

Improving Sickle Cell Transitions of Care through Health Information Technology

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Summary: Sickle cell disease (SCD) is a genetic blood disorder that produces abnormal “sickle-shaped” red blood cells that obstruct blood vessels, leading to life-long anemia, organ damage, increased potential for infections, chronic episodes of pain, and substantially shortened life spans. People with SCD experience multiple transitions of care as a result of SCD’s chronicity and the frequency of acute and chronic events requiring care. Care transitions occur when either the setting (e.g., from home-based to hospital-based care), or the focus of care (e.g., from pediatric-focused to adult-focused care) changes. When care transitions occur, it is necessary to share medical history and other types of health information. These transitions are more likely to be successful when that health information is accurate, tailored to the type of transition taking place, and communicated effectively.

Care transitions are particularly fraught for patients with SCD, few of whom have access to effective transition programs. This project will explore the potential of health information technology (IT) to ease SCD health care transitions. The project will establish a set of requirements to guide the design and development of a technology-enabled tool that meets the needs of patients, their families, and providers in care transitions.

Information will be collected in three ways. First, the project team is conducting an environmental scan to identify potentially relevant scientific literature and information that will provide contextual background about the current state of the field with regard to tool development and use, identify key issues of patients with SCD related to care transitions, and explain the context of care delivered and health data information needed to inform the content, design, and functionality of a tool. Second, the team will conduct 10 focus groups of key stakeholders including parents and caregivers of patients with SCD, providers, IT developers, and SCD patients ages 9 and older to gather qualitative information on experiences with SCD and care transitions, barriers to quality care, and use of technology to inform tool design and functionality. Finally, the team will conduct up to eight key-informant interviews with patient advocates, State Medicaid representatives, attorneys with expertise in privacy and security issues, and relevant policymakers to understand cost issues related to reimbursement by payers, need for proof of effectiveness, sustainability, and potential vehicles for facilitating and funding tool development and implementation. A final report with recommendations for the design and functionality of a health IT-enabled tool designed to aid adolescents and young adults with SCD during transitions of care will be developed.

Project Objectives:

- Gain the necessary background knowledge, including qualitative information from key stakeholders, to establish a set of requirements that would guide the design and development of

a health IT-enabled tool in future phases of work that meets patients', families', and providers' needs to aid adolescents and young adults with sickle cell disease during transitions of care.

(Ongoing)

- Develop an understanding of the environmental context, current facilitators and barriers, health data use and needs of key stakeholders affected by sickle cell disease, including patients, families, and providers. **(Ongoing)**

2012 Activities: This project started in August 2012 with the environmental scan to identify existing tools and tool components to aid transitions of care for people with SCD, focusing on technology-based and mobile health resources and a search for literature to inform the tool's content and functionality. At the end of the year, the team had identified 80 possible tools from which it selected 40 for inclusion in the scan, completed the full text review of the articles, identified preliminary findings, and developed the template for the environmental scan report. The team developed moderator guides and recruitment activities for the focus groups. Materials for the various participating organizations' institutional review boards were submitted. In addition, the team submitted the materials to AHRQ for the Office of Management and Budget clearance required to conduct the evaluation.

Preliminary Impact and Findings: This project has no finding to date.

Target Population: Chronic Care*: Sickle Cell Disease, Pediatric*, Teenagers

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Business Goal: Knowledge Creation

**This target population is one of AHRQ's priority populations.*