



Innovations in Using Health IT for Chronic Disease Management

Findings from the AHRQ
Health IT Portfolio



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Prepared by:

AHRQ National Resource Center for Health Information Technology

Authors:

Brian E. Dixon, M.P.A.

Anita Samarth, B.S.

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Background

Chronic diseases are among the most prevalent and costly of all health problems in the United States.¹ Over 90 million Americans suffer from one or more chronic diseases, and chronic diseases account for 7 of every 10 deaths.² The prevalence of chronic disease has significant implications for health care costs, accounting for three quarters of total national health care expenditures.³ Nearly all growth in Medicare expenditures can be traced to the one half of beneficiaries suffering from multiple chronic diseases.⁴

Chronic disease management requires daily oversight and treatment adjustment. This management is difficult within the current ambulatory care system, which is designed to provide acute and episodic care across disparate health facilities. For example, in addition to a family doctor, patients with diabetes often require care from a variety of specialists, including but not limited to nephrologists, podiatrists, and ophthalmologists. These specialists may order a number of tests, prescribe several medications, or refer the patient to additional specialists. Without timely communication of information, including tests results and medications prescribed, and improved coordination between entities in the fragmented “community of providers,” the continuity of care for a chronically ill patient will remain less than optimal.⁵

Despite national efforts aimed at educating both health care professionals and the general public about the benefits of continuity of care and preventive measures, most Americans continue to receive care only for acute episodes or immediate symptoms and concerns. The issue of time constraints in primary care is a likely contributor,⁶ as 15 or 20 minutes may not be enough time to address patients’ immediate concerns and work with them on the management of their chronic conditions. A lack of access to community resources also may be partly to blame for current inattention to chronic care in many provider settings.³

Many providers and health care organizations are looking toward health information technology (health IT) as a tool to support improved continuity of care. Health IT involves the use of electronic information applications, such as electronic health record (EHR) and clinical-decision support (CDS) systems, to capture, store, and manage clinical information



over time. Improved access to a patient's records and knowledge of medical best practices through health IT applications can help providers spend less time looking for information and more time focused on caring for patients.

Scope

Since 2004, the Agency for Healthcare Research and Quality (AHRQ) has awarded over \$260 million in funding for health IT. The AHRQ health IT portfolio consists of grants and contracts that have planned, implemented, and evaluated the impact of various information technologies on the quality, safety, and efficiency of health care delivery. This report focuses on grants awarded in 2004 and 2005 that are supporting implementation or evaluation of health IT to improve care for patients with chronic illnesses.

Our analysis of this set of grants presents a snapshot of their activities. The scope of our analysis was limited to challenges that these early grantees faced during the development, implementation, or evaluation of a health IT intervention. Evaluation of the projects' final outcomes was not part of this analysis. AHRQ encourages individual grantees to disseminate final outcomes through peer-reviewed journals, trade publications, and other dissemination vehicles.

We reviewed the original applications within the AHRQ health IT portfolio to identify grantees that are implementing information systems to improve care for the chronically ill. For each of the health IT projects included in this analysis, we contacted the lead investigators to schedule interviews. These interviews were the primary data source for this report.

Prior to conducting semistructured interviews, we developed questions and shared them with the lead investigators. This format enabled us to query the investigators about core project design elements, key challenges, lessons learned, and future directions for using IT at their organizations. The stories of these projects are presented below with comparative and analytical elements from the AHRQ National Resource Center for Health Information Technology.



Grantee Characteristics

This subset of AHRQ grantees and contractors, a sample selected out of the larger AHRQ health IT portfolio, have implemented or are in the process of implementing information systems designed to support care processes for the chronically ill. These projects represent various regions of the United States; six projects are located in urban areas and four in rural areas (Table 1).

TABLE 1: CHARACTERISTICS OF PROFILED PROJECTS

Grant	Region	Rural/Urban Projects
Arkansas Delta Inpatient-Outpatient Quality Improvement	Southeast	Rural
Evaluating Smart Forms and Quality Dashboards in an EHR	Northeast	Urban
Home Heart Failure (HF) Care Comparing Patient-Driven Technology Models	Northwest	Rural
Improving Pediatric Safety and Quality with Health Care IT	Northeast	Urban
New Mexico Health Information Collaborative	West	Rural
Patient-Provider Electronic Messenger in Chronic Illness	Northwest	Urban
Project ECHO-Extension for Community Healthcare Outcomes	West	Rural
Showing Health Information Value in a Community Network	Southeast	Urban
Trial of Decision Support to Improve Diabetes Outcomes	Midwest	Urban
Web-based Renal Transplant Patient Medication System	Northeast	Urban

Technologies

We found no dominant technology application. Each project implemented or evaluated a unique application or customized instantiation of an existing application for a targeted chronic illness. The approaches used by the various projects included the following:

- Clinical-decision support (CDS) systems. These systems provide alerts, reminders, and customized data entry forms to help providers interpret clinical results, document a patient's health status, and prescribe medications.



- Health information exchange (HIE) and disease registries. These technologies enable the sharing of information across organizational boundaries so all providers in a community can access a patient's information to provide better care when the patient receives treatment from them.
- Telehealth. These applications use telecommunications technologies to deliver health-related services and information that support patient care, administrative activities, and health education.
- Hospital information systems. These systems help providers manage patient information and track success in treating chronic diseases; examples include laboratory and pharmacy information systems.





Findings

The interviews provided rich detail about grantees' successes, failures, and lessons learned. Major themes from the interviews are discussed below.

System Selection

System selection is the process of choosing a clinical application to meet the needs of an organization or project. This process is burdensome, even in the best of circumstances, because it involves reviewing technical specifications, user functionality, application designs, and technical support agreements. When there are few commercial off-the-shelf (COTS) systems from which to choose, system selection is extremely challenging because clinicians and IT specialists have little information on which to base their decisions.

The AHRQ grantees found few COTS options for managing the care of chronically ill patients. In fact, none of the grantees reported purchasing a system specifically designed to manage the chronic care process. Those grants that implemented COTS solutions (less than one-third) reported that the complexities in chronic care necessitated a high degree of system customization.

Grantees also reported that health care organizations should be careful when evaluating various vendor-based support agreements. One grantee reported that its vendor refused to provide technical support after 5:00 p.m. and on weekends. The vendor's support agreement was problematic because the project involved patient use of the technology. Patients experienced problems with the devices in their homes after-hours and did not have access to vendor-based support. This project recommended that others critically evaluate support packages when performing system selection. Depending upon the scope of the implementation, it may be important for a project to have its own trained support staff rather than having to rely solely on vendor resources.



System Customization and Integration

Given a lack of available COTS solutions, the majority of the grants developed highly customized, local applications using software vendors or internal IT resources. Even those grants in which a COTS solution was purchased ended up customizing their applications to a large extent.

Customization involves both a redesign of a system's functionality and the organizational workflow associated with technical change. Customization requires close management of and coordination with the development partner; often, it is also necessary for the organization to hire in-house development staff. It is important to ensure that the organization has a mechanism to modify or expand the developed solution after the project has been completed to protect its investment either via a continued agreement with the development partner or internal development resources.

CDS systems required the highest degree of customization. One grant required 0.5 full-time equivalent (FTE) physicians to work exclusively on developing alerts, reminders, and other CDS system elements.

Human Resources

Technology enhances health care delivery by supporting health care professionals—not replacing them. Often chronically ill patients are cared for by multiple physicians, and more often, care is provided by a mixture of physicians, nurses, case managers, and other allied health professionals. This complex mixture of professionals requires that each professional have access to health IT systems to obtain patient data and communicate with the other professionals providing care to the patient. The following examples illustrate the variety of professionals involved in the AHRQ-funded CDM projects.

Nurse Educator – One project aimed at improving the Centers for Medicare & Medicaid Services' (CMS) core measures for chronic heart failure (CHF) patients. The project focused on patient-centered education practices. The hospital created a new position, a nurse educator, to coordinate care and provide self-management education for patients with CHF. The hospital information system was configured to alert the educator when a



chronically ill patient is admitted. The electronic alerts prompt the educator to attend bedside meetings with other care providers. Her direct interaction with the patient involves delivery of education on how to do self-care after discharge from the hospital.

Nurse Case Manager – Two projects used nurse case managers to triage CDS alerts for patients with chronic conditions. The alerts were triggered based on health status changes entered by patients into an integrated voice response (IVR) system. The alerts prompted the nurses to followup, sometimes calling patients to ask clarifying questions or recommend immediate next steps. When the alerts were serious, the nurse alerted the patient's physician. The physician could then make changes to the patient's medication or recommend immediate hospitalization in extreme cases.

Case Manager – Another project used case managers employed by the State's Medicaid office to triage CDS alerts for patients who missed appointments or failed to receive a hemoglobin A1-C (HbA1C) test, a routine and recommended marker for the effective management of diabetes. The IT system automatically generated letters from clinics and the Medicaid system to patients, and it notified providers when their patients had been hospitalized for an issue related to their chronic illness.

Nonclinical Assistants – An integrated delivery network utilized nonclinical assistants to review incoming secure messages from patients and forward them to the appropriate clinical staff for response. This prevented physician inboxes from becoming overloaded with questions that other providers might be better able to answer. The same assistant monitored providers' responses to ensure that patients' questions were answered in a timely manner.

The experiences of the AHRQ grantees demonstrate that IT systems can be used to support modern health care's shift towards multidisciplinary care teams or groups of providers working together to provide high-quality care. To support such efforts, the teams using these systems must be involved in the design, selection, and implementation processes. Furthermore, data will need to be standardized to maximize its semantic interpretation and representation as it is shared between systems and team members. These are important concepts for other organizations seeking to implement health IT in support of multidisciplinary care for the chronically ill.



Change Management

Because the implementation of health IT involves substantial process redesign, change must be managed effectively by hospital and practice leadership. The experiences of the AHRQ projects suggest that rapid change is unlikely to occur. Instead, change will happen through a series of small, incremental steps. While the slow pace may seem frustrating at first, this method may increase the likelihood of long-term adoption and use.

A project seeking to develop a community-wide health information exchange (HIE) began with a big vision—exchanging a large variety of clinical data across every provider within 3 years. This reality seemed unfeasible after initial conversations with providers revealed a long list of conflicting needs and wants. The project team carefully examined the notes from these early meetings and narrowed the scope of the project to the development of a community-wide system for exchanging referral information. The revised project laid out an infrastructure that enabled primary care providers to forward information and documents to a specialty care provider when referring a chronically ill patient. The specialty care provider would use the system to retrieve the referral information and forward any resulting notes and recommendations back to the primary care provider.

By limiting the scope of the project, the grantee was able to garner broader buy-in from area providers. The grantee also was able to move the project forward and develop a common infrastructure that could later be reused for additional HIE components. For example, to effectively exchange information between area providers, an HIE requires a complete list of area providers, often called a doctor list. It also requires a master patient index (MPI) or coordinated list of patient identities, since each provider uses a unique ID when referring to an individual patient. The doctor list and MPI are common HIE technologies, and they can be reused in the future to exchange laboratory results, discharge summaries, and other information the community identifies as important. This concept is important for HIE projects as well as other health IT projects that aim to provide services and benefits to a community over the long term.

Implementing new equipment and software can be just as complex as redefining a project's overall scope. A project that implemented an interactive voice response (IVR) system found that patients can sometimes be overwhelmed when interacting with a number of devices.



The project aimed at providing patients with several devices for home monitoring. As the patients' weight, blood pressure, glucose, and other physiologic parameters changed over time, the device would send data to providers via the Internet for monitoring and decision support. However, the inherent complexity required to make these devices work together detracted from the user experience. Patients were easily frustrated when using the different devices and some failed to understand that all of the devices were necessary. The grantee for this project suggested that it may be useful to limit the number of devices, perhaps by combining several devices into one, or simplify the interface.

These examples illustrate that an organization may not be able to implement its original vision immediately. Projects may require a phased approach. One successful approach is to scale back on the project initially, demonstrate results where possible, and gain greater buy-in before expanding to other chronic conditions or areas of clinical practice. If national or vendor guidelines, alerts, or other out-of-the-box components are to be used, ensure local clinicians have a chance to review them and select the most appropriate ones for local implementation. Overall, approach health IT projects from a real-world perspective where small, incremental changes to workflow and clinical practice will yield long-term successes in quality, safety, and efficiency.

Patient Education

The Institute of Medicine's Quality Chasm series, the Chronic Care Model, and the trend toward evidence-based practice encourage patients and providers to receive education about clinical best practices and guidelines.⁷ Patient education can contribute to the improvement of health care quality and safety, which is also the aim of many health IT projects.

Physicians and other providers are under a lot of pressure to treat patients as quickly as possible, leaving them with little time to provide patient education.⁶ It is often difficult for a physician to treat a patient's conditions and address the reason for their visit, while simultaneously providing patient education in the same small window of time. AHRQ-funded CDM projects found that while patient information is available online, those who need this information the most do not have access to a computer.

Two projects within the AHRQ portfolio demonstrate how health IT can be applied to more effectively support patient education. The first project describes how IT can engage patients



to learn more about their health while they are sitting in the waiting room. The second project focuses on supporting primary care physicians who treat complex diseases and patients with multiple chronic conditions.

Patients are often waiting to see physicians or obtain the results of blood work or other laboratory tests. One AHRQ project gave patients the opportunity to use a computer program during their wait time. The application teaches patients about the medications they are taking, including medication names, strengths, dosage, and frequency. Patients enjoy using the application, which is structured like a game. Family members also can sit beside the patient and learn with him or her. This project uses a simple interface that requires only mouse-based input; the design is particularly effective for patients with minimal or no computer skills and those that are very ill. This type of application may be used in many clinical settings as a way to provide patient education without disrupting the limited face-to-face time that patients have with providers.

The second project focused on using telehealth to deliver education. Primary care physicians on the front lines can receive up-to-date information regarding clinical practice for chronic conditions via one project's telehealth network. Physicians also can interact with other primary care physicians and specialists located at the closest academic medical center to discuss complex cases. The group environment enables the physicians to share knowledge and learn from one another. The same telehealth network provides education to nurses and office managers to help them better understand processes for educating patients about their chronic illnesses and providing self-management education. Remote training using telehealth can help the health care workforce learn newer, more effective ways of providing patient education. Telehealth also can be used to provide education directly to patients if providers choose to integrate this technology into their clinical workflow.

Sustainability

The AHRQ projects received limited-term funding, requiring the organizations to determine mechanisms to sustain their health IT activities after grant funds expire. Although some of the projects will complete implementation and transition into an operations and maintenance mode, many are planning to expand their scope. Obtaining additional funding



from health care executives, payers, or grants requires demonstration of return on investment or alignment with mutual strategic goals. The projects reported that sustainability can be achieved when organizations and communities agree that chronic disease management is a top priority for the future of the health care system. The following examples describe how some AHRQ projects intend to continue their activities post-award.

Many payers are interested in developing innovative approaches to chronic disease care because of its impact on health care costs. Aligning HEDIS and CMS measures with health IT projects provided several grants with the opportunity to demonstrate how health IT systems can impact these quality measures. One project involved the State in the development of a pilot project. The objectives of the pilot project were (1) to test the project's EHR and (2) to explore the clinical decision support system's ability to report key measures for the Medicaid population to care managers and health-risk management professionals. The pilot project demonstrated that the system was more efficient and timely in its reporting of CMS measures than the State's current reporting process. The project team is now working with the State to implement their process statewide.

Projects have reported challenges in gaining timely access to CMS data. Given that some payers are interested in exploring pay-for-performance (P4P) initiatives, one project is demonstrating how its quality dashboard for chronic diseases like diabetes and asthma can help providers and payers measure the quality of care provided to these patients. Although there is great interest in P4P initiatives, reaching consensus on a modified reimbursement policy can be challenging. One project had to revise its reimbursement process for physicians who used secure messaging several times before achieving consensus among participating physicians, the provider organization, and local payers.

Improving care for chronically ill patients provides benefits to patients and the community. Several AHRQ-funded projects have achieved sustainability for chronic care initiatives by securing support from community organizations. An HIE project secured support from public health agencies. The same project partnered with school nurses to support asthma treatment in children; the project also received funding from the CDC to do additional research on this chronic condition. Many investigators spoke about the need for continued



support for innovative uses of health IT to improve chronic care. They advocated that such interventions should target the sick and needy populations that consume the most health care resources. There are clearly advantages for organizations, payers, governments, and communities to keep chronic diseases under control and to do so using health IT systems.





Conclusion

The AHRQ-funded laboratory of health information technology projects is producing valuable, informative lessons for the Nation. The portfolio demonstrates that a variety of health IT applications have the potential to transform the quality and safety of care for some of the Nation's most severely ill patients. Despite several challenges associated with developing and implementing health IT for chronic disease management, information technology can be used to improve clinical processes. Technology also can facilitate better knowledge sharing and support improved communication and coordination across care settings. These lessons, along with final outcomes published in the future from this laboratory, are replicable in other organizations and clinical settings. AHRQ and the National Resource Center intend to continue their support of providers in improving the efficiency, quality, and safety of medical care.







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