FINAL REPORT APPENDICES

Assessing the SHARP Experience

JULY 2014

PRESENTED TO:

Dustin Charles Office of the National Coordinator for Health Information Technology U.S. Department of Health and Human Services 200 Independence Avenue S.W. Suite 729-D Washington, D.C. 20201 (202) 690-7151

PRESENTED BY:

NORC at the University of Chicago Adil Moiduddin Vice President, Health Care Research 55 East Monroe Street 30th Floor Chicago, IL 60603 (312) 759-4000



Table of Contents

Appendix A. SHARP Vision Paper (March 2012)	1
Appendix B. Awardee Overview	15
Appendix C. SHARP Output Inventory	17
Appendix D. Count by Output Type	63
Appendix E. Site Visit Summary for SHARPS	64
Appendix F. Site Visit Summary for SHARPc	85
Appendix G. Site Visit Summary for SMART	104
Appendix H. Site Visit Summary for SHARPn	123
Appendix I. Closing Discussion Participants	133
Appendix J. Closing Discussion Method	134

Appendix A. SHARP Vision Paper (March 2012)

Introduction

NORC at the University of Chicago, working under contract to and in consultation with expert staff of the Office of the National Coordinator for Health Information Technology (ONC) at the U.S. Department of Health and Human Services, is pleased to present this paper outlining the basic vision for the Strategic Health IT Advanced Research Projects (SHARP) program. The paper presents the motivation and objectives of the SHARP program both at its inception and in the current context of health care in the United States. It first offers a brief review of the history and mechanics of the program, and the research areas targeted by program funding. The paper then details the anticipated outcomes and benefits to accrue from SHARP in the current environment and reviews the approaches to program management, results dissemination and collaboration that can help extend and accelerate benefits of the program.

Program Background

In February 2009, President Obama signed the American Recovery and Reinvestment Act of 2009 (Pub. L. 111-5) (ARRA). ARRA included provisions that may, in their entirety, be cited as the "Health Information Technology for Economic and Clinical Health Act" or the "HITECH Act". The HITECH Act authorized unprecedented investments to advance the use of health IT to improve the quality, safety and efficiency of health care in the United States (U.S.).

The HITECH Act authorized a number of programs to strengthen this health information infrastructure and promote the adoption of health IT across the country. These include the Medicare and Medicaid EHR Incentives Program, the Information Technology Professionals in Health Care ("Workforce") Program, the Beacon Communities Cooperative Agreement Program, the State Health Information Exchange (HIE) Program, the Health Information Technology Regional Extension Center (REC) Program, and the Health Information Technology Research Center (HITRC).

In recognition of the challenges inherent in achieving a robust digital health information infrastructure that is effectively used by providers and consumers to improve health and care throughout the U.S., the Office of the National Coordinator for Health IT dedicated significant resources to closing the gap between the promise of health IT and its realized benefits—including its direct contributions to achieving the goal of a transformed health care delivery system. The research infrastructure must be designed and

dedicated to supporting the goals of HITECH and overcoming health IT challenges to adoption and meaningful use.

Although not the sole component or program in the U.S. health IT research and development infrastructure, the SHARP Program supports advanced research activities to address key short- and medium-term challenges to the HITECH and its programs. Research includes:

Exploring and defining fundamental research questions within an identified set of high-priority areas which address barriers to the nationwide electronic exchange and use of health information in a secure, private, and accurate manner;

- Providing opportunities for relevant academic and industrial researchers, health IT developers and implementers, health care providers and delivery system researchers, and other stakeholders to collaborate for the purpose of stimulating innovation and translating the results of research into health IT products;
- Creating breakthrough solutions, technologies, and services, for application to health IT in the nearand long-term, and addressing significant challenges and opportunities relevant to the adoption and meaningful use of health IT;
- Identifying a range of model (proof-of-concept) systems that serve as motivating and unifying forces to drive fundamental research in health IT; and
- Encouraging effective use of health IT through rapid dissemination of research results and findings on innovations and novel tools to developers and purchasers of health IT.

SHARP focuses on solving currently-known and anticipated challenges to adoption and meaningful use of health IT, through new methods and advanced technologies. These projects focus on areas ripe for "breakthrough" advances. For example, potential security breaches represent a major threat to public trust in the electronic maintenance and exchange of health information. SHARP research in this area seeks to identify new methods to create tools that will, through their incorporation into deployed technology, enhance data security. In doing so, the program will, in critical areas, close the gap between the promise of health IT and its realized benefits. The SHARP Principal Investigators have designed and dedicated the projects to supporting the goals of HITECH, and overcoming health IT challenges to adoption and meaningful use.

Thus, SHARP Awardees' work addresses fundamental research questions aimed at promoting private, secure, and accurate electronic exchange and use of health information by stimulating innovation and translating research into health IT tools and products. This requires collaboration among medical

informaticists, health care researchers, health IT developers and implementers, health care providers, and other stakeholders. These efforts will promulgate the development and dissemination of previously unforeseen tools, products, and methods that will ultimately improve patient outcomes and quality of care, and catalyze additional private-sector investments in health IT.

Program Overview

The SHARP Program funds four competitively awarded cooperative agreements over the course of four years, each of which focuses on a distinct research domain. Awardees implement collaborative, interdisciplinary research projects that address short- and long-term, well-documented challenges to the adoption of health IT related to four priority domains:

- Security of Health Information Technology: This research area addresses the challenges of developing security and risk-mitigation policies and the technologies necessary to build and preserve the public trust as health IT systems become increasingly ubiquitous. The project goes beyond the need to establish systems to maintain compliance with legal and regulatory challenges in the current context, and looks for opportunities to incorporate sophisticated methods to define policies that address a more nuanced understanding of the objectives of security policy that may be consistently and effectively employed in the context of EHRs, health information exchange, and telemedicine.
- Patient-Centered Cognitive Support: This research area addresses the challenge of harnessing the power of health IT to produce clinical decision support models that integrate with, enhance, and support clinicians' reasoning and decision-making, rather than adding to their workload by offering information at points and in manners not consistent with how clinicians approach decision-making in the context of their daily work. The goal is to develop methods that can be employed to improve the relevance and thus the effectiveness of decision support to facilitate patient-centered care across different health IT tools used by providers.
- Health Application and Network Platform Architectures: This research area focuses on the development of new and improved architecture to support rapid development and dissemination of substitutable applications that share common basic components. In addition to establishing an environment in which developers can continually design and disseminate new applications, the project envisions a graphical user interface where providers can select and download these applications, similar to "app selection" interfaces used by smartphones and other mobile-computing devices. The project also provides applications that facilitate the capture, storage, retrieval, and analysis of data, scalable up to a national level, while maintaining the security and integrity of data from each particular institution.

Secondary Use of EHR Data: This research area focuses on strategies for linking disparate sets of data generated by EHRs and other tools to allow new monitoring and research capabilities to generate new knowledge in support of quality of care and population health objectives. ONC has emphasized collaboration across disciplines and sectors within individual SHARP portfolios, across the four SHARP portfolios, between SHARP and other HITECH programs, and between SHARP and the health IT community writ large as a strategy for maximizing the benefits from public investment in the program.

ONC encourages Awardees to work together and share ideas and practices regarding the design, development, and implementation of their respective projects. Although each domain addresses different areas, all projects revolve around the development and diffusion of health IT innovation and share the following key features:

- Establishing a Research Agenda: Each project implements a research agenda addressing the specific goals of HITECH, the challenges to adoption and meaningful use that are critical to closing the gap between reality and the promise of health IT, and achieving the goal of a transformed health care delivery system.
- Using a Multidisciplinary Approach: Each Awardee works with multiple disciplines as appropriate such as health informatics, computer and information science, and health services research, among others.
- Using Subject Matter Expertise: Addressing the different domain areas within the SHARP program requires advanced subject matter knowledge. Each Awardee develops and implements plans to use internal and external expertise, and help lead nationwide coordination efforts relevant to their research focus.
- Developing Relationships with Other ONC Programs: Where it is of benefit to overall efficiency and effectiveness of the HITECH program, SHARP Awardees collaborate with other programs making strategic contributions in the same or closely related aspects of health IT, such as the State Cooperative Agreement Programs for Health Information Exchange (HIE) and the Beacon Communities.
- Generating Short- and Long-Term Results: Each Awardee project generates intermediate products, tools and/or research in addition to making longer-term contributions to the overall field of health IT.
- Developing Multi-Sector Partnerships: Each Awardee develops partnerships with the vendor community and other private-sector health IT, healthcare, consumer, and other relevant stakeholder organizations to enable the productive exchange of information. Relevant stakeholders that are highly engaged with a project may vary across projects and time, but in general include a variety of

perspectives such as those of healthcare professionals and/or their associations, hospitals and other organizational providers of health services (e.g. home health agencies, community health clinics) and/or their associations, consumers and consumer organizations, and/or federal, state, and local government entities.

- Demonstrating an Institutional Commitment to the SHARP Program: Each Awardee demonstrates institutional commitment to the project by making equipment, facilities, and laboratory space available to the Project's activities. This is significant because it shows the Awardee institution or organization, and not merely the Principal Investigator or project team lead, is committed to the project and its success.
- Conducting an Internal Project Evaluation: Each Awardee uses formative and summative evaluation strategies to conduct (at a minimum) an annual evaluation to measure and report on progress toward achieving its mission and goals. This provides for and informs adjustment of project plans and activities based on the observed progress and contributing factors, thus increasing probabilities of achieving success on project objectives.
- Using a Project Advisory Committee (PAC): Each Awardee forms a multi-stakeholder project advisory committee (PAC), including members of industry and representatives of professional organizations and institutions. The PAC meets regularly (typically quarterly) to help align the work of the Project with external concerns and interests.

SHARP Awardees and Research Domains

As described above, for each of the four domain areas, ONC awarded funding to an academic institution representing a collaborative research group to conduct a four-year interdisciplinary research project. The projects address short- and long-term challenges within the domain area, and forge partnerships among researchers, patient groups, health care providers, and other health IT stakeholders to translate the results of their research into practice.

Through these dedicated research teams, the SHARP program will work toward specific aims in each area, which include:

- Address strategic crosscutting themes that foster collaboration, consistency, and a multi-purpose technology convergence of EHR, HIE, and telemedicine.
- Develop security functions, policies and technology tools that will facilitate increasingly widespread, rapid, and sophisticated, electronic use and exchange of health information while assuring and enhancing individuals' safety and privacy.

- Address the cognitive challenges in health IT, focusing on work-centered design, cognitive foundations for decision-making, adaptive decision support, model-based data summarization, visualization, and distributed teamwork.
- Develop, test, refine, and disseminate models for CDS that are consistent with providers' natural cognitive reasoning processes.
- Establish a series of pipelines using a powerful computing engine (UIMA) and state of the art techniques from natural language processing and data normalization to translate "real world" EHR data into clinical element models (CEMs) representing clinical concepts that can be grouped together by patient to support secondary uses ranging from quality measurement and health information exchange to disease surveillance and genomics research.
- Assemble modular services and agents from existing open-source software to improve the utilization of EHR data for a spectrum of use-cases.
- Develop a user interface that will allow "iPhone-like" substitutability for medical applications based upon shared basic components and a set of services that enable efficient data capture, storage, and effective data retrieval and analytics, which will be scalable to the national level but nonetheless respectful of institutional autonomy and patient privacy.

Programs anticipate that their work will ultimately:

- Improve the maturity of security and privacy technologies and policies to remove a key range of security and privacy barriers that prevent current health IT systems from moving to higher stages of meaningful use.
- Create an integrated multidisciplinary research community in security and privacy for health IT.
- Deliver short-term patient-centered cognitive support tools within the first two years and longer-term breakthroughs in four years, and translate them into real-world health care settings through an elaborate and coordinated effort.
- Make artifacts available to the community of secondary EHR data users manifest as open-source tools, services, and scalable software.
- Develop foundational knowledge and useable, testable prototypes for a national-scale SMArt platform with a burgeoning ecosystem, robust and scalable network data services, and advanced data analytics.
- Bring together researchers, industry partners, clinicians, and other stakeholders to lay the groundwork
 necessary to enable a tectonic shift to a flexible health IT environment that includes SMArt platform
 architecture.

The following sections present a description of each program, its affiliated organization and research domain.

Security of Health Information Technology. The University of Illinois at Champaign-Urbana was awarded program funding in the area of Security of Health IT and looks to advance the requirements, foundations, design, development, and deployment of security and privacy tools and methods. This project is organized around three major health care environments: EHRs, Health Information Exchange (HIE), and Telemedicine (TEL). A multidisciplinary team of computer security, medical, and social science experts are developing security and privacy policies and technology tools to support electronic use and exchange of health information. The objective of this SHARP project is to address strategic crosscutting themes that foster collaboration, consistency, and a multi-purpose technology convergence of EHR, HIE, and TEL.

The first anticipated outcome of the Security of Health IT project is to improve the maturity of security and privacy technologies and policies to remove a key range of security and privacy barriers that prevent current health IT systems from moving to "higher" stages of meaningful use. The second anticipated outcome of the project is the creation of an integrated multidisciplinary research community in security and privacy for health IT that will facilitate progress beyond the scope and duration of this project.

Patient-Centered Cognitive Support. The University of Texas Health Science Center at Houston was awarded the Patient-Centered Cognitive Support SHARP award to establish a National Center for Cognitive Informatics and Decision-Making in Healthcare (NCCD) with eight member institutions to respond to the urgent and long-term cognitive challenges in health IT adoption and meaningful use. NCCD's vision is to become a national resource providing strategic leadership in research and applications for patient-centered cognitive support in health care. NCCD's mission is three-fold:

I. To bring together a collaborative, interdisciplinary team of researchers (from the fields of biomedical and health informatics, cognitive science, computer science, clinical sciences, industrial and systems engineering, and health services research) across the nation with the highest level of expertise in patient-centered cognitive support research;

II. To conduct short-term research that addresses the urgent usability, workflow, and cognitive support issues concerning health IT, as well as long-term, breakthrough research that can fundamentally remove the key cognitive barriers to health IT adoption and meaningful use; and

III. To translate research findings to the "real world" through a cooperative program involving researchers, patients, providers, health IT vendors, and other stakeholders to maximize the benefits of health IT for health care quality, efficiency, and safety.

NCCD leads six research projects to fundamentally address the cognitive challenges in health IT identified by ONC, focusing on work-centered design, cognitive foundations for decision-making, adaptive decision support, model-based data summarization, visualization, and distributed teamwork. NCCD will deliver short-term tools within the first two years and longer-term breakthroughs in four years, and will translate them into real-world health care settings through an elaborate and coordinated effort to support and accelerate the adoption and meaningful use of health IT.

Health Application and Network Platform Architectures. Harvard University created the Substitutable Medical Applications Reusable Technologies (SMArt) project to bring together researchers, industry partners, clinicians, and other stakeholders to lay the groundwork necessary to enable a tectonic shift to a flexible health IT environment that includes SMArt platform architecture. This incorporates a user interface that will allow "iPhone-like" substitutability for medical applications based upon shared basic components. Additionally, the platform will include a set of services that enable efficient data capture, storage, and effective data retrieval and analytics, which will be scalable to the national level but nonetheless respectful of institutional autonomy and patient privacy.

Four specific projects address a number of these goals. Project 1 focuses on the networked services that are required for the SMArt platform and how they scale from the practice to the nation. Project 2 is an investigation of the SMArt platform architecture that includes testing a small number of apps such as medication-management transactions among multiple stakeholders. Project 3 investigates how to retrofit existing commercial and non-profit, open-source health IT platforms so that SMArt apps can be substituted on all of them, as needed. Project 4 lays down the sustainable infrastructure for a SMArt ecosystem whereby apps and platforms can be rapidly tested, shared, and substituted in a SMArt exchange.

Secondary Use of EHR Data. The Mayo Clinic generated a framework of open-source services that can be dynamically configured to transform EHR data into standards-conforming, comparable information suitable for large-scale analyses, inferencing, and integration of disparate health data. The project expands upon evolving methods for using EHR data captured and maintained in disparate formats to create cogent, structured information for uses outside of the primary function of supporting clinical care using the original EHR. Secondary uses addressed by the project include structuring data for health information exchange (HIE), public health applications, quality reporting and clinical research.

A federated informatics research community was assembled for this project, committed to open-source resources that can industrially scale to address barriers to the broad-based, facile, and ethical use of EHR data for secondary purposes. The goal of this project is to make these artifacts available to the community of secondary EHR data users, manifest as open-source tools, services, and scalable software. In addition, partnerships have been considered with industry developers who can make these resources available with commercial deployment.

This project proposes to assemble modular services and agents from existing open-source software to improve the utilization of EHR data for a spectrum of use-cases, and is split into three major projects with interrelated objectives and cross cutting dependencies: Natural Language Processing (NLP), Data Normalization, and Phenotyping. The NLP project works on processing free text entered into EHRs to catalog and structure clinical attributes that describe the patient characteristics, events, diagnoses and procedures documented in the free text. The Data Normalization team works to create a series of tools taking data coded using different EHR formats and transform those data into a consistent structure with a goal to develop a pipeline of normalization tools based on the UIMA processing engine, allowing users to extract and transform structured and unstructured EHR data into a common set of clinical element models (CEMs), which are then stored in a queryable database. The Phenotyping project works with the output of the NLP team and Data Normalization team, namely populated CEMs, to identify cohorts of patients to support secondary applications.

Administration of the SHARP Program

Coordination and collaboration among experts from multiple institutions is essential to the development of innovative research. To create an organizational structure that facilitates the necessary level of collaboration, ONC established and coordinates a federal steering committee (FSC) while each site established and maintains a project advisory committee (PAC). Both the FSC and PACs provide guidance to the Awardees; the FSC supports ONC's oversight of the program and facilitates coordination among Awardees, while the PACs help each Awardee monitor its status and develop its plans.

FSC members include health IT leaders from various government agencies, including the Department of Veterans Affairs (VA), the Centers for Medicare & Medicaid Services (CMS), and the Health Resources and Services Administration (HRSA). The FSC monitors Awardees' progress and status, provides expert

guidance and direction, and helps to shape research agendas and identify dissemination methods for Awardees.

Each Awardee has formed a multi-stakeholder PAC to review, and provide input on, its research methods and results. PAC membership includes industry experts, representatives from professional organizations and associations, and ONC-identified liaisons. ONC-identified liaisons have extensive subject matter expertise relevant to each project. These members regularly report on projects' progress (including successes and issues) to ONC. Other than the ONC liaisons, each project's leadership team selected the additional members of their PAC. Each PAC meets quarterly to discuss progress, and ensure the alignment of project work with external concerns and interests. Each Awardee's PAC directly advises and supports the Awardee. None of the PACs provide advice or recommendations to HHS.

Consistent collaboration among the Awardees and their PACs, as well as between the FSC, Awardees, and ONC play a critical role in ensuring beneficial project results. This ongoing collaboration enables the dissemination of results, and contributes to the Awardees' development of technology transfer strategies and sustainability models that will ensure results reach the market, and that productive research continues after the completion of the award.

Evaluation of the SHARP Program

In addition to Awardees' internal self-evaluations to assess the progress of their research domain, ONC has funded a separate independent evaluation of the program as a whole. This program-wide evaluation seeks to:

- Understand and document how each individual Awardee pursues their research objectives, noting any changes from the original proposal and the evolution of methods and key research activities during the course of the project;
- Document and describe the nature of the outputs being produced within each research domain, including actual methods, tools and products, dissemination activities, knowledge resources (e.g., peer-reviewed publications), and collaborations with experts, ONC, and the Awardees themselves to characterize the potential long-term impact of the program as a whole.

The evaluation uses primarily qualitative methods, stemming from a review of Awardee deliverables and outputs as well as a series of discussions (conducted in-person and by phone) with Awardees and other stakeholders with knowledge of the relevant domains. The evaluation also stays abreast of emerging

trends within each research domain and assesses how they may affect the relevance and potential impact of the SHARP program. ONC's Office of Evaluation and Economic Modeling leads the evaluation under contract with NORC at the University of Chicago, which is in turn being advised by a Technical Expert Panel (TEP).

The Potential of the SHARP Program

While it is very likely that the program will yield quantifiable outputs such as peer reviewed publications, open-source software tools, technology platforms, methodologies and presented abstracts, the stakeholders will only achieve the overall vision for this program over time through the effective use of outputs in health care delivery, research, and related enterprises. The broader objective may be for some of the lines of investigation initiated by SHARP to help identify additional areas of inquiry that lead to new domains of research.

While it may be difficult in a short timespan to assess this type of impact or to determine the extent to which these new lines of inquiry would have been pursued even in the absence of SHARP funding, it will be possible (and useful) to communicate, underscore, and reach consensus within ONC and the SHARP programs on a common vision of what can and should be achieved within each domain. In the sections below, we highlight the potential components of this vision as they relate to each of the specific SHARP domains.

Security of Health Information. While vendors and providers continue to establish systems for maintaining compliance with Federal and State security and privacy requirements, the ultimate success of health IT as an effective vehicle for transforming health care delivery likely requires more than basic compliance with regulation—a sense of trust among patients and providers in the ability of electronic systems to manage health care information is critical as well. Furthermore, as the level of trust in electronic systems changes, and as the science of systems security evolves, it is likely that privacy and security requirements will be a moving target for the health IT industry.

The short-term success of the SHARP domain focused on security may be assessed by understanding the extent to which concepts derived from the program get reflected in upgrades to vendors' telemedicine, EHR and HIE solutions. For example, whether the project motivates changes in access-based service models, approaches to encryption, or formalized paradigms for risk management. Over time, the program may create consistent policies that can be applied across EHRs, HIE and telemedicine and that can evolve in-step with advances in security science. The project might also lead, directly or through derivative research, to the better alignment of the principles underlying technical models, policy, and regulation so

that vendors and providers can seamlessly adapt to changing requirements as public trust and preferences evolve.

Patient-Centered Cognitive Support. A core benefit of EHRs and other forms of health IT used at the point of care is the ability to provide clinicians with better information to guide more-effective decision-making related to treatment, diagnosis, and assessment (e.g., with respect to the ordering of screening tests). Today, many providers hesitate to adopt clinical decision support because methods to deliver the information (e.g., alerts or templates) may challenge their natural cognitive processes or interrupt their workflow during a clinical visit or the documentation thereof. In addition, because effective decision support requires the provision of the "right information for the right patient at the right time," CDS applications that have difficulty meeting this high standard consistently are likely to invite skepticism from many providers.

The Patient-Centered Cognitive Support research domain seeks to develop, test, refine, and disseminate models for CDS that are consistent with providers' natural cognitive reasoning processes. Ideally, these models would allow for CDS that is perceived by providers as being in their "flow" and that makes the information they wished they had, but often do without, more accessible in a timely manner.

The outputs of this particular program area could potentially change the design of CDS applications and functionality available in EHRs and computerized physician order entry (CPOE) applications on the market. A broader vision for this project may involve its potential to dramatically improve provider buyin for the concept of computerized CDS and thus increase take-up and compliance with CDS in the process.

Health Application and Network Platform Architecture. A growing trend in IT system development and delivery is the movement toward the application-centric paradigm (e.g., the Apple store and devices that consume such applications such as smartphones and tablets). Using a similar paradigm, the SMArt project is building the network platform infrastructure that consists of core services and substitutable applications. By uncoupling the core system from the applications and ensuring that they are substitutable, health care providers can replace one application with another of similar functionality without having to incur huge costs, make changes to other applications, or be beholden to the vendor that provided the previous application. Furthermore, this model has the potential to drive innovation by encouraging vendors, large and small, to be more agile and drive innovation from the bottom up.

This project also has the potential to fundamentally alter how vendors design and develop applications for the health care system, driving more modular, highly targeted applications in the process. In addition, vendors that have found it difficult if not impossible to enter the health care market will now be on a more level playing field in terms of opportunities to demonstrate their ability to design and develop applications that truly address complex health care needs. For instance, hospital and ambulatory providers will have the ability to select modular applications that meet specific needs and potentially move away from monolithic, single-vendor systems and toward a 'best of breed' environment. This type of access, coupled with the broad range of apps available, can then help providers meet meaningful use requirements for Stage 1 and beyond.

Secondary Use of EHR Data. The capture and storage of clinical data in standard and consistent formats is necessary for many other applications of health IT such as CDS, quality reporting, and population health. However, data liquidity, which relies on non-standard patient data being converted into a standard, consistent format, remains a significant issue. Even with the growing adoption of EHRs spurred on by HITECH, today's health care system still relies heavily on scanned documents and reports. As a result, relevant clinical information is often not immediately accessible or usable for informing decision-making processes. Given these challenges, secondary uses of the data collected by EHRs have been limited.

The Mayo Clinic's project could potentially produce software tools and resources that will reduce the complexity of converting data into standard formats and integrating previously free-text and non-electronic data into standard electronic formats. This will in turn help establish a critical infrastructure to more effectively exchange, analyze and mine data for patient and population health. A very important contribution of this project will be the data linkages among patient characteristics and disease conditions and the implications for enhancing understanding of the causes of and risks for various disease conditions.

Ultimately, this project is likely to demonstrate how the data at the point of care can be more effectively used for a variety of health care purposes through robust exchange of data in different formats across providers. The services created will also greatly enhance the ability for researchers to apply a wide range of data from clinical encounters to advanced research projects in clinical effectiveness research and genomics.

Conclusions

SHARP is a collaborative, interdisciplinary program focusing on well-documented impediments to EHR adoption and meaningful use. It is designed to create a comprehensive research infrastructure that will continue to encourage breakthrough advances that support EHR adoption even after the completion of the program. In the short term, SHARP Awardees' tools, products, and methods will be disseminated to developers and vendors, and help stimulate greater private-sector investment. In the longer term, Awardees' projects will drive novel approaches to encouraging the meaningful use of health IT and fundamental improvements in care delivery and outcomes. By targeting the gap between understanding of the potential impact of health IT and the implementation of solutions that realize its benefits, the SHARP program can help accelerate nationwide progress toward meaningful use and subsequently facilitate dramatic improvements in the U.S. health care system.

Appendix B. Awardee Overview

As noted in the evaluation report, the SHARP awardees made some adjustments in project structure throughout the Cooperative Agreement. This appendix reflects the organizational structure of each awardee in March 2014. The appendix outlines the institutions involved, the sub-projects that made up each awardee project, as well as the specific institutions that contributed to each sub-project.

Awardee	Institutions	Sub-Projects & Contributing Institutions
SHARPS	University of Illinois, Carl Gunter, PIUniversity of Illinois at Urbana-ChampaignCarnegie Mellon UniversityDartmouth CollegeHarvard University and Beth Israel Deaconess Medical CenterJohns Hopkins University and Children's Medical and SurgicalCenterNew York UniversityNorthwestern University and Memorial HospitalStanford UniversityUniversity of California, BerkeleyUniversity of Wassachusetts AmherstUniversity of WashingtonVanderbilt University	 Audit: University of Illinois at Urbana-Champaign, Northwestern University and Memorial Hospital, Johns Hopkins University and Children's Medical and Surgical Center, Vanderbilt, Carnegie Mellon University, Dartmouth College Automated policy: Dartmouth College, New York University, Stanford University, Vanderbilt University Encryption and trusted base: Johns Hopkins University and Children's Medical and Surgical Center Telemedicine: Dartmouth College, University of Massachusetts Amherst, University of Washington, Carnegie Mellon University, University of California, Berkeley, New York University, Harvard University and Beth Israel Deaconess Medical Center
SHARPC	University of Texas Houston Health Sciences Center, Jajie Zhang, PI Arizona State University Baylor College of Medicine Baylor Health Care System (Baylor Research Institute) Harvard University/Brigham & Women's Hospital Intermountain Healthcare The University of Texas MD Anderson Cancer Center University of Washington University of Kentucky University of Kentucky University of Maryland at College Park University of Missouri VA Palo Alto Health Care System	 Work-centered design of care process improvements in HIT – EHR Usability and EHR Workflow: University of Texas Houston Health Sciences Center, Baylor Research Institute, University of Washington Cognitive foundations for decision making: Implications for decision support: University of Texas Houston Health Sciences Center Modeling of setting-specific factors to enhance clinical decision support adaptation: Arizona State University, VA Palo Alto Health Care System, Intermountain Healthcare Automated model-based clinical summarization of key patient data: University of Texas Houston Health Sciences Center, Harvard University/Brigham & Women's Hospital, Baylor College of Medicine Cognitive information design and visualization: Enhancing accessibility and understanding of patient data: University of Texas Houston Health Sciences Center, University of Texas MD Anderson Cancer Center, University of Missouri

Awardee	Institutions	Sub-Projects & Contributing Institutions
SMART [™]	Harvard Medical School, Issac Kohane, PI Boston Children's Hospital (BCH), Kenneth D. Mandl, Co-PI Children's Hospital Informatics Program at BCH Partners Healthcare MGH Laboratory for Computer Science Regenstrief Medical Informatics	 SMART Platform API and Data Model: Harvard Medical School, Boston Children's Hospital, Children's Hospital Informatics Program at BCH, Regenstrief Medical Informatics SMART Platform Architecture: Harvard Medical School, Boston Children's Hospital SMART Apps with Medication Use Case: Boston Children's Hospital SMART Adaptation of Existing Platforms: Boston Children's Hospital SMART Ecosystem Creation: Harvard Medical School, Boston Children's Hospital
SHARPn ⁱ	Mayo Clinic, Christopher Chute, Pl Intermountain Healthcare/University of Utah, Stan Huff, Co-Pl Agilex Technologies, Inc. Centerphase Solutions, Inc. Clinical Data Interchange Standards Consortium (CDISC) Deloitte Group Health Research Institute Boston Children's Hospital IBM T.J. Watson Research Center Massachusetts Institute of Technology Mirth Corporation MITRE University at Albany – SUNY University of Colorado University of Pittsburgh	 Clinical Data normalization: Mayo Clinic, Intermountain Healthcare/University of Utah, Agilex Technologies, Deloitte Natural language processing: MITRE, Mayo Clinic, University of Colorado, Massachusetts Institute of Technology, Group Health Research Institute, Harvard Children's Hospital Boston, , University of Pittsburgh, Intermountain Healthcare/ University of Utah, University at Albany – SUNY High-throughput phenotyping: Mayo Clinic, CDISC, Centerphase Solutions, Inc., Deloitte, Harvard Children's Hospital Boston, Intermountain Healthcare/University of Utah Infrastructure / Scaling Capacity Technologies: Mayo Clinic, CDISC, Deloitte, Intermountain Healthcare, Agilex Technologies, IBM T.J. Watson Research Center, Mirth Corporation Data Quality: Mayo Clinic, Intermountain Healthcare, Centerphase Solutions, Inc. Evaluation Framework: Mayo Clinic, CDISC, Deloitte, Intermountain Healthcare, Agilex Technologies, IBM T.J. Watson Research Center, Deloitte

Appendix C. SHARP Output Inventory

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Abstract	Gay Males and Electronic Health Records: Privacy Perceptions, Age, and Negotiating Stigma	Stablein T, Hall J, Nissenbaum H, Anthony D.	Paper presented (by Stablein) at the Eastern Sociological Society Annual Meeting, February 2012	http://sharps.org/wp- content/uploads/STABLEI N-ESS-Annual- Meeting.pdf
SHARPS	Patent	U.S. Patent Filing: Generate Random Numbers using Metastability Resolution Time.	Suresh V and Burleson W.	December 2013.	N/A
SHARPS	Patent	Patent for Amulet and Biometrics	SHARPS team	Submitted a provisional patent that covers Amulet and new biometrics.	N/A
SHARPS	Poster	Passive Biometrics for Pervasive	Cornelius C, Marois Z, Sorber J, Peterson R, Mare S, Kotz D.	Workshop on Mobile Computing Systems and Applications (HotMobile), February, 2012.	http://sharps.org/wp- content/uploads/CORNELI US-HOTMOBILE.pdf
SHARPS	Poster	User-controlled Privacy	SHARPS team	Presented to industry professionals visiting Berkeley engineering department, BEARS 2012. Berkeley-EECS Annual Research Symposium, Berkeley, CA.	N/A
SHARPS	Poster	PolicyForge: A Collaborative Environment for Formalizing Privacy Policies in Health Care	Nadas A.	Presented on November 4, 2013 at the public relations event hosted at ISIS 15TH Anniversary Celebration. Invited guests at the event were local entrepreneurs, venture capitalist, and many external collaborators of ISIS.	N/A
SHARPS	Presentation	Get 'Em While Their Young: Bringing Technical and Security Skills to 'Election Geeks – the Next Generation		Election Verification Network (EVN) Conference 2012.	N/A

¹ The four project areas include: 1) Security of HIT (SHARPS); 2) Patient Centered Cognitive Support (SHARPc); 3) Healthcare Application & Network Platform Architectures (SMART); and 4) Secondary Use of EHR Data (SHARPn).

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Presentation	Using SMT solvers to Automate Design Tasks for Encryption and Signature Schemes		A paper that describes AutoStrong was published at the ACM CCS 2013 conference.	N/A
SHARPS	Presentation	Keynote Presentation	SHARPS team	IEEE Pacific Rim International Symposium on Dependable Computing (PRDC 2013).	N/A
SHARPS	Presentation	A wearable system that knows who wears it.		Submitted to MobiSys'14, December 2013.	N/A
SHARPS	Presentation	Ocean: Open Contextual Evidence Add-On for Mobile Applications.	Prasad A and Kotz D.	Submitted to MobiSys'14, December 2013.	N/A
SHARPS	Presentation	Federal Trade Commission Workshop on the Internet of Things	Kohno T.	Panelist, November 2013.	http://www.ftc.gov/news- events/events- calendar/2013/11/internet- things-privacy-security- connected-world
SHARPS	Presentation	Security in Medical Devices	Kune DF.	University of Minnesota Masters in Software Engineering seminar, October 2013.	N/A
SHARPS	Presentation	What can the automotive industry learn from the medical device industry?	SHARPS team	SAE 2013 Electronic Systems for Vehicle Propulsion and Intelligent Vehicle Systems Symposium, October 2013.	N/A
SHARPS	Presentation	Medical Devices	Burleson W.	Workshop on Embedded Systems Security, Montreal, Canada, September, 2013	N/A
SHARPS	Presentation	RFID Privacy: From Transportation Payment Systems to Implantable Medical Devices	Burleson W.	Dartmouth Computer Science Colluquium, September 2013.	N/A
SHARPS	Presentation	Privacy and the Many Layers of Mobile Platforms.	Health IT in the US System	New York University, Information Law Institute/Princeton University, Center for Information Technology Policy. Conference on Mobile and Location Privacy: A Technology and Policy Dialog	N/A
SHARPS	Presentation	Are these mHealth sensors on the same body? The right body?	Kotz D.	Kotz gave an invited talk at NetHealth 2012, the Workshop on	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Presentation	Security and Privacy for Implantable Medical Devices"	Fu K.	SRC/SFI/NSF Forum on Integrated Sensors for Cybersystems - FISC 2030, Ireland	N/A
SHARPS	Presentation	Status and Implications of Health IT in the US System	Anthony R.	Colby College Health, Science, Technology and Society Seminar Series	N/A
SHARPS	Presentation	Trustworthy Medical Device Software	Fu K.	Computer Laboratory Security Seminar, University of Cambridge, U.K.	N/A
SHARPS	Presentation	Secure Audit	Gunter C, Hall JL, Malin B, Sengupta S, Williams L, Zheng K.	Securing Information Technology in Healthcare: Part II (SITH2) co- sponsored by SHARPS Institute for Security, Technology and Society, Dartmouth College	N/A
SHARPS	Presentation	An Amulet for Trustworthy Wearable mHealth	Kotz D.	HotMobile 2012; the 13th International Workshop on Mobile Computing Systems and Applications	N/A
SHARPS	Presentation	An Amulet for Trustworthy Wearable mHealth	Hall JL.	Privacy Research Group; New York University School of Law, Information Law Institute, New York, NY	N/A
SHARPS	Presentation	Presentation at University of Illinois	Datta A.	The University of Illinois-ITI Trust and Security Seminar	http://www.iti.illinois.edu/s eminarsevents/iti-trust- and-security-seminar-tss
SHARPS	Presentation	Privacy and the Many Layers of Mobile Platforms.	Stablein T.	Eastern Sociological Society meetings in New York, NY	N/A
SHARPS	Presentation	Role Mining with Probabilistic Boolean Matrix Factorization	SHARPS team	Presentation at Cal Tech seminar	http://www.vision.caltech.e du/fuchs/mlseminar/
SHARPS	Presentation	The new "Amulet" concept	Kotz D.	The Center for Law, Ethics, and applied Research (CLEAR) in Health Information, of the Indiana University	
SHARPS	Presentation	The new "Amulet" concept	Kotz D.	Hanover, NH, Securing Information Technology in Healthcare: Part II (SITH2) co- sponsored by SHARPS, Institute for Security, Technology and Society, Dartmouth College.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Presentation	Experience Based Access Management (EBAM).	Gunter CA.	University of North Carolina, Charlotte-College of Computing and Informatics	N/A
SHARPS	Presentation	Social Media Inside and Outside the Courtroom: Internet Technology Basics for Federal Judges	Lazebnik R and Hall JL.	Lazenbik talk, Fordham Law School, Center for Law and Information Policy, New York, NY	N/A
SHARPS	Presentation	HIE as an Engineered System	Frisse M.	Keynote address at the Redwood MedNet 7th Annual HIE Conference, July 25, 2013.	N/A
SHARPS	Presentation	Data Segmentation for Health Information Privacy	Frisse M.	Panel discussion at the Redwood MedNet 7th Annual HIE Conference, July 25, 2013.	N/A
SHARPS	Presentation	Informatics	Frisse M.	General talk on informatics, including privacy research, at the Stanford Biomedical Informatics Retreat	N/A
SHARPS	Presentation	PolicyForge: A Collaborative Environment for Formalizing Privacy Policies in Health Care	Nadas A.	2013 Fall TRUST Conference	N/A
SHARPS	Presentation	A model-integrated authoring environment for privacy policies	Levenovszky T.	2013 Fall TRUST Conference	N/A
SHARPS	Presentation	From One Health Record to One Care Plan: One Step at a Time	Frisse M.	HIMSS NW Technology and Education Symposium, October 24, 2013.	N/A
SHARPS	Presentation	Is the Investment in IT Paying Off?	Frisse M.	Panel Discussion with Jacob Reider and Douglas McCarthy, at the Fleming Center (UT) on October 28, 2013.	N/A
SHARPS	Presentation	Harnessing big data for population scale discovery	Stead W.	ECRI Conference: "Data big and small, what healthcare decision makers are using now", November 15, 2013.	https://www.ecri.org/Confe rences/Pages/Annual_Co nference_2013.aspx
SHARPS	Presentation	Research Challenges for the Learning Health System: Report of an NSF Sponsored Workshop	Stead W.	AMIA panel, November 18, 2013. Discussion on four system requirements including: a learning health system (LHS) trusted and valued by all stakeholders; and an adaptable, stable, certifiable and responsive LHS.	N/A
SHARPS	Presentation	Understanding the Challenges with Medical Data Segmentation for Privacy	SHARPS team	HealthTech '13, August 2013.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Presentation	Understanding the Challenges with Medical Data Segmentation for Privacy	SHARPS team	Berkeley TRUST, October 2013.	N/A
SHARPS	Presentation	Understanding the Challenges with Medical Data Segmentation for Privacy	SHARPS team	Berkeley Turst Wise, July 2013.	N/A
SHARPS	Presentation	Context Dependent Expectations of Privacy in Self-Generated Mobile Health Data	SHARPS team	Telecommunication Policy Research Conference, Septebmer 2013.	N/A
SHARPS	Presentation	User Expectations of Privacy in Self-Generated Mobile Health Data	SHARPS team	IEEE International Symposium on Technology and Society, June 2013.	N/A
SHARPS	Presentation	Presentation to the State of Illinois Office of Health Information Technology	SHARPS team	Presented upon the Office's request.	N/A
SHARPS	Presentation	Oral paper presentation	SHARPS team	International Conference on Empirical Methods in Natural Language Processing (EMNLP), October 2013.	N/A
SHARPS	Presentation	Oral paper presentation	SHARPS team	International Joint Conference on Artificial Intelligence (IJCAI). Beijing, China, August 2013.	N/A
SHARPS	Presentation	Purpose Restrictions on Information Use	Tschantz MC, Datta A, Wing JM.	ESORICS 2013, September 2013/	N/A
SHARPS	Publication	Automatically Generating Outsourced Decryption for Pairing- based Encryption Schemes	Akinyele JA, Pagano MW, Green M, Rubin A.	Submitted to PKC 2014.	N/A
SHARPS	Publication		Kurillo G, Han J, Nicorici A, Bajcsy R.	Accepted for Proceedings of Medicine Meets Virtual Reality (MMVR) 2014.	N/A
SHARPS	Publication	Inside Job: Understanding and Mitigating the Threat of External Device Mis-Bonding on Android	Naveed M, Zhou X, Demetriou S, Wang X, Gunter GA.	ISOC Network and Distributed Computing Security (NDSS 14), San Diego, CA, February 2014.	http://sharps.org/wp- content/uploads/NAVEED- NDSS.pdf
SHARPS	Publication	Design Challenges for Secure Implantable Medical Devices	Ransford B, Clark S, Kune D, Fu K, Burleson W.	Book chapter in in S. Carrara, W. Burleson (eds.), Springer, to appear January 2014.	https://spqr.eecs.umich.ed u/papers/49SS2- 3_burleson.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication	Security and Privacy in Implantable Medical Devices	Burleson W and Carrara S.	Book, published by Springer, to apper January 2014. This book contains papers on Security as well as Design of Biosensors, thus providing a unique multi- disciplinary perspective. Chapter authors are all leaders in their respective fields.	<u>https://spqr.eecs.umich.ed</u> u/papers/b1kohFINAL2.pd <u>f</u>
SHARPS	Publication	Identity, Location, Disease and More: Inferring Your Secrets from Android Public Resources,	Zhou X, Demetriou S, He D, Naveed M, Pan X, Wang X, Gunter GA, Nahrstedt K.	ACM Computer and Communication Security (CCS '13), Berlin Germany, November 2013.	http://sharps.org/wp- content/uploads/ZHOU- CCS.pdf
SHARPS	Publication	Building a Smarter Health and Wellness Future: Privacy and Security Challenges	Gunter CA.	Chapter 9 in: ICTs and the Health Sector: Towards Smarter Health and Wellness Models, OECD, October 2013, pages 141- 157.	http://sharps.org/wp- content/uploads/GUNTER -OECD.pdf
SHARPS	Publication	Purpose Restrictions on Information Use	Tschantz MC, Datta A , Wing JM.	18th European Symposium on Research in Computer Security, September 2013.	http://sharps.org/wp- content/uploads/TSCHAN TZ-ESORICS.pdf
SHARPS	Publication	Extraction of Events and Temporal Expressions from Clinical Narratives	Jindal P and Roth D.	Journal of Biomedical Informatics (JBI) – September 2013.	http://sharps.org/wp- content/uploads/JINDAL- JBI.pdf
SHARPS	Publication	Usable Security for Wireless Body- Area Networks	Cornelius CT.	Ph.D. Thesis, Dartmouth College Computer Science, September 2013. Available as Dartmouth Computer Science Technical Report TR2011-741.	http://www.cs.dartmouth.e du/~dfk/papers/abstracts/c ornelius-thesis.html
SHARPS	Publication	EMR Audit Logs	Duff y E, Nyemba S, Gunter GA, Liebovitz D, Malin B.	USENIX Workshop on Health Information Technologies, August 2013.	http://sharps.org/wp- content/uploads/DUFFY- HEALTHTECH.pdf
SHARPS	Publication	Understanding the Challenges with Medical Data Segmentation for Privacy	Chan EM, Lam PE, Mitchell JC.	USENIX Workshop on Health Information Technologies, August 2013.	http://sharps.org/wp- content/uploads/CHAN- HEALTHTECH.pdf
SHARPS	Publication	PUF Modeling Attacks on Simulated and Silicon Data			http://sharps.org/wp- content/uploads/RUHRMA IR-IACR.pdf
SHARPS	Publication	End-to-End Coreference Resolution for Clinical Narratives	Jindal P and Roth D.	International Joint Conference on Artificial Intelligence, August 2013.	<u>http://sharps.org/wp-</u> content/uploads/JINDAL- IJCAI.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication	Audit Games	Blocki J, Christin N, Datta A, Procaccia AD, Sinha A.	International Joint Conference on Artificial Intelligence, August 2013.	http://sharps.org/wp- content/uploads/BLOCKI- IJCAI.pdf
SHARPS	Publication	Trojans	Paar C, Burleson WP.	Workshop on Cryptographic Hardware and Embedded Systems, August 2013.	<u>http://sharps.org/wp-</u> <u>content/uploads/BECKER- CHES.pdf</u>
SHARPS	Publication	Efficient E-cash in Practice: NFC- based Payments for Public Transportation Systems	Baldimtsi F, Lysyanskaya A, Paar C, Burleson WP.	13th Privacy Enhancing Technologies Symposium, July 2013.	<u>http://sharps.org/wp-</u> content/uploads/HINTER WALDER-PETS.pdf
SHARPS	Publication	Modeling and Detecting Anomalous Topic Access	Gupta S, Hanson C, Gunter CA, Frank M, Liebovitz D, Malin B.	IEEE Intelligence and Security Informatics, June 2013.	<u>http://sharps.org/wp-</u> <u>content/uploads/GUPTA-</u> ISI.pdf
SHARPS	Publication	Evolving Role Definitions Through Permission Invocation Patterns	Zhang W, Chen Y, Gunter GA, Liebovitz D, Malin B.	ACM Symposium on Access Control Models and Technologies, June 2013.	<u>http://sharps.org/wp-</u> <u>content/uploads/ZHANG-</u> <u>SACMAT.pdf</u>
SHARPS	Publication	Balancing Security and Utility in Medical Devices?	Rostami M, Burleson W, Juels A.	DAC, June 2013.	<u>http://sharps.org/wp-</u> <u>content/uploads/ROSTAM</u> <u>I-DAC.pdf</u>
SHARPS	Publication	Half-Wits: Software Techniques for Low-Voltage Probabilistic Storage on Microcontrollers with NOR Flash Memory	Salajegheh M, Wang Y, Jiang A, Learned-Miller E, Fu K.	ACM Transactions on Embedded Computing Systems, June 2013.	http://sharps.org/wp- content/uploads/SALAJE GHEH-TECS.pdf
SHARPS	Publication	Hide-n-Sense: Preserving Privacy Efficiently inWireless mHealth	Mare S, Sorber J, Shin M, Cornelius C, Kotz D.	Mobile Networks and Applications, June 2013.	http://sharps.org/wp- content/uploads/MARE- MONET.pdf
SHARPS	Publication	Ghost Talk: Mitigating EMI Signal Injection Attacks against Analog Sensors	Kune DF, Backesy J, Clarkz SS, et al.	34th Annual IEEE Symposium on Security and Privacy, May 2013.	<u>http://sharps.org/wp-</u> <u>content/uploads/KUNE-</u> <u>SP.pdf</u>
SHARPS	Publication	A model-integrated authoring environment for privacy policies	Nadas A, Levendovszky T, Jackson EK, Madari I, Sztipanovits J.	Science of Computer Programming, May 2013.	http://sharps.org/wp- content/uploads/NADAS- SCP.pdf
SHARPS	Publication	Privacy in Mobile Technology for Personal Healthcare	Avancha S, Baxi A, Kotz D.	ACM Computing Surveys, Volume 45, issue 1, March 2013	http://sharps.org/wp- content/uploads/KOTZ- COMPUTING- SURVEYS.pdf
SHARPS	Publication	Fully Integrated Biochip Platforms for Advance Healthcare	Carrara S, Ghoreishzadeh S, Olivio J, et al.	Sensors, volume 12, issue 8, pages 11013-11060, August 2012.	http://sharps.org/wp- content/uploads/BURLES ON-SENSORS.pdf
SHARPS	Publication	Provenance Framework for mHealth	Prasad A, Peterson R, Mare S, et al.	Workshop on Networked Healthcare Systems, January 2013	http://sharps.org/wp- content/uploads/PRASAD- WNHS.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication	Mining Permission Request Patterns from Android and Facebook Applications		Data Mining (ICDM11), December 2012.	http://sharps.org/wp- content/uploads/FRANK- ICDM-full.pdf
SHARPS	Publication	Modeling Privacy Aware Health Information Exchange Systems	Nadas A, Frisse M,	International Workshop on Engineering EHR Solutions (WEES), October 2012	http://sharps.org/wp- content/uploads/NADAS- WEES.pdf
SHARPS	Publication	Understanding Sharing Preferences and Behavior for mHealth Devices	T, Anthony D, Kolz D.	Workshop on Privacy in the Electronic Society (WPES), October 2012	http://www.cs.dartmouth.e du/~dfk/papers/prasad- fitbit.pdf
SHARPS	Publication	Accountings of Relationships	Nissenbaum H.	UNSENIX Workshop on Health Security and Privacy (HealthSec12), August 2012	http://sharps.org/wp- content/uploads/HALL- HEALTHSEC12.pdf
SHARPS	Publication	Vis-à-vis Cryptography: Private and Trustworthy In-Person Certifications	Lehmann CLL Rubin AD	UNSENIX Workshop on Health Security and Privacy (HealthSec12), August 2012	http://sharps.org/wp- content/uploads/GREEN- HEALTHSEC12.pdf
SHARPS	Publication	Formalizing and Enforcing Purpose Restrictions in Privacy Policies		IEEE Symposium on Security and Privacy, May 2012.	http://sharps.org/wp- content/uploads/DATTA- OAKLAND.pdf
SHARPS	Publication	Who Wears Me? Bioimpedance As a Passive Biometric	Crnellus C, Sorber J, Potorson P, et al	USENIX Workshop on Health Security and Privacy (HealthSec12), August 2012	http://sharps.org/wp- content/uploads/KOTZ- HEALTHSEC-12.pdf
SHARPS	Publication	A Contextual Approach to Privacy Online	Nissenbaum H.	Dædalus, the Journal of the American Academy of Arts & Sciences, volume 140, issue 4, September 2011.	http://sharps.org/wp- content/uploads/NISSENB AUM-DAED.pdf
SHARPS	Publication	A Research Roadmap for Healthcare IT Security Inspired by the PCAST Health Information Technology Report	Green MD and Rubin AD.	USENIX Workshop on Health Security and Privacy (HealthSec11), August 2011	http://sharps.org/wp- content/uploads/RUBIN- PCAST.pdf
SHARPS	Publication	A Review of the Security of Insulin Pump Infusion Systems	DC.	Journal of Diabetes Science and Technology, volume 5, issue 6, pages 1557-1562, November 2011.	<u>http://sharps.org/wp-</u> <u>content/uploads/PAUL-</u> <u>JDST.pdf</u>
SHARPS	Publication	Security Risks, Low-tech Interfaces, and Implantable Medical Devices: A Case Study with Insulin Pump Infusion Systems	Paul N and Kohno T.	USENIX Workshop on Health Security and Privacy (HealthSec12), August 2012.	http://sharps.org/wp- content/uploads/PAUL- HEALTHSEC12.pdf
SHARPS	Publication	Tragedy of Anticommons in Digital Right Management of Medical Records	Zhu Q, Gunter CA, Basar T.	USENIX Workshop on Health Security and Privacy (HealthSec12), August 2012.	http://sharps.org/wp- content/uploads/GUNTER -HEALTHSEC12.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication	A Threat Taxonomy for mHealth Privacy	KOLZ D.	International Conference on Communication Systems and Networks (COMSNETS11), pages 1-6, January 2011.	http://sharps.org/wp- content/uploads/KOTZ- NETHEALTH.pdf
SHARPS	Publication	Adaptive Security and Privacy for mHealth Sensing	Mare S, Sorber J, Shin M, Cornelius C, Kotz D.	Security and Privacy (HealthSec11), August 2011.	http://sharps.org/wp- content/uploads/MARE- HEALTHSEC.pdf
SHARPS	Publication	Adapt-lite: Privacy-aware, Secure, and Efficient mHealth Sensing		Workshop on Privacy in the Electronic Society (WPES11), October 2011.	http://sharps.org/wp- content/uploads/MARE- WPES.pdf
SHARPS	Publication	Audit Mechanisms for Provable Risk Management and Accountable Data Governance	Blocki J, Christin N, Datta A, Sinha A.	Conference on Decision and Game Theory for Security (GameSec), November 2012	http://sharps.org/wp- content/uploads/SINHA- DGTS.pdf
SHARPS	Publication	Audit Mechanisms for Privacy Protection in Healthcare Environments	Blocki J, Christin N, Datta A, Sinha A.	USENIX Workshop on Health Security and Privacy (HealthSec11), August 2011.	http://sharps.org/wp- content/uploads/DATTA- HEALTHSEC.pdf
SHARPS	Publication	Awarded best paper: They Can Hear Your Heartbeats: Non- Invasive Security for Implantable Medical Devices	Gollakota S, Hassanieh H, Ransford N, Katabi D, Fu K.	ACM Special Interest Group on Data Communication (SIGCOMM11), August 2011.	http://sharps.org/wp- content/uploads/FU-ACM- SIGCOMM1.pdf
SHARPS	Publication	Computerized Provider Order Entry in Pediatric Oncology: Design, Implementation, and Outcomes	Chon AP and Lohmann C	Journal of Oncology Practice, volume 7, issue 4, July 2011.	http://sharps.org/wp- content/uploads/LEHMAN N-JOP.pdf
SHARPS	Publication	Electronic Health Record-Based Monitoring of Primary Care Patients at Risk of Medication- Related Toxicity		Joint Commission Journal on Quality and Patient Safety 38 (5), 216-223(8), May 2012	<u>http://sharps.org/wp-</u> <u>content/uploads/LEHMAN</u> N-JCJQPS.pdf
SHARPS	Publication	Experience-Based Access Management: A Life-Cycle Framework for Identity and Access Management Systems	Gunter GA, Liebovitz DM, Malin B.	IEEE Security & Privacy, September/October 2011.	http://sharps.org/wp- content/uploads/GUNTER -IEEE-SP.pdf
SHARPS	Publication	Experiences in the Logical Specification of the HIPAA and GLBA Privacy Laws		Workshop on Privacy in the Electronic Society (WPES10), October 2010.	http://sharps.org/wp- content/uploads/DATTA- WPES.pdf
SHARPS	Publication	Exposing Privacy Concerns in mHealth	Prasad A, Sorber J, Stablein T, Anthony D, Kotz D.	USENIX Workshop on Health Security and Privacy (HealthSec11), August 2011.	http://sharps.org/wp- content/uploads/KOTZ- HEALTHSEC.pdf
SHARPS	Publication	Learning from Negative Examples in Set-Expansion	Jindal P and Roth D.	IEEE International Conference on Data Mining (ICDM11), December 2011.	

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication	Medication Administration Quality and Health Information Technology: A National Study of Hospitals	Appari A, Carian EK, M. Johnson ME, Anthony DL.	Journal of the American Medical Informatics Association (JAMIA), October 2011.	http://sharps.org/wp- content/uploads/ANTHON Y-JAMIA.pdf
SHARPS	Publication	Outsourcing the Decryption of ABE Ciphertexts	Green M, Hohenberger S, Waters B.	USENIX Security Symposium, August 2011	http://sharps.org/wp- content/uploads/GREEN- SEC11.pdf
SHARPS	Publication	Patients, Pacemakers, and Implantable Defibrillators: Human Values and Security for Wireless Implantable Medical Devices	Denning T, Borning A, Friedman B, et al.	ACM Conference on Human Factors in Computing Systems (CHI10), April 2010.	http://sharps.org/wp-con tent/uploads/KOHNO- CHI10.pdf
SHARPS	Publication	Policy Auditing over Incomplete Logs: Theory, Implementation and Applications	Garg D, Jia L, Datta A	ACM Conference on Computer and Communications Security (CCS11), October 2011.	http://sharps.org/wp- content/uploads/DATTA- CCS.pdf
SHARPS	Publication	Real-time Human Pose Detection and Tracking for Tele-rehabilitation in Virtual Reality	Obdržálek S, Kurillo G, Han J, Abresch T, Bajcsy R.	Studies in Health Technology and Informatics: Medicine Meets Virtual Reality 19, 173, 320; February 2012.	http://sharps.org/wp- content/uploads/BAJCSY- Stud-Health-Technol- Inform.pdf
SHARPS	Publication	Reasoning about Metamodeling with Formal Specifications and Automatic Proofs	Jackson EK, Levendovszky T, Balasubramanian D.	Model Driven Engineering Languages and Systems (MoDELS11), October 2011.	http://sharps.org/wp- content/uploads/JACKSO N-LNCS.pdf
SHARPS	Publication	Recent Results in Computer Security for Medical Devices	Clark SS and Fu K.	ICST Conference on Wireless Mobile Communication and Healthcare (MobiHealth), October 2011.	http://sharps.org/wp- content/uploads/FU- MOBIHEALTH.pdf
SHARPS	Publication	Potentia est Scientia: Security and Privacy Implications of Energy- Proportional Computing		USENIX Workshop on Hot Topics in Security (HotSec12), August 2012	http://sharps.org/wp- content/uploads/CLARK- HOTSEC.pdf
SHARPS	Publication	Recognizing Whether Sensors are on the Same Body	Cornelius C and Kotz D.	International Conference on Pervasive Computing, Lecture Notes in Computer Science, June 2011.	http://sharps.org/wp- content/uploads/KOTZ- PERVASIVE.pdf
SHARPS	Publication	Regret Minimizing Audits: A Learning-theoretic Basis for Privacy Protection	Blocki J, Christin N, Datta A, Sinha A.	IEEE Computer Security Foundations Symposium, June 2011.	http://sharps.org/wp- content/uploads/DATTA- CSF.pdf
SHARPS	Publication		Kramer DB, Xu S, Kesselheim A.	The New England Journal of Medicine, February 2012	http://sharps.org/wp- content/uploads/KRAMER -NEJM-2012.pdf
SHARPS	Publication	Security and Privacy Qualities of Medical Devices: An Analysis of FDA Postmarket Surveillance	Kramer DB, Baker M, Ransford B, et al.	PLOS ONE, volume 7, issue 7, July 2012	http://sharps.org/wp- content/uploads/FU-PLoS- ONE.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication	Role Prediction using Electronic Medical Record System Audits	Zhang W, Gunter CA, Liebovitz D, Tian J, Malin B.	AMIA Fall 2011 Symposium Proceedings	http://sharps.org/wp- content/uploads/ZHANG- AMIA.pdf
SHARPS	Publication	Securing Electronic Medical Records Using Attribute-Based Encryption On Mobile Devices	Akinyele JA, Pagano MW, Green MD, et al.	ACM CCS Workshop on Security and Privacy in Smartphones and Mobile Devices (SPSM11), October 2011.	http://sharps.org/wp- content/uploads/AKINYEL E-CCS.pdf
SHARPS	Publication	Take Two Software Updates and See Me in the Morning: The Case for Software Security Evaluations of Medical Devices	Hanna S, Rolles R, Molina- Markham A, et al.	USENIX Workshop on Health Security and Privacy (HealthSec11), August 2011	http://sharps.org/wp- content/uploads/FU- HEALTHSEC.pdf
SHARPS	Publication	The Financial Impact of Health Information Exchange on Emergency Department Care	Frisse ME, Johnson KB, Nian H, et al.	Journal of the American Medical Informatics Association (JAMIA), November 2011.	http://sharps.org/wp- content/uploads/FRISSE- JAMIA.pdf
SHARPS	Publication	Machine Generated Algorithms, Proofs and Software for the Batch Verification of Digital Signature Schemes	Akinyele JA, Green MD, Hohenberger S, Pagano MW.	ACM Computer and Communications Security (CCS)	http://eprint.iacr.org/2013/ 175.pdf
SHARPS	Publication	Implementing Formally-Modeled Privacy Policies in Healthcare Communication Systems	Daniel R.	Technical Report #ISIS-13-103	N/A
SHARPS	Publication	Do health care users think electronic health records are important? Exploring group differences in a National Survey	Anthony R and Campos- Castillo C.	Conference paper.	http://www.ncbi.nlm.nih.go v/pubmed/24551321
SHARPS	Publication	A Looming Digital Divide? Group Differences in the Perceived Importance of Electronic Health Records	Anthony R and Campos- Castillo C.	Revise & Resubmit at the journal Information, Communication and Society.	N/A
SHARPS	Publication	The double-edge of Electronic Health Records: Implications for patient disclosure and care quality	Anthony R and Campos- Castillo C.	Under review at Health Affairs.	N/A
SHARPS	Publication	Negotiating Stigma in Contemporary Health Care Settings: Disclosure and the Role of Electronic Health Records	Stablein T, Hall J, Pervis C, Anthony D.	Revise & Resubmit at Social Science and Medicine.	N/A
SHARPS	Publication	Adaptive Regret Minimization in Bounded-Memory Games	Blocki J, Christin N, Datta A, Sinha A.	In Proceedings of 4th Conference on Decision and Game Theory for Security, November 2013.	http://arxiv.org/abs/1111.2 888

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication		Blocki J, Christin N, Datta A, Procaccia A, Sinha A.	In Proceedings of 23rd International Joint Conference on Artificial Intelligence, August 2013	
SHARPS	Publication	Privacy-Preserving Audit for Broker-based Health Information Exchange	D, Gunter C, Datta A.	To appear in ACM Conference on Data and Application Security and Privacy (CODASPY '14), March 2014.	http://seclab.illinois.edu/w p-content/uploads/ 2014/02/spy106-ohA.pdf
SHARPS	Publication	Extraction of Events and Temporal Expressions from Clinical Narratives	Prateek J and Roth D.	Journal of Biomedical Informatics (JBI). Volume 46. Pages S13- S19. December 2013.	http://sharps.org/wp- content/uploads/JINDAL- JBI.pdf
SHARPS	Publication	Using Soft Constraints in Joint Inference for Clinical Concept Recognition	Prateek J and Roth D.	Proceedings of International Conference on Empirical Methods in Natural Language Processing (EMNLP) 2013. Seattle, USA. pp 1808-1814.	<u>http://sharps.org/wp-</u> <u>content/uploads/JINDAL-</u> <u>EMNLP.pdf</u>
SHARPS	Publication	End-to-End Coreference Resolution for Clinical Narratives	Prateek J and Roth D.	Proceedings of International Joint Conference on Artificial Intelligence (IJCAI) - 2013. pp 2106-2112. Beijing, China.	http://sharps.org/wp- content/uploads/JINDAL- IJCAI.pdf
SHARPS	Publication	Purpose Restrictions on Information Use	Tschantz MC, Datta A, Wing JM.	In proceedings of 18th European Symposium on Research in Computer Security, September 2013.	https://www.cylab.cmu.ed u/files/pdfs/tech_reports/C MUCyLab13005.pdf
SHARPS	Publication	Privacy Risk in Anonymized Heterogeneous Information Networks		To appear in Proceedings of 17th International Conference on Extending Database Technology (EDBT'14), March 2014.	http://web.engr.illinois.edu /~lzhang74/papers/aZhan g_privacyRiskHIN_edbt14. pdf
SHARPS	Publication	,	Zhang H, Mehotra S, Liebovitz, Gunter GA, Malin B.	ACM Transactions on Management Information Systems (TMIS), volume 4, number 4, article 17, December 2013.	http://dl.acm.org/citation.cf m?doid=2555810.254410 2

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Publication	Requirements and Design for an Extensible Toolkit for Analyzing EMR Audit Logs	Duffy E, Nyemba S, Gunter CA, Liebovitz D, Malin B.	USENIX Workshop on Health Information Technologies, August 2013.	http://seclab.illinois.edu/w p-content/uploads/2013/ 12/DuffyNGLM13.pdf
SHARPS	Publication	Building a Smarter Health and Wellness Future: Privacy and Security Challenges	Gunter CA.	Chapter 9 in ICTs and the Health Sector: Towards Smarter Health and Wellness Models, OECD, October 2013, pages 141-157. This publication was commissioned by the Organization for Economic Cooperation and Development.	<u>http://sharps.org/wp-</u> <u>content/uploads/GUNTER</u> <u>-OECD.pdf</u>
SHARPS	Recommendations	Recommendation letter produced for NIST ISPAB	SHARPS UMass team and Fu K.	Fu co-authored a NIST ISPAB letter on risks and economics of cyber-security medical devices	http://csrc.nist.gov/groups/ SMA/ispab/documents/cor respondence/ispab-ltr-to- omb med device.pdf
SHARPS	Recommendations	Analysis and Recommendations Concerning HHS Notice of Proposed Rulemaking Covering Changes to Accountings of Disclosure	Nissenbaum H and Hall JL.	Letter to the Office of the National Coordinator for Health Information Technology, December 2011	
SHARPS	Report	Report of Preliminary Findings and Recommendations	SHARPS team	State of Illinois Health Information Exchange Data Security and Privacy Committee September 2012	http://sharps.org/wp- content/uploads/ILHIE_DS PC_Findings_091912_FIN AL.pdf
SHARPS	Report	Flexibility of Privacy Controls for mHealth Systems	SHARPS team	Technical report on flexibility of privacy controls for mHealth systems submitted to ONC in response for comments	http://www.cs.dartmouth.e du/reports/TR2012- 711.pdf
SHARPS	Report	Design of Commercial Implantable Medical Devices	SHARPS team	A library of information on the design of commercial IMDs to assist privacy and security researchers	N/A
SHARPS	Report	Policy Authoring & Reasoning Toolkit (PATRNv 1.0)	SHARPS team	The PATRN toolkit contains formalized policy and rules engines to identify conflicting policies, and streamline policy development related to privacy and security.	https://wiki.isis.vanderbilt.e du/sharps/index.php/PAT RNDownloads.
SHARPS	Report	Exposing Privacy Concerns in mHealth Data Sharing	Prasad A.	Master's Thesis, Technical Report TR2012-711, Dartmouth College, Computer Science, February 2012	http://sharps.org/wp- content/uploads/PRASAD- MASTERS-THESIS.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Report	Current Events: Identifying Webpages by Tapping the Electrical Outlet	Clark SS, Ransford B, Sorber J, et al.	Technical Report UM-CS-2011- 030 Department of Computer Science, University of Massachusetts Amherst, July 2012	http://sharps.org/wp- content/uploads/CLARK- TECH-PAPER.pdf
SHARPS	Report	Active Monitoring Using Real-Time Metric Linear Temporal Logic Specifications	Simko G and Sztipanovits J.	rebluary 2012.	http://sharps.org/wp- content/uploads/SIMKO- BIOSTEC.pdf
SHARPS	Report	An Amulet for Trustworthy Wearable mHealth	Sorber J, Shin M, Peterson R, et al.	Workshop on Mobile Computing Systems and Applications (HotMobile12), February 2012.	http://sharps.org/wp- content/uploads/SORBER -HOTMOBILE.pdf
SHARPS	Report	Charm: A Framework for Rapidly Protyping Cryptosystems	Akinyele JA, Green MD, Rubin AD.	Annual Network & Distributed System Security Symposium, February 2012	<u>http://sharps.org/wp-</u> content/uploads/AKINYEL <u>E-NDSS.pdf</u>
SHARPS	Report	Declarative Privacy Policy: Finite Models and Attribute-Based Encryption	Lam PE, Mitchell JC, Scedrov A, Sundaram S, aWang F.	ACM SIGHIT International Health Informatics Symposium (IHI12), January 2012.	http://sharps.org/wp- content/uploads/MITCHEL L-IHI.pdf
SHARPS	Report	Design Challenges in Secure Implantable Medical Devices.	Burleson W, Clark SS, Ransford B, Fu K.	Design Automation Conference (DAC), June 2012	http://sharps.org/wp- content/uploads/BURLES ON-DAC.pdf
SHARPS	Report	High Stakes: Designing a Privacy Preserving Registry	Czeskis A and Appelbaum J.	Workshop on Usable Security (USEC12), March 2012.	http://sharps.org/wp- content/uploads/DATTA- OAKLAND.pdf
SHARPS	Report	New Definitions and Separations for Circular Security	Cash D, Green MD, Hohenberger S.	IACR International Conference on Practice and Theory of Public Key Cryptography, May 2012.	
SHARPS	Report	Passive Biometrics for Pervasive Wearable Devices	Cornelius C, Marois Z, Sorber J, et al.	Workshop on Mobile Computing Systems and Applications (HotMobile), February, 2012.	http://www.hotmobile.org/2 012/papers/dandp/biometr ics_hotmobile12.pdf
SHARPS	Report	Plug-n-Trust: Practical trusted Sensing for mHealth	Sorber J, Shin M, Peterson R, Kotz D.	International Conference on Mobile Systems, Applications, and Services (MobiSys), June 2012. (Abstract).	http://sharps.org/wp- content/uploads/SORBER -MOBISYS.pdf
SHARPS	Report	Hide-n-Sense: Privacy-aware Secure mHealth Sensing	Mare S, Sorber J, Shin M, Cornelius C, Kotz D.	Technical Report TR2011-702, Department of Computer Science, Dartmouth College, September 2011.	<u>http://sharps.org/wp-</u> content/uploads/MARE- TR.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Report		D Datta A	April 2010.	http://sharps.org/wp- content/uploads/DATTA- CMU-TECH.pdf
SHARPS	Report	Network on a Chip Firewall	SHARPS team	Development of network on a chip firewalls (NoCF), plug-n-trust hardware features, which include securing mobile device chips using a firewall, body-area network protocols, and SHIELD- enabled devices that would enhanced security for individuals using mHealth applications tethered to their smart-phones or implantable medical devices (IMDs)	N/A
SHARPS	Report	PATRN Policy Tutorial	SHARPS team	Guide to using PATRN	https://wiki.isis.vanderbilt.e du/sharps/index.php/Polic yTutorial.
SHARPS	Report	Detecting Privacy-Sensitive Events in Medical Text	Jindal P, Roth D, Gunter CA.	UIUC CS Technical Report	https://www.ideals.illinois. edu/bitstream/handle/214 2/45819/prateekSHARP.p df?sequence=2
SHARPS	Resource	A Batteryless Programmable RFID- Scale Sensor Device	Schulte M, Ransford B.	This resource includes documents (e.g. a step-by-step tutorial, an introduction to the architecture, tutorial slides), apps, code, and video tutorial. 2013.	<u>https://spqr.eecs.umich.ed</u> <u>u/moo/</u>
SHARPS	Resource	Experience Based Access Management (EBAM).	SHARPS team	The creation of audit based Experienced-Based Access Management (EBAM) protocols to maximize provider use of access data from EHRs to most efficiently detect breaches.	<u>content/uploads/GUNTER</u>

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Resource	Charm	SHARPS team	Charm is a coding framework SHARPS developed from the ground up to prototype state-of- the-art techniques in cryptosystem (computer system using cryptopgrahy such as digital signatures for email) and is designed to minimize development time and code complexity while promoting the reuse of components based on EHR and HIE systems.	http://charm-crypto.com
SHARPS	Resource	CCD-to-vMR documentation	SHARPS team	Documentation is publicshed on the OpenCDS Wiki.	N/A
SHARPS	Resource	Revised data set	SHARPS team	Revised data set with taxonomy codes, improved time stamps, and location that shows patient location at time of access.	N/A
SHARPS	Software	Prototype of an amulet board	SHARPS team	This prototype is a non-wearable development board that allows for the development of amulet software and the evaluation of various system aspects of an Amulet. 2013.	N/A
SHARPS	Software	Prototype implementation of the Ocean framework	SHARPS team	N/A	N/A
SHARPS	Software	ILHIE Prototype	SHARPS team	Released a version of the ILHIE Prototype to OHIT in August for installation on ILHIE servers; published Predicate/Reducer Web Service, Test Manager, Inference Analyzer, Probabilistic Predicate Interface, Naïve Bayes predicate, custom CCS categories, and associated data scripts to pre-release source code repositories.	N/A
SHARPS	Software	Prototype implementation using HIBE libraries and REDUCE	SHARPS team		N/A
SHARPS	Software	Drug Abuse Recognizer	SHARPS team	N/A	http://cogcomp.cs.illinois.e du/page/software_view/M edSHARPS

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPS	Software	Medical NER	SHARPS team	This package is still being augmented and refined, while supporting several groups who are planning to use it.	http://cogcomp.cs.illinois.e du/page/software_view/M edNER
SHARPS	Testimony	Software Issues for the Medical Device Approval Process	Fu K.	Testimony submitted to the Special Committee on Aging US Senate Hearing, A Delicate Balance: FDA and the Reform of the Medical Device Approval Process, April 2011.	<u>http://sharps.org/wp-</u> <u>content/uploads/FU-US-</u> <u>HEARING-AGING.pdf</u>
SHARPS	Video	Video	SHARPS team	Video to reach out to medical collaborators. It has had success so far.	https://docs.google.com/o pen?id=0Bw5uO62yaA6m ZWY5MjIxM2YtMThkNi00 ZWE3LTIkMGItOTViOWM 5OWIwZWQ2.
SHARPS	Video	Overview of SHARPS project	SHARPS team	SHARPS video created for ONC.	https://www.youtube.com/ watch?v=sreqsVgwAD4
SHARPS	Workshop	Securing Information Technology in Healthcare: Part II (SITH2)	SHARPS team	Institute for Security, Technology and Society, Dartmouth College, Hanover, NH.	N/A
SHARPS	Workshop	Workshop on Audit and HIE at Northwestern University	Gunter CA and Nissenbaum H.	Northwestern University.	N/A
SHARPS	Workshop	OHIT/SHARPS Workshop	SHARPS team	Workshop held in Chicago on July 22-24, 2013 to demonstrate software, share results, and discuss future directions related to three initiatives: DS2 (Decision Support for Data Segmentation), EBAM (Experience Based Access Management), and Patient Privacy Portal (PPP).	N/A
SHARPC	Abstract	Automated Inference of Patient Problems from Medications using NDF-RT and the SNOMED-CT CORE Problem List Subset	McCoy JA, McCoy AB, Wright A, Sittig DF.	AMIA 2011 Annual Symposium.	http://www.academia.edu/ 691462/Automated_Infere nce_of_Patient_Problems from_Medications_using NDF-RT_and_the_ SNOMED-CT_CORE Problem_List_Subset
SHARPC	Abstract	Reducing Cognitive Load: Exploring Knowledge Model-driven Information Displays	Sittig DF, McCoy AB, Wright A, Franklin A, Cohen T.	AMIA 2012 Annual Symposium.	https://sbmi.uth.edu/dotAs set/601167d5-8b37-45ec- af59-1246792d8999.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Blog	SHARPC blog	SHARPC team	Blog with relevant usability news, promoting project disseminations, discussing usability issues.	http://sharpcblog.blogspot. com/
SHARPC	Poster	Automated Inference of Patient Problems from Medications using NDF-RT and the SNOMED-CT CORE Problem List Subset.	МсСоу ЈА.	AMIA 2011 Annual Symposium.	http://www.slideshare.net/ amccoyphd/automated- inference-of-patient- problems-from- medications-using-ndfrt- and-the-snomedct-core- problem-list-subset
SHARPC	Poster	Alert Overrides: The Impact of Chained Event.	Diaz-Garelli JF, Walji MF, Franklin A, Zhang J.	AMIA 2013 Annual Symposium.	https://sbmi.uth.edu/dotAs set/cda003e2-7e88-4c6d- 8dcc-2be31b9fc4c0.pdf
SHARPC	Poster	Design of an Interactive Laboratory Results Viewer for Critically III Patients.		AMIA 2013 Annual Symposium.	N/A
SHARPC	Poster	Modeling workflows and work products in a multiple sclerosis clinic to guide the design of a new user interface	Berry ABL, Harrington C,	Poster session presented at the Workshop on Interactive Health Systems, Washington, DC.	http://wish2013workshop.fi les.wordpress.com/2013/0 9/berry_et_al_modelingwo rkflowsandworkproductsin msclinic.pdf
SHARPC	Presentation	EHR Usability Hearing	Zhang J.	Peking University Health Science Center, June 8, 2011.	http://www.healthit.gov/sit es/default/files/archive/HIT %20Policy%20Committee/ 2011/2011-05-11/4%20- %20Probst-HITPC%20 Usability%20Hearing%20 2011-04-21%20report% 202011-05-11.ppt
SHARPC	Presentation	Demonstration of SHARP Project Prototypes		Human-Computer Interaction Laboratory Annual Symposium 2011.	http://www.cs.umd.edu/hci l/about/events/symposium 2011/symposium.shtml
SHARPC	Presentation	Facilitating Medication Reconciliation with Animation and Spatial Layout	Claudino L, Khamis S, Liu R, et al.	Proceedings of the Workshop on Interactive Healthcare Systems (WISH2011).	http://hcil2.cs.umd.edu/trs/ 2011-20/2011-20.pdf
SHARPC	Presentation	The Role of Usability, Workflow, and Patient-Centered Cognitive Support in Improving Health Information Technology	Zhang J, Walji M, Butler K, Xiao Y, Hasselkorn M.	2011 AMIA Annual Symposium.	N/A
Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
----------------------	------------------	--	--	---	---
SHARPC	Presentation	Automated Medication Reconciliation and Complexity of Care Transitions.	Bozzo Silva PA, Bernstam EV, Markowitz E, Johnson TR, Zhang J, Herskovic JR.	2011 AMIA Annual Symposium.	www.ncbi.nlm.nih.gov/pub med/22195186
SHARPC	Presentation	Model	Markowitz, E, Bernstam EV, Herskovic JR, et a.	2011 AMIA Annual Symposium.	<u>hcil2.cs.umd.edu/trs/2011- 07/2011-07.pdf</u>
SHARPC	Presentation	Reducing Missed Laboratory Results: Defining Temporal Responsibility, Generating User Interfaces for Test Process Tracking, and Retrospective Analyses to Identify Problems	Tarkan S, Plaisant C, Shneiderman B, Hettinger AZ.	2011 AMIA Annual Symposium.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC32432 00/pdf/1382_amia_2011_ proc.pdf
SHARPC	Presentation	A Bill of Rights for Physician Users of Electronic Health Records	SHARPC team	2011 AMIA Annual Symposium.	N/A
SHARPC	Presentation	Keynote presentation: Biomedical Informatics and Health IT: Challenges and Opportunities in US and in China		2011 International Biomedical Informatics Summit at Peking University.	N/A
SHARPC	Presentation	Meaningful use of EHR through meaningful practice of usability.	Jiajie Zhang	Asian American Pacific Islander Region VI Health Summit 2011.	N/A
SHARPC	Presentation	Rapid Usability Assessment of Commercial EHRs	Walji, M. F., Franklin, A., Zhang, Z., Graves, K., Li, Y., Gu, Y., & Zhang, J.	AMIA 2012 Annual Symposium.	N/A
SHARPC	Presentation	The Medical App Store, Research Data Repositories, and Physician Cognitive Overload: Uniting Three Large, Multisite Grants for Health Care Transformation.	Klann JG, Wright A, McCoy AB, Murphy SN.	2012 AMIA Annual Symposium.	N/A
SHARPC	Presentation	Improving Usability, Quality and Safety: Key Lessons from Airplane Cockpit Design	Payne, T, Butler K, Ruggerio F, Middleton B.	2012 AMIA Annual Symposium.	<u>http://youtu.be/TW8JifrBJ</u> <u>Pw</u>
SHARPC	Presentation	TURFS: A Comprehensive Tool Suite for Usability Evaluation and Redesign.	F., & Zhang, J.		N/A
SHARPC	Presentation	SHARP Project Results Talk	Plaisant C.	Dr. Plaisant gave an invited talk at the AMIA ACMI Winter 2012 symposium and presented results from the SHARP project.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Presentation	Prototype presentation	SHARPC team	Preliminary versions of the prototype have been shown to potential users at AMIA 2013 and during other informal meetings.	N/A
SHARPC	Presentation	Information Visualization for Knowledge Discovery	Shneiderman B.	Seoul National University, Computer Science Dept. Distinguished Lecture Series.	N/A
SHARPC	Presentation	Information Visualization for Medical Informatics	Shneiderman B.	Georgetown University, Dept of Computer Science, Klauer Distinguished Lecture.	http://cs.georgetown.edu/e vents/klauer_2012.php
SHARPC	Presentation	A Sociotechnical Approach to Improve Technology-enabled Healthcare.	SHARPC team	8th Biennial Indian Association for Medical Informatics Conference – Improving Health through IT, New Dehli, India.	N/A
SHARPC	Presentation	Clinical Decision Support: What is it? Why is it so hard? What can we do about it?	Sittig DF.	NLM Informatics Lecture Series 175th Anniversary.	N/A
SHARPC	Presentation	HL7	SHARPC team	Presented to HL7 Arden Syntax working group and authoring tools to work on ArdenML for SSFs.	N/A
SHARPC	Presentation	Information Visualization for Knowledge Discovery	Shneiderman B.	Virginia Tech, Northern Virginia Campus: Leaders in Science & Technology Lecture Series, 2012.	http://www.calendar.vt.edu /main.php?view=event&ev entid=1327952699502
SHARPC	Presentation	Information Visualization for Knowledge Discovery	Shneiderman B.	DataScience DC, 2012.	http://www.meetup.com/D ata-Science- DC/events/56623962/
SHARPC	Presentation	Information Visualization for Medical Informatics	Shneiderman B.	UM Institute for Systems Research Colloquia, 2012.	http://www.isr.umd.edu/ev ents/index.php?mode=4&i d=6823
SHARPC	Presentation	Prototype Presentation	Shneiderman B.	NIH Office of Behavioral and Social Science Research "Visualization Day," 2012.	http://conferences.thehillgr oup.com/obssr/datavisuali zation/agenda.html
SHARPC	Presentation	Nine talks on the role of technology in social participation, healthcare, scientific innovation, and electronic health record informatics	SHARPC team	Human-Computer Interaction Laboratory Annual Symposium	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Presentation	Evaluating and Improving the Usability of EHRs	Wallji M.	Muhammad Walji provided an overview of SHARPC work at the NIST Community Building Workshop on Measuring, Evaluating and Improving the Usability of Electronic Health Records.	http://www.nist.gov/health care/usability/upload/SHA RPC-NIST-June-7-2011- Muh_Walji.pdf
SHARPC	Presentation	Promoting Timely Completion of Multi-Step Processes A Visual Approach to Retrospective Analysis.	Pantazos K, Tarkan S, Plaisant C, Shneiderman B.	Publicly shared information via UMD.	http://www.cs.umd.edu/ localphp/hcil/tech-reports -search.php?number= 2012-09
SHARPC	Presentation	Rights and Responsibilities of Physician Users of EHRs	SHARPC team	VI Jornadas de Sistemas de Información en Salud, Buenos Aires, Argentina	N/A
SHARPC	Presentation	Two talks on SHARP project for 100 participants including a dozen vendors	SHARPC team	Human-Computer Interaction Laboratory Annual Symposium	http://www.cs.umd.edu/ hcil/about/events/sympos ium2011/symposium.shtml
SHARPC	Presentation	Usability Problems and Patient Safety Risks in EHR Design	Franklin A, Simmons D, Graves K, et al.	AMIA 2012 Annual Symposium.	N/A
SHARPC	Presentation	The SHARP Program and the Next Generation of Health Information Technology		AMIA 2013 Annual Symposium.	N/A
SHARPC	Presentation	EHR Certification and Safety Enhanced Design: The need for robust usability testing scenarios	Franklin A, Graves K, Walji M, Zhang J.	AMIA 2013 Annual Symposium.	N/A
SHARPC	Presentation	Fundamentals of EHR Usability	Franklin A, Walji M, Zhang J.	AMIA 2013 Annual Symposium.	N/A
SHARPC	Presentation	The EHR usability symposium: Vendor, user, researcher, and policy perspectives	Zhang J, Graves K, Franklin A, Walji M.	AMIA 2013 Annual Symposium.	N/A
SHARPC	Presentation	An Information-Centric Framework for Designing Patient-Centered Medical Decision Aids and Risk Communication, to appear in Proc. of AMIA 2013	Franklin L, Plaisant C, Shneiderman B.	AMIA 2013 Annual Symposium.	N/A
SHARPC	Presentation	Electronic health record systems: Impact on safety and quality	Franklin A, Graves K, Walji M.	Invited presentation at the 14th Annual Health Services and Outcomes Research Conference, Houston, TX.	N/A
SHARPC	Presentation	EHR usability studies	SHARDC toom	Presentations of EHR usability studies at AMIA 2013 and the Kelsey Research Foundation, Houston TX.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Publication	A Method and Knowledge-base for Automated Inference of Patient Problems from Structured Data in an Electronic Medical Record	Wright A, Pang J, Feblowitz JC, et al.	doi:10.1136/amiajnl-2011-000121	http://www.uthouston.edu/ dotAsset/b4568c22-efa0- 4ded-9dc2- 6e7df3a0fb62.pdf
SHARPC	Publication	A Prototype Knowledge Base and SMART App to Facilitate Organization of Patient Medications by Clinical Problems.	McCoy AB, Wright A, Laxmisan A, Singh H, Sittig DF.	AMIA 2011 Annual Symposium.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/APrototypeKnowledg eBaseandSMARTApptoFa cilitateOrganizationofPatie ntMedicationsbyClinicalPr oblems.pdf
SHARPC	Publication	Application of Electronic Health Records to the 2011 Joint Commission's National Patient Safety Goals.	Radecki RP, Sittig DF.	Journal of the American Medical Association 2011 Jul 6;306(1):92- 3. PMID: 21730246	http://jama.jamanetwork.ht tp://jama.jamanetwork.co m/article.aspx?articleid=1 104039com/article.aspx?a rticleid=1104039
SHARPC	Publication	Clinical Summarization Capabilities of Commercially-available and Internally-developed Electronic Health Records.	Lavmison A McCov AB	Applied Clinical Informatics 2012; 3: 80–93. doi:10.4338/ACI-2011- 11-RA-0066	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/Clinicalsummarizatio nofcommercialEHRsACI2 012.pdf
SHARPC	Publication	Comparative Analysis of the VA/Kaiser and NLM CORE Problem Subsets: An Empirical Study Based on Problem Frequency.	Wright A, Feblowitz J, McCoy AB, Sittig DF.	AMIA 2011 Annual Symposium.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/COREproblemlistsets amia2011.pdf
SHARPC	Publication		Butler KA, Haselkorn M, Bahrami A, & Schroder K.	AMIA 2011 Annual Symposium.	Introducing the MATH method and toolsuite for evidence-based HIT
SHARPC	Publication	Using a Unified Usability Framework to Dramatically Improve the Usability of an EMR Module	Harrington C, Wood R, Breuer J, et al.	AMIA 2011 Annual Symposium.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC32432 70/
SHARPC	Publication	Comparison of Clinical Knowledge Management Capabilities of Commercially-available and Leading Internally-developed Electronic Health Records	Sittig DF, Wright A, Meltzer S, et al.	BMC Medical Informatics & Decision Making. 2011 Feb 17;11(1):13.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/Comparisonofclinical knowledgemanagementca pabilitiesbmc2011.pdf
SHARPC	Publication		Singh H, Classen DC, Sittig DF.	J Patient Saf. 2011 Dec;7(4):169- 174. PMID: 22080284	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/EHR Oversight J P atient Safety 2011.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Publication	Cross-terminology Mapping Challenges: A Demonstration Using Medication Terminological Systems	IRAPPETATION FV/ ("INUTA ("(-)	Journal of Biomedical Informatics, 2012; 45: 613–625.	http://www.ncbi.nlm.nih.go v/pubmed/22750536
SHARPC	Publication	Defining Health Information Technology-related Errors: New Developments Since To Err is Human.	Sittig DF, Singh H.	Archives of Internal Medicine 171(14): 1279-1282; 2011.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/Definition_of_a_com puter_error_vr12.4.pdf
SHARPC	Publication	Providers: Valuable information or just noise?	Murpny DR, Reis B, Kadivala H, et al	Arch Intern Med. 2012 Feb 13;172(3):283-5. PMID: 22332167	http://archinte.jamanetwor k.com/article.aspx?articlei d=1108701
SHARPC	Publication	How the Continuity of Care Document Can Advance Medical Research and Public Health		American Journal of Public Health 2012 Mar 15. PMID: 22420795	http://ajph.aphapublication s.org/doi/abs/10.2105/AJP H.2011.300640
SHARPC	Publication	Development and Evaluation of a Crowdsourcing Methodology for Knowledge-base Construction: Identifying Relationships between Clinical Problems and Medications		J Am Med Inform Assoc. 2012 Sep 1;19(5):713-8. Epub 2012 May 12.	http://www.ncbi.nlm.nih.go v/pubmed/22582202
SHARPC	Publication	Interactive Information Visualization for Exploring and Querying Electronic Health Records: A Systematic Review.		Publicly shared information via UMD	http://www.cs.umd.edu/loc alphp/hcil/tech-reports- search.php?number=2010 -19
SHARPC	Publication	Legal, Ethical, and Financial Dilemmas in Electronic Health Record Adoption and Use.	Sittig DF and Singh H.	Pediatrics 2011; 127:e1042– e1047.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/SittigSinghLegalethic alfinancialdilemmaspediatr ics2011.pdf
SHARPC	Publication			Am J Med. 2012 Feb;125(2):209.e1-7.	www.ncbi.nlm.nih.gov/pub med/22269625
SHARPC	Publication	On the Importance of Using a Multidimensional Sociotechnical Model to Study Health Information Technology		Ann Fam Med. 2011 Sep- Oct;9(5):390-1.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/sociotechnicalmodelf orHITannfammed2011.pdf
SHARPC	Publication	Rights and Responsibilities of Physician Users of Electronic Health Records.	Sittig DF and Singh H.	Canadian Medical Association Journal Feb 13, 2012.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/Physicians_Professio nal_rights-CMAJ_v9- formatted.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Publication	Summarization of Clinical Information: A Conceptual Model	Feblowitz JC, Wright A, Singh H, Samal L, Sittig DF.	J Biomed Inform. 2011 Aug;44(4):688-99.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/FeblowitzSummarizat ionModelJBl2011.pdf
SHARPC	Publication	Technical Evaluation, Testing and Validation of the Usability of Electronic Health Records. (NISTIR 7804)	,,	National Institute of Standards and Technology (2012).	http://www.nist.gov/health care/usability/upload/EUP WERB_Version_2_23_1 2-Final-2.pdf
SHARPC	Publication		D'Amore JD, Sittig DF, Wright A, Iyengar MS, Ness RB.	AMIA Fall 2011 Symposium, 2011:285-94.	https://www.uthouston.edu /nccd/projects/sharpc/proj ect3/PromiseoftheCCDami a2011.pdf
SHARPC	Publication	TURF: Toward a unified framework of EHR Usability	SHARPC team	Published Manuscript in J Biomed Inform 2011; 44: 1056-1067.	http://www.sciencedirect.c om/science/article/pii/S15 32046411001328
SHARPC	Publication	Development of a Clinician Reputation Metric to Identify Appropriate Problem-Medication Pairs in a Crowdsourced Knowledge Base	McCoy AB, Wright A, Rogith D, Fathiamini S, Ottenbacher AJ, Sittig DF.	Journal of biomedical informatics (2013).	http://www.ncbi.nlm.nih.go v/pubmed/24321170
SHARPC	Publication	SYFSA: A framework for Systematic Yet Flexible Systems Analysis.		J Biomed Inform Published Online First: 31 May 2013.	v/pubmed/23727053
SHARPC	Publication	Twinlist: Novel User Interface Designs for Medication Reconciliation	Plaisant C, Chao T, Wu J, et al.	Our paper was presented at AMIA 2013 and received a distinguished paper award.	http://hcil2.cs.umd.edu/trs/ 2013-09/2013-09.pdf
SHARPC	Publication	Integrating a Medical Applications Platform, Research Data Repository, and Patient Summarization	Murphy SN.	Interactive Journal of Medical Research 2013; 2:(1):e11.	<u>http://www.i-</u> jmr.org/2013/1/e11/
SHARPC	Publication	Debunking Health IT Usability Myths		Applied Clinical Informatics. 2013;4:241–250.	http://www.ncbi.nlm.nih.go v/pubmed/23874361
SHARPC	Publication	Comparison of clinical knowledge	McCoy AB, Sittig DF, Wright		http://www.ncbi.nlm.nih.go v/pubmed/23920991
SHARPC	Publication	Matching Identifiers in Electronic Health Records: Implications for Duplicate Records and Patient Safety	McCoy AB, Wright A, Kahn MG, Shapiro J, Bernstam EV, Sittig DF.	BMJ Healthcare Quality & Safety (in press) 2013.	http://www.ncbi.nlm.nih.go v/pubmed/23362505

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Publication	assessment of accuracy across two institutions.		J Am Med Inform Assoc. 2013 Mar 30.	http://www.ncbi.nlm.nih.go v/pubmed/23543111
SHARPC	Publication	Federal Incentives for Electronic Health Record Adoption: Early Results of the HITECH Act	Wright A, Henkin S, Feblowitz J, McCoy AB, Bates DW, Sittig DF.	New England Journal of Medicine (in press) 2013.	http://www.nejm.org/doi/ful l/10.1056/NEJMc1213481
SHARPC	Publication	Validation of an Association Rule Mining-Based Method to Infer Associations Between Medications and Problems	Wright A, McCoy AB, Henkins S, Flaherty M, Sittig DF.	Appl Clin Inform. 2013 Mar 6;4(1):100-9	https://sbmi.uth.edu/nccd/r esearch/pdfs_general/Vali dationofassociationrulemi ningACI2013WrightSittig.p df
SHARPC	Publication	Evidence-based Health IT for Patient-Provider Communication	Butler KA, Haselkorn MP, Braxton M, et al.	ACM CHI, 2013.	http://care.cs.columbia.ed u/chi2013health/CRPaper s/Butler.pdf
SHARPC	Publication	Clinical Decision Support for Colon and Rectal Surgery: An Overview.		Clin Colon Rectal Surg. 2013 Mar;26(1):23-30.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC36991 46/
SHARPC	Publication	State of the art in clinical informatics: evidence and examples	McCoy AB, Wright A, Eysenbach G, et al.	Yearb Med Inform. 2013;8(1):13- 9.	http://www.ncbi.nlm.nih.go v/pubmed/23974543
SHARPC	Publication			Health Serv Res. 2014 Feb;49(1 Pt 2):325-46.	http://onlinelibrary.wiley.co m/doi/10.1111/1475- 6773.12134/abstract
SHARPC	Report	A Human Factors Guide to Enhance EHR Usability of Critical User Interactions when Supporting Pediatric Patient Care	Lowry SZ, Quinn MT, Ramaiah M, et al.	National Institute of Standards and Technology.	http://www.nist.gov/health care/usability/upload/NIST -IR-7865.pdf
SHARPC	Report	Usability testing report, UT Houston	SHARPC team	Conducted RUAs on UT Houston physicians and developed detailed report of time to complete clinical tasks and usability problems in the EHR.	N/A
SHARPC	Report	Usability Testing Report	SHARPC team	Detailed reports of usability problems in the EHR and comparative reports to help providers and others make EHR purchasing decisions.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Report		Chao T, Plaisant C, Shneiderman B.	Publicly shared information via UMD.	http://www.cs.umd.edu/loc alphp/hcil/tech-reports- search.php?number=2012 -03
SHARPC	Report	Review of Safety Enhanced Design	SHARPC team	The team reported none of the products certified by CCHIT provide the CIF summative reports, a portion of Drummond products that include the summative testing materials and results, and the three reports provided by Infogard all include these documents.	N/A
SHARPC	Resource		Osheroff JA, Teich JM, Levick D, et al.		http://marketplace.himss. org/OnlineStore/Product Detail.aspx?ProductId=3318
SHARPC	Resource	Detailed Implementer's Description of Twinlist	Chao T, Plaisant C, Shneiderman B.	Publicly shared information via UMD	http://www.cs.umd.edu/hci I/sharp/twinlist/dev/
SHARPC	Resource	TURF Framework for EHR Usability		Developed accessible guidelines for using the TURF tool to assess EHR usability	https://sbmi.uth.edu/nccd/ ehrusability/evaluation/turf /
SHARPC	Resource	MAPLE Knowledge Base	SHARPC team	Used to infer problems from medications, laboratory results, billing data, procedures and vital signs.	http://jamia.bmj.com/conte nt/18/6/859/suppl/DC1
SHARPC	Resource	Problem Medication Link Knowledge Base	SHARPC team	An ontology-based knowledge base containing nearly 34 million distinct problem-medication pairs	http://jamia.bmj.com/conte nt/18/6/859.long
SHARPC	Resource	Lab tracking visualization and interface	SHARPC team	results to identify missed labs.	N/A
SHARPC	Resource	Medication entry	Killoran P.	Auto-suggesting medication entry interface.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Resource	MultiList Medication Reconciliation Visualization	SHARPC team	Includes an algorithm to help automate reconciliation and a user interface for visualizing medications and reconciling two lists in a visually and cognitively intuitive way. Identifies correspondences between: (1) drugs with the same name; (2) drugs that differ only by brand vs. generic name; and (3) drugs that may be functionally equivalent.	<u>https://wiki.cs.umd.edu/cm sc734_11/index.php?title= TwinList</u>
SHARPC	Resource	MATH Toolsuite	SHARPC team	Tool supports capture of as-is workflows and how to improve them using HIT functions	http://www.uthouston.edu/ nccd/pre-amia- symposium/butler.pdf
SHARPC	Resource	Rapid Usability Assessment Protocol	SHARPC team	Created a method to quickly and effectively identify usability problems in an EHR and provide objective comparisons across EHR systems	https://sbmi.uth.edu/nccd/ ehrusability/evaluation/rua /index.htm
SHARPC	Resource	TURF software tool	SHARPC team	Tool helps semi-automate rapid usability testing process and reduces times to complete assignments.	https://turf.shis.uth.tmc.ed u/turfweb/
SHARPC	Resource	TURF Version 2.0	SHARPC team	Supports user testing, heuristic evaluation and incorporates an analytics modules that allows users to conduct statistical analyses and generate reports.	https://turf.shis.uth.tmc.ed u/turfweb/DownloadView. aspx
SHARPC	Resource	TURF Version 2.01	SHARPC team	Supports user testing, heuristic evaluation and incorporates an analytics modules that allows users to conduct statistical analyses and generate reports.	https://turf.shis.uth.tmc.ed u/turfweb/DownloadView. aspx
SHARPC	Resource	TURF Website	SHARPC team	Includes information about the product, link to download the software, and 29 tutorials describing how to use Turf.	https://turf.shis.uth.tmc.ed u/turfweb/
SHARPC	Resource	New EHR Usability Content	SHARPC team	Updated website with new content relating to EHR usability.	https://sbmi.uth.edu/nccd/ ehrusability/
SHARPC	Resource	Twinlist /dev	SHARPC team	Code and live demos of the user interface of Twinlist.	http://www.cs.umd.edu/hci l/sharp/twinlist/dev/

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Resource	6 Safety Enhanced Design Briefs	SHARPC team	One page documents containing practical advice that EHR vendors can use to improve EHRs for meaningful use.	https://sbmi.uth.edu/nccd/ SED/Briefs/
SHARPC	Resource	A working prototype of one chapter on medication lists is now available through the NCCD website	Johnson T and Plaisant C.	Participated in a two day design workshop at the University of Missouri in November, 2013 to plan and prototype four additional chapters: medication alerts, medication reconciliation, ePrescribing, and allergy lists. User interface mockups and chapters are now underway.	https://sbmi.uth.edu/nccd/ SED/ebook/
SHARPC	Resource	Detailed usability guidelines with specific examples for EHRs	SHARPC team	Detailed usability guidelines with specific examples for EHRs.	<u>https://sbmi.uth.edu/nccd/</u> ehrusability/
SHARPC	Resource		Franklin L, Rahman K M, Plaisant C, Shneiderman B.	A user study was completed comparing the text-only design with the new step-by-step animated design.	http://www.cs.umd.edu/hci I/treatmentexplorer
SHARPC	Testimony	EHR Usability Hearing	Zhang J.	Jiajie Zhang provided testimony at the ONC Certification Adoption Workgroup focused on EHR Usability.	http://healthit.hhs.gov/port al/server.pt/gateway/PTA RGS 0 12811 954429 0 0 18/zhang-testimony- 04-21-11.pdf
SHARPC	Video	AMIA Twinlist	SHARPC team	AMIA Twinlist presentation video.	http://www.youtube.com/watch?v=YoSxIKI0pCo).
SHARPC	Video	MATH Evidence Based Health IT	SHARPC team	YouTube.	http://www.youtube.com/w atch?v=JdvrgljWgA4
SHARPC	Video	Medication Reconciliation demonstration	SHARPC team	YouTube.	http://www.youtube.com/w atch?v=4VyIsPS9r4U
SHARPC	Video	Twinlist Demonstration	SHARPC team	YouTube.	http://www.youtube.com/w atch?v=YXkg9hQppOw
SHARPC	Video	Prototype (demos, videos) available online	SHARPC team	Prototype (demos, videos) available online.	http://www.cs.umd.edu/hci l/treatmentexplorer/
SHARPC	Workshop	National Usability Summit	SHARPC team	SHARPC hosted a national usability summit prior to AMIA 2011.	http://www.uthouston.edu/ nccd/pre-amia- symposium/presentations. htm
SHARPC	Workshop	Clinical Decision Support: A Practical Guide to Developing Your Program to Improve Outcomes	SHARPC team	AMIA 2011 Annual Symposium.	http://www.medinfo2013.d k/node/69

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPC	Workshop	AMIA 10X10 Course on Usability	Zhang J.	The AMIA 10x10 Course on Healthcare Interface Design was successfully completed with 12 students.	http://www.amia.org/educa tion/academic-and- training-programs/10x10- university-texas
SHARPC	Workshop	Fundamental of EHR Usability	SHARPC team	AMIA 2012 Annual Symposium.	http://ehr.bz/ehrbz- archive/amia2012/Funda mentals-EHR- Usability.html
SHARPC	Workshop	Workshop on EHR informatics	SHARPC team	1-day workshop that brought together participants from academic, government and industry to discuss EHR informatics. Eliz Markowitz presented the Systematic Yet Flexible Interfaces framework.	<u>http://www.cs.umd.edu/hci</u> I/sharp/workshop2011/
SHARPC	Workshop	AMIA 10x10 Course	SHARPC team	13 trainees across the country took and completed the course.	http://www.amia.org/educa tion/academic-and- training-programs/10x10- university-texas
SMART	Application	Genomics Advisor	SMART team	Supports integration of consumer- based genomics info and allows clinicians to easily access information across a variety of EHRs/PHRs.	<u>http://smartplatforms.org/s</u> <u>mart-app-gallery/</u> genomics-advisor/
SMART	Application	Meducation	SMART team	Takes typical medication instructions and makes them understandable to patients.	http://smartplatforms.org/s mart-app-gallery/ meducation/
SMART	Application	Patient-Centric View	SMART team	Enables a clinician to call up—in one click—a user-defined suite of SMART apps.	http://smartplatforms.org/s mart-app-gallery/patient- centric-view/
SMART	Application	Pediatric Growth Chart	SMART team	Brings together design and medical specialists to craft a "return to the future" software for support both pediatric needs and parent-communication capabilities.	<u>http://smartplatforms.org/s</u> mart-app-gallery/pediatric- growth-chart/
SMART	Application	Reynolds Risk Score Reporting	SMART team	Used to estimate the 10-year cardiovascular risk of an individual.	http://smartplatforms.org/s mart-app-gallery/cardiac- risk/

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SMART	Application	SMART app for BP centiles	SMART team	First clinical deployment of a SMART app for blood pressure centiles within Cerner system at Boston Children's Hospital.	http://smartplatforms.org/s mart-app-gallery/bp- centiles/
SMART	Application	SMART Diabetes Monograph App 1.0	SMART team	Diabetes monograph module for tracking diabetes care over time, demonstrates the mechanical usability and cognitive efficiency that monographs can provide for disease diagnosis and disease management.	http://smartplatforms.org/s mart-app-gallery/diabetes- monograph/
SMART	Application	SMART Direct	SMART team	A Direct-enrolled clinician can email to any Direct-enrolled recipient not just the patient information but secure access to one or more sender-designated SMART apps.	http://smartplatforms.org/s <u>mart-app-</u> gallery/smartdirect/
SMART	Application	SMART i2b2 release	SMART team	SMART apps available in i2b2.	https://community.i2b2.org /wiki/display/SMArt/SMAR T+i2b2
SMART	Application	SMART Indivo release	SMART team	A strategic realignment of the Indivo personallycontrolled health record API and data model to better map to SMART.	<u>http://indivohealth.org/sma rt-indivo/</u>
SMART	Application	SMART Mirth prototype	SMART team	Enabling SMART apps to run on a cloud-hosted HIE.	http://www.mirthcorp.com/ community/wiki/display/M R/SMART+Container
SMART	Application	SMART Platforms App Store	SMART team	App store for SMART apps available.	http://smartplatforms.org/s mart-app-gallery/
SMART	Application	SMART WorldVistA prototype	SMART team	Open source module that allows SMART apps to run on WorldVistA EHR.	http://vistapedia.com/inde x.php/SMART_Enabling
SMART	Application	SMART v1.0 API and Reference EMR staged for release	SMART Team	Includes a new set of API functionality to support access to Clinical Imaging Data.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SMART	Application	Blue Button REST API Registry Server	SMART team	Completed a Reference Implementation of the major Blue Button REST API components: Registry, Authorization Server, and Clinical API Server; loaded 600 synthetic C-CDAs from the EMERGE project into a public reference server.	<u>http://blue-</u> <u>button.github.io/blue-</u> <u>button-plus-pull/</u>
SMART	Application	SMART-on-FHIR API server	SMART team	Released the world's first open- source FHIR API server; Ported three SMART Apps to run against the FHIR data models and API; extended Blue Button REST API Authorization scheme to work with FHIR server.	<u>plan-for-achieving-</u> <u>healthcare-it-</u> <u>interoperability/</u>
SMART	Application	SMART C-CDA Samples and C- CDA Scorecard	SMART team	Conducted numerous updates and fixes to SMART C-CDA Samples and C-CDA Scorecard.	<u>http://ccda-</u> <u>scorecard.smartplatforms.</u> org/static/ccdaScorecard/# /
SMART	Application	SMART Image Studies Viewer App	SMART team	Developed SMART Image Studies Viewer App to view DICOM images within an image study.	N/A
SMART	Application	SMART Documents List App	SMART team	Developed a SMART Documents List App to display list of documents available for a patient.	N/A
SMART	Application	Services ETL Cell	SMART team	Modularized i2b2 cell that accepts the importing of CCDA documents and transforms data to be presented in SMART apps in i2b2.	N/A
SMART	Blog	SMART Platforms blog	SMART team	Blog with relevant updates on SMART platforms activity.	http://smartplatforms.org/c ategory/news-etc/blog/
SMART	Challenge	SMART App Developer Challenge	SMART team	Developer contest for SMART apps for health, 15 apps submitted, Meducation app winner.	http://challenge.gov/HHS/ 134-smart-apps-for-health
SMART	Poster	Integrating SMART in the i2b2 Platform	SMART team	2012 AMIA Symposium November 2012.	http://smartplatforms.org/2 012/11/smart-on-the- agenda-at-amia-2012/
SMART	Poster	Integrating the CCDA for Real-time Patient Data in the 12b2 Platform	SMART team	AMIA Annual Symposium November 2013.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SMART	Poster	Using SMART and i2b2 to Efficiently Identify Adverse Events	SMART team	November 2013.	N/A
SMART	Presentation	ITdotHealth II Conference	SMART team	ITdotHealth II Conference hosted with presentations by team members; video, slides, executive summary and photos available publicly.	http://smartplatforms.org/ meetings/itdothealth-ii- 2012/
SMART	Presentation	SMART platform and OpenEHR presentation	Tweed R.	SMART platform and OpenEHR presented at HANDI–the Healthcare App Network for Development and Innovation meeting to explore further use in UK and globally.	http://www.handihealth.or g/handi-smart-platform- and-openehr-meeting- 11th-july
SMART	Presentation	SMART presentation	SMART team	MA, March 6, 2012.	N/A
SMART	Presentation	Supporting Multisite Clinical Trials with Software and Policy in i2b2	SMART team	AMIA Summit on Clinical Research Informatics (CRI). San Francisco, CA. 2012 March.	N/A
SMART	Presentation	The SMART EMR View in the i2b2 Platform	SMART team	AMIA Summit on Clinical Research Informatics (CRI). San Francisco, CA. 2012 March.	N/A
SMART	Presentation	Open Source Best Practice and Business Models	Mandl K, Park T, Perakslis E, Shah S, Halamka J.	OSEHRA's 1st Annual Open Source EHR Summit and Workshop.	N/A
SMART	Presentation	The Medical App Store, Research Data Repositories, and Physician Cognitive Overload: Uniting Three Large, Multisite Grants for Health Care Transformation	Klann J, Wright A, McCoy A, Murphy S.	2012 AMIA Symposium.	N/A
SMART	Presentation	Apps to display patient data, making SMART available in the i2b2 platform	SMART team	2012 AMIA Symposium.	http://knowledge.amia.org/ amia-55142-a2012a-1.636547/ t-003-1.640625?gr=1
SMART	Presentation	Apps to display patient data, making SMART available in the i2b2 platform	Wattanasin N.	2012 AMIA Symposium.	http://knowledge.amia.org/ amia-55142-a2012a-1.636547/ t-003-1.640625?gr=1
SMART	Presentation	Building the SMART Platforms Ecosystem: Toward an Apps- Based Health Information Economy	Mandl K, Athey B, Fritsch D, Murphy S, Ross W.	2012 AMIA Symposium.	http://knowledge.amia.org/ amia-55142-a2012a-1.636547/ t-003-1.640625?qr=1
SMART	Presentation	Integrating Substitutable Medical Apps, Reusable Technologies (SMART) in the i2b2 Platform	SMART team	2012 AMIA Symposium.	http://knowledge.amia.org/ amia-55142-a2012a-1.636547/ t-003-1.640625?qr=1

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SMART	Presentation	Supporting Population Queries and Clinical Trials in i2b2 with SMART	Murphy S.	2012 AMIA Symposium.	http://knowledge.amia.org/ amia-55142 -a2012a-1.6365 47/t-003-1.64 0625?qr=1
SMART	Presentation	Decoupling Cognitive and Transactional User Experiences in EMRs: Two Approaches To Advance Clinical Cognitive Support	Kreda D.	2012 Symposium on Human Factors and Ergonomics in Healthcare.	http://www.hfes.org/web/hfes meetings/hcspresentations/ kredappt.pdf
SMART	Presentation	Guiding the Design of Evaluations of Innovations in Health Informatics: a Framework and a Case Study of the SMArt SHARP Evaluation	Ramly E.	2012 AMIA Symposium.	http://knowledge.amia.org/ amia-55142-a2012a-1.6365 47/t-003-1.64-0625?qr=1
SMART	Presentation	Interoperability: Why is it Taking so Darn Long?	Kupermanl G, Solomon H, Koppel R, Jaffe C, Mandel J, Fridsma DB.	2012 AMIA Symposium.	N/A
SMART	Presentation	Medical App Stores, Physician Cognitive Overload, and Research Data Repositories: an Integration	Klann J, Wright A, Mccoy A, Sittig D, Murphy S.	Medicine 2.0 Conference 2012.	http://www.medicine20con gress.com/ocs/index.php/ med/med2012/paper/view/ 975
SMART	Presentation	SMART i2b2 "Patient-centered View" and App Bundle presentation	Murphy S.	2nd Annual i2b2 Users Group Conference.	https://www.i2b2.org/work/ aug.html
SMART	Presentation		Mandl KM, Mandel JC, Murphy SN, et al.	Medicine 2.0 Conference 2012.	http://www.medicine20con gress.com/ocs/index.php/ med/med2012/paper/view/ 977
SMART	Presentation	SMART i2b2 presentation	SMART team	CTSA Informatics Directors Meeting, Boston, MA.	N/A
SMART	Presentation	SMART presentation	SMART team	Presented SMART at HIMSS Collaborative Health Consortium panel in Las Vegas, NV.	N/A
SMART	Presentation	SMART presentation	SMART team	Presented SMART at Institute for Health Technology Transformation Summit.	N/A
SMART	Presentation	SMART presentation	SMART team	Presented SMART at in-person meeting of AppsWorks Interoperability Platform Task Force.	N/A
SMART	Presentation	Indivo X Users Webinar	Mandl KM, Haas D, Kohane I, Franckle T, Kirby C, Halloran Z.	Indivo X Users Webinar.	http://indivohealth.org/indi vo-users-webinar/agenda

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SMART	Presentation	RDF as a Universal Healthcare Exchange Language	Mandel JC.	Semantic Tech Business 2013 panel session June 2013.	http://semtechbizsf2013.s emanticweb.com/sessionP op.cfm?confid=70&propos alid=5226
SMART	Presentation	Developer Tutorial for the Blue Button Community	SMART team	BB Developer Forums in San Francisco and NYC July 2013.	N/A
SMART	Presentation	SMART Monograph App	SMART team	Presented to VA, Salt Lake City August 2013.	N/A
SMART	Presentation	SMART C-CDA/SMART-on-FHIR	SMART team	2013	N/A
SMART	Presentation	Blue Button REST API	SMART team	Internet Identify Workshop 16 and 17 (May; October 2013).	N/A
SMART	Presentation	SMART API	Mandl KD and Mandel JC.	Health Foo (Friends of O'Reilly) Conference (December 2013).	N/A
SMART	Presentation	Patient-Centered Care, Collaboration, Communication and Coordination policy panel	SMART team	AMIA Policy Panel December 2013.	N/A
SMART	Publication	The Shared Health Research Information Network (SHRINE): a prototype federated query tool for clinical data repositories	Weber GM, Murphy SN, McMurry AJ, et al.	J Am Med Inform Assoc 2009;624-30.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC27447 12/?tool=pubmed
SMART	Publication	Sharing Medical Data for Health Research: The Early Personal Health Record Experience.	Weitzman ER, Kaci L, Mandl K.	J Med Internet Res 2010;e14.	http://www.jmir.org/2010/2 /e14/HTML
SMART	Publication	Serving the Enterprise and Beyond with Informatics for Integrating Biology and the Bedside (i2b2)	Murphy SN, Weber G, Mendis M, et al.	J Am Med Inform Assoc 2010;17:124-30.	http://jamia.bmj.com/conte nt/17/2/124.abstract
SMART	Publication	Surveillance of Medication Use: Early Identification of Poor Adherence	Jonikas MA and Mandl KD.	Journal of the American Medical Informatics Association, 2011. In press.	http://www.ncbi.nlm.nih.go v/pubmed/22101969
SMART	Publication	Applications for Electronic Health Records	Mandl KD, Mandel JC, Murphy SN, et al.	J Am Med Inform Assoc. 2012 Mar 17.	http://www.ncbi.nlm.nih.go v/pubmed/22427539
SMART	Publication	Escaping the EHR Trap — The Future of Health IT	Kohane I and Mandl K.	N Engl J Med 2012 Jun 14;366(24):2240-2.	http://www.nejm.org/doi/pd f/10.1056/NEJMp1203102
SMART	Publication	The SMART Platform: early experience enabling substitutable	Mandl KD, Mandel JC, Murphy SN, et al.	J Am Med Inform Assoc. 2012 Jul-Aug;19(4):597-603.	http://jamia.bmj.com/conte nt/early/2012/03/16/amiajn I-2011- 000622.full.pdf+html

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SMART	Publication	Health Care Transformation Through Collaboration on Open- Source Informatics Projects: Integrating a Medical Applications Platform, Research Data Repository, and Patient Summarization	Klann JG, McCoy AB, Wright A, Wattanasin N, Sittig DF, Murphy SN.	Interact J Med Res. 2013 2(1):e11.	<u>http://www.i-jmr.org/article/ viewFile/ijmr_v2i1e11/2</u>
SMART	Publication	SMART C-CDA Collaborative: Perspectives and Debriefing	SMART C-CDA Collaborative	Findings from the SMART C-CDA Collaborative to study and improve real-world implementations of C-CDA December 2013.	https://smartplatforms.org/ wp-content/uploads/ SMART_C-CDA_ Perspectives and Debrief ing_Dec2013.pdf
SMART	Publication	Secondary Use of Health Information: Are we Asking the Right Question?	Kohane I.	Invited Commentary; JAMA Intern Med 2013; 173(19):1806-1807.	http://archinte.jamanetwor k.com/article.aspx?articlei d=1729530
SMART	Publication	Scalable Decision Support at the Point of Care: A Substitutable Electronic Health Record App for Monitoring Medication Adherence	Bosl W, Mandel J, Jonikas M, et al.	Interact J Med Res. 2013 2(2):e13.	http://www.i- jmr.org/article/viewFile/ijmr _v2i2e13/2
SMART	Publication	Computing Health Quality Measures Using Informatics for Integrating Biology and the Bedside	Klann JG and Murphy SN.	J Med Internet Res 2013; 15(4):e75.	https://smartplatforms.org/ wp- content/uploads/jmir_v15i 4e75.pdf
SMART	Resource	Set of most used terms for SMART- enabled container release	SMART team	Developed and released a set of about 2,000 "most frequent" problems, medications, and laboratory tests for a SMART enabled container that can map to the top 85 percentile of most used terms as observed in the Research Data Patient Registry, a centralized clinical data warehouse at Partners Healthcare.	N/A
SMART	Resource	Developer documentation	SMART team	tutorials, references, using the SMART data, update guides, reference EMR installations, demos, code downloads	<u>http://dev.smartplatforms.o</u> rg/
SMART	Resource	SMART enterprise prototype		First milestone build of SMART, a set of modular software tools for SMART-enabling enterprise clinical data systems	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SMART	Resource	SMART module for OpenMRS	SMART team	Adds features necessary to make an OpenMRS instance become a SMART App container	https://modules.openmrs.o rg/modules/view.jsp?modu le=smartcontainer
SMART	Resource	i2b2 source code for SMART	SMART team	Released the EMR like view plugin, a SMART frame app featuring a customizable dashboard of multiple SMART apps running simultaneously in an EMR-like view arrangement in i2b2.	https://community.i2b2.org /wiki/display/SMArt/Source +Code
SMART	Resource	SMART API and Reference Release		API and reference release v.4 available.	N/A
SMART	Resource	Growth-tastic Developer Tutorial	SMART team	In-depth developer tutorial for BlueButton+ Specs (Direct and REST).	N/A
SMART	Video	SMART Platforms Screencast	SMART team	Video overview of SMART platforms project.	http://vimeo.com/2118212 3
SMART	Video	Story of What's to Come in Health IT	SMART team	Video on SMART-enabled Indivo X.	http://vimeo.com/4368059 9
SMART	Video	How Can Every Clinical Visit Be Used to Advance Medical Science?	Kohane I.	TEDMED 2013.	http://youtu.be/P5O66e8r2 QM
SHARPn	Abstract		Li DC, Shrestha G, Murthy S, et al.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Abstract	Using Electronic Health Records to Identify Patient Cohorts for Drug- Induced Thrombocytopenia Neutropenia and Liver Injury	Dathak I. Al Kali A	AMIA 2012 Annual Symposium.	N/A
SHARPn	Abstract	Discovering body site and severity modifiers in clinical texts.	Dligach D, Bethard S, Becker L, Miller T, Savova G.	AMIA Annu Symp Proc. 2013 (podium abstract)	N/A
SHARPn	Abstract	Medication Extraction and Normalization from Clinical Notes	Sohn S, Clark C, Halgrim SR, et al.	AMIA Annu Symp Proc. 2013 (podium abstract)	N/A
SHARPn	Abstract	Comprehensive Medication Extraction and Normalization for Medication Reconciliation	Sohn S, Halgrim SR, Murphy	Mayo Clinic Individualizing Medicine Conference, 2013.	N/A
SHARPn	Portal	Phenotyping portal		Phenotyping portal.	http://phenotypeportal.org/
SHARPn	Poster	A Formal Representation of Phenotyping Algorithm Elements	Jiang G, Pathak J, Tao C, Solbrig H, Chute C.	AMIA 2011 Annual Symposium.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Poster	and Patients	Arratoon M, Bain L, Kush R, Aerts J.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Poster	The Linked Clinical Data Project: Applying Semantic Web Technologies for Phenomics using Electronic Medical Records	Oathak J, Kiefer R, Chute C.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Poster	Mining Genotype-Phenotype Associations from Electronic Health Records and Biorepositories using Semantic Web Technologies	Pathak J, Kiefer RC, Freimuth RR, Bielinski SJ, Chute CG.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Poster	Visualization and Reporting of Results for Electronic Health Records Driven Phenotyping using the Open-Source popHealth Platform	Shrestha G, Murthy S, Li DC, Hart LA, Chute CG, Pathak J.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Presentation	The MiPACQ Clinical Question Answering System	SHARPn Mayo team	AMIA Fall 2011 Symposium Proceedings.	http://www.ncbi.nlm.nih.go v/pubmed/22195068
SHARPn	Presentation	The SHARPn Project on Secondary Use of Electronic Medical Record Data: Progress, Plans and Possibilities	Chute CG, Pathak J, Savova		http://www.ncbi.nlm.nih.go v/pmc/articles/PMC32432 96/
SHARPn	Presentation	Using RxNorm and NDF-RT to Classify Medication Data Extracted from Electronic Health Records: Experiences from the Rochester Epidemiology Project	Pathak J, Murphy S, Wilaert B, et al.	AMIA 2011 Annual Symposium.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC32432 05/
SHARPn	Presentation	Practical modeling issues: Representing coded and structured patient data in EHR systems	Huff S.	AMIA 2011 Annual Symposium.	http://informatics.mayo.ed u/sharp/images/3/32/Com plex Issues in Modeling AMIA Fall Meeting 2011. pdf
SHARPn	Presentation	ADEpedia: A Scalable and Standardized Knowledge Base of Adverse Drug Events Using Semantic Web Technology	Jiang G, Solbrig H, Chute C.	AMIA 2011 Annual Symposium.	http://www.ncbi.nlm.nih.go v/pubmed/22195116
SHARPn	Presentation		Hurdle J, Savova G, Kohn M, et al.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Presentation	An OWL Meta-Ontology for Representing the Clinical Element Model	Tao C, Parker CG, Oniki TA, Pathak J, Huff S, Chute C.	AMIA 2011 Annual Symposium.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Presentation	Analyzing Heterogeneity and Complexity of Electronic Health Record Oriented Phenotyping Algorithms	Conway MA, Berg RL, Carrell D, et al.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Presentation	Analyzing the Prevalence of Hedges in Electronic Health Record Oriented Phenotyping Algorithms.	Conway MA, Pathak J.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Presentation	Clinical Classifications and Biomedical Ontologies: Terminology Evolution, Principles, and Practicalities	Chute C, Cimino J, Musen M.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Presentation	Embracing Healthcare IT Standards in the World of Meaningful Use	Jaffe C, Kush R, Baker D, et al.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Presentation	Practical Modeling Issues Representing Coded and Structured Patient Data in EHR Systems	Huff S.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Presentation	The SHARPn Project on Secondary Use of Electronic Medical Record Data: Progress, Plans, and Possibilities.	Chute C, Pathak J, Savova G, et al.	AMIA 2011 Annual Symposium.	N/A
SHARPn	Presentation	Shared Annotated Resources for the Clinical Domain	Savova G, Chapman W, Elhadad N, Palmer M.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Presentation	A Study of Transportability of an Existing Smoking Status Detection Module across Institutions	Liu M, Shah A, Jiang M, Peterson N, et al.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Presentation	An Evaluation of the NQF Quality Data Model for Representing Electronic Health Record Driven Phenotyping Algorithms.	Thompson WK, Rasmussen LV, Pacheco JA, et al.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Presentation	Executing Electronic Health Records Driven Phenotyping Algorithms using the NQF Quality Data Model and JBOSS Drools Engine.	Li D, Shrestha G, Murthy S, Sottara D, et al.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Presentation	Mining the Human Phenome using Semantic Web Technologies: A case study for type 2 diabetes.	Pathak J, Kiefer RC, Bielinski SJ, Chute C.	AMIA 2012 Annual Symposium.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Presentation	Modeling and Executing Electronic Health Records Driven Phenotyping Algorithms using the NQF Quality Data Model and JBOSS Drools Engine.	Li D, Shrestha G, Murthy S, et al.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Presentation	Towards a Semantic Lexicon for Clinical Natural Language Processing	Liu H, Wu ST, Li D, et al.	AMIA 2012 Annual Symposium.	N/A
SHARPn	Presentation	CouchDB as an Option to Store SHARPn Data	Kaggal V.	Paper discusses storing SHARPn data using CouchDB	Norm CouchDB 9OCT20 12.pdf
SHARPn	Presentation	eMERGE Data Dictionary Harmonization and Best Practices for Standardized Phenotype Data Representation	Pathak J.	eMERGE Data Dictionary Harmonization and Best Practices for Standardized Phenotype Data Representation	http://informatics.mayo.ed u/sharp/images/8/85/EME RGE-Data-Submission- Subgroup-Apr2010- Ver4.pdf
SHARPn	Presentation	Applying Linked Data Principles to Represent Patient's Electronic Health Records at Mayo Clinic: A Case Report	SHARPn team	AMIA Clinical Research Informatics Symposium 2012.	N/A
SHARPn	Presentation	IBM/Mayo Clinic Visit – Review of UIMA Pipeline	Pathak J, Li D, Shrestha G.	IBM staff visited SHARPn team at Mayo.	N/A
SHARPn	Presentation	Implementing Electronic Measures (eMeasures) for Hospitals webinar	SHARPn team	Implementing Electronic Measures (eMeasures) for Hospitals webinar	N/A
SHARPn	Presentation	Integrating VA's NDF-RT Drug Terminology with PharmGKB: Preliminary Results	SHARPn team	Symposium on Biocomputing 2012.	N/A
SHARPn	Presentation	Model-Driven Health Tools Demonstration	Westberg L.	Demonstration of how Model- Driven Health Tools (MDHT) could potentially be used by the SHARP and BEACON projects for working with CCD type document payloads for data sharing and data normalization.	N/A
SHARPn	Presentation	Using Semantic Web Technologies for Cohort Identification from Electronic Health Records to Conduct Genomic Studies	SHARPn team	ACM International Health Informatics Symposium 2012.	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Presentation	NLP workshop at the i2b2 Academic User Group Meeting	Clark C and Savova G.	Presented at the NLP workshop at the i2b2 Academic User Group Meeting.	
SHARPn	Presentation	ReID Software Overview Webinar	Goldstein I and Burford K.	ReID Software Overview Webinar Details: file formats, surrogate approach taken for all PHI Types, invocation of application and support utilities.	
SHARPn	Presentation	Security Roundtable for Cloud- Deployed Clinical Natural Language	SHARPn team	Roundtable of experts in information security, stakeholders from health care and research institutions, and leading cloud service providers to identify prerequisites for secure, regulatory-compliant processing of patient clinical information in externally-hosted computing environments.	N/A
SHARPn	Presentation	UMLS Concepts and Terms in Clinical Notes: Large-scale Corpus Analysis; NCBO Webinar	Wu S.	Showcase of new technologies, projects and ideas in biomedical ontology.	N/A
SHARPn	Presentation	An Information Extraction Framework for Cohort Identification Using Electronic Health Records.	Liu H, Bielinski SJ, Sohn S, et al.	AMIA CRI 2013.	N/A
SHARPn	Presentation	ADEpedia 2.0: Integration of Normalized Adverse Drug Events (ADEs) Knowledge from the UMLS.	Jiang G, Liu H, Solbrig HR, Chute CG.	AMIA CRI 2013.	N/A
SHARPn	Presentation	High-Throughput Phenotyping from Electronic Health Records for Clinical and Translational Research	Pathak J.	Mayo Clinic, August 2013.	http://informatics.mayo.ed u/sharp/images/8/84/SHA RP_HTP_AUG2013.pdf
SHARPn	Presentation	Data Quality	Rea S and Bailey K.	Mayo Clinic, August 2013.	http://informatics.mayo.ed u/sharp/images/c/c5/SHA RPn_Data_Quality_AUG2 013.pdf
SHARPn	Presentation	SHARP NLP	Masanz J, Liu H, Savova G.	Mayo Clinic, August 2013.	http://informatics.mayo.ed u/sharp/images/7/7f/SHAR Pn_NLP_AUG2013.pdf
SHARPn	Presentation	UIMA / DUCC Update	Schor M.	Mayo Clinic, August 2013.	http://informatics.mayo.ed u/sharp/images/d/d3/UIMA DUCC 2013 Update.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Presentation	Data Quality SHARPn	SHARPn team	November 18, 2013,Washington Hilton Featured Presentation - The SHARP Program and the Next Generation of Health Information Technology	http://informatics.mayo.ed u/sharp/images/c/c6/SHA RPn-AMIA-DQ_2013.pptx
SHARPn	Presentation	High-Throughput Phenotyping		November 18, 2013,Washington Hilton Featured Presentation - The SHARP Program and the Next Generation of Health Information Technology	http://informatics.mayo.ed u/sharp/images/b/b6/SHA RPn-AMIA- HTP_2013.pptx
SHARPn	Presentation	Natural Language Processing		November 18, 2013,Washington Hilton Featured Presentation - The SHARP Program and the Next Generation of Health Information Technology	http://informatics.mayo.ed u/sharp/images/6/6c/SHA RPn_AMIA_2013_NLP.pp tx
SHARPn	Presentation	Data Normalization	SHARPn team	November 18, 2013,Washington Hilton Featured Presentation - The SHARP Program and the Next Generation of Health Information Technology	http://informatics.mayo.ed u/sharp/images/0/08/SHA RPn-AMIA-DN_2013.pptx
SHARPn	Presentation	SHARPn_2013_Overview	SHARPn team	November 18, 2013,Washington Hilton Featured Presentation - The SHARP Program and the Next Generation of Health Information Technology	http://informatics.mayo.ed u/sharp/images/5/5f/SHAR Pn AMIA 2013 SHARP panel.pptx
SHARPn	Presentation	Data Normalization	Liu H.	Mayo Clinic, August 2014.	http://informatics.mayo.ed u/sharp/images/a/a7/ONC SHARPnVisit_DN.pdf
SHARPn	Publication	A Hybrid Approach to Sentiment Sentence Classification in Suicide Notes	Sohn S, Torii M, Li D, Wagholikar K, Wu S, Liu H.	Biomedical Informatics Insights. 2012(5 Suppl 1):43-50.	http://www.ncbi.nlm.nih.go v/pubmed/22879759
SHARPn	Publication	Applying Linked Data principles to represent patient's electronic health records at Mayo Clinic: A case report. I	Pathak J, Kiefer RC, Chute CG.	IHI'12 - Proceedings of the 2nd ACM SIGHIT International Health Informatics Symposium. 2012:455-64.	http://informatics.mayo.ed u/LCD/images/5/5d/Patha k-IHI-2012-Poster- V3_UPDATED.ppt
SHARPn	Publication			J Biomed Inform. 2012 Feb 04. [Epub ahead of print] PMID:22326800. DOI:10.1016/j.jbi.2012.01.009.	http://intermountainhealthc are.org/qualityandresearc h/informatics/Documents/s harpn%20project%202012 .pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Publication	Clinical Decision Support with Automated Text Processing for Cervical Cancer Screening	Wagholikar KB, Maclaughlin KL, Henry MR, et al.	J Am Med Inform Assoc. 2012 Apr 29. [Epub ahead of print] PMID:22542812. DOI:10.1136/amiajnI-2012- 000820.	<u>http://jamia.bmj.com/conte</u> nt/19/5/833.abstract
SHARPn	Publication	Conference Analysis in Clinical Notes: A Multi-pass Sieve with Alternate Anaphora Resolution Modules.		J Am Med Inform Assoc. 2012 Jun 16. [Epub ahead of print] PMID:22707745. DOI:10.1136/amiajnI-2011- 000766.	http://www.ncbi.nlm.nih.go v/pubmed/22707745
SHARPn	Publication	Dependency Parser-based Negation Detection in Clinical Narratives	Sohn S, Wu ST, Chute CG.	AMIA Summit on Clinical Research Informatics (CRI). San Francisco, CA. 2012 March	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC33920 64/
SHARPn	Publication	Evaluator's Workbench	SHARPn data normalization team	Published alpha version of Evaluators Workbench	N/A
SHARPn	Publication	Feasibility of Pooling Annotated Corpora for Clinical Concept Extraction	Wagholikar K, Torii M, Jonnalagadda S, Liu H.	AMIA Summit on Clinical Research Informatics (CRI). San Francisco, CA. 2012 March	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC33920 69/
SHARPn	Publication	Integrating VA's NDF-RT drug terminology with PharmGKB: preliminary results	Pathak J, Weiss LC, Durski MJ, Zhu Q, Freimuth RR, Chute CG.	Pacific Symposium on Biocomputing 2012; 400-9.	http://www.ncbi.nlm.nih.go v/pubmed/22174295
SHARPn	Publication	Semantator: Annotating Clinical Narratives with Semantic Web Ontologies	Song D, Chute CG, Tao C.	AMIA Clinical Research Informatics. Mar 2012.	http://www.ncbi.nlm.nih.go v/pubmed/22779043
SHARPn	Publication	The Linked Clinical Data project: Applying Semantic Web Technologies for Clinical and Translational Research Using Electronic Medical Records	Pathak J, Kiefer RC, Chute CG.	ACM International Conference Proceeding Series. 2012; 94-5.	http://informatics.mayo.ed u/LCD/images/5/58/SWAT 4LS-2011-Pathak- Final.pdf
SHARPn	Publication	Towards Event Sequence Representation, Reasoning and Visualization for EHR data.	Tao C, Wongsuphasawat K, Clark K, Plaisant C, Shneiderman B, Chute CG.	IHI'12 - Proceedings of the 2nd ACM SIGHIT International Health Informatics Symposium. 2012:801-5.	http://hcil2.cs.umd.edu/trs/ 2012-07/2012-07.pdf
SHARPn	Publication	Unified Medical Language System Term Occurrences in Clinical Notes: A Large-scale Corpus SHARPn Progress Report –2012 17	Wu ST, Liu H, Li D, et al.	J Am Med Inform Assoc. 2012 Jun 1; 19(e1):e149-56.	http://www.researchgate.n et/profile/Mark_Musen/pu blication/223974426_Unifi ed_Medical_Language_S ystem_term_occurrences in_clinical_notes_a_large- scale_corpus_analysis/file /9fcfd5082f6e2e58d4.pdf

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Publication	Using Semantic Web Technologies for Cohort Identification from Electronic Health Records to Conduct Genomic Studies.	Pathak J, Kiefer RC, Chute CG.	AMIA Summits Transl Sci Proc. 2012; 2012:10-9.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC33920 57/
SHARPn	Publication	Using Semantic Web Technology to Support ICD-11 Textual Definitions Authoring	Jiang G, Solbrig HR, Chute CG.	ACM International Conference Proceeding Series. 2012; 38-44.	http://www.jbiomedsem.co m/content/4/1/11
SHARPn	Publication	Using SNOMED CT to encode summary level data - a corpus analysis.	Liu H, Wagholikar K, Wu S.	AMIA Summit on Clinical Research Informatics (CRI). San Francisco, CA. 2012 March.	http://www.ncbi.nlm.nih.go v/pubmed/22779045
SHARPn	Publication	Towards syntactic and semantic annotations of the clinical narrative.	Albright D, Lanfranchi A, Fredriksen A, et al.	Journal of the American Medical Informatics Association. 2013.	http://www.ncbi.nlm.nih.go v/pubmed/23355458
SHARPn	Publication	Pooling annotated corpora for clinical concept extraction.	Wagholikar K, Torii M, Jonnalagadda S, Liu H.	Journal of Biomedical Semantics. 2013; forthcoming.	http://www.jbiomedsem.co m/content/4/1/3
SHARPn	Publication	Detecting concept mentions in biomedical text using Hidden Markov Model: Multiple concept types at once or one at a time.	Torii M, Wagholikar K, Liu H.	Journal of Biomedical Semantics. 2013.	http://www.jbiomedsem.co m/content/5/1/3
SHARPn	Publication		Pathak J, Bailey K, Beebe C, et al.	J Am Med Inform Assoc doi:10.1136/amiajnl-2013- 001939.	http://jamia.bmj.com/conte nt/early/2013/11/04/amiajn I-2013-001939.abstract
SHARPn	Publication	A common type system for clinical Natural Language Processing.	Wu ST, Kaggal VC, Dligach D, et al.	Journal of Biomedical Semantics. 2013.	http://www.jbiomedsem.co m/content/4/1/1
SHARPn	Publication	Evaluating the Use of Empirically Constructed Lexical Resources for Named Entity Recognition.	Jonnalagadda S, Cohen T, Wu S, Liu H, Gonzalez G.	Will appear in Computational Semantics in Clinical Text. 2013.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC37021 95/
SHARPn	Publication	Systematic Analysis of Cross- Institutional Medication Description Patterns in Clinical Notes.	Sohn S, Murphy SP, Jonnalagadda S, et al.	Will appear in Computational Semantics in Clinical Text. 2013.	http://www.ncbi.nlm.nih.go v/pmc/articles/PMC37021 97/
SHARPn	Publication		Dligach D, Bethard S, Becker L, Miller T, Savova G.	Journal of the American Medical Informatics Association. 2013a.	http://jamia.bmj.com/conte nt/early/2013/10/03/amiajn I-2013-001766.full
SHARPn	Publication	ShARe/CLEF eHealth Challenge 2013, Task 2: Normalizing acronyms and abbreviations to aid patient understanding of clinical texts.	Mowery D, South B, Christensen L, et al.	Submitted to Journal of the Medical Informatics Association. (under review)	http://www.clef- initiative.eu/documents/71 612/599e4736-2667-4f59- 9ccb-ab5178cae3c5
SHARPn	Publication	Evaluating the state of the art in disorder recognition and normalization of the clinical narrative.	Pradhan S, Elhadad N, South B, et al.	Submitted to Journal of the Medical Informatics Association. (under review)	N/A

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Publication	Normalization and standardization of electronic health records for high-throughput phenotyping: the SHARPn consortium.		Journal of the American Medical Informatics Association (JAMIA).	http://jamia.bmj.com/conte nt/20/e2.toc
SHARPn	Publication	Task 1: ShARe/CLEF eHealth Evaluation Lab 2013.		Proceedings of the ShARE/CLEF Evaluation Lab 2013.	http://www.nicta.com.au/p ub?doc=7264&filename=n icta publication 7264.pdf
SHARPn	Publication	Task 2: ShARe/CLEF eHealth Evaluation lab 2013.		Proceedings of the ShARE/CLEF Evaluation Lab 2013.	http://www.nicta.com.au/p ub?id=7265
SHARPn	Publication	Overview of the ShARe/CLEF eHealth Evaluation Lab 2013.	Suominen H, Salantera S, Velupillai S, et al.	Proceedings of the ShARE/CLEF Evaluation Lab 2013.	http://link.springer.com/ch apter/10.1007%2F978-3- 642-40802-1 24
SHARPn	Publication	Building a Knowledge Base of Severe Adverse Drug Events Based on AERS Reporting Data using Semantic Web Technologies	Jiang G, Wang L, Liu H, Solbrig H, Chute CG.	MedInfo 2013.	http://www.ncbi.nlm.nih.go v/pubmed/23920604
SHARPn	Publication	Phenotyping on EHR Data Using OWL and Semantic Web Technologies	Tao C, Li D, Shen F, Lian Z, Pathak J, Liu H, Chute CG.	Smart Health 2013, 31-32.	http://link.springer.com/ch apter/10.1007%2F978-3- 642-39844-5 5
SHARPn	Publication	Clinical Element Models in the SHARPn Corsortium	Oniki T, Zhuo N, Beebe CE, Liu H, et al.	(Under Review) JAMIA 2014.	N/A
SHARPn	Publication	Using Semantic Web Technologies for Phenotyping algorithm Representation and Automatic Execution on EHR data	Tao C, Cheng F, Liu H, Li D, Pathak J, Chute C,	(Under Review) JAMIA 2014.	N/A
SHARPn	Publication	MedXN: an Open Source Medication Extraction and Normalization Tool for Clinical Text	Sohn S, Clark C, Halgrim S, Murphy S, Chute CG, Liu H.	(In Revision) JAMIA 2014.	N/A
SHARPn	Recommendations	Lessons Learned	SHARPn team	Draft document summarizing lessons and recommendations from the cloud security roundtable.	N/A
SHARPn	Resource	Phenotyping code repository	SHARPn phenotyping team	Code repository for phenotyping portal.	https://sourceforge.net/p/s harpn/htp/
SHARPn	Resource	Phenotype Library and Workbench	SHARPn phenotyping team	Online, real-time phenotype execution.	http://phenotypeportal.org
SHARPn	Resource	End-to-end data normalization pipeline	SHARPn phenotyping team	Versions of the data normalization pipeline.	http://informatics.mayo.ed u/sharp/index.php/Data_N ormalization Pipeline 1.0
SHARPn	Resource	Mirth channels	SHARPn data normalization team	Set up the channels for use of MIRTH, an open source data exchange platform.	http://www.mirthcorp.com/ community/mirth- exchange

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Resource	CTS2	SHARPn data normalization team	List of common clinical terminologies used with SHARPN software.	http://informatics.mayo.ed u/sharp/index.php/Termin ologies#Common_Termin ology_Services
SHARPn	Resource	SHARPN NLP Common Type System	SHARPn natural language processing team	Defining common NLP types used in SHARPn	http://informatics.mayo.ed u/sharp/images/0/0a/SHA RPCTS 0.1.jar)
SHARPn	Resource	CEM 'Core Models'	SHARPn data normalization team	Core models developed and available for public consumption	http://informatics.mayo.ed u/sharp/index.php/CEMS
SHARPn	Resource	Clinical Element Models	SHARPn data normalization team	Clinical models and terminology for demographics, labs, drugs, and disorders, and these are made available on the CEM request website	https://intermountainhealth care.org/CEMrequests
SHARPn	Resource	SHARPN cloud resource	SHARPn team	Cloud resource lab for SHARPN tools	http://informatics.mayo.ed u/cirruswiki/index.php/Clo ud Resource Lab
SHARPn	Resource	Clinical Element Model (CEM) Search Tool	SHARPn data normalization team	Search tool for Clinical Element Model	Clinical Element Model (CEM) Search Tool
SHARPn	Resource	cTAKES software GUI		Graphical User Interface (GUI) for cTAKES to facilitate deployment by non-developers and non- NLPers	(https://ohnlp.svn.sourcefo rge.net/svnroot/ohnlp/bran ches/cTAKES-GUI-0.0.1/ ctakes-gui-0.0.1.zip)
SHARPn	Resource	De-identification tool	SHARPn team	MIT/SUNY de-identification tool as part of the SHARPn library	N/A
SHARPn	Resource	NLP evaluation workbench	SHARPn natural language processing team	Allows NLP investigators and developers to compare and evaluate various NLP algorithms.	http://orbit.nlm.nih.gov/res ource/clinical-nlp- evaluation-workbench
SHARPn	Resource	QDM to DROOL Translator	SHARPn phenotyping team	Coding language translator for phenotyping.	http://sourceforge.net/p/sh arpn/htp/code/85/tree/trun k/Qdm2DroolsTranslator/s rc/dist/doc/
SHARPn	Resource	Data Norm - CEM 'Core Models'	SHARPn team	Program output for CEM Core Models.	http://informatics.mayo.ed u/sharp/index.php/CEMS
SHARPn	Resource	Sample XDR Channel – to push data via NwHIN Gateway	SHARPn team	MIRTH Channels.	http://informatics.mayo.ed u/sharp/index.php/NwHIN
SHARPn	Resource	ReceiveXDRMessage – to receive data via NwHIN Gateway	SHARPn team	MIRTH Channels.	http://informatics.mayo.ed u/sharp/index.php/NwHIN
SHARPn	Resource	CemAdminDxtoDatabase – Store Billing Codes to CEM Database	SHARPn team	MIRTH Channels.	http://informatics.mayo.ed u/sharp/index.php/NwHIN
SHARPn	Resource	CemLabToDatabase – Store Labs Results to CEM Database	SHARPn team	MIRTH Channels.	http://informatics.mayo.ed u/sharp/index.php/NwHIN

Project ¹	Type of artifact	Title	Contributors (or team)	Description and/or venue	Website (if applicable)
SHARPn	Resource	CemMedicationToDatabase – Store Meds to CEM Database	SHARPn team	MIRTH Channels.	http://informatics.mayo.ed u/sharp/index.php/NwHIN
SHARPn	Resource	NLP - multiple cTAKES updated releases	SHARPn team	NLP - multiple cTAKES updated releases.	http://sourceforge.net/proj ects/ohnlp/files/icTAKES/
SHARPn	Resource	Phenotype library and workbench release	SHARPn team	Phenotype library and workbench release.	http://phenotypeportal.org
SHARPn	Resource	Infrastructure	SHARPn team	QDM to DROOLS infrastructure.	https://svn.code.sf.net/p/s harpn/htp/code
SHARPn	Resource	Open Source Clinical NLP – More than Any Single System	Masanz J, Pakhomov SV, Hua X, Wu ST, Chute C, Liu H.	Upcoming AMIA CRI 2014.	N/A
SHARPn	Resource	PhenotypePortal	SHARPn phenotyping team	Provides a robust infrastructure for standards-based representation and execution of cohort identification algorithms.	http://phenotypeportal.org
SHARPn	Software	cTAKES software	SHARPN natural language	Clinical Text Analysis and Knowledge Extraction System- an open source natural language processing tool; V2.6 includes updates from prior versions	http://sourceforge.net/proj ects/ohnlp/files/icTAKES/
SHARPn	Software	cTAKES software Apache project	SHARPn natural language processing team	Migration of cTAKES to the Apache Software foundation as an Incubator project to facilitate national and international adoption and contributions	<u>http://incubator.apache.or</u> g/ctakes/
SHARPn	Software	UIMA type system	SHARPn natural language processing team	UIMA Type system for NLP (enhanced cTAKES Type System).	<u>http://uima.apache.org/do</u> <u>c-uima-annotator.html</u>
SHARPn	Video	Drools as Phenotyping Tool		Guide for using Drools for phenotyping.	http://www.youtube.com/w atch?v=jMVIoLhveR0&fea ture=email%7C
SHARPn	Video	Practical Modeling Issues Video Presentation	Huff S.	Video identifies practical issues using clinical element models.	http://informatics.mayo.ed u/recordings/CEMpresent ation8232010/index.htm
SHARPn	Workshop	Computational Semantics in Clinical Text (CSCT) workshop	Sohn S.	Potsdam, Germany, accepted (journal eligible). 2013.	N/A
SHARPn	Workshop	Apache cTAKES		Keynote at 3rd UIMA@GSCL Workshop 2013.	http://gscl2013.ukp.inform atik.tu-darmstadt.de/de /conference/workshops/

Appendix D. Count by Output Type

Output Type	SHARPS	SHARPc	SMART	SHARPn	Total (By output type)
Abstract	1	2	0	5	8
Application	0	0	20	0	20
Blog	0	1	1	0	2
Challenge	0	0	1	0	1
Patent	2	0	0	0	2
Portal	0	0	0	1	1
Poster	3	4	3	5	15
Presentation	43	38	30	44	155
Publication	84	37	12	35	168
Recommendations	2	0	0	1	3
Report	20	5	0	0	25
Resource	5	20	7	25	57
Software	6	0	0	3	9
Testimony	1	1	0	0	2
Video	2	5	3	2	12
Workshop	3	6	0	2	11
Total (By awardee)	172	119	77	123	491

Appendix E. Site Visit Summary for SHARPS

This site visit was conducted in January 2012. The summary was submitted to ONC in March 2012.

Executive Summary: Key Takeaways

Overview. The SHARPS team reports substantial progress towards the goal of enabling new policy and security schemes, protocols, practices and policies applicable to a range of health information technology (health IT) applications, institutional domains and uses cases. Since the inception of the project, they have identified four "clusters" of activities related to their work. In each cluster, SHARPS investigators have made substantial contributions to the literature and general understanding of privacy and security among health care providers, vendors, and privacy and security researchers. Ultimately, their work will lead to new technical and policy designs ensuring privacy and security of health care data as use of mobile health (mHealth) applications, electronic health records (EHRs) and implantable medical devices expands, and as health information exchange (HIE) becomes more prevalent.

Accomplishments. The SHARPS team's achievements include

- development of network on a chip firewalls (NoCF), plug-n-trust hardware features, which include securing mobile device chips using a firewall, body-area network protocols, and SHIELD-enabled devices that would enhance security for individuals using mHealth applications tethered to their smart-phones or implantable medical devices (IMDs),
- the creation of a library of information on the design of commercial IMDs to assist privacy and security researchers,
- the creation of audit based Experienced-Based Access Management (EBAM) protocols to maximize provider use of access data from EHRs to most efficiently detect breaches,
- the creation of formalized policy and rules engines to identify conflicting policies, and streamline policy development related to privacy and security, and
- the creation of a library of data encryption schemes, Charm, that helps apply state-of-the-art techniques in encryption, ciphertext policy and decryption based on keys or biomarkers to EHR and HIE systems.

Challenges. SHARPS investigators emphasize that their work represents a novel opportunity to apply advanced privacy and security techniques developed from decades of computer science research to "real world" health care data and "real world" health care settings. They have encountered a number of challenges:

- ambiguity, internal contradictions and complexity in understanding of "expected" and appropriate instances of accessing patient level data by different types of provider-based users,
- difficulty gaining access to proprietary designs underlying increasingly prevalent technologies that pose security challenges such as IMDs,
- balancing the need for identifying and finding solutions for future security concerns without creating unwarranted alarm among users, and
- defining immediate value of applications, since many of the outputs are libraries, presentations and publications that will prepare the field for future strategic challenges rather than solve immediate problems.

Addressing Challenges. To address these challenges, the team has creatively forged relationships with a range of different types of stakeholders from free clinics and burgeoning HIE efforts to academic medical centers with a commitment to more assiduous auditing, policy development and security processes. The team has also focused on creating and disseminating policy tools that highlight the inadequacy of existing policy rules and procedures used in provider systems and offer solutions for more rationale policy development.

Conclusions. The SHARPS project continues to advance the field of strategic research in privacy and security, and to create pathways that can lead to pragmatic technical and policy solutions to current and future privacy and security problems. They have established new tools to support research and successfully established relationships with providers to apply, test and refine techniques. They seek increased engagement with the scientific leadership at ONC to maximize use of their outputs.

Introduction

On January 23rd and 24th, 2012, the NORC evaluation team conducted a site visit with the Area 1 SHARP awardee: Security and Health Information, or SHARPS, led by the University of Illinois at Urbana-Champaign. We organized the site visit discussions by the clusters detailed below, and included component leads, team members, and Executive Leadership. Specifically, NORC collected perspectives about the program through the sources included in the chart below.

Meeting	Participants			
Introductory discussion with SHARPS Director	Carl Gunter, PhD			
Discussion with Telemedicine cluster contacts	David Kotz, PhD; Yoshi Kono, PhD; Carl Gunter, PhD; Antonios Michalos, MD, MS			
Discussion with Audit cluster contacts	David Liebovitz, MD; Carl Gunter, PhD; Antonios Michalos, MD, MS			
Discussion with Automated Policy cluster contacts	Mark Frisse, MD, MBA, MSc; Denise Anthony, PhD; William Stead, MD; Carl Gunter, PhD			
Discussion with Encryption and Trusted Base cluster contacts	Avi Rubin, PhD, MSE; Matthew Green, PhD; Jon Mitchell, MS, PhD, MIT Carl Gunter, PhD; Antonios Michalos, MD, MS			
Concluding discussion with Executive Leadership	John Mitchel, MS, PhD, MIT; Avi Rubin, PhD, MSE; Matthew Green, PhD; Carl Gunter, PhD; Antonios Michalos, MD, MS			

Exhibit 1: Summary of Site Visit Discussions

Site visit discussion topics included short-term objectives, progress to date, milestones achieved, challenges and strategies for overcoming challenges and, finally, recommendations concerning the entire SHARPS project and the individual components. In the sections below, we provide a brief overview of the SHARPS project and then summarize findings from each set of site visit discussions. To provide

context to the sections below, NORC supplemented site visit findings with information gathered from the SHARPS narrative, SHARPS 2010 and 2011 progress reports, SHARPS PowerPoint presentations, and SHARPS publications.

Project overview

Director Carl Gunter, PhD, Deputy Director Antonios Michalos, MD, MS, and Project Coordinator Andrea Whitesell, of the University of Illinois at Urbana-Champaign, lead the SHARPS projects. SHARPS involves a multidisciplinary team of academics across 12 universities , including University of Illinois at Urbana Champaign, Carnegie Mellon University, Dartmouth College, Harvard University and Beth Israel Deaconess Medical Center, Johns Hopkins University and Children's Medical and Surgical Center, New York University, Northwestern University and Memorial Hospital, Stanford University, University of California – Berkeley, University of Massachusetts Amherst, University of Washington, and Vanderbilt University. An Executive Committee composed of project leads, the Chief IT Scientist and the Chief Medical Scientist; and a Project Advisory Committee composed of academic and industry experts advise and guide SHARPS projects. The chart below displays this organizational structure.





The project includes privacy and security computer science researchers, MD researchers, social scientists, and high-level information officers in health-care organizations. In addition, industrial partners and consultants support the teams. This organizational structure brings together experts from the computer science, policy, ethics and medical fields in order to create innovative and novel solutions to current and anticipated health IT privacy and security issues.

The SHARPS team originally organized itself around 3 environments and 10 components (as displayed above). During the first year of the project, team members realized they needed to collapse the components into a smaller number of focus areas to ensure effective communication of the impact of their work. Subsequently, they developed four major clusters of activity that encompass the 10 components.

² This organizational chart can be found in the SHARPS Project Narrative

Some clusters focus on a single environment (telemedicine, EHRs, HIE), while others address multiple environments. We describe each cluster below and the diagram that follows illustrates this organization:

3 Major Environments	10 Components			4 Cross-cutting Clusters of
	Self-Protecting EHR (EHR-PROT)			Activity
EHR	Policy Terrain and Implications of HIT (EHR-POL)			
	Privacy-Aware Health Information Systems (EHR-PAHIS)		$ \geq $	Telemedicine
	Personal Health Records (HIE-PHR)			
HIE	Experience-Based Access Management (HIE-EBAM)		Audit	
	Responsive, Secure Health Information Exchange (HIE-RSHIE)			Automated Policy
	Implantable Medical Devices (TEL-IMD)		Encryption and Trusted Base	
TEL	Remote Monitoring for Mobile and Assisted Living (TEL- REMOTE)			
	Tele-immersion (TEL-IMMERSE)			
	Patient Safety Assessment (TEL-SAFETY)			

Exhibit 3: Organization of the SHARPS Project, by environment, component and cluster

<u>Telemedicine</u>. SHARPS work on telemedicine involves the growing use and presence of devices that communicate health data. The devices (including the data stored on the devices), as well as the communication networks and intermediaries, present opportunities for potential and significant security violations. Work revolves around telemedicine, mHealth and implantable medical devices (IMDs), and ranges from the development of secure platforms and protocols for remote patient monitoring to identifying safety risks by examining adverse event reports.

<u>Audit.</u> Audit involves the review of software logs to identify instances where staff access patient information (access events). Auditing enables the identification of violations and analysis of access patterns to safeguard privacy over time. As HIE grows, the opportunity for violations increases. The audit team's goal is to create a system that continuously ensures appropriate access to medical records, and guarantees that the system accurately links queries to the correct patient.

<u>Automated Policy.</u> Formalized privacy policies are necessary for greater automation. The automated policy team uses existing policies and high-level modeling tools to develop a formal representation of Health Insurance Portability and Accountability Act (HIPAA) requirements. The developed methods will be publicly available, and subsequently used to formalize other federal, state and institutional policies.

<u>Encryption and Trusted Base.</u> Activity around encryption and trusted base focuses on securing systems by securing their individual components. The team employs strategic and technical strategies to achieve project milestones. This includes the development of several applications, as well as the initiation of partnerships to launch and test applications in real-world settings.

SHARPS addresses both current privacy and security challenges facing health-care stakeholders (e.g., policy development) as well as longer-term security issues that will likely emerge with the increased use of health IT (e.g., breaches to data transmitted from IMDs). Overall, the emphasis is on longer-term concerns and establishing platforms, approaches and methodologies to using "real-world" data to anticipate, understand and solve potential security problems. Like the other SHARP grantees, SHARPS focuses strategically on creating an environment where researchers contribute to improving health IT and its use over time.

Takeaways from individual discussion sessions

Overall, SHARPS addresses privacy and security barriers to the effective use of health IT, while applying separate approaches, strategies and milestones to the work conducted in each cluster. In the subsections below, we present progress to date, define central concepts, and describe the approaches to dissemination and collaboration by each site visit discussion listed above.

Rationale for Project

Although public officials regularly cite the potential benefits of the widespread use of EHRs, considerable public skepticism of health IT remains. Most stakeholders easily understand practices to secure physical records, for example locking filing cabinets. However, stakeholders do not generally understand how experts secure data in an electronic health record (EHR). Subsequently, it is difficult to establish trust in experts' ability to secure data stored in an EHR. Namely, many distrust the security of online information storage due to increased awareness of the potential for identity theft. In addition, highly publicized reports of security breaches and misuse of data lead to further distrust.

These concerns occur against the backdrop of increasingly complex state and federal rules and laws for protecting privacy and security, and an evolving computing environment with an increasing number of locations, channels and devices to store health data. For instance, physicians' professional and personal use of tablets poses new challenges to protecting patient data consistently and assiduously. Finally, as the use of EHRs and HIE increases, the health-care workforce will have access to an increasing amount of data.

In this environment, strategies relying on a trusted workforce and reactive or ad hoc approaches to access controls and audit will likely fall short. Anticipating current and future privacy and security challenges, all of the SHARPS clusters are pursuing more automated, structured and parsimonious approaches to ensuring the privacy and security of health information.

Cluster 1: Telemedicine

The number of devices communicating health data is expanding along with the increased use of health IT. As more devices record, maintain and transmit more data, opportunities for data breaches expand. SHARPS investigators define 'telemedicine' as "the use of information communications technology to conduct healthcare-related activity at a distance." This includes mHealth applications, wearable and mobile computing devices for remote patient monitoring and wellness applications, and IMDs.

SHARPS describes the security risks associated with telehealth devices by examining the pipeline of (1) discrete data services offered by any given device, such as sensing, processing, aggregating, storing and decision-making; and (2) the applications/devices themselves, such as EHRs, PHRs, online applications, implantable devices, and mHealth devices. Every point at which information flows provides an opportunity for a security failure – either through interception involving a breach where someone inappropriately accesses information during transmission (for example, obtaining confidential information about a patient's medical condition), or interference involving a breach where someone inappropriately alters information during transmission (for example, surreptitiously adjusting the settings on an implanted cardioverter-defibrillator³).

Specific SHARPS projects in the telemedicine cluster. Telemedicine cluster activity involves the work of four SHARPS components, and experts across nine universities:

- TEL-REMOTE led by David Kotz,
- TEL-IMD led by Kevin Fu,
- TEL-IMMERSE led by Ruzena Bajcsy, and
- TEL-SAFETY led by Matt Reynolds.
- The paragraphs below describe these team-specific components.

<u>TEL-REMOTE</u>. The TEL-REMOTE team designs secure platforms and protocols (including the sensors carrying wireless traffic) for remote patient monitoring ultimately to protect data quality and patients'

³ According to the National Heart, Lung and Blood Institute, an implantable cardioverter defibrillator is a small device placed in the chest or abdomen to treat arrhythmias (NIH, 2011).
anonymity. The team's work ranges from protocols to products, and includes both hardware and software solutions to security issues. We describe their most recent work below.

- Anonymity-preserving body-area protocols: The team developed anonymity-preserving body-area network (BAN) protocols, which are part of the team's larger effort to identify technical specifications for a secure mHealth system on mobile devices. BANs are composed of sensors that continuously monitor the patient's physiological activities and actions (Chen & Cao, 2010). Specifically, BANs allow for a single point of aggregation and analysis of data from different devices recording and monitoring physiology in different parts of one person's body, as well as a mechanisms to "take action" based on the data (e.g., call an ambulance, or activate an insulin pump). The protocols ensure secure communication between mobile devices and a BAN, preserving data integrity, individual privacy, and patient anonymity.
- Plug-n-Trust: The team also developed a "Plug-in-Trust" mechanism, which is a hardware solution to secure mHealth data processing on unsecure smartphones. In this case, the solution is a smart card, in micro-SD format, that plugs into a slot on common smartphones. (Paper to appear at MobiSys, June 2012)
- NoC Firewall: The NoC firewall is another smartphone-related hardware solution to secure mHealth data. The team successfully developed a firewall to secure chip cores separately. As a result, it is only necessary to trust the chip (instead of the entire phone) to secure patient medical data.
- Amulet: The team is developing a wearable amulet for a trustworthy mHealth body-area network of sensors. The amulet will coordinate secure exchanges of information, making it simultaneously usable and secure. (Paper appeared at HotMobile, February 2012)

The team plans to continue the work described above, with the use of these protocols in real applications to occur over time. The anonymity protocols are not currently compatible with Bluetooth or other commonly used transmissions standards. They are also very early in development of the plug-in for smart phones. Ultimately, the team hopes to work with a vendor to develop this product. They note significant interest in the NoC Firewall for mobile phones since this will allow users to keep sensitive and non-sensitive/personal data on the same phone. However, this technology will require a hardware change and remains at least five years away from usage in real devices.

<u>TEL-IMD</u>. The TEL-IMD team focuses on the security of IMDs, including IMDs partially and fully implanted in the body. Team members have substantial expertise in this area. Several years prior to SHARPS, three of the team members conducted a security analysis of a cardio-defibrillator; this represented one of the first attempts to analyze security threats in the context of a device currently in

circulation. They identified a number of problematic security breaches applicable to other IMDs that potentially have significant implications for the health of the patient; for example the ability to turn therapies on and off,. The team addresses these types of issues from varying perspectives and across a number of devices, focusing on devices for patients with diabetes and cardiac issues.

Team members developed a SHIELD solution to add security to legacy IMDs without modifying the device itself. The shield system, an auxiliary device carried by the patient, serves as a mediator between external and internal equipment. Specifically, using radio design, the shield jams the IMD's messages, which prevents others from decoding the information while also jamming unauthorized commands (SIGCOMM, 2011). Its design allows for backwards compatibility allowing its use with existing IMDs.

The team is conducting security reviews and analyses of diabetes technologies. The team focuses on automated solutions to security issues, and concentrates their efforts on securing insulin pump system architecture and artificial pancreas systems. Insulin pump systems administer pre-programmed amounts of insulin to patients, while artificial pancreas systems substitute endocrine functionality of a pancreas. While there has been great progress in the development of diabetes-related devices, the increased use of wireless communication embedded within the devices present several new security challenges. The team's goal is to ensure a trustworthy infusion system for diabetes patients (Paul, Kohno and Klonoff, 2008). In addition, to address potential low-tech security vulnerabilities (e.g., an individual simply changing the settings of a device) the team is examining a forensic technique to prevent potential breaches and detect any that occur.

In order to provide more opportunities for research on security breaches using real IMDs, the SHARPS team also launched the Open Medical Device Research Library (OMDRL) to house donations of IMDs; they subsequently loan devices to qualified researchers around the world.

The team plans to continue work on the insulin pump system by issuing a security specification and completing the artificial pancreas security review. They also plan to promote the OMDRL to increase awareness and use. Currently, medical device manufacturers identify security risks on their own with no broad oversight. While addressing this particular potential gap in policy is not a short-term objective of the SHARPS program, they did mention that a team member works on similar issues for the U.S. Food and Drug Administration (FDA) and that other team members have assisted the GAO in understanding the potential scope of applicable issues.

<u>TEL-IMMERSE</u>. The TEL-IMMERSE team's projects address the need to add or improve privacy and security protocols for common telemedicine platforms. In this context, the team works to balance the need

for the provider to obtain necessary medical information, while protecting patient privacy. For example, while a physical therapist needs to watch how a patient moves via video conference, they do not need to know what the patient's house looks like. Consequently, the team works to develop devices that allow a physical therapist to see only a bodily image of the patient against a generic background. The TEL-IMMERSE team also developed a prototype to offer greater information security to patients making use of mHealth devices to monitor physiological metrics and activities using Android applications. After providers inform the patient on the optimal set of information necessary for clinical purposes, the prototype allows the patient to specify what the data they will and will not share with their provider. The team is currently setting up user studies to test these applications.

<u>TEL-SAFETY</u>. The TEL-SAFETY team focuses on identifying security risks by examining FDA adverse event reports related to telemedicine. They reviewed, compiled and analyzed several years of reports. However, they found insufficient information related to security failures to continue their work. Although they flagged a number of applicable cases, they found limited details. Given the dearth of data on adverse events related to security risks for telemedicine applications, the team plans to disseminate findings and terminate work at the end of the first year of funding.

FDA designs its databases to collect information about adverse events caused by traditional problems such as device malfunction or human errors associated with use of the device, rather than adverse events caused by purposeful interference with the device's functioning. The fact that FDA does not make a special effort to identify security breaches as a potential source of adverse events may explain the lack of data obtained by SHARPS. Security attacks tend to be extremely subtle and reports may attribute some events to device malfunction rather than a security attack. Additionally, SHARPS investigators noted that, while cyber-attacks on medical devices may not be too common now, this might change as more individuals use these devices and the devices themselves become more sophisticated and begin transmitting more data.

<u>Balancing security concerns with benefits of telemedicine.</u> Team members discussed the concepts of privacy, security and safety at length. In general, broad concerns regarding safety generally outweigh any focus on specific privacy and security risks – even though these risks may in turn affect safety. Team members emphasized the importance of determining current and future telemedicine privacy and security challenges in order to identify areas in need of policy or technical solutions. Due to the novelty of privacy and security research in the health-care context, researchers are still working to define the specific parameters and requirements concerning privacy and security in health-care.

In some cases, priorities such as efficiency and safety may compete with privacy and security. For instance, to ensure the security of a cardio defibrillator, the provider could install a password known only by that provider thereby preventing anybody else from changing the settings on the device. However, this raises significant safety concerns if, for example, the patient is traveling and requires immediate medical assistance involving knowledge of the defibrillator settings.

Another team member framed privacy and security in the context of risk management (i.e., balancing the probability of risks and their potential harm with benefits). Investigators noted that current evidence clearly suggests that telemedicine's benefits far outweigh any potential risk to privacy and security or privacy (so far, there have only been isolated examples of security breaches), but that expansion of device types and their interrelationships increases risks for attack in the future. Although work in this area is important, team members are constantly trying to minimize unwarranted concerns regarding the uses of telemedicine.

Dissemination and collaboration approach. Team members consistently emphasize the importance of dissemination and collaboration involving users, vendors, patients, manufacturers, government/regulators and researchers. Team members also regularly speak at conferences about the security of medical devices. Members of the TEL-IMD team won the Best Paper Award for their work on the SHIELD system. Team members offer workshops like HealthSec (a large health-care computing security conference) and seek to increase awareness of the OMDRL. Team members consistently collaborate with a number of federal government agencies, including the FDA, GAO, CIA, Homeland Security and NIST. While team members make efforts to collaborate with vendors, they note that vendors are sometimes skeptical of the value of their work and that they provide limited access to proprietary specifications and code underlying the devices themselves – a primary motivation for developing the OMDRL as a research resource. Team members consistently collaborate with vendors on strategies to gain the trust of the public without raising unwarranted concern.

Cluster 2: Audit

SHARPS researchers also focus on auditing data from EHRs as a strategy for identifying and addressing risks to privacy. According to SHARPS team members, audit involves "the review of access events after the fact to discover violations and improve protections over time." Currently, providers rely heavily on the accountability of the health-care workforce and assume that employees are not going to violate patient privacy. Current systems to monitor privacy rely on ad-hoc queries if a breach is suspected or more systematic analysis of access to records for specific groups of at-risk patients (e.g., celebrities). SHARPS researchers in the audit cluster are developing systems that continuously monitor/appropriately limit

access to records, and that accurately match patients to their data. In addition, the team intends to develop new analysis strategies to learn about the nature of risks to privacy over time.

Experience-Based Access Management (EBAM). Today, some health systems ensure privacy by controlling who can access patient data under specific circumstances. Establishing prospective controls on access to patient data poses challenges because it is difficult to fully understand the range of ways in which different types of providers access and disclose data as part of their regular work versus other, less-routine pathways. To help address this question, SHARPS team members have developed a continuous process improvement framework entitled Experience Based Access Management (EBAM).

The framework attempts to reflect an ideal access model incorporating actual experience and develop "techniques, and tools to reconcile differences between the ideal access model and the enforced access control (Gunter, Liebovitz and Bradley 2011)." The framework would allow providers to establish the best access policies based on a continuously updated understanding of what types of access they "expect" as consistent with care delivery. The framework would allow frequent identification and analysis of instances of data access that they consider outside the expected range, and allow a provider to adjust enforced controls over data based on this analysis.

Establishing a crisp definition of varying "roles" played by different staff that access patient data represents an important problem for modeling expected access. Using access logs from actual provider organizations, such as Vanderbilt University Medical Center, the team conducts analysis to predict the "role" of an individual based on access patterns and develop a "role-up" algorithm. In role prediction, they examine access logs, stripping out any existing data on the roles and attempt to predict the role based on access behavior. In developing a "role-up" algorithm, they attempt to extend the prediction model by incorporating the nuances of existing roles.

For example, the "role-up" algorithm might suggest that the rules governing access to specific types of information in an EHR should be the same for two different types of users (e.g., nurse practitioners and registered nurses) based on the overlap of expected and unexpected uses by the two types of providers. In making predictions that offer guidance for policy development, the "role-up" algorithm balances between the need to distinguish between two roles, to ensure that rules do not allow a significant number of breaches to go un-detected and to combine similar roles to ensure rules do not deny access to information a user legitimately needs.

Team members have also begun development of a toolkit to for the application of EBAM, entitled Extensible Medical Open Audit Toolkit (EMOAT). EMOAT will include a basic demonstration of multiinstitutional analysis. Specifically, it will provide tools, applications, code and guidance to providers seeking to improve the structure, automation, cost-effectiveness and logic of their approaches to auditing EHR data.

<u>Formalizing policy.</u> SHARPS investigators are creating programming code representing federal, state and institutional policies to facilitate reliable detection of violations. To achieve this, they are developing algorithms to translate laws into computer-readable assessments that will either automatically flag violations for providers or identify access events that require manual review (i.e., the "residual," as described by SHARPS investigators) to ultimately derive and implement a semi-automated approach. To this end, investigators developed two complementary approaches: the HIPAA Reduce Algorithm (which focuses on identifying HIPAA violations based on use and access) and the Manual Audit Optimization approach (which focuses on disclosure violations).

The HIPAA Reduce Algorithm uses data from actual providers to analyze as much of the policy as possible, and produces an output of residual policy or policy violations that cannot be identified automatically. Policies appropriate for automatic auditing versus those that require manual auditing vary depending on the nature of the provider's data. Providers can then understand their "policy residual" in the context of the characteristics of their data. EHRs may not encompass multiple sub-systems in use. In this case, systems integration may offer a remedy. Investigators emphasized that however robust the providers' information systems, the HIPAA Reduce Algorithm will likely identify a residual that requires adjudication by an "expensive human" since, for example, a computer does not intuitively know if the patient is unconscious.

The Manual Audit Optimization learns from experience to examine budget allocation issues in each audit cycle. It estimates losses and updates probabilities for actions in order to determine optimization points. This algorithm uses game theory to collect information from manual reviews and determine whether the process of selecting events for manual review is cost-effective. It is possible to use the manual and HIPAA algorithms together as a hybrid approach by running the HIPAA algorithm and then performing the manual process on the residual.

Team members discussed comments submitted by SHARPS team members in December 2011 on the implications of the Office of Civil Rights (OCR) Notice of Proposed Rulemaking (NPRM), which modifies the HIPAA Privacy Rule's Accounting of Disclosure requirements for protected health information. The NPRM requires provider reporting of how EHR systems are accessed and potential breaches. The new rule intends to give patients more information about the use of their EHR data in

addition to only information on inappropriate disclosure. However, this is highly contested among providers/provider organizations that believe the additional reporting requirements would place tremendous and unnecessary costs on health care providers, and patient privacy groups who would like to see more data for patients. It ultimately intends to decrease the occurrence of breaches by incentivizing providers/providers organizations to examine access reporting before releasing records.

<u>Using context to build better privacy policy and practices</u>. Team members are assessing how details regarding the characteristics of the EHR user, clinical workflow and EHR content types can contribute to setting effective boundaries around legitimate access to records. For example, depending on the workflow in a particular environment access to data may likely be inadvertent or purposeful. Furthermore, information, such as proximity of the user's home address to the patient's home address, may help detect a breach. In addition, events may be more or less problematic depending on the details of the clinical narrative included in the record; subsequently, the SHARPS team is using natural language processing (NLP) to help automate a different approach to audit or policy when records with specific characteristics (e.g., diagnosis of a mental health disorder or STD) are accessed.

In the short-term, understanding some aspects of context will help create algorithms that are relevant to transitions in care and access to data in multiple institutions. The team plans to test their algorithms using data from Vanderbilt and Northwestern to other settings, such as Johns Hopkins and the University of Wisconsin. Throughout 2012, they intend to understand patterns across organizations by comparing outputs, and applying them to other medical centers.

Cluster 3: Automated policy

A formal and transferrable foundation for privacy policies is needed for greater automation and, ultimately, to help facilitate exchange of health information across provider organizations (HIE).

Formalizing institutional policies and use cases. The SHARPS team developed an Automated Policy Framework, which has two components one focused on use cases and another on policies. Use cases define workflow requirements. Work in this area allows two different organizations to formalize how they use an EHR to accomplish specific tasks, e.g., discharging a patient and documenting staff that access the EHR, including the data they need to enter, and the specific steps involved in completing the task. The other side of the framework is policies. Policies constrain use and workflow to intended purposes. Federal, state and institutional policies are applicable to the framework. Using information gathered from RTI's Health Information Security and Privacy Collaboration (HISPC) project, participants sought to identify issues representing policies in a formalized manner. Specific issues include policies that trump others and policies that conflict with one another. The team then applies privacy rules and policies to a series of use cases to ensure they work consistently in different scenarios and provide guidance for efforts to amend or re-calibrate policies to encourage desired behavior.

<u>Standard definitions as an important element of good policy</u>. After examining formalized policies in three states (New Hampshire, California and Tennessee), team members determined that the definitions within a policy are essential for formalization. For example, if a minor's parents in Louisiana die in a car crash, there is no legal way to obtain that minor's health records before a guardian is established. In this case, it is important to know and perhaps re-visit the definition of a minor and the scenarios in which other rules would take precedence so that it does not restrict data access in ways that are more likely to harm rather than protect the individual. While there has been some convergence of policies at the state level (due to initiatives such as HISPC), it is clear that policy varies by state, institution, HIO and institution, and that there is significant disagreement over prioritization of different policies.

Use of formal use cases in modeling exercises that employ a formal definition of privacy policies can illustrate outcomes resulting from strict adherence to policy and identify situations where the outcome is inconsistent with desired objectives. Using a Microsoft policy-modeling tool incorporating critical reasoning called Formula, the SHARPS team is able to validate that policies applied in a particular way achieve desired outcomes.

<u>Understanding and adjudicating contradictions.</u> Team members described significant insights from this work. They determined that policy modeling is possible and that it will make significant contributions to the health IT community. As HIE grows, complexity in terms of applying privacy rules shifts to the institutions. For example, Vanderbilt University Medical Center (VUMC) has 38 different policies that affect workflow and access. At the same time, a relatively small number of use cases account for the majority of information requests.

They have found that formally depicting and communicating authentication and authorization protocols, as well as role definitions and ontologies used at each institution is important to ensure consistent and logical application of privacy rules across institutions. They also note the importance of documenting when and how patients provide consent for release of different elements of their clinical record. The reasoning process enabled by the Formula software can identify gaps, inconsistencies and overlaps across multiple policies. The long-term aim is to simplify and avoid unnecessary complexity by streamlining policies. Finally, validation or system verification is essential. There is a large amount of resources invested in interfaces, while standards are constantly changing.

Ultimately, team members plan to model 12 of the 38 VUMC policies that dominate access requests and workload. In the short term, they plan to complete modeling of five states (to date, they have completed three). The team has also planned a public demonstration environment, which will be more complex and provide a richer view of their work. They plan to expand use cases in a multi-institutional environment.

<u>Understanding actual versus intended roles.</u> One outcome of formally analyzing privacy policies in the context of common use cases is the identification of instances actual roles vary from role definitions intended by the institution. For example, on a previous project, an institution realized that nursing staff routinely wrote prescriptions for patients even though they lacked the authorization to do so. In this scenario, the institution had to rethink how they defined these roles.

To address this issue specifically, the team is attempting to map Northwestern's roles onto recently released standards. They predict that ultimately there are not a large number of roles. They are examining whether role mining from audit logs will result in the top 10 typical roles at hospitals. They could then encourage hospitals to organize roles using these specifications. There is strong value in establishing consistency among groups. Going forward, there is interest in examining what happens as stakeholders introduce new use cases that may conflict with existing policy. The question is whether it is prudent to repair the use case or repair the conflict. Developing standard ways to answer this question is a long-term goal of the project.

<u>Understanding stakeholder perceptions regarding privacy</u>. Part of the team focuses on emerging social understanding of privacy from stakeholder perspectives, especially as they relate to special populations. For example, team members are gathering information on attitudes toward health data among gay men, by focusing on HIV status. They are conducting surveys examining this population. Over the last year, team members have also conducted interviews with hospital staff on perceptions of privacy and health IT. They are focusing on high-risk populations that have specific concerns around the sharing of information. This work is helping them further understand perceptions of privacy issues.

<u>Need for collaboration with health care provider organizations.</u> Part of the unique contribution of the SHARPS program in the areas of automated audit and policy procedures has been their ability to use "real world" EHR data supplied by VUMC and Northwestern. This level of cooperation with health care providers is rare and many providers approach this level of collaboration with some trepidation. In addition to "one-off" assessments using data from health care providers, the privacy field increasingly needs to foster cross-provider collaboration to assess vulnerability in institutional policies that arise from

exchange and greater sharing of data across institutions. Shaping policies that work in multiple institutional settings represents a key challenge.

<u>Collaboration with state and federal efforts involving data sharing.</u> The SHARPS team notes the relevance of their work in the policy area for burgeoning health IT and HIE initiatives centered on state government. The Illinois Office of Information Technology approached the team to build a policy engine that would support the launch of their own HIE capacity and help institutions involved in HIE establish and modify privacy policies. Team members are conducting a gap analysis of presently available and ideal tools to support secure HIE in Illinois.

Team members also met with CMS and Kaiser, but found that privacy and security work sponsored by these organizations does not focus on the most complex problems and longer-term solutions that are the subject of the SHARPS initiative.

<u>Key outputs.</u> Over time, in an attempt to create an accessible tool that providers and policy makers can use in the short and medium term to leverage SHARPS findings, the team plans to release a tool that will provide templates to support policy development. These templates will enable the users to determine contradictions in different sets of applicable privacy rules (i.e., contradictions within a single institution's rules, contradictions between rules of two institutions that share data, and contradictions between institutional rules and state and federal policies). The tool will be also able to determine whether new rules contradict existing policies or interfere with workflow.

Cluster 4: Encryption and Trusted Base

The fourth SHARPS cluster focuses on use of encryption and de-identification tools to create a "trusted base" for ensuring security of health information for a larger system. The team working in this cluster seeks to design encryption and de-identification tools applicable to multiple applications used in a single provider system or a network of health care institutions. The team has achieved several technical and strategic goals over the past six months.

<u>Building the Charm library.</u> On the technical side, while building protocols, algorithms and systems, team members realized they needed to develop a unifying framework ensuring the design of medical record applications reflect security priorities. In practice, this amounts to developing protocols for protecting data through transformation of the data into "nonsense," and then the decryption back into usable data for authorized users that provide specific information (e.g., passwords) that only they can provide.

The team collected a series of approaches or schemes for achieving security of data through cryptography. They formalized these schemes in Python, a customizable language appropriate for depicting and testing schemes. SHARPS investigators plan to release this library of Python-based cryptographic schemes, called Charm, as a tool for security programmers in February 2012. They idea is that cryptographers would have the ability to use Charm as a resource to search and leverage existing approaches to cryptography in designing, building, testing and deploying their own schemes.

Leveraging attribute based encryption and enabling technologies. The schemes incorporated into Charm involve the use of attribute-based encryption (ABE). ABE provides a set of standards for characterizing individuals responsible for encrypting certain types of patient-level data (known as the ciphertext policy) as well as characteristics of users who are assigned keys triggering the decryption of certain types of data for legitimate use (known as the key policy). ABE attributes both of the individuals involved in encrypting and using keys to decrypt data as well as the attributes of the data themselves. For example, in establishing key policies, it is important to understand what constitutes acceptable use of data for different types of users – for example, researchers might get keys that allow for decryption of some data but not all data in an application's database.

To support security in the context of cross-institutional data sharing, the team is also working on cryptographic schemes that allow multiple authorities to set ciphertext policy and distributed ABE (DABE) that would allow different access rules to apply to users that have access to data from multiple institutions' applications. Finally, the team is also working on software components that allow biometrics, such as facial composition or fingerprints to replace passwords as the trigger or key for accessing certain types of data through decryption. These technologies enable more sophisticated cryptographic schemes, and fall into a category known as Fuzzy Identity Based Encryption or Fuzzy IBE. In a related project, the SHARPS team is working with Intel (a member of their Program Advisory Committee) on client-based authentication (CBAT) which uses facial recognition software. The software removes access to information once an authorized individual walks away from a computer where he or she initially gains legitimate access to the information. A prototype of this technology will undergo testing at Johns Hopkins University.

<u>Encryption protocols for compliance with HIPAA.</u> While the approaches catalogued in Charm apply to a range of potential encryption policies, the team has spent considerable effort developing and testing schemes to enforce HIPAA rules. The team's work on HIPAA encryption includes compiling medical records from different providers, deducing encryption policies, and testing whether those policies meet legal standards when applied. The testing approach involves transferring data from a provider

organization to a cloud-based platform, then defining specific queries to extract data from the cloud to create an encrypted database, and finally decrypting specific data elements for an individual user after the user supplies appropriate credentials (e.g., keys). While HIPAA is the largest example of this work, the approach is applicable to other laws. The team is currently in discussions with Vanderbilt to examine their institutional policies.

Application of encryption schemes to de-coupled data elements derived from EHRs. The SHARPS team also participated in the Federal Advisory Committee on PCAST Health IT Report. The report advises the President on health IT and lays out a vision where data elements get decoupled from source medical record systems, stored on a neutral platform and tagged with information related to content, access rights and other meta-data that would allow it to be searchable for a variety of uses including HIE. SHARPS has worked on developing and testing initiatives for cryptographic access controls, auditing, meta tagging, defining security metrics, managing user identities and other functions that would help achieve the PCAST report's vision for HIE. Their contributions led to the HHS NPRM on Metadata Standards to Support National Electronic Health Information Exchange.

<u>Other collaboration with real world providers.</u> The team is also collaborating with Networking Health, a medical student-run free clinic targeting homeless and uninsured persons. Students and volunteers built their own medical record system using MRS (an open source application), but would like to improve its security, and ensure it is capable to handle an increased number of patients since they plan to open another clinic. SHARPS team members helped the students secure a donation for additional equipment, and are currently discussing plans to encrypt their data. The collaboration has a dual purpose – the students get needed security for their medical record system, and SHARPS is able to deploy their ideas in a medical setting.

<u>Additional dissemination and collaboration.</u> The team continues to look for opportunities to work with providers and HIE stakeholders to implement and test schemes available through Charm and other initiatives related to data encryption. Additional collaborations include working on EHR implementation with a specialty group, Pulmonary and Critical Care of Baltimore (PCCAB) and on designing batch signature verification schemes for the Chesapeake Regional Information System for Our Patients (CRISP) which serves as the State Designated Entity for HIE and the Regional Extension Center in Maryland.

Team members are also in the early stages of designing, developing and deploying a knowledge-based authentication technique for patient portals. This project is the result of meetings with practicing medical communities that want to provide patients online access to their medical records, while simultaneously taking advantage of the knowledge that the individual has about their health. Patients know a lot of information about their health; the rationale is that there should be a system/authentication scheme set up to take advantage of that knowledge.

The encryption and trusted base team also consistently participates and presents at conferences. For instance, team members were invited to participate at the Internet Society's Network & Distributed System Security Symposium (NDSS) where they will present on the medical applications of Charm.

Conclusions

The SHARPS project has made substantial progress across the clusters of activity. They routinely disseminate findings through publications, and presentations at conferences. In addition, they publicly test products in development, and release findings to the community. SHARPS investigators emphasize the value of a new community and network to support a body of work that combines the latest computer science privacy and security approaches to the "real world" use cases in health-care delivery.

Over the past several decades, privacy and security experts largely focused their work on the intelligence community, and received funding from the Department of Defense. Their expansion into the health care community, enabled in part through the SHARPS program, represents an important shift for both groups. Team members emphasized the importance of this burgeoning network of researchers for current and future work, and the uniqueness of the SHARP program in facilitating these connections. SHARPS team members are extremely optimistic about the level of collaboration, and subsequently of the medical community's capacity to adopt and incorporate privacy and security-related technologies into their workflows.

While the SHARPS team has enjoyed substantial collaboration with health care providers and entities involved in the electronic exchange of health care data, they continue to experience challenges engaging some vendors. Vendors often view privacy and security enhancements as a cost for that minimizes profits, rather than a feature to differentiate their products. SHARPS researchers have had some success connecting with vendors by providing solutions that can be engineered to reduce costs and minimize adverse impact on use of applications (e.g., by not negatively affecting battery life for example), but this issue remains a challenge.

Overall, the SHARPS teams are creating products, tools and methods that will contribute to significant future advances in health IT. Multiple publications and conference presentations illustrate their impact. In particular, HealthSec has increased attention to the project as it provides an important venue for team

members to highlight achievements. In addition, audit is a prime example of increased awareness and attention to privacy and security field. As one team member stated, that papers on the topic of auditing health information systems usage at HealthSec have increased from one or two in 2010 to over 10 in 2011.

When asked to comment on overall program design and management, SHARPS leadership applauds ONC's vision and commitment in funding a program of strategic research in privacy and security. They also noted a desire for increased engagement with scientific leadership at ONC to explore new applications and catalyze opportunities for both ONC and SHARPS researchers.

References

Chen, Min; Gonzalez, Sergio; Vasilakos, Athanasios; Cao, Huasong and Leung, Victor. Body Area Networks: A Survey. (2011). The Journal of Special Issues on Mobility of Systems, Users, Data and Computing 16: 171-193. Retrieved from: http://mmlab.snu.ac.kr/~mchen/min_paper/Min-0-JNL-2-9-BAN-MONET2010.pdf.

Gunter, Carl, Liebovitz, David, Malin, Bradley. (2011). Experience-Based Access Management A Life-Cycle Framework for Identity and Access Management Systems. IEEE. Retrieved from http://sharps.org/wp-content/uploads/GUNTER-IEEE-SP.pdf.

National Institutes of Health (NIH). (2011, November 9). What Is an Implantable Cardioverter Defibrillator? Retrieved from http://www.nhlbi.nih.gov/health/health-topics/topics/icd/.

Gollakota, Shyamnath, Hassanieh, Haitham, Ransford, Benjamin, Katabi, Dina, and Kevin Fu (SIGCOMM). (2011, August). They Can Hear Your Heartbeats: Non-Invasive Security for Implantable Medical Devices. ACM Special Interest Group on Data Communication. Retrieved from http://sharps.org/wp-content/uploads/FU-ACM-SIGCOMM1.pdf.

Appendix F. Site Visit Summary for SHARPC

This site visit was conducted in August 2011. The summary was submitted to ONC in October 2011.

Executive Summary: Key Takeaways

Overview. The SHARPC works towards two major goals. In the short term, the team works to address the critical usability, workflow and cognitive problems common in health IT systems. In the long term SHARPC's work will eliminate these issues and support provider adoption of health IT and meaningful use of these systems. SHARPC investigators have raised awareness of usability problems with current EHR systems, developed methods and tools to identify usability issues, established guidelines on usability principles and actively engaged with the EHR vendor community, health-care providers and researchers to address these problems. Ultimately, their work will contribute to the field of usability and user-centered design and inform the development of health IT systems that address the needs of both providers and patients.

Accomplishments. Below we highlight major accomplishments of the SHARPC team.

- Developed methods and tools for usability assessment
 - Developed a Rapid Usability Assessment (RUA) tool, designed to identify critical usability issues, and worked with the Gulf Coast Regional Extension Center (GCREC) to test the tool on six commercial EHR products.
 - Developed a framework for EHR usability (TURF "toward a usability framework for EHR usability"), a method for objectively measuring usability, which includes a theoretical model for describing variation in usability. The TURF framework guides system design and helps developers identify principles, guidelines and standards for usability.
 - Developed a tool-based on the TURF framework for conducting semi-automated usability assessments of EHRs.
 - Developed a set of EHR usability guidelines focused on meaningful use. Contributed to the development of the National Institutes for Science and Technology (NIST) EHR usability guidelines.
- Developed evidence-based health IT tools
 - Developed a Modeling and Analysis Toolsuite for Healthcare (MATH). The toolsuite includes workflow modeling, simulation and analytic tools that support rapid design and development of software systems.

- Applied the MATH tool to develop Priority Contact, the first MATH-based product concept which redesigns and optimizes processes for contacting patients about test results and treatment plans. Conducted an alpha study demonstrating a 40% gain in efficiency using the optimized processes developed using the MATH workflow tool.
- Refined cognitive and clinical decision support
 - Completed initial knowledge elicitation from experts on four key conditions: Systemic Inflammatory Response Syndrome (SIRS), renal failure, hypertension, and diabetes.
 - ▶ Completed preliminary analysis of expert knowledge on SIRS and diabetes.
 - Developed a software architecture and framework for providing cognitive support for SIRS and incorporated this into a cognitive support system application.
 - Completed refinement of setting-specific factors (SSF) for diabetes, adopted a data model and a standard terminology (ArdenML), analyzed diabetes rules from Morningside Initiative, analyzed small practice workflow to validate SSF and identification of implementation platform.
- Automated clinical summarization
 - Began developing a clinical knowledge base that could be used by multiple EHR vendors to develop their own clinical summarization systems
 - Completed review of clinical summarization capability of 12 EHR systems
 - > Developed a clinical summarization prototype within the Partners Healthcare EHR
- Cognitive Information Design and Visualization
 - > Developed two semi-automated algorithms for medication reconciliation.
 - > Developed two prototype interfaces for medication reconciliation.
 - > Developed a user interface prototype for tracking labs and studies to prevent lack of follow-up.
- Pan-SHARP
 - ▶ SHARPC staff successfully provided project leadership for Pan-SHARP.
 - ▶ Developed medication management algorithm and user-interface for Pan-SHARP application.
- Other accomplishments
 - ▶ Invitation to join VA Medication Reconciliation Initiative and GE Global Research for MATH.
 - Achieved AHRQ R01 grant and grant from University of Washington for MATH tool suite.
 - Participated in a CDS Meta-consortium led by ONC/AHRQ.
 - Presented to HL7 Arden Syntax working group and authoring tools to work on ArdenML for SSFs.

Challenges. SHARPC represents a new opportunity to improve EHR usability and facilitate systems design that matches provider cognitive workflows and offers effective decision support at the point of care. Investigators note a number of challenges:

- Engaging vendors. Obtaining initial buy-in and entry in the market requires vendor participation.
 However vendors are resistant to focus on usability as it is not a major priority for them in the experience of the SHARPC team.
- Lack of acknowledgement from the vendor community that usability is a science.
- Maintaining partnerships in the process of an evolving and innovative project.
- Compensating for staff turnover in areas requiring highly specialized expertise and adherence to timelines.
- Coordinating with vendor and provider schedules. Vendor product lifecycles are usually 18 months long. These timeframes are a rate-limiting step for the project team, given the pressure to innovate and show translation of the research in the short term.

Addressing Challenges. To address these challenges, the SHARPC team has focused on a small, committed pool of vendors and partners to work with initially. The team has created vendor-usable materials such as toolkits, software, protocols and guidelines which serve as intermediate artifacts providing a more direct impact on usability. The team continued to make significant progress and maintained a coherent pace and core structure despite evolution in the project and staff changes.

Conclusions. The SHARPC project continues to innovate in the field of strategic research in usability and cognitive design, and to create pathways leading to pragmatic technical solutions to current and future problems in the health IT market. They have established new tools and methods to support research and successfully established relationships with vendors to test and improve existing product usability, and develop new usability protocols and guidelines based on scientific research. The team seeks increased engagement with the scientific leadership at ONC to explore opportunities to access real patient sample data and to maximize use of their outputs through vendor participation. Overall, the SHARPC project has achieved significant progress.

Introduction

On August 13th, 2012, the NORC evaluation team conducted a site visit with the Area 2 SHARP awardee team, led by the National Center for Cognitive Decision-Making (NCCD) at the University of Texas at

Houston Health Sciences Center. We organized site visit discussions by the clusters detailed below, and included component leads, team members, and Executive Leadership (See Exhibit 1).

Meeting	Participants
Introductory discussion with Executive Leadership Team	Jajie Zhang, Muhammad Walji, Ricky Ryan, Alainna Talton
Project 1A: Work-Centered Design of Care Process Improvements in HIT: EHR Usability	Jajie Zhang, Muhammad Walji, Amy Franklin, Ricky Ryan, Alainna Talton
Project 1B: Cognitive Support Systems: Customized Tools for Complex Clinical Decision-Making: Workflow	Jajie Zhang, Muhammad Walji, Amy Franklin, Keith Butler, Mark Haselkorn, Paul Nichol, Ricky Ryan, Alainna Talton
Project 2A: Cognitive Support Systems: Customized Tools for Complex Clinical Decision-Making	Jajie Zhang, Trevor Cohen, Muhammad Walji, Ricky Ryan, Alainna Talton
Project 2B: Facilitation of CDS Adoption through Modeling of Setting-Specific Factors	Jajie Zhang, Muhammad Walji, Robert Greenes, Peter Haug, Ricky Ryan, Alainna Talton
Project 3: Automated Model-Based Clinical Summarization of Key Patient Data	Adam Wright, Allison McCoy, Muhammad Walji, Ricky Ryan, Alainna Talton
Project 4: Cognitive Information Design and Visualization: Enhancing Accessibility and Understanding of Patient Data	Jajie Zhang, Muhammad Walji, Catherine Plassant, Todd Johnson, Ricky Ryan, Alainna Talton
Pan-SHARP Activities	Jorge Herskovic, Jajie Zhang, Muhammad Walji, Ricky Ryan, Alainna Talton

Exhibit 1: Summary of SMART Site Visit Discussions

Site visit discussion topics included short-term objectives, progress to date, milestones achieved, challenges and strategies for overcoming them and, finally, recommendations concerning the evaluation of the SHARPC project. In the sections below, we provide a brief overview of the project and then summarize findings from each set of site visit discussions. To provide context to the sections below, NORC supplemented site visit findings with information gathered from the SHARPC narrative, SHARPC 2010 -2012 progress reports, and SHARPC publications.

Project Overview

NCCD at the University of Texas at Houston is leading the SHARPC project in collaboration with partners across the United States. Five research projects, focusing on usability, decision making, clinical decision support, extraction and visualization are attempting to directly and fundamentally address the cognitive challenges in health IT.

The SHARPC team has two major goals for their projects. In the short term, the team aims to address the urgent usability, workflow and cognitive issues of health IT systems and in the long term to conduct

research that eliminates these issues and supports provider adoption of health IT and meaningful use of these systems. *The five research projects are:*

- Work-Centered Design of Care Process Improvements in HIT Generate a set of EHR-specific metrics which foster usability, best practices, system comparisons and guide certification. This project aims to provide tools to increase HIT adoption and cost effectiveness by integrating functions and reducing risks associated with variegated user behavior.
- Cognitive Foundations for Decision Making: Implications for Decision Support Form a new
 approach to clinical decision support (CDS) based on the cognitive constructs of accurate decisionmaking and develop the theoretical basis for clinical summarizations. This project will develop and
 pilot a small EHR that evolves, adapts and proactively reacts to patient and provider needs.
- Modeling of Setting-Specific Factors to Enhance Clinical Decision Support Adaptation Develop methodologies which improve the efficacy and applicability of CDS by integrating patient and environmental specific factors. This project will focus on tailoring CDS to support chronic disease management by incorporating guidance and workflow optimization techniques into EHRs.
- Automated Model-Based Clinical Summarization of Key Patient Data Develop a stand-alone automated clinical summarization engine that yields condition specific, actionable, 1-2 page summaries which can be integrated into existing EHRs.
- Cognitive Information Design and Visualization: Enhancing Accessibility and Understanding of Patient Data - Construct an interface which supports the integration of clinical understanding, decision making and problem solving. This project will also provide metrics to evaluate and compare the efficacy of this open-source interface as compared to commercial interfaces.

Project Team and Organization. SHARPC has coordinated the top experts across the nation to work on the project. The project is made up of a ten-institution consortium: the University of Texas at Houston Health Sciences Center; the University of Maryland; the University of Kentucky; Intermountain Healthcare; Stanford University; Harvard University; the University of Washington; Baylor College of Medicine; the Arizona State University; and Intermountain Healthcare, with 100 people total working on the project.

Dr. Zhang currently serves as the Project Director overseeing two core groups: an administrative core which includes project management, communication, outreach and lab testing and a scientific core which includes the five projects. Each project includes two clusters: cluster 1 focuses on usability design and evaluation and cluster 2 focuses on model-based design (See Exhibit 1). Project leaders present their current work and issues at a monthly review committee and provide each other with advice.

The Project Advisory Committee (PAC) led by Ed Shortliffe advises SHARPC on all scientific aspects of their projects. The PAC team list includes representatives from academic institutions, leading EHR vendors, professional associations, patient groups, hospitals and providers. The team has an annual inperson meeting with the PAC in addition to quarterly conference calls. In addition to the PAC, the Federal Steering Committee also provides advice and guidance to SHARPC.



Project Evolution

The project has evolved since inception but the core goals have remained intact. Originally, six subprojects made-up SHARPC: model-based abstraction, information display, decision-making, communication, team decision and data entry. During the course of the project, ONC suggested removing project five (team decision), which was large and complex in scope and reduced the number of subprojects to five. In addition, each of the individual SHARP projects began collaborating on a pan-SHARP initiative in July 2011. With the ongoing challenges of vendor engagement, ONC suggested one of the senior members of the SHARPC team join ONC for six months. This arrangement will facilitate engagement with the vendor community and identify new opportunities to build tools that influence future releases of vendor products. In addition, the project experienced a change in leadership as one of the co-Project Directors changed positions and Jacob Reider, a former member of the SHARPC PAC moved to ONC. The SHARPC team sees Dr. Reider's ongoing involvement with the project important given his prior role at Allscripts and his familiarity with their project.

Take-aways from discussions

We begin this section with a synopsis of the most significant accomplishments, challenges and lessons learned articulated by SHARPC during the site visit. We follow with a detailed review of each project's current activities and progress.

Accomplishments

The SHARPC team reported progress in each of their individual projects. Notably, they believe they have demonstrated the scientific nature of usability design and successfully helped move the work of usability design from academia into the 'real world'. The work of the SHARPC team informed the NIST EHR Usability guidelines and the final standards and certification criteria for stage 2 meaningful use (MU).^v The SHARPC team believes the inclusion of usability guidelines into MU will encourage a greater focus on usability among provider and vendors in the future.

The SHARPC team also established a usability center. The center makes tools health IT vendors can use and plans to provide substantial support to the vendor community in the short-term. In the long term, they aspire to become a center of excellence in usability, conducting research and offering a range of services in usability design, testing and certification. At the time of the site visit in August 2012, the team produced 22 news and media publications, published 26 peer reviewed papers, delivered 21 keynotes, symposia, and panels, developed 16 software protocols and guidelines, organized 12 meetings and conferences and administered 14 conference oral presentations, among other dissemination activities. In addition, the team produces tools and resources which include top-level guidelines usable by anyone for any platform; code that may be implemented in specific platforms; interactive prototypes that can be plugged into existing products; and products that can be used in module format.

Key Challenges

Below we highlight the most significant challenges and the approaches taken to address each challenge.

Getting initial vendor collaboration has been challenging. Each sub-project within SHARPC found securing EHR vendor participation challenging. Team members found that vendors understand the usability problem and may have an interest in improving usability, but tend to focus currently on making sure upgrades meet MU requirements and addressing bugs in their current products. Discussants acknowledged some usability design recommendations would require a fundamental redesign of vendor products presenting a more intractable problem. Very often improving the usability of any given EHR presents challenges due to the need for resource intensive customized programming.

SHARPC team members noted challenges in coordinating between the EHR design team that generates ideas and the technical team responsible for product development. The technical teams feel pressure to get new product versions to market and address product bugs quickly. The SHARPC team notes it typically takes 18 months to implement a new feature in a vendor product. Vendors have their own processes for determining which features to implement in new releases and client requests often drive the priorities in this area.

In the first couple of years, the SHARPC team experienced numerous challenges securing access to EHR systems. Providers and vendors hesitated to share screenshots or give the SHARPC team access to their proprietary systems. Despite these challenges, the team engaged with several of the leading EHR vendors. They currently have access to 12 EHR systems and may secure an additional partner, Allscripts, in the near future. If Allscripts comes on board, they will have access to five million records. Siemens has expressed interest in the knowledge base that can be used for clinical summarization and they tested six EHR vendor products through their partnership with the GCREC. The SHARPC team has also engaged Epic, Cerner and eClinical Works in initial discussions.

Securing provider participation. Similarly the team experienced some challenges finding providers to participate in the medication reconciliation. Providers do not have a standard, consistent workflow for medication reconciliation and practices in this area continue to evolve. The SHARPC team invested significant time in developing stronger relationships with clinics that offer a 'real world' lab for their medication reconciliation prototypes.

Producing strategic research with short-term impact. The team experiences a natural tension between the traditional timeline for strategic research and the need to create usable tools and products in the short-

term. As researchers, SHARPPC anticipated working on a longer timeframe to produce more strategic results, and therefore faces challenges in meeting ONC's expectation to produce intermediate artifacts with direct impact. Furthermore, discussants noted vendor uptake and diffusion often takes ten years to achieve while the SHARP projects last only four years in duration.

To address this challenge SHARPC disseminates in traditional and non-traditional venues. The team has produced YouTube videos, pursued EHR vendor partnerships, presented at conferences and published in academic journals. According to the team, working directly with EHR vendors provides timely feedback on vendor constraints and enriches the research experience. Using this approach, the team developed concrete artifacts immediately usable to the vendor community. These include reusable software code, usability guidelines and protocols and product prototypes.

Pan-SHARP collaboration. Team members noted some initial challenges getting the pan-SHARP project underway including difficulty in coordinating a large, geographically disperse teams with a diverse set of experiences and alignment of individual project timelines. However, despite initial difficulties in working together, SHARPC finds their work on developing the medication reconciliation algorithm and use case for the pan-SHARP initiative very rewarding and potentially immediately valuable to some EHR developers.

Project 1-A, Work-Centered Design

Project 1A consists of two teams: the Houston team focused on usability and a second team at the University of Washington focused on workflow. This project draws motivation from a recent Agency for Healthcare Research and Quality (AHRQ) report on EHR usability which identified usability as a problem but had no systematic process to improve it.^{vi} According to this report, most vendors indicated they collect, but do not share, lists of incidents related to usability as a subset of user-reported "bugs" and product-enhancement requests. Many vendors did not address potential unintended impacts of their products as a priority design issue. The current project works to improve usability using work-centered design processes.

The project has the following aims:

- Develop methods and tools to quickly identify and prioritize critical usability problems in health IT;
- Develop a work-centered toolkit for removing usability problems in existing systems and for designing new systems;

- Integrate vendor-focused solutions with social-organizational issues in health-care environments to increase stakeholder trust, adoption and ownership of health IT; and
- Provide breakthrough tools that will increase health IT adoption and meaningful use by making HIT function as an integrated, predictable, cost-effective means for health care delivery.

To address the first aim, the team developed a rapid usability assessment (RUA) protocol in a lab-based setting to inspect usability issues and length of time to complete meaningful use tasks. Then the team worked with the GCREC to recruit EHR vendors to participate in usability tests. The team completed full usability assessments on six vendors. Vendor participants included larger vendors, small start-up vendors and one new vendor. The team also applied the RUA protocol in clinic settings to identify site specific problems. Discussants used this data to build a repository of usability problems. Findings demonstrated 1,266 usability challenges related to meaningful use objectives, with 65 issues in the clinical summarization category. They ranked each problem from one to four on a severity scale and returned a full, detailed error report to each vendor. Then the team used expert review to come up with the usability evaluation problems and document usability challenges in providers' experiences. Some common usability issues included: visibility issues where drop-down fields were too narrow to view the full list of response choices; drop-down too long to fit on the screen; and provider alerts on medication lists obscuring key patient identification information. As part of the RUA, the team also used cognitive modeling to calculate the mean time to complete each task. Discussants reported they found an expert user takes 338 seconds to complete a clinical summary, 161 seconds to complete a medication list and 326 seconds for a CPOE order set based on NIST test procedures for certification.

The team developed a framework for EHR usability (TURF) which includes a theoretical model for describing usability differences, a method for objectively measuring usability, a process for designing systems with good usability and identifying principles, usability guidelines and standards for EHRs. The team then developed a semi-automated usability assessment tool, based on the TURF framework. The team is currently testing the use of the TURF tool for better medication administration workflows. The project team observes ambulatory and family practice group clinics to examine workflows and assess provider needs in order to inform the design of user-interfaces for medication administration. The team conducts one-on-one discussions and focus groups to identify user interface requirements. They develop a repository of methods, structured protocols and measures to inform refinement of usability guidelines. They also review the literature and look at the practices of leading software vendors like Microsoft to build off prior work in usability design.

The team applied the TURF framework in OpenVistA to redesign the user interface for documenting allergies. The new interface proved very effective. For example, it halved the time required to document allergies. Originally, it took 91 steps to modify a single allergy. In the TURF design, it takes nine steps. Discussants described that pop-ups often obscure key information and create greater cognitive burden. To address this issue, the SHARPC team redesigned the interface to include a banner to make patient-identifier information more accessible with a patient photo to distinguish patients with the same name. The interface shows current medications and problems, including information on who prescribed the medication, dosage of each drug and instructions for patient education. Additional information on patient visits and problems are collapsible to minimize or eliminate visual overload exists. The team adopted the Microsoft usability guidelines in designing the new user interface.

The usability-assessment tool built using the TURF framework represents an important output from the project. The SHARPC team hopes to use the vendor feedback to improve the usefulness of the tool itself. The team uses an interactive process of getting end-user feedback to make incremental improvement in the tools possible. The anticipated final artifacts from this project include usability guidelines, workflow models and sample screenshots focused on medication review. The project team is currently conducting an environmental scan assessing current guidelines, identifying gaps and gathering feedback from vendors on what if any existing guidelines they use. The team will use findings from the environmental scan to specify guidelines needed and identify the appropriate level of granularity for these guidelines.

Project 1B: MATH for Evidence-based Health IT

The University of Washington and the Veterans Administration (VA) collaborate on project 1B. The team commented that current health IT solutions focus on specific functionality and features rather than their influence on efficiency or quality. The team proposes a shift from system design focused on features to a design model based on evidence-based health IT. In other words, using careful analysis of provider workflow to identify system requirements and functions needed to complete specific tasks more efficiently and effectively than current practice.

To address this vision the team developed health-care specific workflow modeling and simulation tools based on industry standards. The Modeling and Analysis Toolsuite for Healthcare (MATH) integrates workflow and information modeling, conducts simulations and optimizes workflows and use the tool to establish the best information architecture for a system. The toolsuite therefore supports rapid, iterative design that accounts for workflow improvements.^{vii}

Approach

The team developed a suite of tools based on the Business Process Model Notation (BPMN), a national standard developed by the Object Management Group. Extending on a BPMN standard for creating workflow diagrams, the MATHflow tool captures current process and information flow and performs simulations to aid in the redesign of the information flow. The team incorporated both paper (manual) and electronic processes into the workflow analysis and noted that by focusing on digital-only processes, a user may miss opportunities for workflow improvements. They also developed the MATHsim tool that allows for discrete event simulation and assesses different approaches to automate processes that use information coming from either digital or paper sources. Finally, the team developed the MATHview tool that marries information on processes and relevant data to create diagrams used in software development. The suite of tools therefore supports a rapid and iterative process of workflow improvements and software design.

The first product developed from MATH is priority contact, a system that interacts with EHR data to optimize the workflow for contacting patients about test results. The team is currently testing the priority contact system in two settings, a rural health center and at the Veterans Administration (VA) in their computerized patient record system (CPRS) Vista environment. Overall, the suite of MATH tools allow the users to look at key clinical processes as a whole as opposed to a specific task based on the actor.

The tools require rich process descriptions that allow users to think about what they want to accomplish. They facilitate a detailed understanding of workflow by capturing the nonlinearity of many activities. For example, the process description for reviewing a medication list includes a discussion of the potential for using patient-submitted information including handwritten lists or medication bottles. The relevant tool can then demonstrate how a process might be improved if providers have options such as the ability to scan medication bottles at the time of the visit. Using these tools the users themselves can participate in workflow and software design in collaboration with technical staff. This collaboration fosters a better understanding of all the actors involved in a particular process and allows clinical staff to effectively communicate needs with technical staff.

The long-term vision is to create and publish a usable library of tools and resources that for use by EHR developers. A number of commercial entities have expressed interest in the MATH suite of tools. These include 2 large EHR vendors (Epic and McKesson), the University of Washington and a consulting firm. Future partners include Baylor for an AHRQ R01 grant and Duke University.

Project 2A: Cognitive Support

This project focuses on creating cognitive support for clinical decisions and based on the premise that the design of current EHR systems does not appropriately support clinical decision-making. This project seeks to capture and document the knowledge structure and conceptual operations used by experts to make clinical decisions. Providers typically gather clinical data scattered across different sources and aggregate information to develop a clinical assessment. For this project, the team will gather information from subject matter experts to design, develop and iteratively evaluate a cognitive support system (CSS) for clinical decision support. The team plans to use this CSS to design user-interfaces that present information parallel to the natural organization of information provider's use in making clinical assessments.

Progress and Current State

Initially the team worked on capturing clinical decision models and knowledge organization based on existing tools. They started with concept maps and attempted to discover the relationship between different concepts. In going through this process, they realized there may be many relationships between various concepts and clinical decision support models would need to account for this complexity. Initially, discussants thought they could use artificial intelligence (AI) to easily and efficiently characterize the relationship between different knowledge concepts and translate those relationships for the purposes of design. They soon realized they would need to model more complex relationships. Ultimately, the team found some leverage by working to develop a CSS around 'intermediate constructs,' or patterns of clinical data easily recognized by experts that can support clinical decision-making.

In the first year, the team focused on the way providers in an ICU organize knowledge about clinical conditions and how they use the information to make clinical decisions. The team explained that data collected in the ICU provided valuable insights into the way EHRs and paper-based information sources currently organize information and their limitations in supporting decision-making in practice. Discussants explained EHRs were useful sources for new data, but findings from studying ICU providers reveal that the systems do not present data in a manner designed to aid clinical decision making at the point of care. Discussants also noted that providers rely heavily on paper records in the ICU and, generally, EHR's offer more structured information relative to paper records.

The team also focused on capturing clinical knowledge relevant to four clinical conditions: Systemic Inflammatory Response Syndrome (SIRS), diabetes, renal failure and hypertension. The team developed methodologies to capture the process of decision-making using theoretical approaches from medical cognition and cognitive science. The team developed a CSS based on the models that can use the

cognitive models they developed in the initial phase of the project. They have implemented the SIRS model in the CSS. In developing the initial CSS, they used of the SMART platform developed by the Harvard SHARP team. In the current version of the CSS system, the team is using a generic data source platform giving them the capacity to retrieve data from multiple sources.

In practice, the platform is intended to be vendor agnostic. The team has focused their time most recently on developing a prototype application, the SIRSi iPad application, to demonstrate the capabilities of the system. As proof-of-concept, the application currently uses a database containing real but de-identified patient data. The team also made significant progress in adapting the SIRSi interface to function in the context of a commercial EHR, specifically Cerner.

The team also extended the application to the primary care setting. They completed development and validation of the diabetes reference model, recorded the primary care workflow in a walk through simulation at an academic medical center and captured the information seeking needs for a diabetes case in terms of information held within the EHR system used for diagnosis and management. In the second year of the project, the team is conducting further evaluation of 'intermediate constructs' in a clinical context.

The team created a prototype to test intermediate constructs for a psychiatric case. While the literature supports the use of 'intermediate constructs' to support clinical decision-making published empirical studies do not exist. Therefore the SHARPC team is conducting a study with psychiatry residents to demonstrate influences to clinical decision-making with and without the use of intermediate constructs. The study is currently underway but early findings suggest that organizing information around intermediate constructs provides better cognitive support to providers. The team noted the close linkages between the cognitive support project (2A) and project 3 and the project's re-organization supports these connections.

Ongoing Research and Development

Future stages of the work focus on potential commercialization of the SIRSi through their partnership with Cerner. The team also plans to explore the potential use of the architectural framework to encourage the development of small, lightweight 'apps' that run on smartphones and tablets and developing the apps focused on specific clinical settings and problems. The team is assessing options for accessing EHR databases to support the development of these apps.

SHARP 2B: Facilitation of CDS through Setting-Specific Factors

Because different EHR systems have different characteristics, and workflow varies from one location to the next, investigators face difficulties developing broadly applicable resources to support CDS. The 2B team focuses on refining CDS rules by taking into consideration Setting-Specific Factors (SSF) such as local workflows, practice patterns, site characteristics, users and EHR platforms. Initially, they focus on supporting small practices. However, they also work with ONC's Standards and Interoperability Framework's Health e-Decisions Initiative (HeDI) group to devise a nationally adopted representation of CDS knowledge for vendors and producers. Initial areas of clinical focus include diabetes and cardiovascular disease management, as well as related prevention and screening recommendations. The team envisions developing a taxonomy of SSF's and tools for adapting CDS in light of these factors.

Progress and Current State

As part of the Diabetes Morningside Initiative project, the team looked at rules in various clinical settings to see how these differed. Data analysis shows differences in CDS rule expression at Intermountain Healthcare, the VA and Kaiser Permanente. Across these settings, discussants noted variances in threshold times and values such as HbA1c and wording of specific rules decision support rules. They noted this variation coincided with differences in decision support logic in different settings. They also noted variation in triggering criteria, methods for delivering rules, and approaches to choosing threshold values to fit into a local workflow. They worked to extract a core set of information and make it easy to port from one location to the next.

In the second year, the team worked adopting a standard data model. The team initially selected the Quality Data Model (QDM) established for eMeasures. This would align with the model necessary to report on clinical quality measures for meaningful use. However, after an analysis of the QDM specification and vendor update, the team opted to use the Virtual Medical Record as the data model. The team commenced the design of SSF's ontology and completed an assessment of practice workflows and application environment for three small practices. For knowledge representation, the team selected ArdenML, which supports the expression of Arden Medical Logic Modules in XML. Next, the team plans to implement the authoring environment. The team also conducted studies converting ArdenML to produce functioning decision rules, usable in the open-source, Drools, production-rule system. The team is working on interface design to help in the authoring and modification process. The team also focuses on developing an XML approach to manage the decision support artifacts and convert decision logic into artifacts in different systems.

The team has collaborated with others involved in CDS and is part of six CDS initiatives, referred to as the meta-consortium. They continue to identify Beacon communities to assess how they can better support the individual CDS efforts in these communities. The SHARPC team is also engaging with the AHRQ CDS initiatives (GLIDES and CDSC), eRECS and Advancing CDS in an ongoing effort to refine the SSFs. Intermountain Healthcare has expressed interested in knowledge artifacts for years, and discussants report they agree that necessary knowledge will come from multiple institutions. The team lead participates in an HL7 CDS group where they have regular interaction with a VA hospital excited about better ways to design and share CDS knowledge artifacts.

Project 3: Clinical Summarization

For this project, the team starts with the premise that EHRs currently feel like paper records, and in their current framework do not support the cognitive process that providers use. The clinical summarization project seeks to identify the data and methods required to model interactions and to summarize the complex health related information contained in EHRs, and to design automated methods to create accurate and succinct computer generated summaries of complex, chronically-ill patients.

Progress and Current State

In the first year, the team worked to understand how people create intermediate artifacts cognitively and how this impacts their use of EHRs or paper records. The team developed and published the Aortis model that details steps of aggregation, organization and reduction. The team uses their rapid assessment process-based observations of clinicians in the ambulatory setting. Discussants report they found seven major clinical problems in primary care and built handcrafted summarization knowledge for those problems. They worked to auto-develop summarization methods for ontology based approaches.

The team developed a clinical summarization prototype within an EHR to help summarize clinical knowledge. For example, using the summarization knowledge, the user can hover over a diabetes problem and it shows relevant medications, tests and suggestions for what the patient may need, including a visualization of an HbA1c trend. The team notes the challenge in determining how to establish this data standard, for example, the work raises questions regarding how much information should be included (e.g., just diabetes medications or other therapies related to weight problems?). The team uses a similar approach for hypertension and works with clinical and EHR partners to assess results.

The team developed a rigorous understanding of the current capabilities of commercially available EHRs to support clinical summaries and applied their model of clinical summarization to demonstrate gaps in the ability for current EHRs to transform, interpret and synthesize data. The team also developed a

SMART app in an i2b2 container. The app will consist of a newly created clinical summary user interface running on the SMART platform. The app will use the i2b2 registries integrated clinical knowledge base to mine data and create clinical summarizations. The initial scope includes summarizations of 10 common clinical conditions.

The SMART app also links information on medical problems captured in the database with other data elements (e.g., medications). Discussants developed algorithms to understand the relationship between problems and medications and assessed the accuracy of the algorithm compared to manual review. The team found their algorithms work well at identifying problem-medication links. Discussants also work to use natural language processing (NLP) to make use of data on patients contained in free text. The have completed data summarization for diabetes and colon cancer and are now working on systems for asthma, chronic kidney disease, coronary artery disease and hyperlipidemia.

Project 4: Cognitive Information Design and Visualization

This project develops advanced interactive information visualizations that provide patient-centered cognitive support. The team identified two areas of focus; medication reconciliation and tracking patient labs. The team hopes to build of the first two areas and develop a systematic, yet flexible framework that applicable to other clinical areas. Discussants explained that work to date does not lead to a strong definition of medication reconciliation. The project works to address the clinical need for accurate and up-to-date medication lists. Similarly, lab results play a critical role in clinical decision-making and the project aims to ensure providers can easily and efficiently retrieve and process lab results.

Progress and Current State

The team has made significant progress with the medication reconciliation and the lab tracking use cases. For medication reconciliation, the team completed two prototypes with completely different user interfaces. The interfaces build off a medication reconciliation algorithm and automate components of the manual medication reconciliation process while ensuring the providers still have full decision-making power.

Using the current process, if a specialist wants to prescribe for a patient with a recent hospital stay, they must determine what medications the patient was taking during the hospital versus when the patient leaves the hospital. Typically, the EHR systems have each medication list on separate pages and providers need to toggle between different screens to complete the manual reconciliation. In developing the medication reconciliation prototype, the team investigated different algorithms for semi-automating answers to medication questions. The pre-processing algorithm they developed automatically reconciles

identical medications, determines equivalent elements between similar medications and leaves unique medications for reconciliation by the provider. The team developed a prototype that presents the provider with two lists on one screen (a twin list). They also developed a prototype using multiple lists.

Today with lab test result management, providers report it is hard to tell when results are coming back using standard results viewing capabilities inherent in EHRs. The lab results application helps providers see what needs attention and allows for retrospective analysis. The team started to develop design guidelines for a sample of test results. They hope to take the initial limited prototype and gather feedback from medical personnel in different clinical settings to create a more evolved prototype within a year.

The Systematic Yet Flexible Systems Analysis (SYFSA) Framework guides interface design for the two interfaces. The framework helps emphasize the trade-offs between systematicity and flexibility by guiding the design of systems that provide cues (visual and other) encouraging users to follow best practices. Using systematic, consistent approaches, the team can improve efficiency, safety, and effectiveness. For example, the framework helps developers understand the consequences of decision rules and provides context for understanding trade-offs inherent in design decisions. Ultimately, the design of real interfaces also requires support from human factors graphic design experts.

Pan-SHARP

The SHARPC team is collaborating with other SHARP awardees to develop a medication reconciliation app that uses data from the Mayo Clinic and another provider. The data start in HL7, Clinical Document Architecture (CDA) format documents and free text clinical notes with medication lists. The SHARPn project (Mayo Clinic) then captures data in three different forms (HL7, CDA and free text) within their data normalization pipeline. Next, the pipeline manipulates data to create consistent information on medications for all patients in a clinical element model (CEM) format. Next, the data loads into the SMART environment to translate CEM to RDF using the CEM normalization pipeline. Once in this format, a SMART app can use this information to reconcile medication lists from multiple providers. The SHARPS project based at the University of Illinois is developing a way to track the provenance of the data used in a SMART app that provides medication reconciliation. For this project, the SHARPC team is designing the medication reconciliation algorithm and the user interface.

SHARPC has also explored commercialization and partnership opportunities for Pan-SHARP. They have partnered with the VA and Ringful, a company that develops and sells mobile applications to healthcare and consumers. Ringful wants to adapt the medication reconciliation application so consumers can manage their own active medication list. The VA wants to incorporate the Pan-SHARP UI for their

medication reconciliation efforts. SHARPC discussants noted working together can help accelerate commercialization of the products generated from each of the SHARP projects.

Suggestions for ONC

Overall, the SHARPC team felt that they had made significant progress with the support of ONC. They did highlight one area where ONC might prioritize efforts to further support the mission of the SHARP program: getting EHR vendors engaged. The team noted the need for vendor uptake of SHARPC project artifacts such as guidelines, recommendations and software prototypes to advance the field of usability, cognitive design and decision support. Designing and developing clinical systems that are usable and useful have longer term implications on EHR adoption and meaningful use of these systems.

Conclusions and Recommendations

SHARPC makes notable contributions to the science of usability, specifically in the context of EHRs. The recommendations generated from the project informed the NIST usability guidelines. The team also helped ensure usability requirements were included in the EHR certification criteria for stage 2 MU. The team continues to explore opportunities for commercialization of various project artifacts by actively engaging with the vendor community with mixed success. The SHARPC team routinely disseminates findings through traditional academic avenues, such as publications and presentations at conferences, and seeks out opportunities to generate developer and industry interest. In addition, the SHARP C team continues to aggressively explore opportunities for commercialization of their project outputs.

Appendix G. Site Visit Summary for SMART

This site visit was conducted in July 2012. The summary was submitted to ONC in September 2012.

Executive Summary: Key Takeaways

Overview. The SMART team reports substantial progress towards the goal of enabling a platform-based architecture for substitutable medical application development for use within multiple EHR systems, scalable to the national level but respecting institutional autonomy and patient privacy. The SMART team has identified four clusters of activities related to their work since project inception. In each cluster, SMART investigators have made substantial contributions to the literature, 'buzz', and general understanding of the applicability of iPhone-like substitutable medical apps in health IT among developers, EHR vendors, and health care researchers. Ultimately, their work will lead to new approaches to development and design in health IT which focus on substitutable apps targeting the specific needs of consumers, both providers and patients.

Accomplishments. The SMART team's major achievements include:

- Release of the v.4 SMART Data Model and SMART API, ready for public use
- First generation, limited SMART enablement in a Cerner EHR at Boston Children's Hospital
- Development of the SMART BP Centiles App, which enables pediatric blood pressure percentile calculations
- Successfully SMART-enabled i2b2, OpenMRS, and Indivo
- Currently enabling SMART for Mirth Results, a clinical data repository
- Ongoing collaborative project with the University of Southern California (USC) Information Sciences Institute (ISI) to implement SMART app access to live enterprise clinical data systems
- Working with Georgia Tech Interoperability Innovation and Integration Lab to adopt SMART for their Apps labs, regional health providers, and incorporating SMART into a multi-state Direct exchange.

Challenges. SMART investigators emphasize that their work represents a novel opportunity to apply platform architecture with substitutable apps to a long-standing monolithic healthcare system, with a goal to create innovation in the market stimulating development of more efficient, usable and substitutable healthcare information systems. Recognizing the complex nature of a project which aims to change the healthcare landscape, they note a number of challenges to accomplishing their goals:

- Obtaining initial buy-in and entry in the market requires vendor participation, and vendors are resistant to adopt the substitutable app model given their long-standing investments in existing EHR models
- Project needs change during the process of creating innovation, and the inherent variability makes maintaining partnership involvement and cohesion in multi-partner agreements a challenge
- Working with the Resource Description Framework (RDF) and XML syntax has been confusing for web developers to manage data payloads as many are not accustomed to using this format
- Balancing the need to maintain deployment partner involvement while timing versioning and upgrading of new releases to assure SMART is up-to-date and bugs are fixed
- Limited access to real sample data presents a barrier to testing and evaluating the usability and utility of the apps, containers and ecosystem

Addressing Challenges. To address these challenges, the team has creatively forged relationships with a set of stakeholders who are open to working with substitutable medical apps and not heavily invested in existing health IT models; who are comfortable with the natural variability and limited available funds in participating in an innovative, open source project funded by a federal entity; and who have the potential to create an initial 'buzz' in the market, including start-up EHR vendors, existing open source EHR vendors and proprietary vendors who have existing relationships and ties to Harvard University. The team has also focused on a small, committed pool of developers to work with the project initially and has created extensive developer guides in addition to providing one-on-one assistance to developers.

Conclusions. The SMART project continues to innovative in the field of strategic research in platform architecture and medical applications, and to create pathways that can lead to pragmatic technical solutions to current and future problems in the health IT market. They have established new tools and methods to support research and successfully established relationships with vendors to develop apps and containers for use in the SMART ecosystem. The team seeks increased engagement with the scientific leadership at ONC to explore opportunities to access real patient sample data and to maximize use of their outputs. Overall, the SMART project has achieved significant progress.

Introduction

On June 11th and 12th, 2012, the NORC evaluation team conducted a site visit with the Area 3 SHARP Awardee team: Substitutable Medical Applications, Reusable Technologies, or SMART, led by Harvard University. We organized the site visit discussions in the groups shown in Exhibit 1 below. Each meeting included component leads, team members, and Executive Leadership.

Exhibit 1: Summary of SMART Site Visit Discussions

Meeting	Participants
Introductory discussion with Executive Leadership Team	Rachel Badovinac, Zak Kohane, Josh Mandel, Ken Mandl
Operational Aspects of the Program	Rachel Badovinac, Josh Mandel, Mike McCoy, Shawn Murphy
Technical Aspects of the Program	Rachel Badovinac, Josh Mandel, Nikolai Schwertner
Pan-SHARP Collaboration	Rachel Badovinac, David Kreda, Jorge Herskovic, Josh Mandel

Site visit discussion topics included short-term objectives, progress to date, milestones achieved, challenges and strategies for overcoming them and, finally, recommendations concerning the evaluation of the SMART project. In the sections below, we provide a brief overview of the SMART project and then summarize findings from each set of site visit discussions. To provide context to the sections below, NORC supplemented site visit findings with information gathered from the SMART narrative, SMART 2010 and 2011 progress reports, SMART site visit preparatory memo, and SMART publications.

Project Overview

Co-Principal Investigators Ken Mandl and Zak Kohane, along with Rachel Badovinac Ramoni and Joshua Mandel lead the SMART project. SMART involves a multidisciplinary team of 13 academics and industry leaders, which includes an Executive Committee composed of project leads, a Chief IT Scientist, and a Chief Medical Scientist. Finally, a Project Advisory Committee composed of academic and industry experts advise and guide the SMART projects.

The team at Harvard University created the SMART project to provide a stable, usable foundation for building applications (apps) to enhance the functionality associated with EHRs and similar health IT tools. This foundation includes back-end network design and a front-end user dashboard. The platform will allow users with some medical information system to add new functionality to their base system or substitute specific functionality native to their system with a version of the same functionality offered
through a SMART app. The platform will include a set of services that enable efficient data capture, storage, retrieval, and analytics. These features will be scalable to the national and include features ensuring institutional autonomy and patient privacy.

The SMART team conducts their research through four domains of work. Project 1 focuses on the networked services required for national implementation of the SMART platform. Project 2 is an investigation of the SMART platform architecture that includes testing a small number of apps such as medication-management transactions among multiple stakeholders. Project 3 investigates how to retrofit existing commercial and non-profit, open-source health IT platforms to be SMART-ready. Project 4 lays down the sustainable infrastructure for a SMART ecosystem whereby apps can be rapidly tested, shared, and substituted in a SMART exchange.

The SMART platform focuses on substitutable medical apps which allow the purchaser of an app to replace one app with another without being a technical expert. In addition, the purchaser will not have to re-engineer the existing apps in use or seek assistance from any of the vendors of previously or currently installed apps. This allows developers to rapidly create a large marketplace of apps for consumers to choose from.

The SMART team anticipates that an environment characterized by substitutable apps constructed around shared core components would drive down healthcare technology costs, support standards evolution, accommodate difference in care workflow, foster competition in the market, and accelerate innovation. A physician using an EHR, a CIO running a hospital system, or a patient using a personally-controlled health record (PHR) would all be empowered to readily discard an under-performing app and install a better one.

Three main components comprise the SMART architecture:

- Data Sources, which feed the data that provides the information necessary to address a functional requirement;
- Containers, which are typically an existing medical information system in use that provides data to an individual app; and
- Apps themselves, which manipulate data and provide an interface for users to view and interact with information to meet a functional requirement.

The containers for SMART are systems that have implemented the SMART Application Programming Interface (API). To date, these include the SMART sandbox where development and testing activities take place; i2b2, a registry system used for facilitating clinical research; Indivo, a personally-controlled health record; an open-source EHR called OpenMRS; and an installation of the Cerner inpatient EHR at Boston Children's Hospital. The SMART team developed the API using an open-source format. To access apps, users with systems that have implemented the SMART API will be able to participate in an app exchange.

Takeaways from Individual Discussion Sessions

In the subsections below, we present progress to date, define central concepts, and describe the approaches to dissemination and collaboration by each site visit discussion.

Discussion 1: Executive Team Leadership

The Executive Team Leadership discussion focused on the following key topics:

- Executive team vision of program;
- Progress toward goals;
- Challenges in managing the grant and program; and
- Anticipated outcomes.

Executive Team Vision for the Project

The team had an ambitious goal: to create a software framework and an open source platform for substitutable medical apps that can function across multiple EHRs. Together, these features have the potential to overcome significant economic and technical barriers between and among clinical IT systems. When the team first proposed modular app architecture and an app exchange, it wanted to create a user community around medical apps. The team envisioned designing a more approachable project for developers by leveraging Web standards, presenting predictable data payloads, and abstracting details of enterprise health IT systems.

The discussants explained they began with a vision they felt could be successful, but also an understanding that their project relied on buy-in from outside entities that might be slow given the novelty of the ideas. Understanding the challenges, the project leads sought support for developing the SMART platform through the SHARP program. Project leads described their approach as a 'sidecar strategy' in which the goal is not to develop an entire EHR for clinical users but to create a platform for the development and sharing of functionality that makes use of EHR data to support clinicians in their daily tasks and improve and expand upon the native functionality of many EHRs.

The ultimate goal is to encourage the development of additional apps using the SMART API, and introduce the substitutable app model as a way to shape the current health IT landscape and drive innovation.

Project leaders anticipate that when SMART hits a critical mass, it will create demand around the idea of substitutable functionality for a broader set of medical information systems products. They expect that developers who work for vendors but are outside the user community will want to develop apps. They also noted that vendors might find it useful to move to a distributed model for app development to meet end-user needs. If the SMART environment generates a way for existing EHRs to work with a larger developer community, this would be an innovation in itself, allowing developers to innovate without being disruptive.

Progress toward Goals and Accomplishments

Because of the SHARP program, the SMART team moved their vision forward rapidly. The project began with no apps and no standard API but quickly progressed to development of the first alpha in six months. After one year, the team held a national developer contest with a prize of \$5,000 awarded to the best developer-built SMART app. The White House Chief Technology Officer, Aneesh Chopra, also promoted the project and developer challenge. In the first 48 months, the SMART team achieved the following key goals:

- A usable anchor system for public consumption with the .4 release of the SMART Data Model and SMART API;
- First generation, limited SMART enablement in a Cerner EHR at Boston Children's Hospital;
- Development of the SMART BP Centiles App, which enables pediatric blood pressure percentile calculations;
- SMART-enabled i2b2, OpenMRS, and Indivo;
- Currently enabling SMART for Mirth Results, a clinical data repository;
- Ongoing collaborative project with the University of Southern California (USC) Information Sciences Institute (ISI) to implement SMART app access to live enterprise clinical data systems; and
- Working with Georgia Tech Interoperability Innovation and Integration Lab to adopt SMART for their own apps labs, regional health providers, and incorporating SMART into a multi-state Direct exchange.

API Strategy. The SMART Executive Team discussed their strategy for the API. The platform relies on a common API, intended to allow for scale and appropriate for federally sponsored development initiatives. For example, the Centers for Disease Control (CDC) wants to release one app for management which can be used with different systems and which runs on an API, and the SMART team is working with CDC to move this idea forward.

Currently, the project has developed an API which has been in use and stable for one year. This API allows for use of apps that are "read-only," meaning they provide data to end-users such as clinicians but do not incorporate functionality allowing clinicians to manipulate the data themselves using "write" functionality. The project team made this decision because of the need to establish a stable API for a period and because they felt a read-only version can incorporate many functions and achieve significant usage.

In order to accomplish their goals, the SMART team emphasized they will not be inventing a standard. Instead, they will borrow where they can from existing vocabularies and standards to represent commonly required information such as smoking history. Project leaders felt that most app developers will not want to know the details of standards such as the Continuity of Care Document (CCD) format, so the team provides developers only the concrete details using RESTful (conforming to REpresentational State Transfer constraints) calls. A central goal of this project is to make a usable platform for development so that developers with different backgrounds can build an app for use in a SMART environment. The team provides developers with a user-friendly comprehensive guide to development in the environment, making it as simple for them as possible.

Creating Basic Apps for Important Use Cases. The team has created use cases to test and demonstrate the value of using apps created in the SMART. For example, apps available through the SMART environment allow providers to look at a standard flow sheet of labs and then configure and export the information to create graphs in a modern web interface. Another key feature that sets SMART apart from other EHRs is its ability to do a text search across all textural content of patient records. To take this a step further, the team is layering SMART apps on top of health information exchange applications to allow searches of textual information from a patient's records across multiple institutions. There is another SMART development effort that will leverage the Direct messaging platform to facilitate targeted secure messaging between patients and providers that allow patients better access to their medical information online.

Rationale. The project operates under the premise that health IT systems meet basic requirements but do not satisfy the needs of end-users. SMART project leaders feel the project will extend existing investments by establishing a path for current EHR users to build upon or improve the functionality they already have.

In the current market, there are hundreds EHR vendors, but the SHARP team argued that the actual number of influential companies is small. The team contended that many of the larger vendors focus more on implementation than innovation in the current environment. If this is true, projects like SMART may offer a pathway for competition and greater innovation driven by a broader group of vendors and EHR products in the future.

Implementations. Currently, the SMART team is working with a number of organizations on integrating their API. As noted above they have done so successfully with i2b2, OpenMRS, Indivo, and Boston Children's Hospital (Cerner). They are also working actively with health information exchange initiatives, one Beacon community, the Microsoft Health Vault health record bank, and the University of Southern California (USC). The team has made progress in each implementation at the early stages, and each of these deployments informs the final structure and content of SMART v1.0.

Evidence of Uptake - Vendors. Project leaders note that SMART may have already influenced a range of vendors to develop app strategies. Following a recent SMART conference, Allscripts announced its app strategy. To the team's knowledge, other vendors are likely to follow suit. Microsoft and GE are creating health-related apps and Athena Health is sending three representatives to an upcoming SMART developer meeting. At the University of Michigan, developers are implementing SMART apps to complement their use of Epic following their engagement with the SMART team at the IT.health meeting. Finally, the SMART team has worked with Surescripts and CVS on pharmacy-related projects and has been working with for-profit hospitals such as the Hospital Corporation of America.

Evidence of Uptake - Providers. After only two years, the team has implemented the SMART API at Boston Children's Hospital where the CIO asked for an app that allowed for blood pressure (BP) tracking for children with hypertensive disorders. Normal ranges for BP among children change over time, making it important to track the centile amounts for BP readings that compare an individual child to the population. The team reported that use of the SMART platform enabled a highly efficient development of the app and significant savings compared to what it would have cost otherwise. Furthermore, the app is now available for use by any system with a SMART API, not just the system at Boston Children's Hospital. So far, SMART leaders report positive feedback from providers whose systems, on their own,

lack the versatility that SMART offers. Even at the current stage with a read-only API, the system has proven useful in real world settings.

Dissemination Activities. SMART continually shares their work through peer-reviewed publications and active involvement with the user community. The SMART team works to bring together leaders to discuss needs and build buy-in for specific uses of the SMART platform to meet these needs. The team employed this engagement strategy in collaborations with companies such as Indivo, Google, Microsoft, and Dossia.

The team noted that they have moved beyond traditional academic mechanisms for diffusing their findings. The team participates in the Health 2.0 meetings, where they engage with smaller EHR start-up companies to discuss the use of the SMART platform. Discussants explained that because vendors do not read academic journals as standard practice, it is essential to meet them in these settings. In short, this is a non-financial entrepreneurial approach – the start-ups can easily participate with a limited developer workforce since SMART gives them a large developer community for creating new apps and enriching the functionality of their base products.

Although they do not rely exclusively on academic publications, several academic journals including the Journal of the American Medical Informatics Association and the New England Journal of Medicine have recently published their work. They held an early IT.health meeting to achieve developer buy-in during the project's first year and held a second IT.health meeting in September of 2011 with about 100 participants. The team engaged developers via a nationwide app challenge and the winner, a technology company called Polyglot Systems, continues to speak highly of SMART. The team also competed at a National Health Services (NHS) hackathon in the United Kingdom and won. The NHS has since shown interest in SMART.

Key Challenges

Obtaining Initial Buy-In/Entry in the Market. Project leadership noted that SMART faces challenges to success in the proprietary market among the larger vendors. As such, their entry in the market relies largely on working with open-source EHRs and smaller start-up companies. When open systems have broadly adopted SMART, project leadership anticipates that proprietary vendors will either collaborate with SMART or create their own app platforms. Although they welcome the use of the SMART platform by proprietary vendors, by some definitions, the project will be successful if the idea of substitutable applications (in whatever form) evolves and becomes common among vendors of proprietary systems.

Maintaining Partnership Involvement and Cohesion in Multi-Partner Agreements. For projects involving multiple partners, the SMART noted challenges with deploying the SMART API in different environments with different needs. Even among environments using the same base system, variation in system configuration can lead to challenges with the deployment of SMART apps. The SMART team has also experienced some difficulty maintaining extensive involvement from industry partners for what they perceive as a strictly academic project. In some cases, they engage with partners to some extent only to find that substantial collaboration is not feasible. Because of the nature of the work, collaborators often act as subcontractors under the grant and therefore the SMART team must work to build in flexibility in the amount of resources required and the expectations associated with these partnerships.

Timing. In the next year, the team will release a new v1.0 SMART, but they will have limited ability to evaluate uptake and this may impact the product's utility. The constrained overall timeline for SHARP gives the team less time to do pilot roll-outs that would provide important feedback to improve v1.0. While SMART is getting considerable uptake now, the team expressed concerns that their current period of performance does not provide enough time for the concept to become widely understood and successfully adopted. A number of organizations have agreed to adopt the technology and the team noted that their collaborators will very likely need technical support beyond the time allotted by the grant. The team is actively working on obtaining other sources of funding to carry the project forward when the grant period ends.

Spending Expectations. The SMART team also notes difficulty in spending project resources predictably and evenly through the course of the grant. Open source development and use of de novo software platforms require confronting challenges and making many adjustments early to allow the products to reach a certain level of maturity before marketing efforts can take place. The project spending has largely focused on the initial phase of the project in finding partners, developing the initial platform and API, and securing partnerships from relevant organizations.

Anticipated Outcomes

The SMART team felt that the true value of their project may not manifest until after the industry moves on from the initial post-HITECH focus on adoption and implementation. They reason that once health care providers have widely adopted health IT applications generally and EHRs in particular, there will be an acute need to improve on the functionality available through these applications. Moving beyond implementation, the SMART team feels that health care providers will look for systems that can help them adopt new models of care delivery and financing (e.g., accountable care organizations) and will have a much better sense of what they need out of their health IT systems.

In this environment, the SMART project leaders feel that providers will demand flexibility and innovation from vendors that will lead to the broader adoption of a substitutable app based model for accessing health IT functionality. Also, the availability of a core set of apps through SMART will give new entrants of the health IT market the ability to build from a basic set of functionality and innovate in ways that improve upon what the market currently has to offer. Many on the SMART team also participated in the development of i2b2 and note that small companies were critical to the uptake of i2b2 over a period of about six years before usage reached a critical mass. As such, they believe finding smaller companies that can use SMART represents an important strategy for advancing their work.

Next Steps

In the near future, the project intends to add contracts and subcontracts with WorldVista (another open source EHR), Polyglot, and Startup Health, along with other potential candidates. Next, the SMART team will turn to developing example apps to address use cases associated with disease management, including diabetes. They will also develop apps related to monitoring pediatric growth; use of genomics and personalized medical data; and SMART apps to access third party clinical decision support (CDS) and ontology norms such as RxNorm. There are also plans to initiate a Developer Challenge following the release of SMART v1.0.

Discussion 2: Operational Aspects of the Program

In discussing operational aspects of the program, we explored the SMART team's collaborative work implementing the SMART API with an initial set of medical systems. In particular, we covered:

- Overview of operational approach;
- SMART i2b2;
- SMART Indivo;
- Other SMART implementations; and
- Operational challenges.

Overview of Operational Approach

In their early implementation efforts, the SMART team focused on apps for clinical use, use in research, and use with personally-controlled health records by collaborating with i2b2 and Indivo. The sidecar strategy has been an effective approach from the start to achieve uptake and flexibility. While the team had hoped to begin with a broader community of vendors, the initial enthusiasm from vendors did not translate into real participation. Generally, vendors expressed indifference or even resistance to the SMART model. One large vendor noted that SMART would need to prove their worth with other partnerships in order to make their case.

The team ultimately chose i2b2 as an initial partner for the API because it allowed them to distribute the benefits of their apps widely without needing to come to terms with each user, and provided the flexibility inherent in using an open source product. Sixty medical centers use the i2b2 application to support clinical research. Because Harvard investigators developed i2b2, the SMART team had relationships in place with the i2b2 users.

From the software perspective, the set up allowed them to build one API specification and deploy SMART apps to the 60 i2b2 sites. Each of the organizations using the SMART API has the ability to test the security and resistance of the interface because it is open source; this ability has also promoted acceptance and participation.

SMART i2b2

i2b2's main function is to repurpose clinical data from an EHR, with the option to add in registry data, genomic data, and other kinds of data. The vast majority of providers use i2b2 for EHR data. They typically enter in diagnoses, demographics, medications, labs, and procedures, and about half enter notes that can be analyzed using natural language processing (NLP). SMART works with the enterprise version of i2b2 intended for hospitals because they are EHR-based and can demonstrate clinical use cases.

Users currently use i2b2 as a mechanism to call up routine clinical data relevant to a cohort of patients. The SMART i2b2 app includes analytical tools that can call up information on a single patient in a "monograph" which can be accessed by a clinician seeking to get a quick understanding of the progression of a specific disease or condition in a single patient. So far, the team has created and deployed an app that allows clinicians to call up a monograph of all relevant information for patients with diabetes. But the team is also working on similar approaches for other diseases including asthma and depression. To allow SMART apps to access data in i2b2 installations, the team transformed the i2b2 medical record research platform into a SMART container. With i2b2 repositories functioning in near real-time, SMART apps provide patient specific views of the i2b2 data that supports clinical purposes.

The apps most in demand, thus far, include imaging and NLP for notes. Apps that use NLP can help a clinician search written notes to find the most relevant information. For example, if a patient has seizures over a period of 12 years and the provider cannot remember what medications they were taking six years ago, the app can help pinpoint where the relevant information exists. Longitudinal advanced text searches help find the visit where a clinician discussed and prescribed the medication.

SMART Indivo

Indivo is a personally-controlled health record that provides an easy way for developers to build functionality allowing patients to learn about their conditions and medications. Indivo obtains data in two ways, some functionality rely on patient-entered data, while other functionality including those facilitated by SMART require the use of a connector app that allows data exported from an EHR to be used in Indivo.

The SMART team fully translated Indivo into a SMART container and serves data apps to meet two use cases: 1) patient portals that allow patients to view a disease monograph with their information, and 2) SMART apps that allow patients to share data with caregivers, providers, and family. Boston Children's Hospital currently uses SMART Indivo, and the University of Michigan Health System collaborated with SMART to define use cases for the patient-facing apps. Indivo has its own data model sets that track medications, labs, and other apps in addition to those built using the SMART API. In collaboration with Indivo, the SMART team is moving toward convergence of the Indivo and SMART models. By incorporating the use of SMART apps, the Indivo patient portals can deliver more customized content to patients. For example, traditional portals may not offer a summary of data useful to patients managing specific chronic illnesses.

The SMART Indivo project also provides apps that help patients learn more about their specific conditions and medications. For example, the Meducation app, which won the first SMART development challenge, starts by pulling a patient's medication list from EHR data and then allowing the consumer to find information about these medications including interactions and likely side effects. Additionally, SMART Indivo offers direct secure messaging between patients and providers, a sought-after feature for patients. SMART Indivo can also be detached from the EHR completely, allowing patients to enter, learn about, track their own medications, and interact with other patients on the same medications. The

SMART team is interested in combining these concepts in the future to work on medication reconciliation.

Other SMART Installations: WorldVistA, Mirth, and OpenMRS

The team has also successfully implemented the SMART API with open source EHR companies such as WorldVistA and OpenMRS. To help establish a long-term relationship, the SMART team visits site that use these open source systems in order to learn the culture in place at deployment sites and develop contract mechanisms that facilitate adoption. They note that ONC has helped them establish new contracts, notably with WorldVistA.

In the case of WorldVistA, the SMART team works directly with the application's developers who will handle deployment aspects. Open source EHR organizations represent ideal partners for SMART in many ways because they tend to be smaller organizations and, compared to proprietary software vendors, they allow easier access to the of information necessary for building APIs to access their data.

Further, open source EHRs are available for anyone to download. WorldVistA can run on any desktop, meaning anyone can innovate on it easily without having to worry about the operational aspects of a clinical deployment.

The SMART team arranged for a student and an expert to build an OpenMRS project prototype last summer. The team noted it was successful in part because the developer had access to all OpenMRS staff and could contact these staff directly when a problem arose. The team found that, when working with proprietary vendors, simple issues sometimes took many days to resolve because of the need to file tickets and reports, wait for opportunities to discuss the problems with a limited group of individuals, and wait for those individuals to personally de-bug the "locked-down" application.

Operational Challenges

Vendor resistance creates an ongoing operational challenge for the SMART team, and discussants explained that it is hard to garner full engagement from these entities when the grant allows them to provide very limited financial resources to vendor partners. To address this challenge, the team seeks collaboration with open source software companies and small start-up EHR businesses.

The team also notes the need for systems upgrades even as deployment continues. They have identified gaps in the data model that present a significant challenge for data fidelity. Efforts to upgrade the data model represent a break operationally as the team cannot secure as many deployment partners while they

are upgrading the system significantly. Promising backwards compatibility across versions means that the team cannot change the core structure of messages creating the potential to imprint mistakes for a long period. To address this issue, the team is working out the issues now with a small number of committed users involved.

Access to sample data has also been a significant challenge. The team used a sample of 50 patients for the Developer Challenge but it took a few months to get the data set even for restricted use. Typically, when building functionality, one may work closely with a vendor or have an in-house data agreement. Because of the open environment for SMART development, finding usable test data represents an important challenge. The open environment allows the team to watch the data run, using anonymous data with a synthetic layer on top. However, they face limits in their ability to generate synthetic data for disease specific cases. The team emphasized the need for access to broader sets of real sample data.

Discussion 3: Technical Aspects of the Program

The technical discussion focused on the following themes:

- Structure of the technical team;
- Open source development process;
- Architecture design and process; and
- Technical challenges and successes.

Structure of the Technical Team

Joshua Mandel is the lead architect in charge of the technical team. The team includes two full-time software engineers, Nikolai Schwertner and Arjun Sanyal.

Open Source Development Process

The team published the SMART API specifications, client libraries, and reference implementations under an open source license. Open source platforms and technologies, including Linux, Apache, and DJango serve as the building blocks for the reference application. GitHub is the source for distribution of the product as well as versioning, bug tracking, and code review. All of the code updates are available in realtime in the public repositories on GitHub.

Architecture and Design Process

The SMART architecture leverages open web standards to employ use of substitutable medical apps. The architecture addresses developer needs, focusing on four key items:

- 1. User interface (UI) integration, using HTML5 web apps integrated via in-line frame;
- 2. W3C's Resource Description Framework (RDF) Data model for simple clinical statements;
- 3. API with resource-oriented, RESTful access to data; and
- 4. Authentication, using oAuth to delegate.

1. UI Integration. The technical team knew they wanted to use web app development given how successful it was for Google and Facebook. Internally, they considered using native apps for the iPhone but decided against this. An app developer however can make a native app in SMART if desired; the team simply does not provide the tools to do so. The team continues to stay true to the model where developers can use a web toolkit to build apps.

The team sought out a development user interface already familiar to most developers. As much as possible, the SMART team encourages developers to start by developing apps using the SMART connect browser rather than those using their systems' back-end processing language. Developers can create many useful apps this way. Developing apps that use legacy code such as MUMPS usually requires the use of a separate server.

2. Data Model. Data are available to apps via a server-to-server RESTful API, as well as an in-browser proxy. Over time, the team plans to expand the data models to address app developers' needs. From the start, the technical team wanted to offer developers a specific, constrained data payload and detailed documentation on options. In this way, developers can build SMART apps for one environment in a way that translates easily into other environments.

They are currently working on the fourth beta version of the data model and plan on releasing version 1.0 in the second quarter of 2013. The technical team develops features for the next version based on inputs from developers working on specific use cases. They work in iterative cycles: allowing two to three months between each release of a new version of the SMART data model. The gap between v.3 and v.4 was significant; the team implemented a six month cycle between them with many new features. SMART team members expressed concerns that the scope of change may have overwhelmed the user community.

To address these needs, the team released updated how-to guides for app developers. In general, they aim to make improvements to the data model in manageable steps.

The current app developer community includes developers who built for the challenge and kept up with SMART APIs. A good example is the group from Polyglot that developed the Meducation app that allows patients to access their medication list and look up information related to their prescribed medications. Originally, the team from Polyglot designed the alpha version of the API during the challenge. The SMART technical team continues to work with the developers to track necessary changes to the app through different versions of the API. The SMART team communicates changes and updates by directly emailing known members of their developer community and announcing updates on Google. With the current size of the developer group, the SMART team works with them to provide direct support and make necessary changes between versions.

3. API. For the API, the SMART team defines a set of resources to correspond with different types of data and makes these resources available to developers depending on the data included in the container they access. The team provides a single interface, but provides many ways to allow users access to different apps. Indivo runs their SMART apps in the web to allow easy access to patients. i2b2 also has web accessible SMART apps, but other i2b2 SMART apps must be loaded on a user's computer. Cerner at Boston Children's Hospital had install apps directly on the users' desktops because when a provider runs Cerner, it runs on a desktop hosted on Citrix in a virtual private network (VPN).

4. Authentication. The SMART team decided to use the oAuth web standard for authentication or confirmation to ensure that only appropriate individuals are accessing data through SMART apps. oAuth controls how SMART apps access data by asking authorized users to provide credentials to verify their identity and confirming their authorization to access the requested data.

Technical Challenges

To date, developers have given the SMART team high marks on setting up a data model that is easy to use and providing useful guidance for development. We review a few challenging areas below.

RDF/XML Syntax. The SMART API delivers data in a format known as the resource description framework (RDF). Some developers struggled with use of the RDF syntax necessary to manage SMART data payloads. The team noted that many developers lack familiarity with this tool. To address this, the SMART team is exploring more intuitive ways to express RDF data. Currently, the team has created working prototypes to translate SMART RDF payloads into a more familiar format.

Container Coding of Local Data into Standard Medical Nomenclatures. To fully implement SMART, a provider organization must code all labs, medications, and problems into standard vocabularies used by the SMART API, including RxNorm, Logical Observation Identifiers Names and Codes (LOINC), and Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT). This coding can be done incrementally to meet specific user needs, but does pose challenges and delays depending on the data format used by systems serving as SMART containers.

Lessons Learned Based on the Developer Challenge

The team learned a lot from the developer challenge. The team provided developers with a sample data set from 50 patients for medications, problems, allergies, labs, and demographics, and gave broad instructions for participants to develop apps that help clinicians and patients achieve care objectives or health objectives. They received many questions through their Google group regarding use of the API. These questions helped the team refine their training and help documentation. They also identified the need to help developers who have trouble using RDF/XML by publishing client libraries using other languages such as Python and Java. One developer contributed their own client library to allow other app developers to use .NET. Finally, the team learned about the developers' willingness to use real versus imaginary data. Use of pretend data as part of the challenge helped the SMART team expand and improve the functioning of their API.

Discussion 4: Pan-SHARP Collaboration

The SMART team is collaborating with other SHARP awardees to develop a medication reconciliation app that uses data from the Mayo Clinic and another provider. The data start in HL7, Clinical Document Architecture (CDA) format documents and free text clinical notes with medication lists. The SHARPn project (Mayo Clinic) then uses their normalization pipeline for these messages to take data in three different forms (HL7, CDA and free text). Next, the pipeline manipulates data to create consistent information on medications for all patients in a clinical element model (CEM) format. Then the data is loaded into the SMART environment to translate CEM to RDF using the CEM normalization pipeline. Once in this format, a SMART app can use this information to reconcile medication lists from multiple providers.

For this project, the SMART team is also working with other SHARP awardees on issues such as creating medication lists (SHARPc). The team also worked with the SHARPS project based at the University of

Illinois to develop a way to track the provenance of the data used in a SMART app that provides medication reconciliation.

Suggestions for ONC

Overall, the SMART team felt that they had made significant progress with the support of ONC. They did highlight one area where ONC might prioritize efforts to further support the mission of the SHARP program: facilitating access to real-world health data. In the context of the SMART project, team members noted that they are not able to explore user experience and novel algorithms comprehensively without using real data from health care providers caring for patients. SMART team members see the potential for a collaborative effort to establish a repository of "real world," health IT-generated data that is de-identified to explore the development of new apps or for the work of other SHARP projects.

Conclusions and Recommendations

The SMART team successfully established a platform with core services for substitutable health IT applications supporting tangible, innovative work. SMART investigators attribute their success to the use of a 'sidecar strategy' for demonstrating the value of SMART apps that extend and improve on functionality native to EHRs, PHRs, and registries.

The SMART team routinely disseminates findings through traditional academic avenues, such as publications and presentations at conferences, and seeks out opportunities to generate developer and industry interest through networking at meetings such as Health 2.0, hosting SMART-focused developer gatherings, conducting a successful nationwide developer contest, and maintaining public online forums dedicated to SMART. In addition, they publicly test products in development, releasing findings to the community via Google user groups in addition to sending personal emails to developers.

The SMART team's accomplishments relied on successful and substantial collaboration with developers as well as open source EHR vendors, start-up EHR vendors, and major provider organizations. Major vendors have not yet adopted their model as a strategic initiative, but, SMART researchers have had some success connecting with vendors locally in Boston, and anticipate additional vendors will participate over time. New app strategies in development by major vendors including Cerner, Allscripts, and Epic demonstrate increased awareness and attention to the potential of substitutable medical applications. Overall, the SMART team's work may lead to the emergence of a new, distributed model for developing health IT applications.

Appendix H. Site Visit Summary for SHARPn

This site visit was conducted in October 2011. The summary was submitted to ONC in January 2012.

From October 21st to 26th, 2011, the NORC evaluation team conducted a site visit with the SHARP awardee for Area 4: Secondary Use of EHR Data or SHARPn led by the Mayo Clinic at the American Medical Informatics Association (AMIA) 2011 Annual Symposium in Washington, D.C. During the course of the site visit, we collected perspectives about the program through the following sources:

- Discussion session with the Natural Language Processing (NLP) Team (ten participants)
- Discussion session with the Data Normalization Team (five participants)
- Discussion session with the High-throughput Phenotyping (HTP) Team (four participants)
- Discussion session with Executive Leadership (five members participated)

During the meeting we learned about SHARPn's objectives and progress overall and in each of these areas and discussed role of the role of the SHARPn's role in the pan-SHARP effort to initiate a joint sub-project on medication reconciliation working across all of the SHARP awardees. In this summary, we provide a brief overview of the SHARPn project and then present findings from each set of site visit discussions.

Project overview

Principal Investigator Christopher Chute, PhD and Project Manager Lacey Hart, both of the Mayo Clinic lead the SHARPn working with over one hundred investigators and staff at over a dozen institutions. The project expands upon evolving methods for using EHR data captured and maintained in disparate formats to create cogent, structured information for uses outside of the primary function of supporting clinical care using the original EHR. Secondary uses addressed by the project vary and include structuring data for health information exchange (HIE), public health applications, quality reporting and clinical research.

The project is split into three distinct teams with interrelated objectives and cross cutting dependencies. The first focuses on Natural Language Processing (NLP) and includes a cadre of institutions and investigators working on processing free text entered into EHRs to catalog and structure clinical attributes that describe the patient characteristics, events, diagnoses and procedures documented in the free text. This task ranges in methods and complexity depending on the nature of the free text; for example, free text entered by a clinician in specifically defined fields (e.g., "chief complaint") is more straightforward to process than a completely unstructured clinical note. The SHARPn project's data normalization team works to create a series of tools taking data coded using different EHR formats and transform those data into a consistent structure. The data normalization team's goals is to develop a "pipeline" of normalization tools allowing users to extract and transform structured and unstructured EHR data into a common set of clinical element models (CEMs). The CEMs, also being developed by the data normalization team, consist of a series of attributes that, taken together, represent a specific patient characteristic, diagnosis, procedure or event. These CEMs are then stored in a queryable database. The infrastructure for supporting this "pipeline" of tools and generating CEMs is the UIMA processing engine. A prototype of the overall pipeline and CEM creation exercise was tested in a process taking data from Intermountain Health, a project collaborator in Utah, along with Mayo's own clinical data to populate CEMs using both institutions' data.

Finally, the project's phenotyping team works with the output of the NLP team and data normalization team, namely populated CEMs to identify cohorts of patients to support secondary uses. For example, one of the phenotyping sub-projects is to identify the CEMs relevant to the numerator and denominator of national quality forum (NQF) endorsed quality measures to facilitate reporting. To identify patients or encounters meeting specific criteria the phenotyping team defines processes for users to query a CEM database and apply Drools, a forward-chaining rules based language to isolate the data needed to generate quality measures, identify a research cohort or similar patient grouping tasks.

Takeaways from individual discussion sessions

Although they are all focused on the overall challenge of making electronic data generated by the health care delivery system usable and accessible for a range of secondary analytic purposes, the different components of the project did work somewhat independently. In the paragraphs below we outline takeaways from each group we met with, highlighting accomplishments to date, challenges encountered, dissemination activities and areas of coordination across these components as well as other SHARP awardees.

Natural Language Processing

Guergana Savova, PhD; a SHARPn Co-Investigator from Harvard's Children's Hospital Boston leads the large NLP team including eight to nine institutions and dozens of sub-investigators and staff. To guide their work on SHARPn, the NLP team developed a 4-year project plan with about ten tasks; the tasks are each essentially small projects whose focus varies depending on the type of free text subject to extraction and the type of data (e.g., medications, lab results, diagnoses) to be captured.

The sub-projects within the NLP team work on tools that address specific use cases, such as identifying instances of drug-repurposing based on data from clinical notes or assessing the impact of specific conditions on quality of life. For the Pan-SHARP project, the NLP has re-focused on medication information and away from their initial objectives focused on laboratory results information.

Each site volunteers to lead one or more tasks. The team uses the Apache software philosophy (i.e., everyone is able to express their opinion and every meeting is documented in writing). This ensures consistency across the project, and allows those who miss a meeting to catch-up quickly. Much of the work across these teams builds on a common approach funded by other organizations, the Clinical Text Analysis and Knowledge Extraction System (cTAKES) application, an open source tool available to the public. Specifically, the team's work creates new code that allows the use of cTAKES and similar tools to conduct different data extraction activities.

The NLP team has reached a number of major milestones since the inception of the SHARP Program. In September 2010, the team released a dependencies parser. In December 2010, they released the medication extraction module. And, in March 2011, they released the smoking status modifier. In May 2011, they released the first end-to-end application that processed clinical notes into medication CEMs. Then in June 2011, they integrated this tool into the SHARPn, UIMA supported pipeline to support the "tracer shot" which tested the ability to normalize EHR data from a large group of patients across Intermountain Healthcare in Utah and the Mayo Clinic. This was process was demonstrated at SHARPFest 2011. At SHARPFest, they processed close to one million nodes, and created about 3 million CEMs. In other words, the team showed the extraction of information of one million clinical notes and documented them to CEMs.

Although the primary goal of the NLP team under SHARPn is to provide inputs for the data normalization and phenotyping teams, the NLP group also makes tools available for use for the entire field. Initial response to these releases has led the team to distinguish between the needs of two key stakeholder groups – users new to NLP and experts within the field.

To make their tools most accessible the NLP team focuses on usability, and then on integration of outputs to ensure that the components are interoperable. To use the tool effectively, users must have access to SNOMED. SNOMED is free in 14 countries, but other countries must pay one million dollars for a license, the team is working on increasing the availability of SNOMED for those interested in using cTAKES.

<u>Dissemination and collaboration</u>. The NLP team develops tools in an open source environment and makes them available on SourceForge. When the grant was written, Mayo anticipated a focus on researchers as the key target audience. However, as the project evolved, the team realized that the consumers would include non-researchers that did not have significant knowledge of NLP. This has greatly shifted how they deliver their products. The team has subsequently worked to make the tools user friendly. For example, the team implemented features to facilitate the development of a timeline and restricted the pipeline to enable users to download what they need.

A major audience for cTAKES and other NLP tools are developers working on special projects for EHR vendors. Gathering information regarding specific vendors using cTAKES is difficult, because they are not required to inform investigators they are using the software. The team normally finds out that people are using the software through word-of-mouth. Vendors using cTAKES include Cerner, GE and Med3000. While the team often hears from smaller vendors that are asking for expertise, they do not typically hear from larger vendors (since they tend to have NLP experts on site). Although SHARP does not provide funding for technical assistance and support, this is an important need, particularly to assist smaller organizations.

There are a number of collaborations currently taking place involving the NLP team. Information from SHARPn will benefit the VA Share Project (the one million veterans' project); the i2b2 Community; the NCBC (National Center for Biomedical Computing), and the eMERGE Pharmacogenomics Research Network (PGRN). In addition, standards organizations will also benefit from the research, especially the Continuity of Care Consortium's efforts towards inter-sharable data models. The NLP team also collaborates with other SHARP projects. For example, last year SHARP 3 demonstrated an application that used cTAKES to extract information on medication dosage and frequency from clinical notes.

Data Normalization Team

SHARPn's normalization team is led by Stanley M. Huff, MD, a SHARPn Co-Principal Investigator from the University of Utah. The team develops CEMs and works to create a collection of modular tools accepting data from a wide variety of formats and using those data to populate CEMs. Their work will allow users to customize the way they use these tools depending on of the desired application. The data normalization team will use output from tools developed by the NLP team, as well as structured data in a variety of formats to populate CEMs.

The team is focusing on building a number of "pipeline" tools that can be used interchangeably or in concert to normalize heterogeneous data. The plan is to gradually expand the variety of input formats that can be accepted by these pipelines, with NLP, HL7, and collective lists for lab values being slated for the

first quarter of 2012. While the prototype for the "tracer shot" used XML, they anticipate the final product being versatile enough to handle queries in RDF, XML, SQL, or other formats. Ultimately, these tools will work together to serve as a single "pipeline" for data normalization that, from a user perspective, will seem like a single application with multiple modular tools that transform a variety of data types into a set of CEM concepts.

Although it will seem like a single application, the pipeline software will not be a single, unified program. The model they are working off of is more modular, a library of "pipe-type artifacts" that can be used as needed. This is intended to allow users to work with the tools in different ways depending on the type of data they are normalizing, their desire to further customize some of the installations and the response time they require (i.e., near-real time normalization for emergency clinical care versus a longer window with more validation for research).

As mentioned above, for the "tracer shot" exercise, the normalization team developed an initial prototype integrating normalization tools and NLP tools in a single pipeline to demonstrate the end-to-end conversion of data from the Intermountain' s system and Mayo's system to a CEM database. The team anticipates having their core CEMs finished by the end of 2011. These models will include diagnoses, procedures and demographics, and are being developed collaboratively with project staff from HL7 and the International Standards Organization (ISO). Finally, the team plans to have a version of their normalization pipeline software production-capable by early summer 2012 and have already been in discussions with the Southeast Minnesota Beacon program about testing and use in a real-world environment.

<u>Dissemination and collaboration</u>. The normalization team contributes regularly to discussions taking place within national and international standards-certifying organizations, but they are unsure of how their work will translate into 'deliverables' in the early phases of the project. Much of their current work focuses on establishing standards and norms for use of tools that will be part of the pipeline. While they intend to release modules as early and often as its development allows, their overarching goal is to foster effective use of the tools to create comparable and consistent information.

The team intends for their products to be open source. They note, however, that Linux, which is free to download and run, has developed a market for companies to offer for-profit services including installation, maintenance, and technical support. They are therefore cautious of releasing the pipeline frameworks before standards for their use have been promulgated and adopted, as it could lead to other entities using their own proprietary approaches to use their tools, defeating the "true open source" intent

of the project. ONC has been made aware of this possibility, and that the team remains open to the possibility of keeping the tools proprietary in the initial releases.

While the team is confident that their products have already generated some attention in the academic community, they recognize that ONC's goal for the project is to disseminate products in the business sector, as well. They remain unsure of which models for HIE will be widely adopted by individual providers, and consequently the most effective channels through which to push data normalization and their project outputs to foster adoption for clinical purposes.

Phenotyping Team

The phenotyping team is led by Jyotishman Pathak, PhD of the Mayo Clinic, working collaboratively with Dr. Chute and others. To date, the team has focused on making use of tools from normalization and NLP efforts to identify groups of patients relevant to two use cases, identifying specific cohorts of patients using data from multiple EHRs and developing quality metrics that are part of stage 1 of meaningful use. The team's work on SHARP builds from their prior work on eMERGE and PGRN where the focus is on developing phenotypes to be used in genomics research and pharmaceutical efficacy.

Part of the cross-EHR testing use case, involves using phenotyping algorithms that leverage the tools developed by the NLP and data normalization teams as well as the Drools-based logic to data streams from Mayo and Intermountain to examine the consistency in phenotyping results and work to explain variation in terms of differences in coding and workflow at the two institutions. In order to establish algorithms and processes that produce consistent results, the phenotyping team is also investigating business process management (BPM) tools used in other industries (e.g., the financial sector) in consultation with work-flow specialists from health care with the goal of understanding the sensitivity of phenotyping results to variation in practices across institutions.

A large portion of the team's work to date has focused on innovative use of Drools, a rule language with inferencing capabilities with a user-front end targeted to clinicians. The team is working to take structured criteria and translate it into Drools rules. They will be using the criteria (most likely specified in XML) and converting it into a workflow based on Drools. For the initial use cases being tested, the goal is to achieve a positive predictive value of over 95% across institutions.

Differing organizational processes and procedures is an inherent challenge to ensuring a positive predictive value of 95%. For example, the team worked on an algorithm that required the use of a measure that is automatically generated in Mayo's EMR. However, when this algorithm was used at Vanderbilt and Northwestern the accuracy decreased substantially because their systems did not

automatically generate this measure. Figuring out these nuances is essential to ensure that project outputs are useful at organizations across the nation.

The team's focus is on identifying cohorts of patients with diseases that are more common, as opposed to rare diseases, since vendors and clinicians would be more interested in the common diseases. This is a departure from their eMERGE and PGRN work that sometimes focuses on rare conditions of interest from the perspective of clinical research. For example, the team will design phenotyping algorithms using CEMs specifying body mass index (BMI), since this is an essential marker for management of chronic illness and there are important variations, omissions and inconsistencies in the way it is captured by different institutions using different EHRs.

For the BMI effort, an algorithm published at Harvard was used to determine whether the weight entered into EHRs was valid. They used a decision tree, if the weight changed they calculated how much it changed and compared it to how much time elapsed. They then determined the standard deviation across all the patients' weights and examined the ranges over time. Another group has begun the developing a similar algorithm for height. Once the algorithms are developed, the next step is to determine what to do with a suspicious observation (i.e. should the questionable item be flagged or deleted?).

In developing parsimonious phenotyping algorithms that work across different systems, the team is working to exploit the inter-relationships between queries for validation. Any given query that is used for a secondary purpose is likely a series of smaller queries. For example, it is possible to run a complex query examining males under 75 years old who are diabetic and whose blood sugar readings are out of control, but by modifying the component queries, users can identify females with the same condition or males or females with healthy blood sugar levels.

Another focus of the team, is working to normalize, standardize and socialize robust phenotyping algorithms by developing a phenotype algorithm library. Historically, phenotyping processes are hidden in SAS or SQL code or even word documents. Templates are not available and consistency and rigor of research using EHR data is compromised as a result.

Overall goals of the project are ambitious and the applications highly varied. The phenotyping approaches they design and test apply to comparative effectiveness, quality reporting, chronic disease management, genomics research, clinical research, population health monitoring and a host of other secondary uses. The process is extremely time consuming and iterative and efforts to apply a semi-automated and transparent approach require a rigorous effort to leverage existing patents, work-flow paradigms and research conducted by other groups to ensure efficiency. Beyond the two use cases prioritized above,

team members are focusing on National Quality Forum (NQF) quality measures related to the management of diabetes care and lipid management for coronary heart disease as these are clinical priority areas identified by Mayo.

<u>Dissemination and collaboration</u>. The phenotyping team has published several papers, and plans to continue to disseminate their interim findings. They are the most widely published team across the SHARPn project, owing in large part to their ability to leverage the eMERGE and PGRN work. The team has also begun collaborating with several organizations including NQF (on quality metrics), integrating health care enterprise (IHE) on support for meaningful use, and Mitre on studying phenotyping algorithms used in their popHealth and Query Health software initiatives.

Beyond publication, dissemination efforts center around developing the algorithm library and making this library accessible by stakeholders involved in coding and software development in addition to the research community. The goal for the library is to create a repository that will exist well beyond the SHARP program. Although the work itself is not necessarily new, the theory driving the work is novel. Previously, this work was completed in siloes without collaboration. Their goal is to ultimately create a library and public portal where someone interested in the subject can search the component, and avoid duplicating existing work.

Executive Leadership

Finally, we met separately with the executive leadership team at SHARPn including the PI Dr. Chute, Ms. Hart and leads from each project teams described above. The team described the intense effort that went into pulling together components developed by the NLP and normalization team into the UIMA pipeline to execute the "tracer shot" pilot.

Much of the discussion focused around recent guidance suggesting that the programs must accelerate the rate at which they planned to produce research products, prototypes and artifacts of immediate value. SHARPn leadership emphasized the tension inherent in their goal of producing meaningful, "game-changing" strategic research while also trying to produce immediately usable products that can be successfully adapted to support meaningful use of EHRs.

SHARPn leadership noted that the Medicare and Medicaid EHR Incentive program focused intentionally on achieving immediate change. Their understanding of the SHARP program, particularly, the emphasis on "strategic research" implies substantial leeway on the part of individual awardees allowing deliberate, thoughtful approaches that require more time. Over the first year, the leadership team has focused on

balancing these competing priorities. In doing so, they report continuing to take a strategic and long term approach while finding opportunities for "quick wins" in some areas.

The executive leadership group affirmed the project's adherence to its core values and proposed schedule. The SHARPn team reports being slightly ahead of schedule in meeting their original goals. The team is prepared to meet the interim deliverables they established in their proposal and work to address the postaward focus on producing usable outputs more quickly.

In terms of producing and releasing useful artifacts at a fast clip, project leadership noted that the NLP team benefits from building on research conducted over the last eight years in making cTAKES accessible to the developer community and continuing to release code that allows cTAKES to work for a number of different use cases. The phenotyping team is creating new knowledge in the form of the algorithm library, testing methods to improve the consistency and validity of results generated by using common phenotyping algorithms across institutions and their extensive publication list detailing their efforts and their relevance to clinical and research spheres. Overall, the project rests on a commitment to open source philosophy and making all code and products free and available to the public. As a result of this commitment, stakeholders such as developers and programs currently access some of the team's work products, even those still "in development".

Leadership expressed some reservation about dissemination and promotion of results in high profile venues such as HIMSS. They felt that forums where for-profit vendors release and demonstrate software and components that are ready for market did not suit many of their activities that will not result in standalone applications that could be independently demonstrated and that emphasis on dissemination in these venues would not produce notable returns for the effort expended. The leadership re-iterated their sense that the strategic goals of the project required careful consideration for dissemination venues where they could have the greater impact such as, perhaps the OSCON Open Source Convention, collaboration with other initiatives and peer reviewed literature (all of which are already a focus for the team).

Recommendations, conclusions, and key takeaways

Overall, we found that the SHARPn project has made substantial progress towards its goals and has stayed on track as much as feasible given the complexity and uncertainties inherent in their work and their perception of the evolving expectations from ONC. Each team emphasized the importance of collaboration across their project and with other researchers as essential for their individual efforts to lend value to the field expeditiously. They expressed an eagerness to share results and tools with others and disseminate in appropriate forums.

They also acknowledged that some of the processes they are looking to formalize and improve with rigorous methods (e.g., cohort identification using EHR data, quality reporting) are already being implemented in ad hoc ways by others. Consequently, they face the burden of assuring that there work remains relevant by showing its superiority to existing practices as well as through active collaboration with projects such as popHealth, Query Health, health information organizations and other initiatives that are addressing similar problems. Finally, they noted that it's critical that the thrust of their work not be mistaken for software development of "off the shelf" solutions. While their focus is on relevance to day to day use cases and practical application, they note that the research is at an early stage and a tremendous amount of work needs to be done both in conjunction with their efforts, and subsequent to their work, to apply many of the tools, algorithms and methods they design to software used by stakeholders, particularly, clinicians on a daily basis.

Appendix I. Closing Discussion Participants

Meeting Discussants	Meeting Schedule	Reason / Focus for Meeting
Jiajie Zhang, Krisanne Graves, Muhammad Walji	January 28, 2014 11am – 12:00pm	Core team working directly with Principal Investigator Jiajie Zhang on SHARPC.
Stan Huff, Christopher Chute	January 29, 2014 12:00 – 1:00pm	Core leadership on SHARPn including Principal Investigator Christopher Chute.
Carl Gunter, Antonio Michalos	February 10, 2014 12:30 – 1:00pm	Core leadership on SHARPS including Principal Investigator Carl Gunter.
Raj Ratwani, Terry Fairbanks	February 10, 2014 3:30 – 4:15pm	MedStar staff who investigated health IT on behalf of SHARPC.
Robert Greenes	February 18, 2014 3:00 – 4:00pm	Key SHARPC investigator that transitioned the project's setting-specific-factors usability work to work focused on supporting the Standards and Interoperability Framework.
Jyoti Pathak	February 18, 2014 10:00 – 10:30am	Key SHARPn investigator responsible for developing tools to allowing providers and researchers to identify patient cohorts and report on NQF quality measures.
Ben Scheiderman	February 19, 2014 1:30 – 2:00pm	Key SHARPC investigator responsible for developing tools to support medication reconciliation.
Guergana Savova	February 21, 2014 2:30 – 3:00pm	Key SHARPn investigator responsible for developing tools that allow providers and researchers to identify patient cohorts and report on NQF quality measures.
Ivan Handler	February 26, 2014 10:30 – 11:00am	Chief Information Officer at the Illinois Office of Health Information Technology who collaborated with the SHARPS program.
Ken Mandl, Rachel Ramoni	February 28, 2014 2:00 – 3:00pm	Core leadership on SMArt including Principal Investigator Ken Mandl and Project Manager Rachel Ramoni.
Michael Morris	March 4, 2014 3:30 – 4:30 pm	Provider represented Network Health who collaborated with the SHARPS program.
David McCallie	March 7, 2014 2:30 – 3:30pm	Cerner executive who has worked with some of the SHARPn tools.

Appendix J. Closing Discussion Method

Objectives. The closing discussions focused on perceptions and understanding of successes stemming from the PIs' involvement in SHARP ("What went well?") and challenges or problems they faced ("What didn't go well?"). We also asked PIs to articulate lessons learned, both for themselves and potential lessons learned for other stakeholders such as government sponsors, providers, vendors and others.

These conversations covered not only logistical and process successes and challenges, but specific program achievements, as well as the PIs' understanding of the how these achievements may influence health IT in the short, medium and long term. We also discussed the PIs' impressions of the effectiveness of the SHARP program overall, including specific feedback on the role played by ONC and other SHARP awardees. Finally, as part of understanding successes and challenges, we discussed ways in which awardees collaborated with ONC programs outside of SHARP, including the Standard and Interoperability Framework, the Blue Button Initiative and others.

Discussants. We conducted a series of key informant meetings with PIs, key co-investigators and other stakeholders such as collaborating providers and vendors.

As part of the initial conversations with PIs, we obtained their advice on other investigators and stakeholders to contact for further discussion. We based the criteria for selecting additional discussants on the extent to which they could provide further detail and explanation of themes emerging directly from the PI meetings.

In assessing the PIs' suggestions, we selected additional discussants based on their knowledge of specific artifacts or tools developed by SHARP awardees and their ability to provide additional insight on lessons learned for industry, sponsors and researchers. Appendix D lists the discussants, as well as the reason and focus for each meeting.

Methods and process. We developed a custom agenda for each discussant to achieve the goals described above. Each agenda for the PI meetings included the following topics:

- Most important successes of the project
- Mechanisms by which project outputs may influence health IT adoption over time
- Key challenges, particularly with respect to transitioning the research results into practice
- Important lessons learned from all involved

- Role of ONC and other SHARP awardees
- Collaboration with ONC on non-SHARP activities
- Role of this type of funding for future health IT work

Each agenda included specific sub-topics based on a review of different components of each SHARP awardee and our prior knowledge of the project's work based on a review of recent progress reports. We designed agendas to assure that the NORC evaluation team obtained necessary and consistent information across each of the PI meetings while allowing sufficient flexibility for an open-ended discussion.

The same lead interviewer conducted each meeting and each meeting included a dedicated note taker. A second interviewer took part in some of the meetings. We sent agenda topics to discussants ahead of time. PI meetings lasted one hour and additional stakeholder interviews lasted a half hour. In addition to taking verbatim notes for all the meetings, our team recorded each PI meeting to facilitate review and clarification of the points raised.

Analysis and reporting. From the interview notes, we abstracted themes related to each of the three main lines of inquiry (successes, challenges and lessons learned). Given the variation across programs, we initially conducted this exercise for each awardee and then looked at potential patterns in themes articulated by stakeholders across awardees. We report our findings as descriptive summaries of themes associated with each line of inquiry first on an awardee by awardee basis and then synthesized across awardees. We draw on findings from these closing discussions and other research activities to suggest lessons learned at the conclusion of the final report for this task order.

http://healthit.hhs.gov/portal/server.pt?open=512&objID=1195&parentname=CommunityPage&parentid=97&mode =2&in hi userid=11673&cached=true

^{vi} McDonnell C, Werner K, Wendel L. Electronic Health Record Usability: Vendor Practices and Perspectives. AHRQ Publication No. 09(10)-0091-3-EF. Rockville, MD: Agency for Healthcare Research and Quality. May 2010.

^{vii} Keith A. Butler, PhD, Mark Haselkorn, PhD, Ali Bahrami, PhD, & Konrad Schroder, M.S. Introducing the MATH Method and Toolsuite for Evidence-based HIT. AMA-IEEE

ⁱ University of Illinois Board of Trustees. *Strategic Healthcare IT Advanced Research Projects on Security*. <u>http://sharps.org/</u>

ⁱⁱ The University of Texas Health Science Center at Houston (UTHealth). *National Center for Cognitive Informatics & Decision Making in Healthcare*. Retrieved from <u>https://sbmi.uth.edu/nccd/</u>

ⁱⁱⁱ SMART Platforms. SMART. Retrieved from <u>http://smartplatforms.org/</u>

^{iv} Mayo Clinic. Strategic Health IT Advanced Research Projects (SHARP): Research Focus Area 4 - Secondary Use of EHR Data. Retrieved from <u>http://informatics.mayo.edu/sharp/index.php/Main_Page</u>

^v Office of the National Coordinator for Health Information Technology Standards and Certification Criteria Final Rule. Washington (DC): Available from: