Using Clinical Information Technology in Chronic Disease Care: Expert Workshop Summary

Prepared for
CALIFORNIA HEALTHCARE FOUNDATION

by
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About the Author

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About the Foundation

The **California HealthCare Foundation,** based in Oakland, is an independent philanthropy committed to improving California's healthcare delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality healthcare.

For more information about CHCF, visit us online at www.chcf.org.

Contents

I. Introduction

Workshop participants were convened to forecast how physician offices, clinics, and group practices will apply clinical information technology to chronic disease care.

CHRONIC CONDITIONS SUCH AS DIABETES, ASTHMA, and coronary artery disease are the major causes of illness, disability, and death in the United States. In 2000, the medical cost of chronic disease amounted to 75 percent of direct health care spending, and the indirect costs of lost work, pain, and suffering were much higher. The optimal management of patients with chronic diseases requires the tracking of patients over time to monitor the progression of the disease, compliance with treatment, and preventive care.

A major focus of the California HealthCare Foundation (CHCF) is to improve chronic disease care by standardizing access to, and improving the use of, clinical information at the point of care. This focus is based on the conviction that access to timely, accurate, well-organized electronic data will improve the quality of care for patients with chronic diseases. Many providers have, over the years, promoted systems to improve care for chronic disease patients, ranging from automated disease registries that combine encounter, lab, and pharmacy data to more functional electronic medical records. Combinations of technical, logistical, and resource constraints have slowed implementation and deployment of these systems. Obstacles include:

- Inconsistent data formats, coding schemes, and timing of information delivery in a range of areas, including outcomes, procedures, lab results, pharmacy orders, etc.;

- Complexity and cost of matching up information about patients that comes from different sources, given the lack of a uniform patient identifier;

- Incomplete data in existing electronic health information systems, which limits the ability to create useful, consistent "maps" of chronic disease states and their care; and

- Limited functionality in existing disease registries.

On October 16, 2003, CHCF convened an expert workshop to forecast how physician offices, clinics, and group practices will employ clinical information technology (IT) applications to chronic disease care in the next three to five years. Workshop participants included experts from academic and commercial research organizations, medical groups, integrated health care systems, physician organizations, government, and IT vendors.

A list of participants is contained in the Appendix.

This report presents a summary of the workshop, including the reporting of findings and the facilitator's interpretation and forecasts. It includes a description of how clinical information technologies will contribute to chronic disease care in the future and an analysis of the driving forces and barriers to applying two major forms of clinical IT — disease registries and electronic medical records — to chronic disease care. The report also includes a forecast for the next three to five years of the likely pace and trajectory of the adoption of clinical IT applications in three practice settings: solo and small group practices, large group practices, and community clinics.

II. Summary of Key Findings

The essential characteristics needed to support chronic disease care are not all present in existing clinical IT systems.

Essential Elements of Chronic Disease Care

The forecasting session started from the premise that chronic care will be an important factor for improving health care quality and controlling costs. Over time, chronic care will be supported using a full menu of approaches, including "heroic" providers who keep all the information they need in their head; manual, paper-based systems; computerized disease registries; and comprehensive electronic medical records with registry components. Whatever the technology used, effective chronic care must include the following functions:

- Identify who in the population has the disease;

- Track one or more outcome measures that indicate how well the disease is being managed (and identify which patients and providers are outliers);

- Track one or more process measures that indicate whether disease management protocols are being observed (and identify which patients and providers are outliers);

- Prompt the provider to observe the protocols and to take the required measurements and perform the needed actions; and

- Provide feedback to the provider, group, or plan about overall performance, with a range in reporting from the individual patient level to the aggregate.

The expert group described the essential characteristics of the clinical IT systems needed to support those functions. These characteristics are not all present in existing clinical IT systems, and it is essential that they be integrated over the next several years. The vital characteristics include:

- ***Support for a full range of chronic care processes.*** Clinical IT should apply to all aspects of the continuum of chronic disease care. Specifically, it should support outreach to those with a given disease who are missing aspects of their care. It should operate at the point of care, providing both decision support and documenting the clinical encounter. And it should support population profiling and reporting.

- ***A patient-focused and longitudinal approach.*** Disease-focused IT systems are limited in their capacity and usefulness and might contribute to further fragmentation of

care. Especially in complex conditions with many co-morbidities, such as diabetes and heart disease, a focus on the entire patient is essential. Other efforts to monitor and analyze the chronic care provided to a given population or by a given provider group have captured a snapshot view but have not been able to show the evolution of the population's care over time. An effective clinical IT system for chronic care must give providers a complete, current picture of the patient's care and outcomes. Part of a patient focus includes the capacity to capture and represent information about a patient's self-care behavior.

- *Application across the continuum of care.* Related to the previous points is the requirement that clinical IT span the continuum of care, from the patient's home to the lab, pharmacy, office visits, and other sites of care. It should ideally be accessible by and useful to the entire care team and not just a single provider.

- *Real-world applicability.* Clinical IT support for chronic care must work in the real world. Specifically, it must, as much as possible, draw on existing data flows or integrate easily into existing workflows. It must be "tunable" to fit different conditions, initiatives, and approaches to chronic care. It should replicate common features of paper medical records, such as the face sheet, that provide essential information.

Disease Registries and Electronic Medical Records as Chronic Care Tools

Clinical IT support for chronic care today is not yet capable of supporting all the characteristics described in the previous section. Current systems are evolving from two starting points: electronic disease registries and electronic medical records. (See Figure 1 on the following page.) Neither fulfills all the criteria of "gold-standard" information support. This section describes how both

disease registries and electronic medical records (EMRs) interact today with chronic care processes, how their functions are likely to expand in the future, and the barriers each must overcome to be a high-functioning chronic care tool.

Disease Registries

In general, a disease registry is a system to register and track all cases of a given disease or health condition in a specific population. In the context of chronic disease care, a disease registry is "a computer application for capturing, managing, and providing access to condition-specific information for a list of patients to support organized clinical care." (Jane Metzger, First Consulting Group)
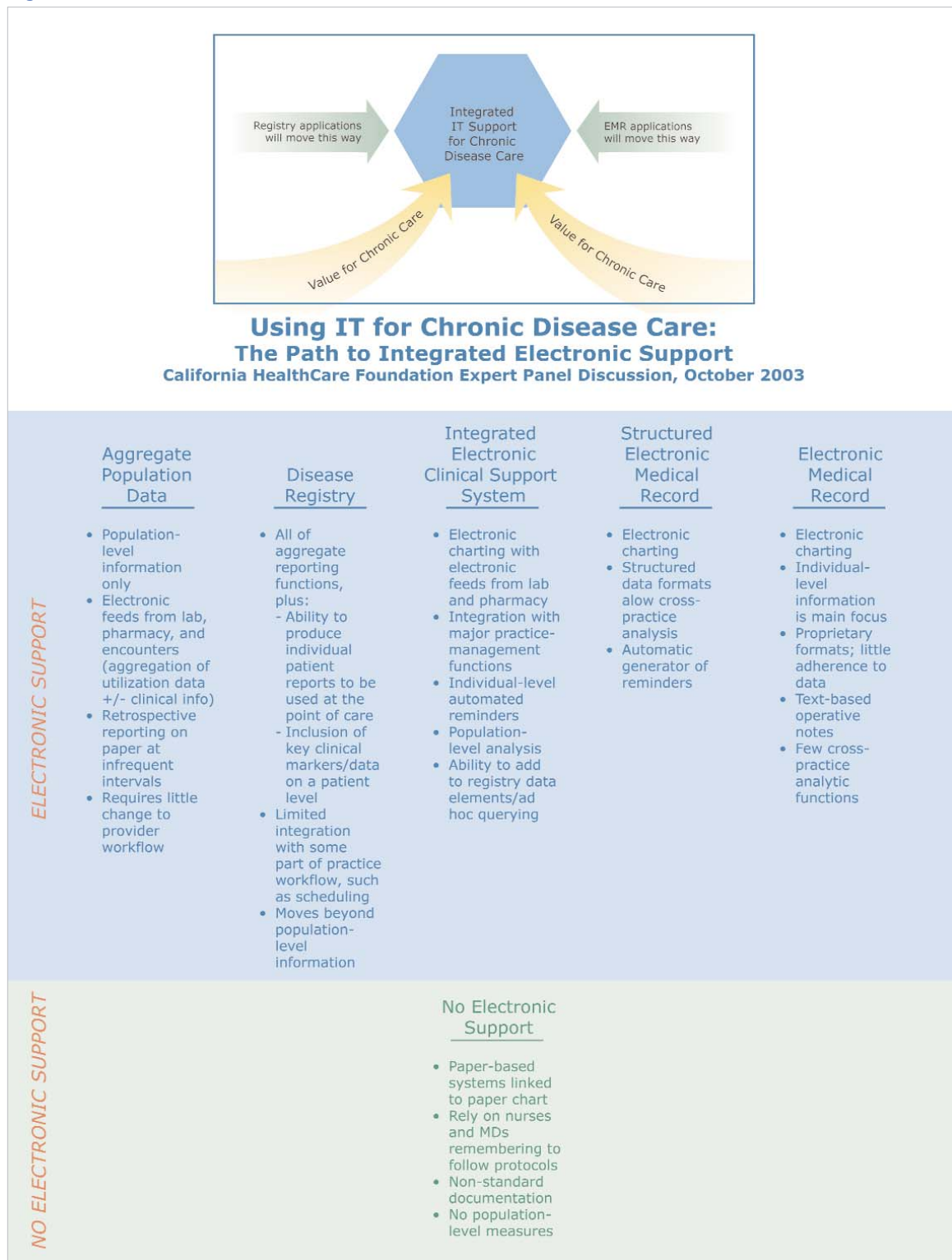
Registries typically aggregate information about cohorts of patients who share a clinical disease or demographic characteristic. Ideally they include electronic feeds from laboratories, pharmacies, and clinical encounters, though most in use today do not.

Facilitator Comment

The utility of a disease registry for chronic care depends largely on two factors: the completeness and timeliness of its data feeds and the richness of its reporting functions. At a minimum, disease registries are used to report retrospectively about the treatments the population received. As the reporting capabilities expand, so does the utility of registries for chronic care. Important reporting functions include the capability to:

- "Slice" retrospective reports by provider, group of providers, patient subpopulation, and other factors;

- Produce individual patient reports that can be used during patient encounters at the point of care;

- Link those reports to standards of care in order to suggest tests and treatments; and

- Include selected patient outcomes and other clinical markers.

Figure 1. The Evolution of IT in Chronic Disease Care

Using IT for Chronic Disease Care:
The Path to Integrated Electronic Support
California HealthCare Foundation Expert Panel Discussion, October 2003

ELECTRONIC SUPPORT	Aggregate Population Data	Disease Registry	Integrated Electronic Clinical Support System	Structured Electronic Medical Record	Electronic Medical Record

	• Population-level information only
	• Electronic feeds from lab, pharmacy, and encounters (aggregation of utilization data +/- clinical info)
	• Retrospective reporting on paper at infrequent intervals
	• Requires little change to provider workflow
		• All of aggregate reporting functions, plus:
		  - Ability to produce individual patient reports to be used at the point of care
		  - Inclusion of key clinical markers/data on a patient level
		• Limited integration with some part of practice workflow, such as scheduling
		• Moves beyond population-level information
			• Electronic charting with electronic feeds from lab and pharmacy
			• Integration with major practice-management functions
			• Individual-level automated reminders
			• Population-level analysis
			• Ability to add to registry data elements/ad hoc querying
				• Electronic charting
				• Structured data formats alow cross-practice analysis
				• Automatic generator of reminders
					• Electronic charting
					• Individual-level information is main focus
					• Proprietary formats; little adherence to data
					• Text-based operative notes
					• Few cross-practice analytic functions

NO ELECTRONIC SUPPORT	No Electronic Support
	• Paper-based systems linked to paper chart • Rely on nurses and MDs remembering to follow protocols • Non-standard documentation • No population-level measures

Few disease registry systems include all these functions today, but they will expand their offerings in these directions. Several barriers stand in the way of applying disease registries in chronic care. These include:

- *Patient identification.* The absence of a uniform patient identifier makes it difficult to aggregate information about a single patient from multiple sources, such as a lab, pharmacy, emergency room, and possibly several different clinics.

- *Lack of information standards.* There remains a lack of data format and transmission standards for laboratory, pharmacy, and, especially, encounter data. To the extent that registries must compile data from several organizations, a substantial cost will be associated with integrating multiple coding formats until standards are established.

- *Ownership and control of registries.* Because registries must aggregate information from several sources, there is concern over who owns and controls the data contained in the registry. Many providers, for example, do not trust health plans that aggregate patient data. Existing players who wish to establish a registry may not be able to persuade all their business partners — let alone their competitors — to participate, and new, specialized registry organizations might lack local credibility.

Electronic Medical Records

EMRs are suited in different ways to support chronic disease care. In contrast to disease registries, which are designed expressly for population health management (and have concomitant shortcomings in their use for individuals), EMRs are oriented initially toward individual patient charting and management. Many EMRs have structured data elements, which enable sorting and reporting about populations. But most are not primarily designed to support chronic care in a population.

Simple, stand-alone EMRs are designed for electronic charting. Their main focus is individual-level information. Many of them have proprietary data formats and don't adhere to broader data standards. To the extent that they have narrative notes, such as progress reports or operative notes, they are text-based and may not be searchable. They support very little cross-practice analysis.

Few newly installed EMRs are stand-alones anymore; instead, most EMRs offer a more structured electronic record. The structured data formats allow a much wider range of cross-practice data analysis. Many functions that are useful for chronic care, such as the automatic generation of reminders about patient visits, tests, and so on, are built into these systems.

For EMRs to be fully functional for chronic disease care, they need a higher level of integration with other data systems. Useful integration includes electronic feeds from lab and pharmacy information systems and integration with other major practice-management functions, such as patient scheduling, billing, and online ordering. EMRs also require higher-level reporting functions, including population-level analysis of the records to identify people with a given condition who might not already participate in a chronic care program. Further, more advanced disease registries have sophisticated, ad-hoc querying. The addition of this function further enhances the utility of EMRs.

Forecast of Clinical IT for Chronic Disease Care in Three Practice Settings

The diffusion of clinical IT to chronic disease care will not occur all at once and won't be uniform across different practice settings. As with other technologies, large and sophisticated group practices will have the financial and technical resources to make use of advanced clinical IT applications before smaller practices will. Clinics that receive special funding for capital investments

will be able to install clinical IT sooner than those that must fund all capital improvements internally. This section looks at three practice settings: solo and small group physician practices, large group practices, and community clinics. For each setting, it provides an assessment of the driving forces and barriers to applying disease registries and EMRs for chronic care, as well as a forecast of likely developments.

Analysis of Solo and Small Group Practices

DRIVING FORCES

- Growing incentives for use of IT in chronic care: pay for performance, Medicare, pay for data, malpractice insurance discounts

- Physician and practice profiling by payers and independent evaluators that rewards consistent adherence to chronic care guidelines

- Interaction with independent practice associations (IPAs) that contract with solo and small group practices in the form of technical assistance, group purchasing, training, and incentives

- Availability of clinical IT systems through application service providers (ASPs) that don't require costly purchases but use monthly service fees

Solo and Small Group Practices

Solo and small group practices—with a group size of up to 10 people—are the least receptive market segment for clinical IT applications in chronic disease management. They have a relatively low penetration of EMRs and other clinical IT. Adoption of applications for chronic disease management will likely be limited by the same barriers.

BARRIERS

- Fragmentation of solo and small group practice market makes sales, marketing, and technical support inefficient—not vendors' first target market

- Small practices don't have the capital resources to invest in clinical IT or the human resources to evaluate systems and services; they are under financial and time pressures

- Investments in IT are hard to justify in the economics of a small practice

- Solo and small group doctors are resistant to the possible loss of control over data about their practices

Large Group Practices

Large group practices, especially those with more than 100 physicians, are the most likely to have clinical IT systems already and to have the most capacity to apply them to chronic disease care.

Analysis of Large Group Practices

DRIVING FORCES

- These practices typically have sufficient capital and qualified IT and clinical professionals to evaluate systems and manage their implementation

- The leaders of some large group practices are willing to innovate and experiment

- Many practices already have an existing information infrastructure; chronic care applications are incremental

- There are success stories of applications of clinical IT to chronic care in this segment

- Large practices are the primary target market for clinical IT vendors

- Market incentives, including pay for performance, malpractice incentives, and others, fall heavily on large groups

BARRIERS

- Chronic disease care might not be the primary application priority for large group practices

- IT and clinical professionals' time and attention are limited; other initiatives might take precedence over chronic care systems

- It is difficult to change practices throughout large, complex organizations

- The fragmented nature of health care delivery and financing limits the case for return on investment (ROI) for IT; economic justification of these investments is commensurately difficult

Community Clinics

Community clinics are at once a very congenial and a very hostile environment for applying clinical IT to chronic disease care. On the one hand, they have a strong culture of cooperation, information sharing, and adherence to standard information formats, as well as a history of using regional partnerships and other collaborative resources to accomplish large-scale organizational changes. On the other hand, they lack incentives to change their practices. They also (like other practice settings) have a diverse installed base of information systems in different clinics.

Analysis of Community Clinics

DRIVING FORCES

- Access to collaborative resources, such as regional partnerships, for best practices and technical assistance

- A cultural ethos of information-sharing, along with little resistance to standards for uniformity of data formats

- Salary-based compensation helps limit conflicts of interest about the use of capital resources

- Availability of capital from Medicare and other government sources

BARRIERS

- Lack of financial and other incentives, such as pay for performance

- Diverse and fragmented installed base of information systems across clinics

- Little experience with clinical data exchange and IT support

Facilitator Forecast

Although some community clinics have applied clinical IT to chronic care, their success has been variable. Just as several networks of clinics have conducted common program and even IT development in the past, they will need to develop and refine a culture and common framework for thinking about how to use IT for chronic disease care. Government policy (federal and state) on grants for capital improvements and federal loan guarantees are the crucial variable in whether community clinics invest in clinical IT for chronic care.

Accelerating Application of Clinical IT to Chronic Disease Care

The expert workshop examined several initiatives being considered by CHCF and added several other possible initiatives. The experts agreed that the following types of programs (some mentioned in the workshop plus additional programs) could substantially accelerate the application of clinical IT to chronic disease care.

- *Standard formats for data exchange.* Initiatives are under way in California to standardize lab and pharmacy data exchange. For example, California HealthCare Foundation's California Clinical Data Project (www.chcf.org/topics/view.cfm?itemID=81398) is a collaborative effort of health plans, provider groups, and laboratories to address underlying barriers to the access and use of integrated clinical data to support chronic disease management. The project focuses on the development and use of data standards to facilitate integration of critical lab, pharmacy, and other clinical information. This effort and others in California should be coordinated with similar projects being conducted by the Quality Improvement Organizations (QIOs) of the Centers for Medicare and Medicaid Services (CMS). Further, these initiatives should be extended to include other types of clinical data such as radiology. Other approaches to facilitate the availability of clinical data are underway that allow a variety of providers to view patient data housed at other institutions (i.e. allowing a private physician to view patient data from a recent hospitalization).

- *Creating community infrastructures for health information.* The Markle Foundation, in its Connecting for Health program (www.connectingforhealth.org), is creating a roadmap of immediate steps for building a health information infrastructure and convening working groups and other forums to overcome barriers to implementation.

A similar mechanism could be established to help solo and small group practices apply clinical IT to chronic care.

- ***Guides to help providers integrate clinical IT and chronic care.*** Many provider organizations are willing to consider clinical IT applications, especially when they are replacing existing information systems. Physician practices, especially smaller ones, are often overwhelmed by the complexity of the choices they face. Information and assistance in two areas would be particularly helpful: (1) a buyer's guide that shows "trajectories" or decision trees leading from different IT starting points through to full use of clinical IT for chronic disease care and (2) material that helps link the changes in IT to practice redesign. CHCF has commissioned a series of publications designed to help prospective buyers of systems for chronic disease care, including a disease registry primer, a product review of computerized registries for chronic disease care, and several reports, including a buyer's guide, on electronic medical records.

- ***Collaborative forums on applying clinical IT to chronic care.*** One of the advantages that community clinics have is their experience with regional collaboratives for IT and other common issues. Improving Chronic Illness Care (www.improvingchroniccare.org), for example, is a program of the Robert Wood Johnson Foundation (www.rwjf.org) based at the McColl Institute for Healthcare Innovation at Group Health Cooperative in Seattle. ICIC has created a Chronic Care Model, which it disseminates through guides for providers, regional collaboratives, and conferences.

- ***Development of approaches to activate consumers.*** Knowledgeable, active patients and consumers are important for the successful care of chronic disease. The challenge is how to activate patients. So few consumers have encountered clinical IT systems that it's difficult to generalize about what impact they might have. Many excellent consumer Web sites exist to support consumers' self-management. Others, such as Healthscope, (www.healthscope.org), help consumers select health plans, hospitals, medical groups, and insurance plans and include some information about chronic disease care.

III. Conclusion

Technologies are getting better each year and becoming easier to install, learn, and use.

CLINICAL INFORMATION TECHNOLOGY SYSTEMS WILL be essential to improving the quality and consistency of care for people with chronic diseases. Getting to the next stage — putting these technologies into common use across many practice settings, including solo and small physician groups, large medical groups, and community clinics — will require a substantial investment of time and capital on the part of many in the field. Incentives, such as pay for performance and objective measurement of the quality of care, are increasingly in use to encourage providers to adopt clinical IT. The technologies are getting better each year, offering better functions at lower cost, as well as becoming easier to install, learn, and use. Clinical IT systems will evolve from two main starting points: disease registries whose roots are to track populations with a given disease and the care they receive, and electronic medical records whose purpose is to chart patients' health status and treatment.

Health care providers who wish to investigate clinical IT systems, disease registries, electronic medical records, and other ways of improving care for people with chronic disease, are referred to the many resources cited above. The iHealth & Technology topic list on the California HealthCare Foundation's Web site (www.chcf.org) includes extensive resources on computerized disease registries, EMRs, and other support for chronic disease care.

Appendix: Participant List

Forecasting the Adoption of Clinical IT in Chronic Disease Management: An Expert Panel

October 16, 2003

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