and last)
- ✓ Age
- ✓ Gender
- ✓ Contact information (phone number)
- ✓ National identification number (where available)
- ✓ Guardian details (for minors)
- ✓ Automatically generated unique patient identifier

*B. Screening Data Capture Module:* For each screening encounter, the system must record:

- ✓ Date of screening
- ✓ Screening location/site
- ✓ Type of test performed

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- ✓ Test result (e.g., Reactive, Non-Reactive, AA, AS, SS, SC, Unknown)
- ✓ Name or ID of the health worker conducting the test
- ✓ Counselor notes or observations

Each screening event must be linked to the corresponding individual record to allow multiple entries over time.

*C. Follow-Up and Referral Module:* The system must support documentation of post-screening actions:

- ✓ Referral status (Yes/No)
- ✓ Referral facility or destination
- ✓ Follow-up status and outcomes
- ✓ Notes on patient counseling or interventions

*D. Program and Event Metadata:* The system must capture contextual information for each outreach activity:

- ✓ Name of outreach event
- ✓ District and specific location
- ✓ Team lead or responsible officer
- ✓ Partner organizations involved

### **3. Data Quality and Validation Requirements**

- ✓ Mandatory fields for critical data points (e.g., name, age, result)
- ✓ Standardized input formats (e.g., dropdowns for test results)
- ✓ Prevention of duplicate records through unique identifiers or validation rules
- ✓ Error-checking mechanisms during data entry

### **4. User Roles and Access Control**

The system must enforce role-based access to ensure data security:

- ✓ Data entry personnel: limited to input and edit
- ✓ Supervisors: review and validate data
- ✓ Administrators: full access, including system configuration
- ✓ Restricted visibility of sensitive patient information.

### **5. Offline Functionality**

Given field conditions, the system should:

- ✓ Allow data entry without internet access
- ✓ Sync automatically when connectivity is restored

## 6. Reporting and Analytics

The system must generate:

- ✓ Summary reports (number screened, genotype distribution, demographics)
- ✓ Event-based reports
- ✓ Referral and follow-up tracking reports
- ✓ Exportable data formats (e.g., Excel) for external reporting

## 7. Data Security and Privacy

The system must comply with ethical standards for handling medical data:

- ✓ Secure login with password protection
- ✓ Encrypted data storage where possible
- ✓ Controlled data access and sharing
- ✓ Regular data backups

## 8. Scalability and Sustainability

The solution should:

- ✓ Support increasing volumes of data over time
- ✓ Be easy to maintain and update
- ✓ Allow integration with other health information systems if needed

## 9. Usability Requirements

- ✓ Simple and intuitive interface for field staff
- ✓ Mobile-friendly (smartphone/tablet compatible)
- ✓ Minimal training required for effective use

## 10. Implementation Considerations

- ✓ Initial pilot testing during a screening event
- ✓ Iterative improvements based on user feedback
- ✓ Training of staff prior to full rollout

This registry is a critical component in strengthening the impact, accountability, and reach of our screening program. Careful adherence to these requirements will ensure the system is reliable, secure, and fit for purpose in real-world field conditions.

Kindly review and provide feedback or additional considerations before we proceed. We look forward to working with your entity to bring this idea to reality. Thank you.

Sincerely

Mutatiina Derrick.

Founder & Executive Director, TSCA

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**TACKLE**  
**SICKLE CELL**  
**AFRICA**  
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