Final ACTION Contract Report

Improving Sickle Cell Transitions of Care Through Health Information Technology:

Recommendations for Tool Development

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Improving Sickle Cell Transitions of Care Through Health Information Technology: Recommendations for Tool Development

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Introduction

Project Overview

This final report combines and synthesizes project findings to provide context and present recommendations.

The goals of this project were to—

1. 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 information technology (IT) tool that meets the needs of patients, families, and providers to aid adolescents and young adults with sickle cell disease (SCD) during transitions of care.
2. Develop an understanding of the environmental context, current facilitators and barriers, health data use, and needs of key stakeholders affected by SCD, including patients, families, and providers.

This report includes a brief overview of SCD and the current knowledge about care transitions experienced by individuals with SCD. It also provides a conceptual framework to provide context to better understand transitions of care in SCD and locate this project in that context. The methodology section for each project task and key findings describes the research and analysis conducted over the course of the project that led to the summary recommendations in the subsequent sections of this report.

Overview of Project Tasks

Environmental Scan (Task 1)

The Lewin Group (Lewin, Falls Church, VA), in partnership with Children's National Medical Center (CNMC, Washington, DC); Cincinnati Children's Hospital Medical Center (CCHMC, Cincinnati, OH); The Nemours Foundation (Nemours, Tampa, FL); and the National Initiative for Children's Healthcare Quality (NICHQ, Boston, MA), collectively, the Lewin Team, conducted an environmental scan to search the relevant peer-reviewed literature and grey literature, including pertinent Web sites and other information sources, for two purposes. First, the team searched for existing tools to inform and aid the development of a tool to improve transitions of care for persons with SCD and other chronic conditions that occur in young populations. The search focused on, but was not limited to, applications (e.g., smart phone applications or Web-based portal applications), mobile health, electronic health records (EHRs), and personal health records. Second, the team searched for literature and content that would inform the tool's content, functionality, and effectiveness. This initial scan was updated in 2014. The updated findings, in addition to a summary of what was previously done, are included below.

OMB Clearance (Task 2)

In preparation for the focus group task, the Lewin Team developed and submitted materials for clearance from the Office of Management and Budget (OMB). Clearance is required prior to conducting information collection activities involving 10 or more non-Federal respondents. The OMB clearance package materials consisted of descriptions of our approach to conducting focus groups and key informant interviews as well as copies of moderator guides, demographic forms and recruitment materials. No public comments were received, and official OMB clearance was awarded for the focus groups on August 20, 2013, which allowed the team to begin planning and recruitment for the focus groups to be conducted in the fall of 2013.

Focus Groups (Task 3)

The goal of the focus group task was to obtain diverse perspectives from stakeholder groups regarding SCD care transitions, and the potential use of technologically-enabled health management tools during care transitions. The Lewin Team conducted 11 focus groups across six stakeholder types between October 2013 and December 2013 at each of the four partner sites. In addition, Lewin staff conducted four key informant interviews during February and March 2013 to obtain additional context from individuals with critical areas of expertise that did not lend themselves to focus group research.

Recommendations for Tool Development (Task 4)

The goal of the Recommendations for Tool Development task was to produce final recommendations that are actionable, highly relevant, and generalizable to multiple audiences, addressing key issues of SCD care transitions and reflective of the needs of priority populations most commonly affected by SCD. To that end, the Lewin Team synthesized information collected through previous project tasks to develop a comprehensive report that summarizes main findings, key themes, and operational constructs of care planning and care transitions for patients with SCD. This report provides a synthesis of the main findings, organized around two care transitions: (1) from home to the emergency department (ED); and (2) from pediatric to adult care. Final recommendations focus on a health IT tool for the transition from the home to ED.

Background and Purpose

Overview of Sickle Cell Disease

SCD is a serious, genetic blood disorder that affects approximately 70,000 to 100,000 Americans,[1] including one out of every 375 African Americans,[2] and 1 in every 16,300 live births among Hispanics.[3] Persons with SCD produce red blood cells that become abnormal or "sickle-shaped" in response to oxidative stress. These cells have a dramatically shortened lifespan resulting in chronic anemia. They obstruct small blood vessels, leading to organ damage which can affect virtually every organ of the body, with increased potential for infections, acute and chronic pain, and a substantially shortened life expectancy.[4] SCD patients may also have cognitive impairments due to central nervous system sequelae from their disease (e.g., history of strokes) even in the absence of overt physical disability.[5] The complexity of the disease with its resultant multi-system, multi-organ involvement necessitates a carefully integrated care regimen. This regimen requires high quality acute and chronic treatment and prevention to achieve optimal health. In addition, close monitoring and careful adherence to medical regimens between encounters with the health care system are important, especially across care setting transitions. The variable and often high readmission rates for patients with SCD attest to the fact that this monitoring and coordination is often lacking.[6] Also, despite knowledge about effective treatments, the delivery of care to patients with SCD is not well studied relative to its prevalence.[7]This has resulted in a lack of knowledge about specific strategies for care delivery that ensure optimal health outcomes and lifespan for patients. Furthermore, patients with SCD are typically young, and belong to racial and ethnic minorities. Many individuals with SCD come from vulnerable populations that may not have had adequate opportunities to voice their concerns and needs.[8]

As recently as 30 years ago, children with SCD usually did not survive into adulthood. Now, as a result of advances in screening and treatment,[9] more than 90 percent of individuals with SCD reach adulthood, and life expectancy is typically into the fifth decade.[10] With increased life span, individuals with SCD often encounter additional transitions of care, including changes in the setting of care (e.g., from home-based to hospital-based care, and vice versa) or in the discipline of care (e.g., from pediatric to adult care).

An emerging framework posits that transitions in health care can be considered as experiences of crossing cultures or subcultures. According to the Institute of Medicine,[11] cultures can be characterized by:

- Shared ideas, meanings, and values
- Being socially learned and not genetically transmitted
- Patterns of behaviors that are guided by these shared ideas, meanings, and values
- Ongoing modification through lived experience

Transitions in health care can be thought of as times when different cultures must be navigated and accounted for, and communication needs must address the different values and information needs that result from them. Results from the environmental scan suggest that independence as a value is more important among adult-oriented health care professionals, while values such as interdependence and support, or relationship-building, are more characteristic of pediatric cultures

and are likely more familiar to patients as they emerge from pediatric environments into other settings. Beyond the pediatric and adult subcultures in medicine, primary care values can differ starkly from those espoused in emergency and inpatient settings, where time is short and acuity is premium. Transitions are further complicated by the developmental changes in the patients themselves, as they progress from childhood to adolescence and into young adulthood, each phase of which may be characterized by changes in values, shared ideas, and behavioral norms which themselves constitute "cultures." The following sections will provide a brief overview of the care transitions experienced by individuals with sickle cell disease. The findings from all of the project tasks presented in this final report highlight some of the needs and values of the cultures involved—both shared and distinct—as well as ways these ideas drive behaviors and can be harnessed to improve care and health for patients with SCD. Collectively, these insights informed the final recommendations proposed in this report.

Overview of Care Transitions and Role of Technology in Care Transitions

Times of care transitions have been shown to be particularly challenging for patients with SCD and are associated with increases in morbidity and mortality.[10,12-14] The reasons for this are not fully understood but are thought to be at least partly related to care delivery.[15] For example, few patients have access to effective adolescent to adult transition programs for SCD.[9,16] Although a 2010 survey of pediatric SCD providers described that the majority claimed to have transition programs in place, they were often newly formed and without the ability to transfer care to adult providers with specific expertise in SCD.[17] During times of transition, when new providers may be unfamiliar with the patient and with their illness, and when clinical needs are often serious and acute, a need to share medical history and other types of health information is especially critical. The literature suggests that transitions of care are more likely to be successful when relevant health information is accurate and up-to-date, tailored to the type of transition taking place, and communicated effectively.[18] Preliminary evidence supports the idea that health IT can be helpful for the communication needs related to SCD and other chronic and serious conditions.[19] For example, in one study of patients with SCD, a handheld wireless device was used to implement a pain management protocol and found to result in high rates of both participation and satisfaction.[19] Technology-based tools and applications—or "apps"—have also been effective in improving care transitions for other chronic diseases such as diabetes and HIV; these tools may serve as prototypes for such a tool for SCD.[20-24] Thus, technology-based tools are a promising avenue for facilitating important transitions for individuals with SCD. The subsequent sections will detail the types of care transitions that are experienced by individuals with sickle cell disease—pediatric to adult and across care settings—as well as the role of technology.

Pediatrics to Adult

There is great phenotypic variation among individuals with SCD. For example, while the vast majority have illness trajectories characterized by moderate levels of crises and morbidity, 15 to 30 percent have a mild, relatively uneventful course and another 15 to 30 percent have very poor outcomes.[12,14,25] Not surprisingly, those patients with more severe clinical phenotypes are also more likely to encounter psychosocial barriers to care.[26] In addition, SCD patients exhibit a range of developmental heterogeneity, from normal or above average functioning to being moderately or severely disabled.[27,28] Thus differences between the health care culture in pediatrics and that of

adult medicine, which can be challenging and confusing for any patient, may be amplified for those with disabilities. All of this variation contributes to the critical concern that patients tend to be unprepared for the level of responsibility they need to assume for their own care when they transition to an adult care facility.[15] Furthermore, the lack of adult SCD providers with the knowledge, understanding and interest in caring for patients who have a condition that was previously only seen in pediatrics, further limits access to high quality care and the ability to bridge the gap.[29,30] The dearth of adult SCD providers is likely to be especially challenging during the time of life when SCD care needs are high since young adult patients are more likely to develop end-organ dysfunction from ongoing hemolysis and vaso-occlusion and have high health care utilization.[31,32]

The transition from pediatric to adult care should ideally be a long-term, coordinated process, with attention to early and steady preparation and the ability for patients to practice and subsequently master skills in self-management and independence.[15,33] It should not be a discrete event that occurs when a patient reaches a certain age. Experts agree that transition support for the patient should be systematically and routinely integrated into care plans well before the time of departure from the pediatric care setting, and that adult and pediatric providers should work collaboratively to share information.[13] One published study described many providers involving families in transition planning and routinely providing information about adult providers, but a minority of pediatric providers seeing adolescents without their parents, having patients schedule their own visits, or having the patient meet the adult provider prior to transition.[17] Age and pregnancy were cited in the literature as the most frequent triggers for transitions, suggesting that such discrete events may not allow for adequate preparation, assessment of individual readiness, or accounting for the developmental differences among patients with SCD who may have cognitive and neurological deficits.[16]

Across Care Settings (e.g., Home to Emergency Department, Inpatient to Outpatient)

Care setting transitions occur when a patient moves from one physical location of care to another. This may include moving from home-based to emergency care or from inpatient to outpatient care. The admission and discharge processes are integral parts of care setting transitions and are complicated by patients' interactions with unfamiliar care providers. There is an increased need for communication between patients and providers and between providers with different values, need for information, and levels of familiarity with the patient and with SCD. As with age transitions, care setting transitions are periods of increased risk for morbidity and mortality for individuals with SCD. [14,34]

The literature shows that young adults with SCD (ages 18–30) have increased ED utilization.[34] This may be partially explained by the finding that some patients do not recognize that care obtained through the ED is less than ideal for their disease. Increases in disease severity and limited access to adequate primary or ambulatory care also likely contribute to increased ED use.[34] Patients may depend on the ED as a convenient and reliable source of care without recognizing the benefits of care continuity and coordination.[35]

Hospital admissions for patients with SCD tend to be unplanned and urgent, a challenge to successfully executing care setting transitions for patients with SCD. A retrospective study of

inpatient data for patients with SCD indicates that 78 percent of hospital admissions were associated with the diagnosis of an SCD crisis, which was more common in young adult than adolescent admissions.[32] In these cases, the hospitalist may depend on the patient/caregiver for a medical history since the urgency of the admission provides limited time to contact the patient's primary care team in the absence of an electronic medical record or other immediate form of health information management.[36]Further, if the admission occurs after hours or on weekends, the primary care team most familiar with the patient and his/her needs may be unavailable. This is problematic as studies have demonstrated that patients and their caregivers are often unable to accurately convey their medical histories, such as their diagnoses and medications, with the detail required by providers.[32] Similarly, communication of the treatment provided during ED visits or hospitalization is essential to ongoing chronic care management with individuals with SCD. It seems that health IT tools could be helpful in ensuring appropriate and timely communication during care transitions in either direction.

Use of Health Information Technology in Culturally Diverse Populations

The SCD population is young and racially and ethnically diverse. While more advantaged populations (e.g., more educated, wealthier, white) have traditionally benefitted more from health innovations than less advantaged populations and minorities (characteristic of patients with SCD), innovations in health IT and mobile health (mHealth) may disrupt or even reverse the normal pattern of health technology diffusion because minority populations tend to adopt new mobile technology earlier than whites.[37] Young adults, minorities and cell phone owners in need of health information are more likely than others to turn to their phones to look for health information. African Americans and Hispanics are more likely to own smartphones than whites and are more likely to use their mobile phones to access health information online. [37] African-American cell phone owners are also more likely to receive health or medical information via text and download applications to track their health. [37] Consequently, individuals with SCD are probably more likely to use a smart phone based application to assist with some aspects of their disease management. Further, as detailed in the final Environmental Scan Report, technology-based tools have already been used successfully by patients with SCD to help with some aspects of disease management although not specifically during transitions in care.

Organization of This Report

The methodology used for key project tasks is presented below, followed by the findings organized into four categories: care setting transitions (especially from home to the ED), transition from pediatric to adult care, health IT concerns and challenges, and existing tools or tool components that could be leveraged for future tool development. An overall analysis and summary follows the key findings. The report ends with conclusions and recommendations that can help guide the development of a health IT tool to improve transitions of care for persons with SCD. Literature reviewed is appended to this report.

Methods

Description

The Lewin Team includes three children's hospitals in different geographic settings (Children's National Medical Center in Washington, DC, Cincinnati Children's Hospital Medical Center in Ohio, and Nemours in Florida) in addition to NICHQ in Boston and Lewin, also in the DC metropolitan area. In assembling this team, the project benefited from the expertise and, via focus groups and interviews, the experience of large groups of patients, caregivers, and other stakeholders to capture both the rigor and richness of the qualitative information needed to identify and ultimately meet SCD transition needs. Diverse perspectives and theme saturation ensured that the most important issues around a personalized, patient-centered, health management tool emerged. Also, the project timeline was designed to ensure that each task built upon its predecessor, allowing the team to make use of lessons learned and results from previous tasks to inform subsequent tasks. For example, the findings from the environmental scan helped to identify topics of interest for key informant interviews and focus groups. And, in turn, the focus groups brought to light concerns and topics that were not addressed in the first scan and were therefore further explored in the 1-year environmental scan update.

Environmental Scan

An initial environmental scan (conducted October 2012–December 2012) included searches for literature, Web sites and other sources, such as the ITunes App Store, to identify existing tools and their features (including curricula, technology apps, and other aids for individuals living with SCD and their family members and providers) that would inform the content and functionality of a health IT-enabled tool to improve transitions of care for persons with SCD. The scan followed two parallel tracks. The first track searched for existing tools in the market (both for sale and freeware) while the second track identified studies of tools and other materials to inform tool development relevant to SCD, SCD patient needs, transitions of care, and best practices in mHealth applications. Tools and articles were included if they were:

- Relevant to SCD or other chronic health conditions (e.g., cystic fibrosis); and
- Applicable to use by nonprofessional audiences (i.e., patients and caregivers) who are the primary stakeholder groups for this project.

Tools included in the scan were organized into five areas of relevance: (1) relevant to pediatric to adult care transitions; (2) relevant for care setting transitions (e.g., hospital to home); (3) facilitates the management or monitoring of a specific disease or condition; (4) functions as a personal health record and facilitates the collection and storage of general health information; or (5) connects users with others who share a common condition and allows them to share experiences and information.

The literature review was guided by three search goals:

1. Understand issues and problems that occur during both types of care transitions for patients with SCD, including the needs and priorities of patients and families during times of transition.

2. Seek evidence of effective transition practices and care coordination approaches for patients with chronic conditions, including SCD and similar conditions among pediatric and young adult populations.
3. Identify current best practices and advances in health IT and mobile health that may be relevant to tool design and development for a tool for SCD.

An environmental scan was conducted from January to February 2014 to update the baseline review to incorporate studies and tools published or released in the year since the initial environmental scan was conducted. To ensure comparability with the original scan, the same search criteria, goals, and areas of relevance were used when conducting the update. Tools or areas of interest that were mentioned by the focus group participants or during the key informant interviews were given priority (e.g., video capability, tools that would assist during an acute pain crisis).. Combined findings from the literature and tool searches of the initial scan and update are presented in Appendixes A and B.

Key Informant Interviews

The Lewin Team conducted four interviews (February and March 2013) with key informants including a State government representative, an attorney with expertise in privacy and security issues, a representative from the Office of the National Coordinator, and a patient advocate and SCD researcher to gain the perspectives of other stakeholders not represented in the focus groups. The team researched potential interviewees, leveraging the team's network where possible. In some cases, individuals directed interviewers to an alternative interviewee who they believed would be better equipped to participate in the discussion. Interviews were one hour in length and conducted via telephone. Two comoderators and one research analyst conducted the interviews using interview guides developed by the team. Following the interviews, the team debriefed to identify and reflect upon the key pieces of information discussed. Summary notes were distributed to the entire Lewin Team for comment and review. The annotated summary notes were then analyzed in conjunction with the focus group analysis as well as the environmental scan results, allowing for a cohesive assessment of key themes as described in this report.

Focus Groups

The overarching goal of conducting the focus groups was to obtain diverse perspectives from six stakeholder groups regarding SCD, care transitions, and the use of technologically enabled health management tools. The Lewin Team conducted 11 focus groups across six stakeholder types between October 2013 and December 2013 at each of the four partner sites representing geographically diverse clinical settings. The six stakeholder groups included: (1) patients ages 9-13; (2) patients ages 14-17; (3) patients ages 18+; (4) parents/caregivers of children and young adults with SCD; (5) providers including primary care physicians, hematologists, social workers, and psychologists; and (6) IT developers. Each group had between 5 and 12 participants.

Table 1. Overview of focus groups

Organization	Group	Participants	Date
CCHMC	Patients 9-13	9	November 6, 2013
	Parents/caregivers	12	November 6, 2013
	Providers	5	November 7, 2013
	Providers	8	November 7, 2013
NICHQ	IT developers	7	October 28, 2013
CNMC	Providers	9	October 23, 2013
	Patients 18+	6	November 21, 2013
	Parents/caregivers	10	November 18, 2013
	Patients mixed ages	9	December 2, 2013
Nemours	Patients 14-17	10	October 21, 2012
	Parents/caregivers	9	October 21, 2013

The Lewin Team used a strategy of grouping patients by age that allowed participants to relate to and feel at ease with other participants, and thus increased the likelihood they would share salient and honest concerns. It also enabled the team to capture experiences particular to age or setting that may be relevant to transition needs, while allowing the moderator to use facilitation techniques appropriate for specific age levels. As Table 1 shows, the team scheduled the 11 focus groups so that the IT Developer group occurred in the middle and could be informed by earlier groups and then could inform the later ones.

Recommendations for Tool Development

The Lewin Team developed recommendations for the development of a health IT tool based on the findings of the environmental scan and focus group tasks. The Lewin Team interpreted and analyzed the findings in the environmental scan and focus group reports, along with the data gathered from key informant interviews and the environmental scan update not covered in detail in either previous report. The project team also brought to bear their collective subject matter expertise, including experience working with SCD populations and developing health IT tools, to develop actionable recommendations and next steps. The draft recommendations were shared with team members at several stages, and the team convened for brainstorming sessions to identify and interpret key findings. Through feedback and discussion, the diverse perspectives of the team were incorporated. The data and feedback were synthesized using the content expertise of the project team, and final recommendations were developed and vetted by the Lewin Team before final submission.

Findings

This section presents a summary of project findings. Findings are organized into four categories:

1. Care setting transitions (especially from home to the ED)
2. Transition from pediatric to adult care
3. Health IT concerns and challenges
4. Existing tools or tool components that could be leveraged for future tool development

The first two sections summarize and synthesize data from all of the project's tasks (i.e., the literature reviewed in environmental scan, key informant interviews, and the focus groups) to provide context for the recommendations below. The environmental scan and focus groups identified several key insights related to transitions from adolescent to adult care and care in the ED. The health IT section addresses concerns raised primarily in the interviews, such as privacy, meaningful use, and interoperability. The final section draws primarily on the results of the environmental scan, which identified several SCD-specific tools.

Care Setting Transitions

Findings from both the environmental scan and the focus group tasks clearly pointed to the ED as a critical transition site to consider and address. Long wait times and insufficient treatment of pain during SCD crisis in the ED can lead to increased morbidity (or mortality) and long-term end organ damage.[38-40] Issues with transition from pediatric to adult care also often emerge in the ED, which can become the default site of care if primary care lapses during this period, making it an important site for both setting-based and age-related SCD transitions. The literature cites many factors contributing to the sub-optimal transition from home to the ED, including the tendency for the majority of these transitions to be unplanned and urgent.[36] Sickle cell patients presenting to the ED with a pain crisis may not be able to initially convey their medical histories with the level of detail often required by providers due to their acute symptoms (e.g., pain).[41] This presents an added barrier for SCD patients seeking ED care during a pain crisis when health information needs are critical to appropriate treatment.

The focus group findings confirm that the emergency department is a critical transition site to consider and address. Specifically, adjusting to an adult ED is perceived as the most difficult transition for adolescents with SCD. Focus group participants explained that the ED is often the primary point of care for young adults with SCD during an acute crisis when adult primary care has not yet been established. Participants in the caregiver focus group expressed concern over the long wait times in the adult ED, where trauma and other acutely life threatening conditions seem to take priority in the triage process over the equally acute crises of SCD.

A patient advocate said during an interview that legitimacy of pain is a key issue in the ED. Even when a patient has the knowledge and capacity to convey pain treatment needs, treatment is often delayed by the lack of objective physiological measures that providers can use to validate the patient's self-report of pain levels. He further addressed the need for leveling the patient-doctor relationship; during crises patients are at their worst and don't represent the whole people they are ("with jobs and families"). If providers were able to get to know the whole individual outside of

their crisis, this could improve communication and the provision of care. For example, the focus group modality of this project afforded insight into the whole patient, with plans and dreams that go beyond their illness.

The emphasis by patients on the need to enhance ED care through shortened wait times for treatment and better protocols for triage of SCD crises, together with the greater emphasis among providers on primary and longitudinal care, reflects NICHQ's experience in serving as the coordinating center for the HRSA Sickle Cell Disease Treatment Demonstration Program.[42] In that effort, families preferred a strong focus on speedy and compassionate care in the ED setting. Based on this insight, developing tools to optimize communication between patients and providers during this type of care transition could help address this need.

Pediatric to Adult Care

One of the major challenges for patients with SCD identified in the literature related to adolescent to adult transitions. The transition from pediatric to adult care encompasses primary, specialty, and acute care settings. Patient focus group participants reported feeling hesitant about transitioning from adolescent to adult care given the unfamiliarity with new health care providers and the facilities, a finding that was supported in the environmental scan. Major barriers identified related to the perceived lack of patient readiness by both patients and providers,[17] and the dearth of adult providers with SCD expertise.

The environmental scan identified several articles (18 out of 53) concerned with the transition from pediatric to adult care for adolescent with SCD. This transition is crucial for reasons including the dramatic increase in life expectancy for SCD patients in the last several decades,[35] and the dearth of adult providers with specialized SCD knowledge.[43] Further, literature describing patient perspectives indicated that patients often fear leaving their adolescent or pediatric provider and feel unprepared for the transfer.[5,43-46]

During the focus groups, concerns regarding pediatric to adult transitions were reported by patients, parents, and providers. The adolescent participants expressed hesitancy around transitioning to adult care and their parents echoed the hesitancy. One participant in the age 14-17 focus group said, "If we could take [our pediatric doctor] with us to all of our future appointments and hospital visits that would be awesome." Participants also noted concerns about providers lacking a comprehensive understanding of a patient's SCD-specific needs.

Providers, patients, and caregivers all expressed the belief that the transition from pediatric to adult care would be smoother if the patient and family have clear expectations, the patient functions independently, and communication between providers occurs. Participants discussed potential efforts that might ameliorate this transition, including efforts to familiarize adolescents with adult care providers and settings during the process of transition, better communication between pediatric and adult providers, and care coordination by community health workers or patient navigators.

During an interview, a patient advocate described how at the age of 35 or so, his parents still provide practical support during crises and felt that this was appropriate. His experience highlighted that transition is not a hard line between dependence and independence and self-

sufficiency, but rather a continuum. As an educated professional, he is able to highlight this issue in a way that many other patients cannot.

Health Information Technology Concerns and Challenges

There is clear indication of the potential benefits of a health IT- enabled tool to improve health outcomes for SCD patients. Patients and parents are familiar with technology, although they may use it differently (e.g., parents search for health-related information, patients use technology as a means of distraction during pain crises).[37,47] Research has shown that minority populations more readily adopt new technology, and young African Americans and Hispanics are more likely to own smart phones and access health information on their phones and online.[47] There are types of information that are important in both an emergency setting (i.e., diagnosis, medical history indicating severity of disease, vital signs and current pain regimen and other medications) and for patients engaging with new physicians as they transition to adult care. Findings also include challenges and suggestions for tool functionality, data exchange, and design, most of which will be covered in more detail in the following Recommendations section.

Based on the focus group discussions, patients and parents would welcome the development of tools that would help them share health information particularly when they are seeking acute care management in the emergency department. Providers identified many possible uses for a patient-centered transition tool that could be used to track health information and facilitate communication. They placed a high priority on a tool to facilitate providing a "snapshot" of the patient to a provider, including salient health and general introductory information. Other potential features and uses included: providing a health summary, enabling disease tracking, facilitating communication, and providing support for transitions, all of which are discussed in more detail below.

During the interview with a privacy lawyer who also has experience with health IT and public health, the major concerns that emerged were FDA approval, reimbursement, and authorization and consent. Sharing information across care teams was identified as a primary question, as well as concerns around the Health Insurance Portability and Accountability Act (HIPAA) and the Federal Education Rights and Privacy Acts, which affects medical information held and exchanged in a school setting or record and which is more restrictive than HIPAA.

Additionally, any tool based on mobile technology would face issues with variations among States, such as how State laws compare to HIPAA and the definition of a minor. Although disabilities are not as legally challenging in the pediatric population because the parent acts on behalf of the child, they become more critical as you approach transition age because the patient may not be a minor but has cognitive impairments and there are variations across States as to who can speak/act on behalf of the patient. There are additional privacy and security considerations if there are mental health/substance abuse issues.

Leveraging Current Technology

The Lewin Team conducted an in-depth review of 51 tools as part of the environmental scan, described in Appendix C. During the scan, research found no health IT tools that met all or most of the anticipated needs of patients with SCD who are undergoing medical transitions and few tools

that are intended for use by patients with SCD (see Appendix B for Key Characteristics of Tools Reviewed).

Current research about the experience of living with sickle cell disease includes the importance of effective and efficient coordinated care (including high quality acute care and chronic treatment and preventive care) to ensure that patients achieve optimal health.[48] During the environmental scan and its update, tools were identified that address some of the common issues that arise from living with SCD such as pain management (e.g., Wireless Pain Intervention Program for At Risk Youth with SCD), accessibility of personal health information during both routine health care encounters and in emergencies (e.g., SiKL), and the need for social and familial support (e.g., Sickle Cell Warriors).

The environmental scan uncovered only one tool, a paper (nontechnology based) curriculum that addresses transition specifically for SCD adolescents: Sickle Cell Disease Treatment Demonstration Program Transition Curriculum.[42] However, a number of tools were identified that address transitions from pediatric to adult care for the general population (e.g., Healthy Transitions, Journey to Adulthood a Transition Travel Guide) that might be leveraged and adapted to the SCD population. For example, the Web site, Healthy Transitions, provides downloadable interactive tools designed to help adolescents develop skills as they move to adult care, such as scheduling appointments, managing prescriptions, and securing health insurance. These are skills that all adolescents, including those with SCD, need to own as they become less dependent on their parents to manage their health care. A potential direction for future research would be to identify what SCD-specific components, such as genotype, or pain management plans, could be added to this type of tool.

Recommendations

Transition as a Process of Navigating Different Cultures

As previously discussed, transition is the process of changing from one situation, form, or state to another. By definition, any transition is an encounter with a different context, be it temporal, physical, cultural, or psychological. Transitions in health care can also be considered as times when different cultures must be navigated. Each care transition is characterized by changes in values, shared ideas and behavioral norms which themselves constitute "cultures." Clear communication between and among patients, families and providers is an important element of the process of successfully negotiating the different cultures encountered during care transitions. The goal when a patient experiences a transition is for the patient to experience a "continuous healing relationship" as articulated by the Institute of Medicine in Crossing the Quality Chasm and for the care received in all settings to fulfill the six dimensions of quality (safe, timely, effective, efficient, equitable and patient centered).[49]

In this project, the team explored two important transitions that occur in the lives of youth with SCD: the transition from home to the ED in the context of an acute illness episode (in most cases, a pain or other type of "crisis"); and the transition from the pediatric health care setting to the adult health care setting for ongoing chronic care management. On occasion, the transition from pediatric to adult care takes place abruptly when an acute episode occurs around the time of the temporal transition, but for the purposes of this report, the team will consider these transitions as distinct.

The results from the environmental scan, focus groups, and key informant interviews strongly endorse the recommendation that a health IT tool to support SCD patients should facilitate the most important care transition for patients and families affected by SCD: home to ED. It is posited that a focused technology-based tool that supports timely, reliable communication and exchange of health information as part of a comprehensive transition program holds promise to deliver crucial information appropriate to the situation, patient, and provider.

Pediatric to Adult Care Transition

Much evidence documents the difficulty many youth with special or chronic health care needs have in effectively transitioning from the pediatric to adult health care system.[18,50] These challenges include the difficulty of finding adult health care professionals with the knowledge, skills and interest in caring for young adults with genetic conditions, as well as navigating the culture of adult compared with pediatric care. These issues affect youth with SCD, but the salience of achieving a seamless transition for youth with SCD is heightened by the data indicating a significant increase in health care utilization and mortality during this time of transition.[13,14]

Because the needs of youth with SCD in making an effective transition to adult care are not dramatically different than the needs of all youth with chronic health care needs, the team recommends that a more generic approach to facilitating such transitions be undertaken, potentially with condition-specific components. Moreover, the specific functionality of an application to enable pediatric to adult transition is less apparent. Mechanisms are needed for training youth over time, for

coaching them in navigating the health care delivery system, and, potentially, for transmitting valid medical histories.

Although other tools may be of value, such as those to support aspects of the transition from pediatric to adult care settings, the Lewin Team recommends as a highest priority that health IT application development efforts focus on one tool that serves the home to ED transition as this is where the need is greatest and the functionality can be readily developed. Further detailed recommendations about this potential tool are outlined in the following sections.

Home to ED Transition

In focus groups, patients with SCD expressed frustration, anger, and emotional pain regarding their encounters in the adult ED. Patients report long waits and substantial under-treatment for their pain, as well as the subjective experience of discrimination.[40] Such bias is amply documented in the literature, and was also consistently articulated by the participants in the focus groups. The salience of this finding, and its specificity to patients with SCD, make this a high priority for the development of specific interventions including the exploration of the potential contribution of a health IT application.

Patients and physicians participating in the focus groups expressed the belief that the lack of familiarity of the ED staff with a particular patient with SCD, and with the details of their condition and their optimal treatment plan, is a major contributor to both the delays and the inadequacy of care and pain treatment. Moreover, patients and physicians in the focus groups theorized that, because ED staff sees patients with SCD only when in severe distress, they may not have an appreciation for them as whole individuals, with typical levels of social and professional function and capabilities. Patient and parent focus group participants also noted they wanted to experience timely triage and appropriate and rapid treatment in the ED. These focus group participants also want to receive care by ED providers who come across as both compassionate and knowledgeable about their condition and successful treatment strategies.

Recommendations for a Home to ED Care Transition Tool

An electronic tool or application for the home to ED care transition should be developed that would operate on a smartphone or tablet to help improve the experience of care during this important transition. Probably, a tool or app for a smartphone would be most appropriate as focus group results showed smartphones were the type of technology most available to young SCD patients. The primary users of this tool would be patients, parents, and other caregivers, and providers the secondary users. An electronic tool or application could better facilitate transitions from home to ED by ensuring patients, parents, and family members have requisite medical information readily available in one place during an emergency thus improving communications with ED providers.

Tool Users and Content

As noted above, the primary user of the tool should be patients and their parents or caregivers. However, it is anticipated that providers might also view some of the information provided through the tool, either directly on the patient's smartphone, or through some form of health information

exchange whereby the tool exports relevant data to the treating provider's health IT system, such as an EHR. Although there is a widespread use of smartphones among patients and parents, it is unknown if providers would view information on a patient's smartphone as credible and subsequently use the information as a basis for health care decisions. As such, this issue should be researched in conjunction with further assessment of possible technical approaches to exporting data from the tool to a provider's EHR, as described in more detail in the section on tool design below.

Focus groups agreed that the tool should have a succinct summary of a patient's important health information and include a combination of static and dynamic information. Strategies to ensure regular updating of dynamic information would need to be explored to ensure accurate information is available when needed or to indicate the date of the information update. The listing below details the type of static and dynamic information that should be included in the tool for ED transitions:

Static Information

- Demographic information: name, date of birth
- Sickle Cell genotype

Dynamic Information

- Demographic information: address; telephone number; email address;
- Past medical and surgical history (brief summary)
- Medication and food allergies
- Baseline lab results
- Blood bank information and transfusion history
- Medications
- Typical location of pain when a patient experiences a pain crisis
- Pain management plan (home, ED and inpatient setting)
- Treatment algorithms for pain
- Provider information (contact information for primary care provider, sickle cell team members, and specialists patient sees)
- Pharmacy information (telephone number, fax number, address)
- Health insurance information
- Disability level (if applicable)
- Information about guardian, medical power of attorney, if applicable

The health information above could be very useful for patient encounters with the health care system, ED, or hospitals, as well as for those transferring to adult care. Having key medical information readily available could potentially obviate the need for patients and parents to repeatedly recount their medical history to multiple health care providers during an acute pain episode, which was described as a burdensome task by both parents and patients in the focus groups. Having a tool that details the sickle cell genotype, medications, pain treatment plan and/or

algorithm could also serve as valid documentation when patients seek acute care management and could facilitate more timely treatment in the ED. Many families in the focus groups as well as one of the key informants reported that ED providers often doubt SCD patients' verbal reports of the degree of pain they are experiencing, as well as the medications and dosages needed to treat their pain episodes. Based on the Lewin Team's clinical experience, some patients and parents carry this information in a written form (e.g., a wallet card or "Passport"), which could be digitized as part of the recommended app. Information technology developers could assess the feasibility of digitizing this written information.

Focus group participants in the 18 and older and mixed ages groups reported using their smartphones and other technology as distractions during pain episodes. As SCD patient visits to the ED are often due to pain crisis, it is possible that a health IT tool for ED care transitions could align with other related apps within an overall portfolio or "ecosystem" that might include elements that could serve as a distraction from pain or during lengthy stays in the ED. The IT developer focus group clearly recommended any app developed be simple and targeted to a specific use. So while we do not recommend merging these related apps, it might be possible for an "app ecosystem" to be formed where a family of related apps each focused on a critical need of SCD patients such as the ED care transition tool, apps that distract patients during pain crisis, and health service management tools like calendars to monitor appointments and provider contact information.

While these recommendations for tool content are rooted in the findings from focus groups, key informant interviews, and the environmental scan, future development should include additional qualitative and pilot research to assess and identify strategies to maximize potential patient and caregiver uptake and acceptability of the tool during the design and development stages.

Tool Appearance and Functionality

Participants in the IT developer group recommended that the tool/application should be simple to use, sleek, and modern in appearance, to effectively compete with other mobile tools/applications currently on the market. IT developer and patient focus group participants also noted that the tool should be fun to use and engaging while requiring minimal data input from users, instead, leveraging existing data sources wherever possible to pull data into the tool. For example, through health information exchanges the tool may be able to tap into a patient's pharmacy health information management system and import in data about a patient's medications directly into the tool.

Two potentially important tool functionalities —conveying validated information about the patient's condition and treatment plan, and providing an indication of a patient's humanity beyond their illness in nonacute crisis contexts—also appear worthy of further exploration as part of tool development.

The environmental scan yielded a few applications already in existence that may have some direct relevance and could be leveraged for future tool development. A full list of applications/tools identified through the environmental scan can be found in Appendix C. These applications include:

- "ITriage Mobile Health" which includes symptom checker and listing of emergency departments;
- "Gazelle" which allows direct access to lab data; and,
- SiKL, which is a personal medical record for individuals with SCD and includes listing of medications and pain management plans specific to the patient.

Although the above tools address some of the needed functionality to facilitate transitions from home to ED, they do not include important customized information, such as pain treatment algorithms. Also, it is unknown if the above tools can be used on different smartphone platforms that patients and families currently use or would be interoperable with differing health IT and health information exchange systems currently used by health care institutions. Future tool development should include an assessment of these applications and their features (likely to be updated over time as well) and how they could be used, combined, or adapted to optimize care transitions. Any tool developed to support ED transitions for SCD patients must interoperate with the health IT systems used by SCD patients' providers to receive applicable data from those systems, and if possible, share data across systems as patients may see multiple providers.

Additional functionality is simply to serve as a source of distraction from pain, although many popular games could likely serve such a purpose without directly connecting to the SCD tool. In addition, an application could serve to help track the severity of pain. Patients in our focus groups said that pain tracking wasn't a valuable function for them, although a recent peer-reviewed publication suggested some receptivity to using a mobile application to track pain among patients with SCD.[51] Pain tracking might also be a feature that providers would find useful for validating the degree of pain as well as understanding trends in pain and anticipating the clinical course. Thus, while the team is not recommending including pain tracking functionality in the initial iteration of the tool, further study is warranted to understand the need for this feature and its potential role in implementing more effective treatment programs.

During a key informant interview, the team learned about the use of video diaries to help health care providers better understand patients' lives and ability to function. Our focus group participants did not specifically comment about the use of video diaries. Consequently, further study is needed to assess which patients would want to develop and share video diaries with their providers and whether providers would actually reference or find useful a video diary or introduction during an acute health care encounter. It is currently unknown if inclusion of this type of information in a tool may help to ensure culturally more sensitive and humanistic delivery of care to these patients.

The tool should be available at literacy levels appropriate for SCD patient populations and in additional languages besides English. The tool should be designed to be utilized at varying developmental capabilities so as to allow co-management by parents or other caregivers.

Tool Design

The team recommends that a health IT tool developed to support patients with SCD not be tethered to an electronic health record system for one specific provider, such as a patient portal. Instead, the tool should be cloud-based, and thus able to tap into health information exchange to obtain data from many applicable sources such as providers, pharmacies, and other care settings. Further study will be needed to assess the best approach for transferring information from an electronic health

record at various provider sites to this ED transition tool, but likely health information exchange could be leveraged to help facilitate this in some ways. Electronic exchange of health information is not currently universal across States. Thus, strategies need to be developed to ensure that the process of electronically sending patient's health information to the tool is consistently functional across the information exchange architectures employed in different States. Furthermore, there is the critical element of information security, which should be a key future research element. Safeguards such as password protection and authentication of users according to their specific roles would need to be in place to ensure the privacy and confidentiality of personal health information. A validation strategy needs to be developed to assure the accuracy of important health data such as genotype and pain management strategies and a mechanism for regularly backing up the data in the tool needs to be considered.

Recommendations for Next Steps in Development

The following are general recommendations for next steps in the development of the recommended tool:

- ***Develop an understanding of which existing clinical data exchange standards are applicable and could be leveraged to facilitate the population of data in a health IT tool for SCD patients*** (as well as the export of data from the tool to a provider). Existing standards such as the Continuity of Care Document HL7 specification should be used for clinical content where possible (lab test results, transitions, etc.) and, when necessary, modified or adjusted (for new populations not currently covered by existing standards, etc.). New standards should only be developed (in a consensus driven, transparent process) when no standards exist.
- ***A pilot tool should be developed and tested to test the standards and confirm the way the team has articulated the problem and translated that to a solution.*** Rather than becoming a working prototype, this pilot should instead be considered a use case (i.e., a list of steps, typically defining interactions between a role, known in Unified Modeling Language as an "actor," and a system to achieve a goal). Furthermore, the pilot tool should be sent to testing bodies that exist for EHRs (e.g., Open Source Electronic Health Record Alliance) to create a secondary certification.
- ***As part of the tool development process, developers should conduct an ethnographic study (i.e., participant observation) to better understand a patient's experience seeking care in the ED*** for a pain episode or other sickle cell complication. This type of direct observation would help better inform the most effective development of wireframes or initial prototypes of the tool.

The IT developers focus group and the Lewin Team members as a whole recommend that patients and families should be engaged throughout the design process to review tool prototypes and provide ongoing feedback—from drawing wireframes to beta testing. These stakeholders should work closely with the software engineering team to ensure that the tool is built to suit their needs. An iterative design walk-through analysis (IDWA) is one method to help achieve this high level of engagement. With IDWA, small, incremental advances in tool development are reviewed by patients and their feedback is incorporated directly into the subsequent tool iterations. This process is repeated until the desired tool is developed. Patients and families who participated in the

focus groups were highly engaged and could, potentially, be recruited to participate in the development of a health IT tool. In addition, patients, families and providers from other regions of the United States that are more ethnically and linguistically diverse should also be approached to participate in tool development to ensure that the perspectives of patients who are Hispanic and non-English speaking are incorporated in the tool.

Areas for Future Research

To further the development of a health IT tool to improve transitions from home to ED, better understanding is needed in the following areas. These recommendations for further study are organized into two topic areas: (1) user needs and adoption and (2) tool design and technology.

User Needs and Adoption

- Provider acceptance of sickle cell patient information presented by patients on electronic tools (such as smartphones) or application compared with other forms such as verbal or secure message from another health care provider.
- Home to ED transition needs of sickle cell patients who are Hispanic or speak another language besides English, since the focus group participants were almost entirely African-American and English speaking.
- Variation in experience of home to ED transition by severity of illness. Focus group participants were not classified by disease severity. Consequently it is unclear if disease severity plays a role in patient's experiences of care transitions.
- More in-depth assessment of patients' interest in pain tracking functionality to better understand the need for this feature and its potential role in implementing more effective treatment programs.
- Potential functionality that might provide an indication of a patient's humanity beyond their illness in non-acute crisis contexts. Assess which patients would want to develop and share video diaries for example with their providers and whether providers would actually reference or find useful a video diary or introduction during an acute health care encounter. It is currently unknown if inclusion of this type of information in a tool may help to ensure more culturally sensitive and humanistic delivery of care to these patients.
- Analysis of different payment or incentive models for care transition tools are needed to assess if incenting use of this tool might impact health care utilization (e.g., readmission).

Tool Design and Technology

- Consent and data sharing guidelines across institutions and within and across States. Specifically, if there are universal consent forms that could be used by patients and families and how these might be incorporated into a tool.
- In-depth assessment of privacy and security considerations such as if there are mental health and/or substance abuse issues among SCD patients who are using the tool, particularly given State laws vary widely on these issues.

- Approaches for transferring information from different electronic health record systems at various provider sites to a health IT tool, such as leveraging clinical data exchange standards and health information exchange tools. Furthermore, strategies need to be developed to ensure that the process of electronically sending patient's health information to the tool is consistently functional across the information exchange architectures employed by different States.
- Strategies to ensure regular updating of dynamic information needs to be explored to ensure accurate information is available when needed, to indicate the date of the information update. Mechanisms to validate medical information presented in the tool.
- A detailed and targeted assessment of the three applications identified through this project and their features (likely will be updated over time) and how they could be used, combined or adapted to be useful to optimize care transitions in the ED.

Limitations

The focus groups did not include perspectives of patients of different ethnicities, and the team especially missed representation from the growing population of Hispanics with SCD. Additionally, focus groups did not include individuals with milder symptoms of SCD and provider groups did not include ED staff members, both critical stakeholder groups. The focus groups had limited participation from adults with SCD and few providers who specifically treat this group. Future work could specifically target these populations to ensure that their perspectives and needs are represented in the proposed tool's development.

An application may be able to transmit valid and credible medical information that might result in more timely care, and, even enhance the overall humanity of the patient's experience and interaction with providers. Nonetheless, addressing operational barriers related to patient flow and wait times or the prioritization of pain management relative to other priorities in the ED are outside the scope of such an application and still need to be addressed. Similarly, it is not realistic to believe such an application can fully address the complex and subtle issues of racism and discrimination that are likely strong contributing elements to the experience of patients with SCD. Although an application is unlikely to solve all of the challenges, it could still contribute to quality and experience of care.

Although a particular area of interest for our research, the focus group participants did not discuss details about the specific types of functionality that they would like to see or use in a health IT tool. Patients and caregivers discussed the ways in which they currently use online and mobile technologies, such as Facebook groups or gaming devices, but did not extrapolate from their experience to offer insight into what specific functionality would be desired in a health IT tool for their SCD. They did say they want it to expedite care in the ED. Among the group of IT developers, it was agreed that a tool could be designed and programmed to function in whatever way was needed most, and did mention some core features (e.g., attractiveness, actionable feedback, low burden of data entry) but they also did not outline any specific functionality that they believed was crucial for a successful health IT-enabled tool.

Conclusions

Living with SCD is extremely challenging. Many of these challenges are common to living with any significant pediatric chronic condition—the sense of isolation, unpredictable nature of illness, and decreased ability to participate in regular activities. A few of these challenges are distinctive to SCD—among them the lack of social awareness about the disease, concern about racial bias during health care encounters, the primary manifestation of being in pain and the need for treatment with powerful narcotics and the need for the ED as a particularly prominent site of care.

The importance of the ED as a prominent site of care, the well-documented difficulty patients with SCD have in that setting and the potential for an application to meaningfully improve that care lead us to recommend the development of an application to enhance the transition between home and the ED for youth with SCD.

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Appendixes

Appendix A: Literature Search General Findings From the Environmental Scan

Content/Focus/Topic	Environmental Scan
SCD focus	
Yes	27
No	24
N/A	3
Content Category	
Both	15
Inform design/content	34
Inform functionality	5
Search Goal	
(1) Transitions of care for patients with SCD, including the needs and priorities of these patients.	9
(2) Transition practices and care coordination approaches for patients with chronic conditions, including SCD, among pediatric and young adult populations.	11
(3) Best practices in health IT and mobile health.	17
(1) AND (2) Transitions of care for patients with SCD, including the needs and priorities of these patients. Transition practices and care coordination approaches for patients with chronic conditions, including SCD, among pediatric and young adult populations.	11
(1) AND (3) Transitions of care for patients with SCD, including the needs and priorities of these patients. AND (3) Best practices in health IT and mobile health.	0
(2) AND (3) Transition practices and care coordination approaches for patients with chronic conditions, including SCD, among pediatric and young adult populations. Best practices in health IT and mobile health.	5
(1) (2) and (3) Transitions of care for patients with SCD, including the needs and priorities of these patients. Transition practices and care coordination approaches for patients with chronic conditions, including SCD, among pediatric and young adult populations. Best practices in health IT and mobile health.	1

Appendix B: Key Characteristics of Tools Reviewed

Characteristic	Total # of Tools (N 51)
Disease Focus	
SCD-focused	8
Chronic disease-focused	18
Non-chronic disease focused (e.g., general mobile medical apps)	25
Archetypes/Categories of Tools	
Age transition	10
Care setting transition	11
Disease/condition-specific monitoring	18
Disease-related social groups and resource sharing	9
General health management/ information sharing	3
Intended Use Setting (all that apply)	
ED	15
Home	40
Inpatient	18
Occupational Health	4
Outpatient visits	16
School-based Clinic	6
Functionality (all that apply)	
Medication tracking	37
Lab or other test result tracking	18
Enables recording of health information	39
Problem lists or problem management plan	13
Pain management plan	5
Used for self-management or self-monitoring of care/symptoms	26
Records/track health goals	19
SCD genotype tracking	3
Contains insurance information	11
Contains provider contact information	23
Appointment scheduling	6
Available in literacy level targeted at ≤ 4th grade level	7
Available in languages other than English	5
Patient control distribution of information	32

Appendix C: List of 51 Tools Included in the Environmental Scan

Tool ID #	Tool Name	Hyperlink	Date Accessed
1	Sickle Cell Disease Tracker	NA	December 2012
2	SCD Resource Locator	https://itunes.apple.com/us/app/sickle-cell-disease-resource/id464204107?mt=8	December 2012
3	Cancer.Net Mobile	http://www.cancer.net/multimedia/mobile-applications	December 2012
4	OATBook	https://itunes.apple.com/us/app/oatbook/id494664506?mt=8	December 2012
5	My Medications	https://itunes.apple.com/us/app/my-medications/id478343764?mt=8	December 2012
6	Diabetes Buddy (Diabetes App)	https://itunes.apple.com/us/app/diabetes-app-blood-sugar-control/id387128141?mt=8	December 2012
7	Glucose Buddy	https://itunes.apple.com/us/app/glucose-buddy-diabetes-helper/id294754639?mt=8	December 2012
10	WebMD Pain Coach	https://itunes.apple.com/us/app/webmd-pain-coach/id536303342?mt=8	December 2012
11	Carebook Lite/ CareInSync	NA	December 2012
12	Axial Patient (Axial Care Transition Suite)	http://axialexchange.com/patient/	December 2012
13	iBlueButton	NA	December 2012
19	Crohn's Diary	https://itunes.apple.com/us/app/crohns-diary/id349021016?mt=8	December 2012
24	MedXCom for Patients	NA	December 2012
25	bant	NA	December 2012
26	PocketHealth	NA	December 2012
28	Adolescent and Young Adult Health Care Passport	(Paper tool –link unavailable)	December 2012
29	Discharge Preparation Checklist	(Paper tool –link unavailable)	December 2012
32	FitBit	http://www.fitbit.com/product/mobile/iphone	December 2012
33	Asthmapolis	http://asthmapolis.com/	December 2012
34	Crohnology	http://crohnology.com/	December 2012
38	GI Monitor	http://www.wellapps.com/products/gimonitor	December 2012
40	Gazelle	http://mygazelleapp.com/features/	December 2012
42	YouMe IBD	NA	December 2012
44	Follow My Child	NA	December 2012
46	Children's Hospital Boston Transition Toolkit	http://newenglandconsortium.org/brochures/Transition-Toolkit-Complete.pdf	December 2012
47	Wireless Pain Intervention Program for At Risk Youth with Sickle Cell Disease	http://www.ncbi.nlm.nih.gov/pubmed/22627570	December 2012
49	PKU Toolkit	http://newenglandconsortium.org/toolkit/intake-form.html	December 2012
51	Emergency Information Form for Children With	NA	December 2012

Tool	Tool Name	Hyperlink	Date Accessed
	Special Needs		
52	Being a Healthy Adult: How to Advocate for Your Health and Health Care	http://rwjms.umdnj.edu/boggscenter/products/BeingaHealthyAdultHowtoAdvocateforYourHealthandHealthCare.html	December 2012
53	Healthy Transitions	NA	December 2012
54	It's Time To Transition	NA	December 2012
55	Journey to Adulthood a Transition Travel Guide	NA	December 2012
58	ER Connect	NA	December 2012
65	Young Epilepsy	NA	December 2012
67	Universal Transfer Form, American Medical Directors Association	http://www.amda.com/tools/universal_transfer_form.pdf	December 2012
68	Your Discharge Planning Checklist	http://www.medicare.gov/publications/pubs/pdf/11376.pdf	December 2012
69	Taking Care of Myself: A Guide for When I Leave the Hospital	http://www.ahrq.gov/qual/goinghomeguide.pdf	December 2012
70	Royal Children's Hospital Melbourne Transition Checklists Tools	http://www.rch.org.au/transition/factsheets_and_tools/Transition_Checklists_Tools/	December 2012
72	Shared Care Plan	https://www.sharedcareplan.org/OtherPages/Phms.aspx	December 2012
74	HealthVault	NA	December 2012
75	SmartPlatform	http://smartplatforms.org/author/kmandl/	January 2014
76	SiKL	NA	January 2014
77	Sickle Cell Warriors	https://www.facebook.com/SickleCellWarriors	January 2014
78	Sickle Cell Disease and Thalassemia Health Record	NA	January 2014
79	SCDTDP Transition Curriculum	(paper tool – link unavailable)	January 2014
80	Safe Pregnancy and Birth	http://hesperian.org/books-and-resources/digital-commons/	January 2014
81	Personal Experiments	https://www.personalexperiments.org/	January 2014
82	Relational Agents Group	http://relationalagents.com/index.html	January 2014
83	PediQUEST	http://clinicaltrials.gov/show/NCT01838564	January 2014
84	CORAnet Mobile EMR Solution	NA	January 2014
85	SCDwebCMR	www.scdcare.com	January 2014

NA = The Web site for this tool is no longer available.

Appendix D: List of 53 Articles Included in the Environmental Scan

1. 2nd Annual HIMSS Mobile Technology Survey, sponsored by Qualcomm Life. December 3, 2012. http://www.himss.org/files/himssorg/content/files/FINALwithCOVER.pdf.
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15. Findings and lessons from the enabling patient-centered care through health it grant initiative. (Prepared by Westat Under Contract No. HHSA 290200900023I.) AHRQ Publication No. 13-0011-EF. Rockville, MD: Agency for Healthcare Research and Quality; January 2013. http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.278.6533&rep=rep1&type=pdf.
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19. Frost & Sullivan. Moving beyond the limitations of fragmented solutions: empowering patients with integrated, mobile on-demand access to the health information continuum. A Frost & Sullivan White Paper. Mountain View, CA: 2013.

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