

# SickleREMOTE: A Two-Way Mobile Messaging System for Pediatric Sickle Cell Disease

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Sickle cell disease (SCD) is the most prevalent inherited disease, generally affecting patient lives from early childhood. Effective medical care requires frequent monitoring, such as tracking the frequency, severity, and duration of painful events. Conventional monitoring requires patients to carry forms, which are easily lost, or laptop computers, which are impractical to scale to a large generally underprivileged population. Text messaging (SMS) has become a favored method of mobile communication in the SCD population. We propose a disease-tailored SMS platform that may resolve several limitations of self-report monitoring. We present the findings of the planned interim "optimization" analysis of an ongoing clinical trial.

As shown in Fig. 1, An automated system, called sickle cell disease REporting and MONitoring TElemedicine (SickleREMOTE), using mobile SMS adaptations of validated clinical tools, is being piloted in adolescent (age 12-18) patients at a comprehensive pediatric SCD program. Participants receive training while hospitalized for an acute painful event. Totally 23 subjects completed the inpatient and out-patient protocol, analysis of compliance, accuracy and user-satisfaction was preformed on self-reports of pain and quality-of-life (i.e. PROMIS Pediatric Pain Interface Scale) queries. Additional analysis is shown for 18 participants who have completed the 30-day post-hospitalization outpatient protocol.

Compliance with at least one daily self-report to an automated pain query was 95% and 91% of the inpatient and outpatient days, respectively (Fig. 2). Response accuracy was 99% following the predefined short response convention. 67% outpatient PROMIS responses were reported with 98% reporting accuracy. All participants expressed high satisfaction with the platform, and expressed intent to use SickleREMOTE to help track pain events.

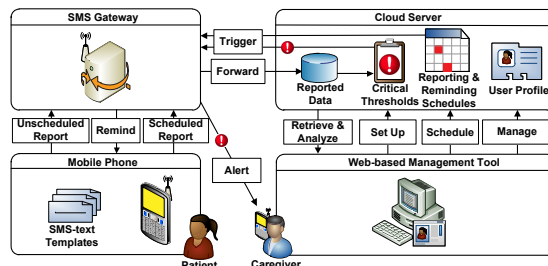


Figure 1. System overview of SickleREMOTE

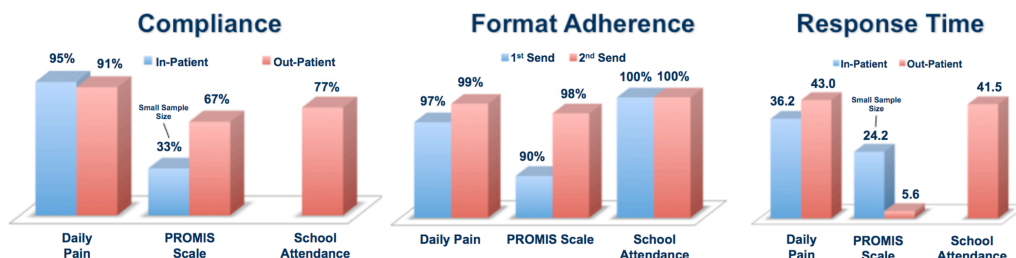


Figure 2. Clinical Trial Evaluation Results

Interim analysis of compliance and user-satisfaction suggests that SickleREMOTE promises to be an effective mobile health tool for adolescents with SCD to monitor their disease. Additional optimization is ongoing to enhance SickleREMOTE as a robust mobile-based outpatient monitoring system.