Supporting Statement

Part A

Improving Sickle Cell Transitions of Care through Health Information Technology Phase 1

Version: January 3, 2013

Agency of Healthcare Research and Quality (AHRQ)

Table of Contents

Part A. Justification

1. Circumstances that Make the Collection of Information Necessary

The mission of the Agency for Healthcare Research and Quality (AHRQ) set out in its authorizing legislation, The Healthcare Research and Quality Act of 1999, is to enhance the quality, appropriateness, and effectiveness of health services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health systems practices, including the prevention of diseases and other health conditions. AHRQ shall promote health care quality improvement by conducting and supporting:

1. Research that develops and presents scientific evidence regarding all aspects of health care;
2. The synthesis and dissemination of available scientific evidence for use by patients, consumers, practitioners, providers, purchasers, policy makers, and educators; and
3. Initiatives to advance private and public efforts to improve health care quality.

Also, AHRQ shall conduct and support research and evaluations, and support demonstration projects, with respect to (A) the delivery of health care in inner-city areas, and in rural areas (including frontier areas); and (B) health care for priority populations, which shall include (1) low-income groups, (2) minority groups, (3) women, (4) children, (5) the elderly, and (6) individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.

This project is the first phase in AHRQ's effort toward the development of a health information technology (HIT) enabled tool designed to aid adolescents and young adults with sickle cell disease (SCD) during transitions of care. SCD is a serious, genetic blood disorder that affects approximately 70,000 – 100,000 Americans, including one out of every 500 African American and one out of every 36,000 Hispanic American births.[1] Persons with SCD produce 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.[2] SCD has been noted to be understudied relative to its prevalence[3] resulting in a lack of knowledge about the important variables and domains that determine health outcomes for patients. Furthermore, patients with SCD, typically young, minority, and often of lower income status, have had few opportunities to voice their needs and concerns about their health and health care.

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, more than 90 percent of individuals with SCD reach adulthood, and life expectancy is typically into the fifth decade.[4] Persons with SCD experience multiple transitions of care as a result of the chronicity of SCD, frequency of both acute and chronic events requiring care, as well as the advancements in life expectancy. Transitions of care occur when either the setting of care changes (e.g., from home-based to hospital-based care) or the focus of care changes (e.g., from pediatric-focused to adult-focused care). When transitions of care occur, a need to share medical history and other types of health information arises. Transitions of care are more likely to be successful when this health information is accurate, tailored to the type of transition taking place, and communicated effectively.[5]

Times of care transitions are particularly fraught for patients with SCD and currently, few patients have access to effective transition programs for SCD.[6,7] In a 2010 survey of pediatric SCD providers, the majority claimed to have transition programs in place but they were often newly formed and without the ability to transfer care to adult providers with specific expertise in SCD.[8]

Preliminary evidence suggests that HIT can be helpful for SCD and similar conditions. In particular, a technology-based tool has already been used successfully by patients with SCD to help with some aspects of disease management. In one study, a handheld wireless device was used to implement a pain management protocol and found to result in high rates of participation and satisfaction.[9] Technology-based tools or applications—"apps" —have also been effective in improving care transitions for other chronic diseases such as diabetes and HIV, which can serve as models for this tool.[10,11,12,13,14]

Improving transitions of care is the focus of AHRQ's plans to respond to the Department of Health and Human Services' (HHS') SCD Initiative announced in 2011.[15] The overall HHS SCD initiative, which is aligned with AHRQ's mission, aims to improve the health of persons with SCD through various activities, including developing and disseminating evidence-based guidelines, increasing the availability of medical homes that provide SCD care, and supporting research in areas such as pain and disease management, all of which could also be supported through the use of an effective HIT enabled tool.

The goals of this project are 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 HIT-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.

2) 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.

To achieve the goals of this project, the following activities and data collections will be implemented:

1) **Environmental Scan** – AHRQ will execute a literature review to identify potentially relevant scientific literature and information from other literature and sources as well as complete a search for existing tools that aid transitions of care for persons with SCD or similar conditions. This will provide contextual background about the current state of the field with regards to tool development and use, identify key issues of patients with SCD related to care transitions, and understand the context of care delivered and health data information needs to inform the content, design and functionality of a tool. This activity does not impose a burden on the public and is not included in the burden estimates in Section 12.
2) **Focus Groups** – AHRQ will facilitate ten focus groups of key stakeholder groups including: parents/caregivers of patients with SCD; health care providers (e.g. SCD specialists, primary care physicians (PCPs), hospitalists and emergency room (ER) physicians); IT developers; SCD patients ages 9-13; SCD patients ages 14-17; SCD patients 18 and older; and SCD

patients of mixed ages; to gather qualitative information on stakeholder experiences with SCD and care transitions, barriers to quality care, and use of technology to inform tool design and functionality. Each group will consist of 10 participants and will be asked to describe their particular experiences with health care transitions, communication practices, information needs and technology use in order to develop relevant "use cases" which will be used by investigators and tool developers for the later phases of the project. The in-person nature of focus groups allows for a more in-depth and targeted discussion, including participant experiences, impressions and priorities in a detailed fashion. See Attachments 1 to 7 for the focus group moderator guides and associated respondent materials.

3) **Demographic Questionnaire** – AHRQ will implement a short demographic questionnaire at the start of each of the ten focus groups to collect basic demographic information to allow the team to contextualize findings from each focus group. Questionnaires are tailored to each focus group category: parents/caregivers of patients with SCD; providers, hospitalists and ER physicians); IT developers; SCD patients ages 9-13; SCD patients ages 14-17; SCD patients 18 and older; and SCD patients of mixed ages. See Attachment 8 for the focus group demographic questionnaires.

4) **Key Informant Interviews** – AHRQ will conduct eight key informant interviews with stakeholders such as State Medicaid representatives, attorneys with expertise in privacy and security issues, representatives from the Office of the National Coordinator for Health Information Technology (ONC), Office of Chief Scientist, and other relevant policy makers. Qualitative information gained will contribute to tool development recommendations particularly in terms of cost, issues related to reimbursement by payers, needs for proof of effectiveness, sustainability, and potential vehicles for facilitating and funding tool development and implementation. Five of these stakeholders will be Federal government employees and therefore are excluded from the burden estimates in Section 12. See Attachment 9 for the key informant interview guides.

This study is being conducted by AHRQ through its contractor, The Lewin Group in partnership with Children's National Medical Center, Cincinnati Children's Hospital Medical Center, Nemours Children's Clinic-Jacksonville, and the National Initiative for Children's Healthcare Quality, pursuant to AHRQ's authority to conduct and support research on healthcare and on systems for the delivery of such care, including activities with respect to the quality, effectiveness, efficiency, appropriateness and value of healthcare services and health care technologies. 42 U.S.C. 299a(a) (1), (2) and (5).

2. Purpose and Use of Information

The information gained from the focus groups and key informant interviews will be used to understand if and how a patient-centered, HIT-enabled tool can improve the health of individuals with SCD during care transitions.

Focus groups as a form of qualitative research are an important vehicle for gathering and explicating insight from the field, especially if, as in this case, the important domains are not yet understood, and need to be outlined by respondents, rather than suggested by investigators. Thus active recruitment and qualitative

techniques are a means to incorporate this necessary and important perspective into the derivation of effective interventions.[16] The primary objective of the focus groups is to gather more richly nuanced information from sickle cell disease stakeholders. The in-person nature of focus groups allows for a more in-depth and targeted discussion, including participant experiences, impressions and priorities in a detailed fashion.

3. Use of Improved Information Technology

Each focus group will be audio recorded. A team member from each clinical site will review the recordings of focus groups conducted at that site to capture key issues and document discussion summaries and findings. By audio recording focus groups, the team is able to limit the number of external staff in the room during the discussion to just the two co-moderators. Reducing unnecessary staff may support more open discussion by participants. Only members of the research team will be able to listen to the recordings. Recordings and notes will be stored as electronic files on password protected computers. Recordings will be summarized by the research team and erased once summaries are checked for accuracy. Summaries of the focus group may be reproduced in whole or in part for use in presentations or written products that result from this study. Neither participant names nor any other identifying information (such as voices) will be used in presentations or in written products resulting from the study.

4. Efforts to Identify Duplication

The purpose of this data collection is to gather stakeholder input relevant to the development of a potential tool which would be completed under future phases of this effort depending on the results and findings gathered in this foundational, information-gathering phase. This study is also important as the SCD population is under-researched and there is limited information available about public knowledge, perceptions, and attitudes about SCD.[17] A preliminary search of the literature and web-based sources confirmed this and uncovered limited existing information resources relevant to this effort. A PubMed search using search terms “sickle cell disease,” “care transitions,” and “HIT or health information technology” returned less than eight articles for sickle cell disease and care transitions, one article relevant to HIT and care transitions but not related to SCD, and no articles that were relevant to all three search terms. Furthermore, the project team, including hematologists and recognized sickle cell clinicians and experts (as outlined in Section 8b), recognize the absence of effective interventions, including technology-based interventions, to meet the needs to sickle cell disease patients during transitions of care and thus support the need for such a tool.

5. Involvement of Small Entities

Neither the focus groups nor the key informant interviews will include small business or other small entities, and thus the information collection poses no burden on these entities.

6. Consequences if Information Collected Less Frequently

This is a one-time data collection activity to understand the needs of stakeholders as they pertain to SCD and care transitions and possible uses for an HIT-enabled tool.

7. Special Circumstances

This request is consistent with the general information collection guidelines of 5 CFR 1320.5(d)(2). No special circumstances apply.

8. Federal Register Notice and Outside Consultations

8.a. Federal Register Notice

As required by 5 CFR 1320.8(d), notice was published in the Federal Register on February 2nd, 2013 for 60 days, and again on April 29th, 2013 for 30 days (see Attachment 10). No comments were received.

8.b. Outside Consultations

AHRQ has engaged The Lewin Group and their ACTION Team to support the design and implementation of focus groups, and analysis of the findings. The Lewin ACTION Team includes:

- Anjali Jain, Managing Consultant, The Lewin Group
- Jennifer Frost, Senior Consultant, The Lewin Group , Project Manager and Task Leader
- Rebecca Cherry, Senior Research Analyst, The Lewin Group, Project Staff
- Charles Homer, National Initiative for Children's Healthcare Quality, Scientific Advisor
- Jay Berry, Harvard, Scientific Advisor
- Elissa Faro, National Initiative for Children's Healthcare Quality, Project Manager
- Marianne McPherson, National Initiative for Children's Healthcare Quality, Task Lead
- Carl Cooley, National Initiative for Children's Healthcare Quality, Scientific Advisor
- Suzette Oyeku, National Initiative for Children's Healthcare Quality, Project Director
- Ivor Horn, Children's National Medical Center, Project Director
- Lisa Tuchman, Children's National Medical Center, Scientific Advisor
- Emily Meier, Children's National Medical Center, Task Lead
- Maria Britto, Cincinnati Children's Hospital Medical Center, Project Director
- Lori Crosby, Cincinnati Children's Hospital Medical Center, Scientific Advisor
- Karen Kalinyak, Cincinnati Children's Hospital Medical Center, Scientific Advisor
- Stephanie Pabst, Cincinnati Children's Hospital Medical Center, Project Support
- Paul Pitel, Nemours, Project Director
- Robin Miller, Nemours, Scientific Advisor
- Jean Wadman, Nemours, Task Lead

9. Payments/Gifts to Respondents

AHRQ will provide each focus group participant with a $50 cash or cash equivalent incentive such as a gift card or money order pending the policies and processes of each organization and needs of the community. This will serve as an incentive for participants to partake in focus group activities and will help offset any cost to the participants for their participation, such as local travel and time or child care. The use of incentives in the $40-$50 range has been well documented as an appropriate reimbursement for adolescent patients and parents/caregivers.[18,19,20] Researchers suggest that such incentives, when coupled with an opportunity to give back to a disease-specific community and a desire for peer socialization, may help patients and parents/caregivers choose to participate in focus group research.[21] The use of incentives is also appropriate for other stakeholder groups. The Council of Professional Associations on Federal Statistics reports that when physicians or medical providers were offered an incentive to participate in a study they received an average of $15 for 25 minutes of their time.[22] Considering the expected length of the focus groups, $50 is an appropriate amount as a token to compensate for the time and effort of providers as well.

10. Assurance of Confidentiality

Individuals and organizations will be assured of the confidentiality of their replies under Section 944(c) of the Public Health Service Act. 42 U.S.C. 299c-3(c). That law requires that information collected for research conducted or supported by AHRQ that identifies individuals or establishments be used only for the purpose for which it was supplied.

Each clinical site will notify parents and adolescents that information obtained through patient focus groups will not be shared with parents/caregivers. If, however, the adolescent reveals or does something that is considered a serious risk to themselves or others, the team will intervene to protect the parent's and/or adolescent's safety. The parental permission form will contain language such as, "The investigators continue to have ethical and legal obligations to report child abuse or neglect and to prevent any participant from carrying out threats to do serious harm to him or herself or others. If keeping such information private would immediately put you, your child or someone else in danger, the investigators will release information to protect your child or another person."

Each organization will follow specific consent and assent processes that meet the requirements of that organization's IRB procedures. Consent and assent forms can be found in Attachment 11. These forms will include the notation that "Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, Section 944(c) of the Public Health Service Act. 42 USC 299c-3(c)."

Information that can directly identify the respondent, such as name and/or social security number *will not* be collected as part of the focus group discussion. Names of participants will be collected during the recruitment process along with dates of birth to confirm age, but this information will not be shared beyond the staff of the clinical site conducting recruitment and will not be included in any summaries of focus group discussions or reports and findings. Recruitment data will be stored on password protected and locked computers at each site hosting the focus group.

Data transfer of sensitive data to and from subcontractors, federal and state agencies, and other clients are completed by SFTP or through physical transfer of removable media, typically compact disks (CD). Lewin encrypts and password protects all datasets using SecureZip which meets FIPS 140.2 security standards. Any media that contains federal agency sensitive data is labeled "[Agency] Sensitive Information". E-mail is used to transfer data only if the data contains no sensitive information.

The Lewin Group office building has physical security systems in place to prevent unauthorized entry and access to both computer systems and hard copies of files. The office has a key pass entry system with a receptionist on duty during working hours. During non-working hours, the office is accessible to key holders only. Additionally the building is patrolled by a security officer throughout the day and remotely monitored by video cameras in the elevators and other building entrances.

11. Questions of a Sensitive Nature

Focus group discussions will include questions about health and health care delivery experiences which can be considered to be of a sensitive nature. Some participants, especially adolescents who may not want to present themselves as diverging from peer norms, may not want others outside of their health care team to know they have sickle cell disease. Others may not want to share information about medications, other conditions, and medical procedures such as blood transfusions, reproductive health, feelings about families and relationships, and other sickle cell disease symptoms they endure. Participants will not be required to answer any questions during the focus group discussion they do not feel comfortable answering. However, the questions being asked and information sought is necessary as it will enable the team to pinpoint health care needs that are not being met through the current system, which will contribute to the goals and design of a technology-enabled tool to support this population. This information will also point to gaps in care that might be amenable to change and that are currently related to poor health outcomes that will further improve tool development recommendations.

12. Estimates of Annualized Burden Hours and Costs

Exhibit 1 shows the estimated annualized burden hours for the respondents' time to participate in this research. The screener questionnaire will be completed by 150 potential focus group participants and takes an average of 5 minutes to complete. The demographic questionnaire will be completed by each focus group participant and takes 6 minutes to complete. All of the focus groups and key informant interviews will last 2 hours except for the IT developer focus group which will last 4 hours. Each focus group will consist of 10 persons. There will be two focus groups with providers, three with parents/caregivers, one group for IT developers, and one focus group with each of the four patient groups. Key informant interviews will be conducted with eight individuals. The total burden is estimated to be 249 hours annually.

Exhibit 2 shows the estimated annualized cost burden associated with the respondents' time to participate in this research. The total cost burden is estimated to be $7,996 annually.

Exhibit 1. Estimated annualized burden hours

Form Name	Number of respondents	Number of responses per respondent	Hours per response	Total burden hours
Focus Group Screener	150	1	5/60	13
Demographic Questionnaire	100	1	6/60	10
Provider Focus Groups	20	1	2	40
Parent/Caregiver Focus Groups	30	1	2	60
IT Developer Focus Group	10	1	4	40
Patients 9-13 Focus Group	10	1	2	20
Patients 14-17 Focus Group	10	1	2	20
Patients 18 & older Focus Group	10	1	2	20
Patients mixed ages Focus Group	10	1	2	20
Key Informant Interviews	3*	1	2	6
Total	353	na	na	249

* Five of the interview participants will be Federal government employees and therefore are excluded from the burden estimates

Exhibit 2. Estimated annualized cost burden

Form Name	Number of respondents	Total burden hours	Average hourly wage rate*	Total cost burden
Focus Group Screener	150	13	$26.89[a]	$350
Demographic Questionnaire	100	10	$26.89[a]	$269
Provider Focus Groups	20	40	$88.78[b]	$3,551
Parent/Caregiver Focus Groups	30	60	$21.74[c]	$1,304
IT Developer Focus Group	10	40	$44.27[d]	$1,771
Patients 9-13 Focus Group	10	20	$0[e]	$0
Patients 14-17 Focus Group	10	20	$0 [e]	$0
Patients 18 & older Focus Group	10	20	$21.74[c]	$435
Patients mixed ages Focus Group	10	20	$0[e]	$0
Key Informant Interviews	3	6	52.72[f]	$316
Total	353	249	na	$7,996

[a] Based on the mean wages for Physicians & Surgeons, All other (29-1069), All Occupations (00-0000), Software Developer (15-1132). Wages for children averaged in as $0.

[b] Based on the mean wages for Physicians & Surgeons, All other (29-1069)

[c] Based on the mean wages for All Occupations (00-0000)

[d] Based on the mean wages for Software Developer (15-1132)

[e] No wage data for children

[f] Based on the mean wages for Lawyers (23-1011), Social and Community Service Managers (11-9151), Medical and Health Services Managers (11-9111), and Computer and Information System Managers (11-3021)

*National Compensation Survey: Occupational wages in the United States May 2011, "U.S. Department of Labor, Bureau of Labor Statistics." http://www.bls.gov/oes/current/oes_nat.htm#15-0000

13. Estimates of Annualized Respondent Capital and Maintenance Costs

Capital and maintenance costs include the purchase of equipment, computers or computer software or services, or storage facilities for records, as a result of complying with this data collection. There are no direct costs to respondents other than their time to participate in the study.

14. Estimates of Annualized Cost to the Government

Exhibit 3 shows the estimated total and annualized cost to the federal government over 18 months. The total cost to the federal government of this data collection effort is $264,043. This figure includes development of draft and final plans for conducting focus groups and interviews; development of materials including moderator guides for each stakeholders group (seven guides in total), recruitment materials for all four sites, consent forms; facilitating IRB approval processes at four sites; logistics coordination including securing facility space; recruitment of participants; incentives for participants (as described in section 9 above); and analyzing and summarizing findings as well as preparing final reports.

Exhibit 3. Estimated Total and Annualized Cost

Cost Component	Total Cost	Annualized Cost
Project Development	$23,689	$15,793
Data Collection Activities	$169,586	$113,057
Data Processing and Analysis	$16,000	$10,667
Publication of Results	$33,472	$22,315
Project Management	$18,319	$12,213
Overhead	$2,977	$1,985
Total	$264,043	$176,029

15. Changes in Hour Burden

This is a new collection of information.

16. Time Schedule, Publication and Analysis Plans

The results of the focus group data collection effort (including demographic questionnaires and key informant interviews) will be summarized and reported in a Final Focus Group Report to AHRQ that may be posted on the AHRQ website or otherwise disseminated as an AHRQ product. The final version of this report is expected to be delivered to AHRQ on or around February 14, 2014. The results of the environmental scan will be summarized and reported in a Final Environmental Scan Report to AHRQ that may be posted on the AHRQ website or otherwise disseminated as an AHRQ product. The final version of this report is expected to be delivered to AHRQ on or around February 21, 2013. These efforts will be conducted within the timeframe of the overall project, which began August 30, 2012 and will end May 29, 2014.

As stated in section 1 above, the goals of the project are 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 HIT-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.

2) 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.

To accomplish these goals, the following analysis plans for the focus group, demographic questionnaire, key informant interviews and environmental scan activities will be used.

Analysis of focus groups (and accompanying demographic questionnaires). The focus group task will employ a modified qualitative analysis approach. Demographic questionnaires collected during each focus group will be input into a secure excel database. The team will summarize totals and averages for each key demographic question for all focus groups and across participant categories. The focus group data collection will commence upon OMB approval. Each focus group session will be recorded by written notes as well as audiotaped to allow later review and enhancement of notes. Notes will be recorded into an Access database. Moderators and observers will meet immediately after the focus group to debrief, review the written notes, and discuss major findings that will be integrated into a summary of the notes. In order to prepare the summaries after the completion of the focus groups, notes will be reviewed and enhanced using the audiotapes as needed, including direct quotations from the focus groups that point to salient ideas or thoughts that emerged from the groups. The focus group moderators will then review the notes and themes, adding comments and additional themes as needed. Preliminary recommendations (unless it is the final group for each type of participant) will include a discussion of any new or incompletely explored areas so that these can be incorporated into the focus group guide for the remaining groups. For each type of focus group (patient, parent, provider, IT developer) themes will be compiled across the different focus groups and sites. Moderators will identify two types of themes —themes that seem to converge across sites from those that diverge or differ by setting. A discussion among all three sites will then ensue to agree on common and divergent themes, identify additional supportive quotes for the themes and identify major and minor themes.

This modified method of qualitative analysis allows a rigorous and independent approach to the identification of an agreement around important themes that impact tool development, but truncates the need for full transcription of each focus group meeting, and recording of every utterance [into a database, with subsequent cleaning of data, etc.] and instead allows the main themes to be captured by those that were present during the focus groups themselves with independent review by senior staff members who were not present as well as moderators from other sites. For any disagreement or questions about themes, audiotapes, notes, and direct quotations will be available for independent review. While the full formal analysis (with transcription and comprehensive data collection) is often needed for publication-standard manuscripts, the main findings that impact tool development will not be compromised using this less formal approach. Such a modified "topline report" approach has been used to obtain focus group results for health matters by other government health agencies.

Analysis of key informant interviews. Similar to the focus groups, the interviewer and the listener (a member of the team who will be listening and taking manual notes; interviews will not be audio-recorded) will debrief after each interview to discuss main findings and key themes and

compose a summary of each interview that will be shared with the other project leaders from which relevant tool recommendations will be derived. If interview results also spur additional questions for the focus groups or the last phase of the environmental scan, these will also be incorporated into remaining focus group moderator guides and scan approaches. Senior level review will then be conducted before findings are summarized into the focus group report.

Analysis of environmental scan. The environmental scan task will also employ a systematic approach to evaluating and analyzing literature and tool information similar to the analytic approaches used for evidence syntheses of other types (systematic reviews, best-evidence reviews, etc.). For the tool research, AHRQ will collect and document standard demographic data that will allow for the categorization and inventorying of the tools appropriately. Tools will be categorized into the following three broad categories of: (1) relevant to pediatric to adult care transitions; (2) relevant for care setting transitions; and (3) facilitates information sharing between patients, providers, and community and social service agents. Data collection will be input into a secure web application (REDCap) designed exclusively to support data capture for research studies. Results will be summarized to identify similarities and differences across existing tools in the marketplace as well as to inform tool recommendations. For the literature search, descriptive data from each article according to relevant categories developed *a priori* will be collected through a secure Excel data base and then summarized both quantitatively (where possible, e.g. sample size involved in study or year of publication) and qualitatively for the final summary. Bibliographic information will be captured through EndNote. The environmental scan will be conducted between October 2012 and December 2013.

17. Exemption for Display of Expiration Date

AHRQ does not seek this exemption.

List of Attachments:

Attachment 1 -- Moderator Guide and Respondent Materials for Patients Ages 9-13
Attachment 2 -- Moderator Guide and Respondent Materials for Patients Ages 14-17
Attachment 3 -- Moderator Guide and Respondent Materials for Patients Ages 18+
Attachment 4 -- Moderator Guide and Respondent Materials for Patients – Mixed Ages
Attachment 5 -- Moderator Guide and Respondent Materials for Parents/Caregivers
Attachment 6 -- Moderator Guide and Respondent Materials for Providers
Attachment 7 -- Moderator Guide for IT Developers
Attachment 8 -- Demographic Questionnaires
Attachment 9 -- Key Informant Interview Guides
Attachment 10 -- Federal Register Notice
Attachment 11 -- Consent and Assent Forms
Attachment 12 -- Part A Bibliographical References
Attachment 13 -- Justification of Focus Group Allocation by Site
Attachment 14 – Focus Group Screener Questionnaires