

# Final Report

AHRQ Contract AHRQ Contract 290-04-0006

Vanderbilt University

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# Chapter 1: Overview and Executive Summary

## Preface

This document summarizes Vanderbilt University's six-year effort to establish, operate, and evaluate on the Nation's earliest and largest health information exchanges. It serves as the Final Impact Report for AHRQ Contract 290-04-0006 awarded to the State of Tennessee and its sole sub-contractor, Vanderbilt University. As required, we include: an executive summary that includes all tasks; background information that includes findings and literature reviews, methodologies, results, limitations and implications for stakeholders (rural and urban). Recommendations for future research are provided as well as some discussion of the impact of our program's findings on health care policy-making.

This report is divided into ten chapters. To a significant extent, our organization is modeled after the guidance for State health information exchanges funded through the Office of the National Coordinator.

- In this first chapter, we provide an overview and executive summary. It is our best attempt at how scores of concerned individuals worked together to create a novel approach to health care delivery that has saved lives and saved money.
- In the second chapter, we describe the extensive planning process that both preceded and overlapped the initiation of the AHRQ-funded effort. We attempt to provide some lessons learned using a widely known planning framework.
- In the third chapter, we describe the governance model that built and maintained the trust necessary to create and maintain our approach to care. We describe differences between the governance we thought we needed in 2004 and the governance model that proved effective both as the project matured and as the Memphis effort was more tightly integrated into a state-wide approach to HIE.
- In the fourth chapter, we describe the business and technical operations central to ongoing operations. We outline the types of professionals we found necessary to create and support the work and we outline how these requirements changed over time.
- In the fifth chapter we present a brief overview of the project finances. The project received financing from AHRQ, from the State of Tennessee, and from Vanderbilt University. We describe variances in our budgets due to the uncertainties in exchange formation.
- In the sixth chapter, we describe the legal and policy issues surrounding our exchange effort. We emphasize the key role played both by the Markle Connecting for Health Common Framework and the vital and ongoing participation of a broad array of stakeholders in Memphis.
- In the seventh chapter we describe the technical infrastructure. Based on Vanderbilt-developed systems in use in our Medical Center for over 15 years, we describe how exchange can be accomplished to great scale at a cost of approximately \$1 per patient per year.
- In the eighth chapter, we describe at length our evaluation and impact studies. Evaluation was a major component to our effort from the earliest days of the product. We describe our planning approach and our study of usability, use, workflow, test ordering, hospital admissions decisions, impact on specific disorders, and our estimated financial impact.

## *Chapter 9: Sustainability*

- In the ninth chapter, we address our current views on sustainability based on our economic analysis, our experience in Memphis, and findings from across the United States.
- In our final chapter we summarize our project's contribution medical informatics research, its' relationship to the national health information technology agenda, and the guidance our work may provide as the Agency for Healthcare Research looks forward to enrich its research portfolio. Most important, we express a central belief we share – the availability of more comprehensive set of data from across provider settings can substantially improve the lives of both the individuals who receive care and the professionals who deliver care. Our project has changed the careers of those who labored to realize its' success. It is our hope these labors will endure and be reflected in the health of the community we were privileged to serve. Background and Purpose

## **Findings**

### **The State of the Exchange**

As of October first, 2010, users of the Exchange have access to 7.5 million encounter records on 1.7 million patients; these encounter records come from all major hospitals and some large clinics in the Memphis area – over 14 organizations submit data. Through the Exchange, clinicians can access 4.9 million chief complaints, 45 million laboratory tests, 5 million radiology reports, and 2.1 million other reports and documents. When non-clinical encounter records are included, the database has some information on 2.8 million individuals who have received care in Memphis since it was activated in May of 2006.

- Patients: 2,853,933
- Patients with Clinical Data: 1,697,695
- ICD-9 Admission Codes (Chief Complaints): 4,921,320
- Labs: 45,237,209
- Microbiology Reports: Unknown
- Radiology Reports: 5,098,360
- Other Reports and Documents: 2,170,531

Approximately 519 users have access to the system. Some are administrative personnel who access the system for data quality assurance purposes. The overwhelming majority of uses are by those who care directly for patients. These clinicians are located across over 30 sites

### **Planning**

Many factors and initiatives led to the initiation of this project. Facing a looming crisis in the State's Medicaid program, Tennessee's recently elected Governor understood the role a health information technology could play in improving the quality and efficiency of health care delivery and financing. A former health care executive and Nashville, Mayor, Governor Phil Bredesen was well versed in the health care information technology's transformative potential. His Commissioner of Finance and Administration responsible for Medicaid operations – Dave Goetz – had a similar commitment. The poor payer mix in the Memphis region and the perilous state of Memphis' major county hospital – the Regional Medical Center (the MED) – served as a strong local focus. Despite a history of discord manifest from a past effort to establish a community health information management information system

(CHIMS), health care delivery leaders understood that the failure of the MED would have potentially catastrophic financial consequences to the entire region.

To respond to these events, the State Commissioned a six-month study led by Vanderbilt University. Coincident with this process the State requested Vanderbilt to respond on its behalf for a regional demonstration program funded through the Agency for Healthcare Research and Quality (AHRQ). The planning initiative began formally in July of 2004. The AHRQ grant was awarded to the State and to Vanderbilt as a sole sub-contractor in October of 2004.

The planning exercise led to the definition of core entities and core data required by AHRQ. It outlined a governance model, a financial model, potential factors for evaluation, and savings estimates that could be used as a basis for sustainability. John Kotter's work on large-scale projects served as one guide to the overall effort. (Kotter 1995)

The planning exercise led to the initial guiding coalition and its decision to focus on bringing to bear in emergency room care settings as much information as possible from in-patient and ambulatory clinical encounters. The Vanderbilt architecture was endorsed because Vanderbilt offered to host this architecture and because the architecture placed minimal burdens on Memphis participants; no changes to their data standards were required. The exercise suggested some of the legal and policy issues that had to be addressed both for the overall organizational framework and the data-sharing agreements vital to maintaining transparency, trust, and privacy.

The planning exercise also suggested areas of focus for studying the economic and clinical impact of the Exchange. It further endorsed and used an accelerated planning technique routinely employed at the Vanderbilt Center for Better health. This technique is called a Design Shop; it combines consensus-building sessions with breakout group work focused on specific tasks. Finally, the planning exercise suggested ways to manage both governance and project management. A governing board was suggested; it was composed of a leader from every data contributor and many of the safety net clinic users (who would later contribute data). Although AHRQ and State funding flowed from the State through Vanderbilt, control of all activities was very much in the hands of the community whose commitment and effort were essential to realizing benefit.

Planning and pilot studies continued throughout the six-year period. Numerous Design Shops were conducted both directly to support the project and to use the lessons learned to advance efforts in other regions and states. These contributions are described at greater length in Chapter 4.

## **Governance**

Governance efforts were guided by a few simple principles. First, local control and trust is the most essential prerequisite for successful adoption and improved care. Second, such trust can be enhanced by a low-profile project management office from Vanderbilt that brought best national practices into the Memphis area and allowed these practices to be personalized and modified in ways that enhanced ownership but did not lead to actions that were fundamentally contradictory to national views. Third, State (and County) Government roles were crucial to provide a broader layer of trust among the Memphis participants and the Vanderbilt project management team. This trust was in part imposed and in part simply supported through the State's role as policy makers and funders of health care services in the region. Also, since Vanderbilt is itself a health care provider (albeit over 200 miles

away), the State's strong guiding hand assured the Memphis provider communities that there were no "hidden agenda" among the Vanderbilt team supporting this project.

As required by AHRQ, a Technical Advisory Panel (TAP) was created as an active and participatory group of national efforts who could both ensure the project remained leading edge and reassure both Memphis and State leadership that their investments were sound. This group was not simply "window dressing." Its oversight and reports very much influenced support from both the Community and the State.

## **Finance**

Capital for the project was provided through an AHRQ and State funding and *pro bono* services from Vanderbilt. Vanderbilt use AHRQ funding according to the grant budget and expended all allocated funds. Vanderbilt was able to return over \$1 million to the State of Tennessee. This was largely the result of Vanderbilt's contribution of computing infrastructure without charge to support the Memphis for approximately four years.

Our operational experience suggests that an exchange based primarily on hospitals can be provided for approximately 1.5 million people at a cost of approximately one dollar per person per year. Marginal costs to expand the exchange will very much depend on the extent to which ambulatory care systems are standardized. Our experience in connecting with a number of large providers using a common ASP platform (NextGen) suggests that ASP-based approaches allow for expansion at little technical cost. The cost of contracting and data-sharing agreements, however, is significant.

Our experience provides some important lessons: to the extent that ambulatory systems are standardized and data-sharing policies are the result of wide-spread consensus among providers and the public, effective data-sharing will become a low-cost and commonplace occurrence. We believe exchanges such as ours will become a basic "infrastructure" upon which value can be created, much as a network confers value by the services it supports. To the extent that barriers are thrown in the way of such consensus, costs will increase and net benefit will decrease. State, federal, and community leadership therefore are essential.

## **Legal policy**

Our legal and policy efforts were extensive and the difficulty, time, and true value of these efforts were not understood completely at the outset. In contrast to the challenges faced by other exchanges in that early period, we found incorporation as a non-profit relative straightforward; we do not believe we took any efforts to achieve this success but rather attribute it to the relative inexperience at the time among those who grant non-profit status. The organization is called the MidSouth eHealth Alliance. At the conclusion of the grant, this organization is responsible for all aspects of Exchange operation.

Our primary contribution to the region and to the national dialogue was in our early application to Memphis of the Markle Foundation's Connecting for Health policies. The documents provided a foundation for the creation of a legal framework that maintained trust among the organizations. Of equal importance, the process in which patient advocates and care providers participated over the initial six-nine month initial effort proved to create a community of supporters whose primary interest was in patient care and not simply high-level organizational objectives. This group served as the basis for a standing committee of the Board that modified policies and provides other guidance to the Memphis Exchange on an ongoing basis.

## Technical infrastructure

The technical infrastructure was based on the informatics architecture in use at Vanderbilt Medical Center for over fifteen years. In comparison to most other exchanges, it employed a novel system in which data can be submitted in almost any format. These data are parsed by a common set of software engineers supporting the Exchange. Parsing includes ensuring the data are complete and syntactically correct. Each data element is “tagged” with a specific high-level descriptor (e.g., “x-ray report,” “white blood cell count”). Demographic data are stored in a record locator service (a relational database) and actual clinical data are stored in a variant of Vanderbilt’s StarChart database. Each organization has a specific partition in this database we called a “vault.” Within the constraints imposed by the data-sharing agreements, each participating organization controls its own vault until another institution accesses data. At that juncture, accessed data are retained in logs so that they can be referenced independent of future contributing organizational decisions. Hence, data non-repudiation is present both at the vault level and at the institutional use level.

The core StarChart database was but a platform for use. Access through secure Web browsers was ensured through a simplified version of the Vanderbilt StarPanel interface. This interface was a passive Web browser with no two-way messaging other than simple query functions and display options. Web access required two-factor authentication. Print reports were also created and used extensively by one large institution.

Where standards were concerned, our system was capable of “standardizing” message on the “outbound” prior to display. We LOINC-encoded over fifty common laboratories to demonstrate the feasibility. Although some of the display features of LOINC were rarely used, the demonstration of this capability will be critical for two-way interoperability between the Exchange and other clinical systems.

We also demonstrated the capability of displaying prescription medication histories by sending registration messages to both SureScripts (via Regenstrief’s system) and to the NextGen ASP. We were capable of displaying these messages through our Web interface and during the limited trial of this system were able to draw some conclusions about the importance of this capability. Our initial position was – and remains – that most medication history can be obtained directly from SureScripts and a requesting EHR or clinical system. We suspect that most medication histories will be complemented with patient-provided comments through Web Portals or PHRs, and the Exchange may prove to be a valuable intermediary under these circumstances.

## Evaluation and impact

Our evaluation showed consistent use for approximately 7% of ED visits. Use by safety net clinics and hospitalists grew over time. The primary retrieved document was the dictated discharge summary (94% of usages included a request for these documents). Suggestion boxes and formal surveys were employed to assess usability and to make improvements. Extensive efforts were made to study the impact of the Exchange on workflow. Workflow documentation of each site showed two distinct patterns of use. At one institution, nurses or clinical assistants queried the Exchange, printed documents, and attached them to the clipboard holding the ED encounter form. 68% of usage over a two-year period was due to this approach. In the second use pattern, clinicians accessed the data directly through a Web browser. In restricted areas, this access was simplified by the use of a “whiteboard” Web display that listed all admissions taking place within the last 24 hours. Each row in the display listed the patient’s name, identifiers, the number of encounters from the current

institution, and the number of encounter records available from other care settings. Simply selecting a row displayed the entire Exchange record. In safety net clinics and among hospitalists, access was direct and focused on one patient.

Our medication history pilot showed both the potential and challenges of obtaining a prescription medication history through the Exchange. We found that connectivity was encumbered more by contractual than by technical means. We demonstrated the feasibility of passing messages through a second Exchange (the Indiana Health Information Exchange) to and from SureScripts. We noted the significant rise in results when retail pharmacy histories were included in the SureScripts service. We also demonstrated the feasibility of obtaining medication histories from a NextGen ASP serving many Memphis providers. Where e-Prescribing is concerned, we also planned and completed a small e-prescribing trial in Memphis in the early days of the new CMS regulations. In these early days, we found the value of the service incomplete largely because many safety net pharmacies were not yet capable of receiving prescription orders in electronic form.

Our financial impact analysis was striking. Although ED usage was low and no incentives were provided either for Exchange use or clinical behaviors, a case-control study of approximately 15,000 patients in each arm demonstrated significant decreases in admissions from the emergency department and, in some settings, decrease utilization of head and body CTs. Savings due to the 3-4% percent reduction in admissions from the ED accounted for the vast majority of estimated societal savings. Although the ED admission savings were consistent with our own highly conservative models, a decrease in test ordering was far lower than published predictions.

## **Summary**

We accomplished much in the six-year course of the AHRQ-State grant:

- We conducted an extensive planning exercise.
- We formed a guiding coalition and governance structure.
- We established industry-level business and technical operations.
- We developed and maintained rigorous finance management.
- We developed and implemented a wide range of legal and policy agreements to maintain trust, protect privacy, and govern Exchange operations.
- We implemented a comprehensive health information exchange serving every major hospital, several safety-net clinics, and one major county-run clinic. (One hospital is in the State of Mississippi.)
- We transferred operations and control from Vanderbilt University to a local governing Board and a commercial exchange technology firm. Because of our work, this region has a mechanism to sustain the exchange through ongoing operational support.
- We proposed and implemented an extensive evaluation program that provided guidance for future efforts and demonstrated a significant financial impact.
- We disseminated lessons learned and findings to numerous state, regional, and national bodies.
- We held numerous workshops to explore issues, develop plans, and to disseminate lessons learned.
- We developed, implemented, and evaluated a pilot service to provide prescription medication histories through the Exchange.
- We conducted a brief e-prescribing pilot; this pilot ultimately become part of state-wide e-prescribing efforts

In retrospect, we identified at least twelve overlapping stages in Exchange formation. The project was initiated as a result of state leadership. It was initially guided by planning and clarified through the AHRQ proposal; the guiding coalition of State and local leaders was a crucial early step; an awareness of common need arose as providers understood how stronger clinical oversight could help them control their own futures. An aggressive technical and policy effort led to early introduction and “quick wins” through anecdotes of a life saved and care improved. Local control and Exchange extension reinforced new wins. Even unsuccessful applications to Federal agencies (AHRQ, CDC, ONC) helped a broader segment of the community understand the potential for robust exchange. Finally, the dissemination of the model – and the people appears to be instrumental in charting a long-term course for the State of Tennessee.

Our experience suggests that both our process model and our technical model can make substantial contributions to our national exchange. Our process models documented the time and effort required to create and maintain an accountable level of trust. Our Vanderbilt-based architecture was shown to be a robust, scalable, and very inexpensive model for health information exchange. With widespread convergence on issues central to data standardization and privacy considerations, and data-sharing provisions, we believe future efforts will realize even greater benefit as costs to integrate across a wider array of ambulatory-based EHRs, laboratory devices, and other technologies. This broader integration will foster more effective care coordination and allow for demonstration of care impact across entire populations and not just those who seek hospital or emergency department care.

### **Recommendations for Policy Development and Future AHRQ Research**

As our project evolved, we noted the growing presence of exchange services that complemented exchange organizations. From the outset, we realized that some services (e.g., medication histories) could be provided directly to caregivers independent of any health information organization supporting exchange. Information could also be exchanged between data providers and patients. In the course of our work, we estimate that a small number of patients (we estimate fewer than 5%) are beginning to incorporate their health information in personal health records.) Finally, providers sharing a common ASP model are beginning to exchange messages among one another independent of the exchange. Health plans as well are very much involved in exchange. In Tennessee, a separate exchange service (Shared Health), funded by Blue Cross Blue Shield of Tennessee, continues to play a role across the state. We believe current market forces, data-sharing impediments, and other factors will only accelerate the trend to “exchange” data within a region through a variety of means. The purely hierarchical model of provider through regional exchange through state exchange through national networks is too simplistic. Indeed, an analysis of messaging traffic among providers and other health care entities would suggest that such a model is applicable only to a very limited set of data and purposes.

What are the implications of these observations? First and foremost, the architect Louis Sullivan’s “form follows function” rule is quite applicable. People and organizations exchange data with one another for a range of purposes. Each organization supporting exchange for an individual purpose generally has other reasons to support its technical infrastructure and hence can expand exchange activities within restricted parameters at a marginal cost. It is possible, therefore, that the focus of regional exchanges will be largely restricted to unique regional issues among participants. Quality indicators, readmission rates, and care coordination programs are candidates. If this model is correct, then regional

exchanges will closely resemble their CHMIS precursors achieving the aspirations of these earlier efforts at lower cost, a climate conducive to secure sharing, and an environment that provides economic incentives for sharing activities. States, too, will play a role in light of their responsibility to support public health activities, support care facilities, and manage their Medicaid programs.

From a policy perspective, community activism will focus attention on the necessity for a patient-centric approach to care. State governments can use their considerable regulatory power to demand exchange capabilities as part of their procurements and funding. They can also use fees from health care transactions to provide oversight and key infrastructure that would be hard to maintain solely on market principles. The Federal governments role is primarily to adopt standards and policies that encourage exchange both across the nation and within DoD, VA, and other federal providers. Federal guidance on secondary data use policies will also be welcome. Many of the current privacy recommendations and policies are confusing and potentially inhibitory to secondary uses in the public interest that are widely accepted by the public. Where public acceptance is concerned, privacy approaches may be advanced if the “contextual integrity” of public expectation is assured through policies and technologies that ensure the use of data is consistent with social and public norms and traditions.

Work in health information exchange will also have a significant impact on the AHRQ agenda. For example, in September of 2010, AHRQ awarded \$473 million in grants and contracts to support patient-centered outcomes research. Of this amount, at least \$50 million has been awarded to create all-payer claims databases and similar resources. Clinical data available through exchange can both complement such databases and arguably shift the focus from databases designed primarily to adjudicate payment to a data-rich environment based on clinical labs, medications, problem lists, complications, and other expressions in coded or natural language programs. This shift in data types may be accompanied with a shift in control. At present, use of these databases has been dictated in conformity with law to health plans and government agencies. In the future, projects such as Memphis suggest the potential for a far greater degree of control over data. Acting on behalf of individuals who seek care in these institutions, community-based exchanges presage a more economically successful era of Community Health Management Information Systems (CHMIS). Additionally, consumer-driven databases like the popular PatientsLikeMe site will add another perspective onto our use of clinical data to advance research. As all of these initiatives progress, our research environment may emerge with a range of overlapping data resources, each designed for different purposes and each working in complement with others to drive local and national results.

Our effort also emphasizes the importance of a wide range of biomedical informatics research efforts funded through institutions, non-profits foundations, for-profit companies, and government. The wide range of programs funded through the Office of the National Coordinator (ONC) is but one example. The impact of our work on both the State HIE awards and the BEACON communities is self-evident; the technologies, policies, and evaluation also make significant contributions.

The importance of additional research in the four research areas mandated through the Strategic Health IT Advanced Research Projects (SHARP) Program is also emphasized by our findings. SHARP research in security of health information technology is motivated by the constraints imposed by our limited capabilities to ensure patient and public expectations are met consistently through our current health information technology infrastructure; despite extraordinary effort and focus, and a degree of operation far above

general applications of HIPAA, the relative inflexibility of our capability to promote accountable care and to advance secondary use demonstrates the enormity of the work ahead. Technology must work in concert with policy and not simply be focused on implementation of such policy. Similarly, the potential for secondary use of clinical data for appropriate purposes has not been realized; even after six years of operation, our project lacked the organizational commitment, the consent infrastructure, the high-level analysis tools, and the policy infrastructure to leverage the potential of exchange. Although our technology is inexpensive, easy to implement, and capable of great scale it must interact with a range of applications through standard interfaces along the lines exemplified by the SHARP healthcare applications and network platform research.

Finally, our work very much emphasizes the need for far more extensive means of supporting the knowledge management and cognitive effort required to enhance patient care. Current HIT initiatives will not be sufficient to manage the growing and overwhelming complexity of data and information. Indeed, rigid automation of the status quo may even retard our ability to achieve the vision of 21st century health care consistent with societal need. Future systems will require a far greater capacity to integrate weak signals from disparate resources and migrate clinical use of health care information technology from the manipulation of transactions to the management of knowledge. Our approach to health information exchange provides a unique and critical foundation for pursuing such research.

To a certain degree, one can argue that the past six-years presages a greater divergence between “exchange” as a verb and “exchange” as a noun. The former, we believe, will be commonplace; it will be achieved technically through a range of means and services; it will be sustained by immediate value to care; and it will be governed by generic provisions to federal and state privacy laws and policies. The latter, we believe, will accelerate more extensive secondary use of data locally and in advance of the slower national consensus. Our experience suggests that the Memphis exchange and similar architectures in Nashville and other communities are examples of the platforms upon which AHRQ and other groups can support vital health care quality and care delivery research.

The Agency for Healthcare Research is to be applauded for its vision in supporting five-year programs before the creation and growth of ONC and other federal groups. AHRQ’s solicitation clearly stated that developing more efficient and effective means for exchange was an essential prerequisite to widespread measurement of and improvements in health care delivery quality.

## Chapter 10: Concluding Comments

### Meeting AHRQ's requirements

Vanderbilt has met the AHRQ requirements.

**Milestones.** Vanderbilt met all milestones for both for definition of core entities and core data elements as well as for demonstration of 25%, 50%, and 100% exchange of data elements among these core entities.

**Technologies.** Vanderbilt's derivative technologies (e.g., ICA) have been adopted in other regions within the state (and country), the design principles developed in the project have been adopted in defining TN's state-wide plan, and the personnel have assumed leadership in state-wide efforts. These technologies were very much the result of AHRQ's requirement to "reduce risk by building on proven experience."

**Leveraging existing efforts.** Vanderbilt was successful in leveraging provider based IT initiatives and, to a more limited degree, leveraging the expertise of one managed care organization and one health plan in the region. Vanderbilt's Medicaid impact statement was delivered on time and the integration of Medicaid into statewide plans has been largely achieved.

**Evaluation.** Vanderbilt developed and delivered a comprehensive evaluation plan. It has studied impact on workflow, satisfaction, and financial impact. Although we were unable to demonstrate quality improvement in a systematic way, our qualitative work did record anecdotes of dramatic care improvement in some instances.

**Governance.** Vanderbilt's governance model was similar to many others. It can be differentiated in only a few ways: we used care delivery professionals to advocate for consumers; we required minimal involvement of formal clinical and financial work groups; and we stayed very focused on specific ED activities to realize quick wins and build trust.

**Legal.** Arguably, our early adoption of the Markle Connecting for Health Framework had great national impact. Our data-sharing agreements have been shared with many other HIEs and a national workshop held in 2005 brought paying participants from 20 states to learn from our experience.

**Sustainability.** Vanderbilt's HIE sustainability plan for Memphis became far simpler because of our emphasis on fundamental, universal services and not value-add services. Using a model of what economists called "facilitated user networks," we concluded that the keys to sustainability were low costs and an equitable annual fee payment by large providers. We argue our costs (approximately \$1 per person per year or less) are among the lowest reported. We can document reduced savings in overall hospital admission and test costs that exceed by 2-3 times the annual operating costs for the exchange in its current form. Overall, we believe a very low cost "shared utility" model coupled with specific programs offers the best solution for sustainable improvement.

**Widespread adoption.** Although our architecture could scale to an entire state, our project focused on *regional* implementation; our experience is that statewide adoption takes time and trust; rarely in the United States is this degree of dissemination extant even today. In addition to trust concerns, financial barriers are also considerable. Our work suggests that

exchange can be performed at low cost; the barrier, in our mind, is perceived *value*. Exchange is economically an immature market where neither buyers nor sellers know the value of their offering and where the characteristics of a useful “product” are not a matter of widespread consensus. Although HITECH’s incentives to adopt certified EHRs employing standards will lower the *cost* of connectivity even more, the *value* of connectivity within a community remains uncertain and merits further formal study.

## **Application to Federal and State Policies**

The Federal government, states, non-profits, and for-profit companies have supported a wide range of health information technology initiatives since our project began in 2004. In this section, we highlight how the lessons learned from our project could or have impacted the course of these events. We separate our discussion into programs initiated prior to the HITECH Act of 2009 and those after HITECH. Where programs have spanned across this divide, we have placed them in one category or another based on our view of their contemporary impact.

### **ONC Programs Prior to HITECH**

Much of our early work was heavily influenced by Brailer and Thompson’s initial ONC strategic plan unveiled in the summer of 2004. (Thompson and Brailer 2004) Brailer’s approach was heavily centered on Regional Health Information Organizations (RHIOs) and the work in Santa Barbara, Cincinnati, and Indianapolis. Most studies and estimates published at this time overstated the measurable financial benefits and many understated the political complexity and implementation cost. The ongoing technical mantra of “interoperability” may have distracted many from a closer attention to the measurement of immediate value. But ONC’s work across its’ many programs did foster a heightened awareness of both the value and challenges with exchange and, in our view, set the foundation for progress.

ONC played an influential role in our Design Shops and collateral activities supported by the Memphis project team through the Vanderbilt Center for Better Health. Dr. Frisse helped revise an ONC HIE proposal in Baton Rouge one week after Katrina; this led to the formation of LaHIE – the current state-designated entity for ONC’s State HIE program. His widely disseminated email concerning the need for HIE data post-Katrina is cited by the Markle Foundation as one of the events that led to the initiation of the Katrina Health Project. (Markle Foundation 2006) When the Gulf States regional health information project was commissioned through ONC and managed by the Southern Governor’s Association, Vanderbilt conducted several workshops and played a supporting role for many months. When the State of Louisiana wanted to re-engineer its’ ONC-sponsored HIE activities, they came to the Center for Better Health and worked with Vanderbilt Staff. This relationship continues to this day. The Vanderbilt Center for Better Health conducted two workshops to help prepare for their Statewide HIE application and Dr. Frisse advised on and contributed to the preparation of the Louisiana’s State HIE proposal. Vanderbilt’s Design Shop methods and the Vanderbilt team were also central to initial HIE planning for Mississippi, for Medicaid Transformation Grant planning in Alabama, for an initial workshop on large-scale government management held in Washington and sponsored by David Blumenthal, an AHRQ Design Shop on clinical decision-support, and a later ONC-sponsored workshop that led to the creation of some of ONC’s education initiatives.

Working through AHRQ, Mark Frisse and Vicki Estrin applied to the program preparation their expertise in data-sharing agreements and the results of their workshops in privacy and security. Although the Tennessee application was not selected in the initial phases of HISPC, both Frisse and Estrin spoke at and participated in regional and national HISPC meetings. (Dimitropoulos 2007) Workshops on long-term care in New York State and on health care reform in Puerto Rico also were impacted by our Memphis experience.

Dr. William Stead played a major role in the Commission for Systemic Interoperability. (Commission on Systemic Interoperability 2005) Their report was mandated by Congress and largely preceded ONC's formation. Dr. Stead was a primary driver for the report section emphasizing the need for a prescription medication history resource. The spirit of this work was carried through into our medication history service collaboration with the Regenstrief Instituted.

Neither Vanderbilt nor Memphis formally participated in the Nationwide Health Information Network. In our view, the one year period for both the NHIN I and the NHIN II efforts was too short in duration to achieve the intended results. In NHIN I, we believed that the scope of activity was too broad and "industrial" in light of the state of technology. In preparation for an unsuccessful application to CDC, we studied in great deal the specifications and use cases associated with NHIN II and found them too complex, too detailed, and possibly self-contradictory. Like many others, we nonetheless learned much from these pilots and were able to incorporate some of their lessons into our past and current work.

### **Meaningful Use**

Meaningful Use is a term used to describe legislative requirements necessary for EHR adoption. The criteria that must be met to demonstrate adoption under Meaningful Use provisions are a subset of the functions required to use EHRs effectively. These criteria were mandated as an effort to ensure EHRs would be employed through a network of technologies in support of a broader system of care. EHR adoption is essential for exchange and, through Meaningful Use provisions, exchange is conversely an essential pre-requisite for EHR adoption. Much of the exchange of data required to demonstrate Meaningful Use does not require the type of Exchange we created in Memphis, but such an exchange can be used to support these needs.

HITECH calls on the secretary of health and human services to develop specific "meaningful use" objectives. The Meaningful Use provisions address three stages of EHR adoption. The first stage (2011-12) focused on primary EHR features and demonstration of capabilities. These regulations have been published. The second stage (2013-14) will focus on demonstrating use. The third stage is expected to focus on measurable outcomes. The first stage requirements have been "divided into two groups: a set of core objectives that constitute an essential starting point for meaningful use of EHRs and a separate menu of additional important activities from which providers will choose several to implement in the first 2 years." (Blumenthal and Tavenner 2010)

The core objectives and metrics are based on the use of EHRs in health care. These objectives include tasks essential to creating a medical record: patients' vital signs and demographics, active medications and allergies, up-to-date problem lists of current and active diagnoses, and smoking status. Other core functions address safety and quality and are designed to support a number of clinical decision support functions, clinician order entry, e-prescribing and the capability to connect to external entities (e.g., pharmacies, health plans, and other providers). Many of these functions are already available in

commercial EHRs. A second group of criteria offers clinicians a choice of adopting any five of 10 additional tasks. These choices include the capability to perform drug formulary checks, incorporate clinical laboratory results into EHRs, provide reminders to patients for needed care, identify and provide patient-specific health education resources, and employ EHRs to support the patient's transitions between care settings or personnel.

Our belief is that much exchange of communication among EHRs in Memphis and elsewhere will be the result of point-to-point messaging or supported through secure "private" networks of single vendors or broader vendor coalitions. This is particularly true where eligibility determination, formulary status, e-prescription transmission, laboratory testing, and medication history services are concerned. (Surescripts 2010) We believe the NHIN Direct specifications will unite these various "exchanges" to allow for interactions among them.

We believe the Exchange we have created in Memphis will play a central – but not exclusive – role in supporting Meaningful Use. It can leverage its existing communications, record locator services, and exchange capabilities to expand the regional participant base at a low marginal cost. Although "exchange" of messages is a given and will be very inexpensive, we suspect the most vital role our repository-based Exchange model may play will be in the effective measurement of quality and in real-time or post-hoc support for and measurement of factors vital in care transitions. In the former instance, our Exchange was able to track influenza complaints and encounters in "real time" and is capable of alerting all participants to any hospital re-admission. In the latter instance, our Exchange is capable identifying discharged patients and supporting staff to ensure they receive adequate follow-up.

In light of the critical role the Exchange may play in regional quality metrics, we suggest with some irony that the Memphis Exchange may very well become a successful instance of the failed Memphis CHMIS that Paul Starr wrote about in his 1999 Health Affairs article on technology and policy. (Starr 1997)

### **State Health Information Exchange**

The State Health Information Exchange Cooperative Agreement Programs are the product of the "American Recovery and Reinvestment Act of 2009, Title XIII - Health Information Technology, Subtitle B—Incentives for the Use of Health Information Technology, Section 3013, State Grants to Promote Health Information Technology." The initial funding opportunity announcement and a subsequent July 6, 2010 program information notice (PIN) suggest how our AHRQ-funded project experience can inform the ongoing interest in the role of States in HIE. ONC requires states to:

- Initiate transparent, multi-stakeholder processes to address exchange needs.
- Monitor and track meaningful use capabilities
- Assure trust of information sharing
- Set strategy to meet gaps in HIE capabilities for Meaningful Use including policies, core service provision, and broad connectivity.
- Facilitate reporting to public health and CMS
- Address five primary domains: (1) governance; (2) finance; (3) technology; (4) business and technical operations; (5) legal and policy.

Where transparency, stakeholder inclusion, and trust are concerned, our experience identified many common barriers and suggests approaches to surmounting these barriers. Much of our early success was due to highly visible and sustained leadership directed towards a focused objective of common concern. Although our work emphasizes the

accomplishments and demonstrates the potential to achieve a far higher degree of connectivity both in scope and depth, at present, the Exchange lacks widespread ambulatory connectivity. Although much of this connectivity could be achieved through our model, it is possible that a hybrid effort involving our “vault” model and ancillary exchange services can and will provide an alternative; time will tell. Although we did not submit test results directly to public health agencies, we worked for many months on an effort to receive CDC funding to accomplish this and, in our effort, developed an approach that can be implemented easily. The tight relationships between our project and the many other efforts in the state have led to a focused state-level plan that will achieve many of the desired outcomes motivating the State Grants program. Rather than summarize how our work impacts each of the five domains, we have instead reported our contributions through the previous separate chapters for each of the five domains.

## **BEACON COMMUNITIES**

The Memphis HIE has played an important role in Memphis’ February 2010 application to the ONC-sponsored Beacon Community Cooperative Agreement Program. The Memphis BEACON application proposed to extend the AHRQ-funded HIE with countywide diabetes registry operated as part of the ongoing technology infrastructure. It was designed to address the need of all of the estimated 77,000 individuals living within the Shelby County, Tennessee area. This registry was to be enriched with EHR records from primary care providers and endocrinologists. Enhanced care coordination enabled by the diabetes registry and expanded EHR adoption was to shift the point of access for diabetes care toward the ambulatory care setting.

The Memphis BEACON project proposed to: (1) To improve diabetes care for all individuals with diabetes throughout the county as measured by a composite of four diabetes care indicators (i.e., A1c testing, LDL-C testing, clinical foot exams and retinal eye exams); (2) improve diabetic control and reduce complications among high-risk diabetic patients as measured by clinical values (e.g., Hgb A1c, LDL-C and blood pressure, rate of potentially avoidable ED visits, rate of uncontrolled diabetes preventable hospitalizations, and rate of lower extremity amputations); (3) reduce health disparities in diabetes care delivery.

Although this program was not funded by ONC, it does reflect a significant sea change within the Memphis Community in at least two ways. First, the proposal exemplifies a shift in leadership attitude from the necessary “building” stages to subsequent “applying” stages. Health information exchange is no longer the primary question in Memphis. Rather, it is how the exchange of health information can improve health by creating upon the low-cost infrastructure capabilities that improve care and lower cost. Second, a far broader group of constituents was mobilized toward the common aim of diabetes control. This broader community involvement – in care delivery, in philanthropy, and in research – is emblematic of the transformations set forth by the original AHRQ-funded program reported herein.

## **Privacy and Security**

Our work emphasized the importance of additional research in the four research areas mandated through the Strategic Health IT Advanced Research Projects (SHARP) Program. SHARP research in security of health information technology is motivated by the constraints imposed by our limited capabilities to ensure patient and public expectations are met consistently through our current health information technology infrastructure; despite extraordinary effort and focus, and a degree of operation far above general applications of HIPAA, the relative inflexibility of our capability to promote accountable care and to

advance secondary use demonstrates the enormity of the work ahead. Technology must work in concert with policy and not simply be focused on implementation of such policy.

The same issues inhibiting exchange in clinical care settings – privacy, data sharing, security, and trust – are also central barriers to legitimate “secondary use” of clinical data. In Memphis, the potential for secondary use of clinical data for appropriate purposes is not yet taking place; The Exchange has only in the waning days begun to address the organizational objectives, the consent infrastructure, the high-level analysis tools, and the policy infrastructure required to leverage the Exchange to explore systematically the application of data to populations. (Evaluation work on specific disease outcomes based on Exchange data and led by the University of Tennessee provides much-needed awareness of the Exchange’s repositories as an analytic tool.)

Our observations strongly suggest the need for additional research in a number of related domains:

- **Policy.** Our work demonstrated the value of the Markle Connecting for Health Framework and the benefit of heightened community awareness due in large part to the importance HITECH has placed on these issues. The leadership shown by ONC, RTI, and others involved with HISPC has also prepared communities to foster exchange. Still, a concerted federal effort is essential. Alignment among health and consumer privacy laws will be of equal importance. Clear guidance emerging from ONC, coupled with resources available from ONC, AHRQ, and other groups will be required to accelerate compliance with the many complex privacy regulations. In the final analysis, change in privacy practices and community trust is the result of efforts “on the ground” within communities. Support for these efforts is critical. One hopes that with time each community will not of necessity “reinvent the wheel,” but instead build on the experience of others and focus more on the need to “institutionalize” new privacy practices in the activities of every individual who managed personal health information. Trust takes time and effort; it will not happen uniformly or quickly. .
- **Access and Directory Services.** Like early NHIN pilots and most other HIE initiatives, our work did not employ a federated network of directory service to access practitioners but instead employs a “hard wired” directory service. This approach will not scale easily if at all. Additional research in this area will be required to find robust models. In the interim, state HIE efforts can be immediate beneficiaries and provide one option for developing persistent directory coordinating services. Firms that already have extensive directory services may play a vital role. These include claims processing firms (e.g., Emdeon), eligibility organizations (e.g., CAQH), e-prescribing intermediaries (e.g., SureScripts). Their current approach was summarized in their testimony to the NHIN Workgroup of the HIT Policy Committee on December 16, 2009. (Council for Affordable Quality in Healthcare 2009; Emdeon 2009; Surescripts 2009)
- **Authentication.** Our work employed only relatively simplistic but cumbersome two-factor authentication methods. These approaches are expensive to support and do not easily scale. Our choice to employ two-factor authentication and to set a higher barrier for access was the result of the absolute need to reduce risk of unauthorized breach while trust was being built (and while Medicaid budgets were being cut). Our approach was more or less “all or none” in that access to the system at any time would allow one access to all records within the system much as is the case for many organizations using EMRs. Audits and real-time IP address checks were our primary enforcement vehicles. There is a very real need for authentication methods that are easier to use, less expensive to maintain, and more aligned with native systems in health care settings. Our

“single sign-on” project accessing Exchange data through the Baptist Hospital Web portal is one approach, but more generalized approaches are essential.

- **Authorization.** Our authorization approach was equally simplistic. If one sent a registration event from a known site and a user from that site accessed the data from a known IP address with two-factor credentials, one assumed the individual was authorized to access the record. Our approach did not distinguish among care setting context, roles, or data needs and hence were far coarser than would be required in generalized, nationwide settings. Ultimately, one can imagine system where authorized individuals are given keys to decrypt only certain parts of a medical record or transition. These approaches are being evaluated at Hopkins and Vanderbilt by studying attribute-based encryption as part of a larger SHARP-funded effort to advance security and privacy research (see <http://www.sharps.org>).
- **Anonymous data.** Our experience at Vanderbilt suggests that data can be made anonymous to a prescribed degree of probability. Vanderbilt employs this approach in its CTSA work (<http://www.mc.vanderbilt.edu/victr/pub/vuctsa/>). Such approaches will be of growing importance as the need for community and public health monitoring systems grows. Assuring the anonymity of these databases will require ongoing monitoring and research.
- **Representation – data.** Our system sufficiently tagged data to identify the nature of its content. Some data – labs, encounter codes, and pharmacy records in particular, are specific enough that their implications are inherent in the type of data. For example, a psychiatric drug may indicate psychosis and a lithium lab level may indicate bi-polar disorder. It is therefore simple to block telegraphing a specific disorder by blocking all messages of this type. But when dictated reports are involved (even radiographic reports), all bets are off. Accordingly, we believe it will require much more structure of data or stronger natural language techniques to allow one to transmit dictated reports under situations that preclude disseminating information about specific medical conditions. Over time, attribute-based encryption technique may provide additional assurances, but at present, our means of representing data are not sufficiently robust to accommodate some privacy concerns without eliminating a very large body of information necessary for optimal care.
- **Representation – users of data.** Identifying who is requesting information also becomes more essential as exchange becomes more commonplace. Clear understanding of roles is an important aspect of classifying users in context. Role classifications and declarations are extremely complex in that they are at times transient (Dr. X covers for Dr. Y this weekend only), they are not reflexive (X may see Y’s data but Y may not see X’s data), and they aren’t consistent (when in the role of a doctor, X may see Y’s data, but when in the role of a patient, X may not see Y’s data). Incremental approaches to role standardization are essential both at the institutional and later at the national level. Current research efforts among standards bodies and other groups has advanced our ability to represent roles and relationships, but an overall consensus model for HIE has not yet emerged.
- **Context.** Many of the policy and representation issues raised by our work arguably may be better understood through a framework of contextual integrity. (Nissenbaum 2010) Nissenbaum posits contextual integrity as an “alternative benchmark for privacy, to capture the nature of challenges posed by information technologies.” Contextual integrity ties adequate protection for privacy to norms of specific contexts, demanding that information gathering and dissemination be appropriate to that context and obey the governing norms of distribution within it. In other words, one must model expectation for use and demonstrate that any use is consistent with expectation.

Traditionally, one can trace information flow through the three states of collection, aggregation, and use. Collection limitation – a principle of the Markle Foundation and EU work – is perhaps an unnecessarily low barrier since it's primarily goal is to prevent inappropriate data use by not collecting data in the first place. Contextual integrity – if properly explored and modeled may afford more exchange of data while still remaining consistent with personal preferences and social norms.

- **Encryption.** Our Exchange efforts recognized that encrypting all data would be an ideal approach to ensure unauthorized breach and, in the course of our work, Federal policies moved towards this encryption. But if one encrypts data, one may find more value in encrypting it in such a way that sensitive components of a record require different keys than more generic components. Under a totally encrypted approach, one could keep the data “open” and rather than grant access, instead grant keys to decrypt specific records or portions. We believe this approach merits investigation as our SHARP security work applies attribute-based encryption to exchange. In addition, Vanderbilt researchers are also exploring means by which similar encryption techniques can be applied to patient matching algorithms.
- **Audit logs.** We designed our system to accommodate large-scale audits. We view provable and demonstrable audit capabilities and practices as essential prerequisites to maintaining trust. But much more can be done. As messages become transitive (going from A to B to C to D), there are times where some assurances must be made that the use of data among all parties conforms with expectations. Means of tracing data across audit logs must be found. Although this issue mentioned in Gartner/ONC's NHIN I summary report, little attention has been paid to this requirement. As a second line of inquiry, audit logs themselves may provide insights into users and patters that are not explicit through formal roles. Evidence-based access management (EBAM) is an approach used by some researchers to understand how audit logs may provide insight into authorized access policies. The work on the Memphis Exchange (and some of the team members) will be applied to this line of inquiry as EBAM is studied in the context of HIE through the ONC-funded SHARPS security grant.
- **Mobile health.** We do not believe that policy-making processes can possibly stay ahead of technology and data demand. New devices – particularly in mobile monitoring and in personal health records – will require different social conventions and different technology and policy means to assure data are secure and private in conformance with individual expectations. Reconciling these myriad devices within a highly restrictive policy framework is neither possible nor in the interest of innovation. On the other hand, failing to attempt to reconcile use of current and future devices with current paradigms and policies is equally hazardous. Clear dialogue between the “bleeding edge” PHR / mobile health community and the more conservative “national health infrastructure” community must be fostered and maintained. In reconciling approaches, a far richer set of experiential data will become available to help understand factors that influence our health.

## Usability

With the introduction of data from many other institutions, providers using the Exchange were forced to contend with far more information than that available from a single system or a single care encounter. They naturally expressed their frustration in finding information and in separating “signal” from “noise.” Our effort validated the need for far more extensive means of supporting the knowledge management and cognitive effort required to enhance patient care. In an era of distributed care coordinated through information exchange, rigid

automation of the *status quo* may retard our ability to achieve the vision of 21st century health care consistent with societal need. Future systems will require a far greater capacity to integrate weak signals from disparate resources and migrate clinical use of health care information technology from the manipulation of transactions to the management of knowledge. (Stead and Lin 2009) Although our technology is inexpensive, easy to implement, and capable of great scale it must ultimately manage data from an ever-widening array of devices and applications. Our approach to health information exchange provides a unique and critical foundation for pursuing research aimed toward standard approaches and for studying the provision of care in a data-rich environment of overwhelming complexity.

### **Other Observations and Recommendations**

As our project evolved, we noted the growing presence of exchange services that complemented exchange organizations. First, some services (e.g., medication histories) could be provided directly to caregivers independent of any health information organization supporting exchange. Second, information could also be exchanged between data providers and patients. In the course of our work, we estimate that a small number of patients (under 5%) were beginning to incorporate their health information in personal health records. Third, providers sharing a common ASP model are beginning to exchange messages among one another independent of the exchange. Finally, health plans as well are very much involved in exchange. In Tennessee, a separate exchange service (Shared Health), funded by Blue Cross Blue Shield of Tennessee, continues to play a role across the state.

We believe current market forces, data-sharing impediments, and other factors will only accelerate the trend to “exchange” data within a region through a variety of means. This suggests the insufficiency of any approach based on a strictly hierarchical exchange model. In these models, providers communicate through only regional exchanges, which in turn communicate through state exchange and ultimately through national networks. Although such hierarchical models may be applicable to a limited set of data accessed for specific purposes, more complete and connected models are likely to be more pervasive and robust.

What are the implications of this perspective on exchange? First and foremost, the architect Louis Sullivan’s “form follows function” rule is quite applicable. People and organizations exchange data with one and other for many different reasons. Each organization supporting exchange for specific purpose generally has developed a technical infrastructure for an array of business needs. Hence, these organizations can expand exchange activities within restricted parameters at a marginal cost. It is possible, therefore, that the focus of regional exchanges will be largely restricted to unique regional issues among participants. Quality indicators, readmission rates, and care coordination programs are candidates. If this model is correct, then regional exchanges will closely resemble their CHMIS precursors achieving the aspirations of these earlier efforts at lower cost, a climate conducive to secure sharing, and an environment that provides economic incentives for sharing activities. (Rubin 2002) States, too, will play a role in light of their responsibility to support public health activities, support care facilities, and manage their Medicaid programs.

From a policy perspective, community activism will focus attention on the necessity for a patient-centric approach to care. State governments can use their considerable regulatory power to demand exchange capabilities as part of their procurements and funding. They can also use fees from health care transactions to provide oversight and key infrastructure that would be hard to maintain solely on market principles. The Federal government’s role is primarily to adopt standards and policies that encourage exchange both across the nation

## *Chapter 10: Concluding Comments*

and within DoD, VA, and other federal providers. Federal guidance on secondary data use policies will also be welcome. Many of the current privacy recommendations and policies are confusing and potentially inhibitory to secondary uses in the public interest that are widely accepted by the public. Where public acceptance is concerned, privacy approaches may be advanced if the “contextual integrity” of public expectation is assured through policies and technologies that ensure the use of data is consistent with social and public norms and traditions.

Work in health information exchange will also have a significant impact on the AHRQ agenda. For example, in September of 2010, AHRQ awarded \$473 million in grants and contracts to support patient-centered outcomes research. Of this amount, at least \$50 million has been awarded to create all-payer claims databases and similar resources. Clinical data available through exchange can both complement such databases and arguably shift the focus from databases designed primarily to adjudicate payment to a data-rich environment based on clinical labs, medications, problem lists, complications, and other expressions in coded or natural language programs.

This shift in data types may be accompanied with a shift in control. At present, use of these databases has been dictated in conformity with law to health plans and government agencies. In the future, projects such as Memphis suggest the potential for a far greater degree of provider access to data covering all aspects of an individual’s care – not just those aspects delivered by any one provider. Acting on behalf of these individuals, community-based exchanges presage a more economically successful era of Community Health Management Information Systems (CHMIS). Additionally, consumer-driven databases like the popular PatientsLikeMe site will add another perspective onto our use of clinical data to advance research. As all of these initiatives progress, our research environment may emerge with a range of overlapping data resources, each designed for different purposes and each working in complement with others to drive local and national results.

To a certain degree, one can argue that our experience over the past six-years presage a greater divergence between “exchange” as a verb and “exchange” as a noun. The former, we believe, will be commonplace; it will be achieved technically through a range of means and services; it will be sustained by immediate value to care; and it will be governed by generic provisions to federal and state privacy laws and policies. The latter, we believe, will accelerate more extensive secondary use of data locally and in advance of the slower national consensus. Our experience suggests that the Memphis exchange and replicates in Nashville and other communities are examples of the platforms upon which AHRQ and other groups can support vital health care quality and care delivery research.

The Agency for Healthcare Research is to be applauded for its vision in supporting five-year programs before the creation and growth of ONC and other federal groups. AHRQ’s solicitation clearly stated that developing more efficient and effective means for exchange was an essential prerequisite to widespread measurement of and improvements in health care delivery quality.

## **Acknowledgements**

Any attempt to acknowledge the contributions of every key contributor to this effort will be incomplete. Over the course of a six-year period, this effort literally helped transform a community – and many in the community were central to this transformation. At the Federal level, the Investigators wish to thank those from AHRQ most involved with the effort - Jon White, Erin Grace, Angela Lavandros – as well as Scott Young and Susan Christensen; these individuals worked at AHRQ and supported the project during critical stages. Farzad Mostashari, Claudia Williams, Doug Fridsma, Chuck Friedman, Melinda Beeuwkes Buntin, and others from ONC also provided valuable perspectives over the years. Janet Marchibroda, Jennifer Covich Bordenick and others from the eHealth Initiative fostered a community in which our efforts advanced. Carol Diamond and her associates at the Markle Foundation provided us both the opportunity of developing and using important parts of the Markle Connecting for Health Framework. Jerry Hinkley and Alan Brisken were authors of key portions of the Markle documents agreements. Our National Technical Advisory Panel provided advice to our team, the community, and the State throughout the project.

Leadership from the State of Tennessee was essential. Will Pinkston, working at the time as an aide to Governor Bredesen, was perhaps the most important direct contact during the formative early months. As we have stated throughout our report, our effort could not have succeeded without the commitment and sustained efforts of both Governor Phil Bredesen and Commissioner David Goetz. Antoine Agassi, Melissa Hargiss, Brent Anthony, and many other leaders and staff in the State played an equally important supportive role.

Only a few universities would have been up to the task of envisioning, planning, and executing on this ambitious agenda. Vanderbilt clearly was. The technical aspects and the broader vision are very much the result of Dr. William W. Stead's vision and leadership. Dr. Ed Hammond contributed greatly to this vision and to the early days of the Technical Advisory Panel. Diane Seloff played a vital early role in planning this effort. Carol Aronson, Marinea White, and many others supported the legal and administrative activities through the life of the project. Julia Faber was responsible for much of the legal support. The Vanderbilt Informatics Center team also made significant contributions. These leaders include Dr. Dario Giuse, Randy Bates, and Dr. Ed Shultz. Vanderbilt's highest leadership – in particular Dr. Harry Jacobson – shared in this vision, spoke often on its behalf, and ensured a remarkable degree of support. Dr Jeff Balser – first as Dean and later as Vice Chancellor – has also been a constant advocate. Few universities would have exhibited a devotion to a cause and an assurance in their technologies sufficient to contribute and support technologies to this effort for many years.

Most of all, the investigators wish to thank the many individuals in Memphis Tennessee who continue to sustain and grow this activity. These include the many clinicians who used the system, the administrators who supported these clinical efforts, the many members of the Operations Committee who created and maintained the data sharing, and our Board.

Finally, we acknowledge the almost 2 million individuals and sought care in the course of this project and who trusted their providers and systems of support to a degree sufficient for us to explore ways of improving their care. Since each of us and everyone we know and love are at one time or another potential beneficiaries of our care system, as future beneficiaries of the systems we build, we thank those believed in us enough to get us to this point.

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