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Report to the National Commission  
for Quality Long-Term Care

## Essential but Not Sufficient:

# Information Technology in Long-Term Care as an Enabler of Consumer Independence and Quality Improvement



Prepared by:  
BearingPoint, Inc.



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## Authors' Note

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The National Commission for Quality Long-Term Care is a non-partisan independent body charged with improving long-term care in America. The appointed commissioners reflect a diversity of experience in government, academia, quality improvement, and long-term care. The Commission was convened in October 2004. It grew out of an industry-led quality initiative called Quality First, A Covenant for Healthy, Affordable, and Ethical Long-Term Care. Funding for the Commission's work is provided by the Alliance for Quality Nursing Home Care, the American Health Care Association, and the American Association of Homes and Services for the Aging. The Commission was originally convened and housed at the National Quality Forum, but is now an independent commission at The New School.

[www.ncqltc.org](http://www.ncqltc.org)

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## Executive Summary

*We must use technology more effectively to enhance consumer independence and promote consistently better quality of care. We must design a health information technology infrastructure that addresses the unique needs of long-term care users and providers while ensuring the interconnectedness of electronic information—as well as consumer privacy and security—in both the long-term and acute-care systems.*

*– Out of Isolation: A Vision for Long-Term Care in America  
The National Commission for Quality Long-Term Care*

This report examines the role of information technology in long-term care and makes recommendations to The National Commission for Quality Long-Term Care (the Commission) on how long-term care can be transformed through the application of health information technology (HIT). To effectively address this issue of the role of HIT in long-term care, we must establish and maintain our focus on a clear goal: To optimize quality of life for all within the constraints of our available resources and our understanding of the human condition. Note that this goal is not exclusive to seniors or those involved in long-term care; this goal applies to the entire healthcare community. We cannot achieve this goal for long-term care without considering all of healthcare.

Our central thesis is this: HIT can be an enabling force in all aspects of healthcare transformation; yet, while it is essential, HIT is not sufficient for achieving this

transformation. To achieve our goal of optimizing quality of life within the constraints of our available resources, we must combine the adoption of HIT with the realignment of incentives for improving consumer-centric outcomes and efficiency as well as a strong business case for the adoption of HIT by the many diverse long-term care stakeholders. These incentives must be driven and the business case embraced by changing our healthcare culture by focusing on systems-level continuous process improvement that is driven by information transparency and flow.

Long-term care can serve a special role in the transformation of healthcare because long-term care is just like the rest of healthcare, only more so. Long-term care tends to be more fragmented, deals with a wider spectrum of healthcare issues, provides a wider range of services for seniors of varying levels of cognitive and functional status, faces greater workforce and financing challenges, and, compared to the rest of the healthcare system, has been slower to adopt technology. Because these challenges within long-term care are so pronounced, long-term care is the ideal “poster child” for the cause of technology-enabled transformation in the entirety of the nation’s current healthcare discussion. Healthcare will benefit as the long-term care sector’s particular focus on functional status, wellness, and transition management is integrated into shared solutions.

The six areas for change as outlined in the Commission’s vision for long-term care—culture transformation, empowering individuals and families, workforce, technology, regulation, and finance—are enabled by HIT:

*“HIT can be an enabling force in all aspects of healthcare transformation; yet, while it is essential, HIT is not sufficient for achieving this transformation. We must combine the adoption of HIT with the realignment of incentives and systems-level continuous process improvement for improving consumer-centric outcomes.”*

- **Culture Transformation**—HIT can enable information sharing through electronically enabled communities of practice and other forms of social networking, online educational programs, the raising of expectations through quality reporting and outcomes transparency.
- **Empowering Individuals and Families**—HIT can help reduce isolation among seniors and caregivers through electronically enabled social networks, online training for caregivers, and personal health records (PHRs) that can be shared with caregivers and remote family members.
- **Workforce**—HIT can enable streamlined, coordinated training through learning management systems and modular educational programs; efficient resource-to-need matching and optimization of workforce scheduling and distribution of effort through enterprise resource planning applications and related technologies.
- **Technology**—Technology can enable the improved application of other technologies by supporting the HIT infrastructure such as the emerging Nationwide Health Information Network (NHIN); the network effect of HIT results in greater utility of previous technology investments (for example, widespread adoption of electronic health records (EHRs) make them more effective as information-sharing tools among healthcare providers and create new opportunities for implementing more advanced technology solutions).
- **Regulation**—HIT can help reduce reporting burdens through data extraction and automatic report generation and can deliver greater consistency in reported data through the use of reporting requirements based upon unambiguous, computable queries; rapid-cycle refinement of reporting requirements, made possible through HIT, can result in reports that are more aligned with quality outcomes and process improvement.
- **Finance**—HIT can support greater transparency of actions and outcomes that enable greater alignment of financial incentives and reimbursement models with quality outcomes.

We offer the following recommendations for consideration by the Commission and all stakeholders in long-term care:

1. Make quality long-term care a national priority.
2. Accelerate industry-wide collaboration and leadership around the use of HIT in long-term care.
3. Explore legislative options to promote long-term care's transformation through HIT.
4. Establish federal leadership entities and positions dedicated to long-term care technology.
5. Support the development of innovative technologies and the adaptation of existing technologies for use in the long-term care setting.
6. Reduce or remove barriers to innovation in and the adoption of technology in long-term care.
7. Pursue regulatory reform and professional licensure enhancements to enable the expanded use of remote care.
8. Develop a global market for long-term care technology through information exchange and market development.

9. Promote a research agenda to evaluate the cost, quality, and efficiency benefits of applying information technology solutions to long-term care in order to establish scoring models for Centers for Medicare and Medicaid (CMS) and other third-party coverage decisions.
10. Pursue sustainable funding models that accelerate the adoption of HIT in long-term care.
11. Encourage the adoption and application of consumer-centric, continuous process improvement methodologies in long-term care.
12. Support the development of longitudinal PHRs, PHR-related standards, and consumer-centric mechanisms for linking long-term care providers and other settings through PHRs.
13. Support the foundational work required to create the standards, common tooling, and shared infrastructure necessary to support health information exchange and semantic interoperability.
14. Promote information flow and outcomes transparency as a fundamental driver for transformation.
15. Promote the use of open source software solutions to address some of long-term care's technology needs—especially for infrastructure and shared requirements.

With the right leadership and the right strategy, the long-term-care community can serve as transformation's focal point, the beacon for other healthcare stakeholders to follow.

## 1. Introduction

*We must use technology more effectively to enhance consumer independence and promote consistently better quality of care. We must design a health information technology infrastructure that addresses the unique needs of long-term care users and providers while ensuring the interconnectedness of electronic information—as well as consumer privacy and security—in both the long-term and acute-care systems.*

– *Out of Isolation: A Vision for Long-Term Care in America*  
The National Commission for Quality Long-Term Care

For every believer in the notion that technological advances will someday provide answers to society's weightiest problems, you likely will find a cynic who sees nothing new under the sun and has grown weary of unfulfilled hype. Among those cynics, you probably also will find at least a few who think that society's problems are largely a result of technology's failings rather than a target for technology's curative powers.

As with many philosophical quandaries, the truth may lie somewhere in the middle. Technology can provide solutions through innovations that apply our growing understanding of the human condition to the problems that overwhelm our society; technology can also negatively impact our lives through its thoughtless application or unintended consequences.

We can best apply technology to our problems by having a clear understanding of our ultimate goal and by focusing on that goal, avoiding the lure of a novel approach or the premature sense of accomplishment when reaching an early milestone on a much longer path; the recognition of these steps can serve as a motivator for pressing on, but must not be mistaken for the goal itself.

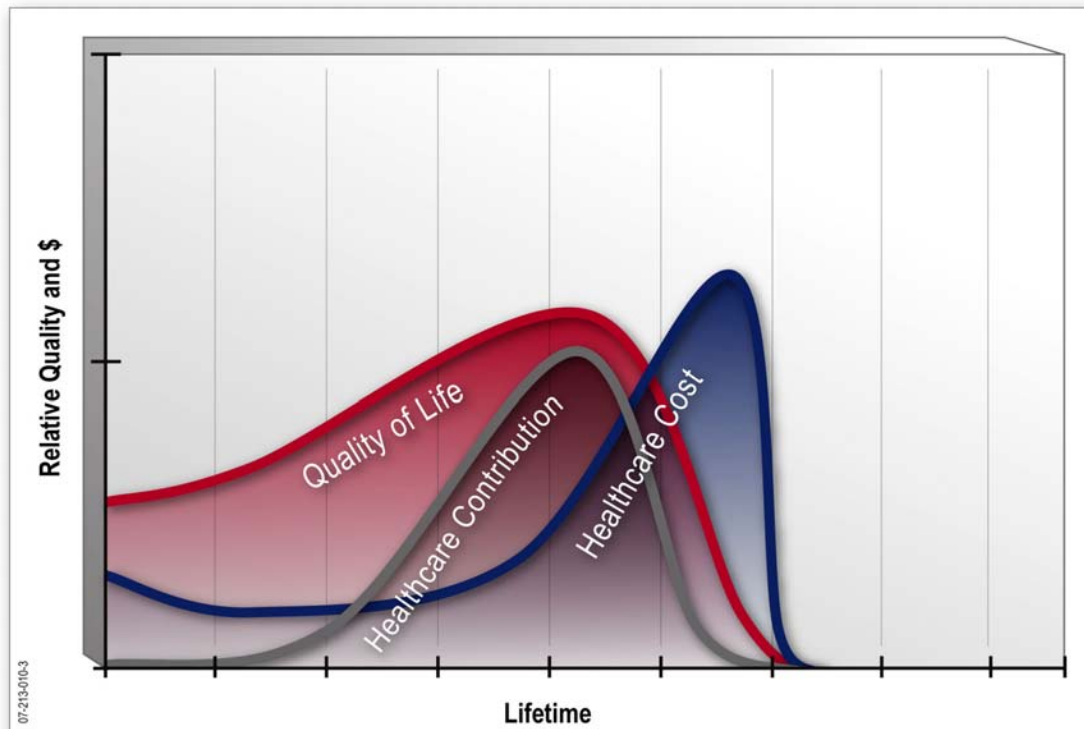
*The goal is to optimize quality of life for all within the constraints of our available resources and our understanding of the human condition.*

It is with this perspective that we consider the intersection of technology and long-term care. The goal is not the adoption of health information technology (HIT) in long-term care, nor is it the utilization of that technology. It is not electronic health information exchange that supports healthcare providers in their understanding of a patient's needs. It is not the medical informatician's holy grail of semantic interoperability. It is not even reducing costs and raising the quality of long-term care through continuous process improvement. All are merely prerequisites to achieving the goal.

**The goal is to optimize quality of life for all within the constraints of our available resources and our understanding of the human condition.** If one were to plot this concept on a graph, the goal would be to reshape the Healthcare Expenditure Curve in such a way as to maximize the area under the Quality-of-Life Curve.

**Figure 1-1** portrays the overlapping relationships between a person's quality of life, the cost of her healthcare, and her individual contributions to covering the cost of healthcare over time. The overlap of these curves is reflective of their interdependency; interventions that change the shape one curve have the potential to effect changes in the others.

**Figure 1-1. Approximations of Quality of Life, Cost of Care, and Contribution to Cost over Time.**

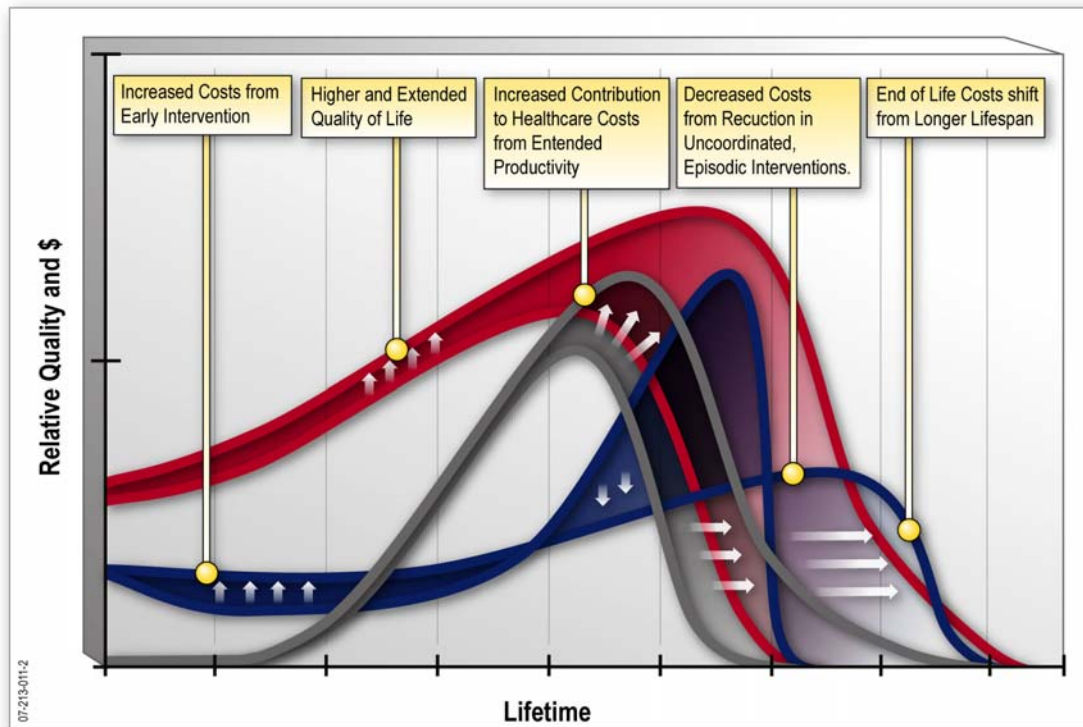


Note that this goal is not for seniors or for those involved in long-term care alone, but for the entire healthcare community; in fact, we cannot achieve this goal for long-term care without considering all of healthcare.

We can change the shape of the Quality-of-Life Curve through various interventions. These interventions can indirectly impact the Quality-of-Life Curve by extending the capacity of available resources or apply them in more effective ways; increasing the productivity of seniors (thus expanding available resources through their increased contribution to the cost of the current or future care); and reducing the use of resources by eliminating redundancy of effort or by eliminating particular interventions that are proven to be ineffective. Other interventions can impact the Quality-of-Life Curve directly by adding meaning, purpose, and enjoyment to life or reducing pain and suffering.

**Figure 1-2** shows the relative changes that can occur in the Quality-of-Life and Healthcare Cost Contribution Curves if we change the way we apply our healthcare resources.

**Figure 1-2. Potential Impact of Various Interventions on the Quality-of-Life Curve.**



Keeping our focus on the ultimate goal helps us maintain a systems-level approach to developing and implementing strategies for moving toward that goal. The alternative to systems-level thinking—narrow thinking that targets localized or short-term needs—may be effective in producing immediate results in a limited context, but often solutions that result from narrow thinking are not scalable or generalizable for uses outside of the original context.

We emphasize the general principles of focusing on a goal and implementing a systems-level approach because they are exquisitely germane to the topic of technology in long-term care. A goal-driven, systems-level approach is the only way to effectively address the complex challenge of transforming something as byzantine as our current healthcare system. Transforming each sector of healthcare in exclusion of the rest of the healthcare system would be like treating a patient with multiple conditions by hiring many specialists to treat separate maladies without a coordinated plan to manage the patient holistically. While some treatments might be remarkably effective, the net effect of uncoordinated care and unintended consequences might be wasted resources, increased complications, or even death. Similarly, the myriad complexities of integrating HIT into long-term care create a network of challenges that must be addressed within the context of the broader healthcare community.

Local optimization of healthcare processes that does not consider the ultimate goal may result in a paradoxical increase in the total cost of care or a lessening of quality of life. Illustrating the essence of what it means to be “penny wise and pound foolish,” this example, unfortunately, is an all-too-frequent hallmark of our current approach to care and has resulted in our painfully expensive and fragmented healthcare experience. Piecemeal approaches do not work in patient care; they will not work in our efforts to transform long-term care.

## 1.1 How this Report is Organized

Achieving our goal of optimizing the Quality-of-Life Curve to guide our actions requires both the big-picture perspective as well as specific, tactical steps. Therefore, this report focuses both on the long-term care setting within a larger context—addressing how technology can help optimize quality of life for all—and on what steps need to be taken to realize that optimization. Specifically, this report discusses strategies for transforming long-term care by leveraging HIT to improve the quality of care and the quality of life for people living and working in long-term care settings, from home care through hospice.

*This report discusses strategies for transforming long-term care by leveraging HIT to improve the quality of care and the quality of life for people living and working in long-term care settings, from home care through hospice.*

This report, organized from the general to the specific, presents our approach to achieving this goal:

- Section 1 establishes the goal we aspire to achieve, considering the nature of transformation itself and how information technology plays an essential supporting role in enabling continuous process improvement. We discuss the role of long-term care as the model environment for addressing information technology-enabled transformation for all of healthcare.
- Section 2 provides a brief review of the national landscape of HIT current efforts for healthcare and discusses the implications for long-term care.
- Section 3 examines the vision for long-term care as expressed by the Commission in their September 2006 publication *Out of Isolation: A Vision for Long-Term Care in America*. We suggest specific ways in which HIT can be a fundamental enabler of this vision.
- Section 4 discusses some of the requirements for driving long-term care's transformation using information technology.
- Section 5 provides summary recommendations for the Commission's consideration based upon the findings presented in this report.
- Section 6 concludes this report with something of a rallying cry around which we can all gather to further this cause.

This report is subject to several caveats:

- The need for long-term care services is not age specific but is related to an individual's level of cognitive and physical function, wellness, and capacity for independent living. Nevertheless, the majority of long-term care services are consumed by the elderly. Though we include all ages in this group, for the purposes of this report, we refer to the collective users of long-term care services as "seniors" for ease of reading. We also use the term "consumers" to reference the more general population of healthcare services users.
- This report contains no original research nor does it attempt to present a fully comprehensive treatise on the applicability of information technology to the long-term care setting. We highlight examples of specific technologies or applications of technology that serve both to illustrate our points and to support our recommendations.
- In particular, we do not dwell on the important issues revolving around privacy and security in electronic health information exchange. These issues are not exclusive to the long-term care setting and require a much longer discourse than can be managed in a

report of this scope. As a general principle, we believe that consumers should be in control of the movement of their healthcare information and that information technology can be used to empower individuals to manage the ways in which their personal health information is used—both for their own care and for secondary uses that lead to advances in our ability to provide care for all.

- The perspectives and recommendations contained in this report are supported by documented research and have been informed by experts and thought leaders in long-term care. We acknowledge, however, that we came into this project with certain views or biases that we hope will stand up to the scrutiny of our readers. Ultimately, the opinions contained in this report are those of the authors alone and not necessarily those of BearingPoint or the report’s sponsors.

## 1.2 Understanding the Drivers of Transformation

As one considers the irrefutable evidence of the transformative powers of information technology in other industries, it is easy to see why many thought leaders have concluded that a large bolus of information technology is the cure for healthcare ills. Former Speaker of the House Newt Gingrich, for example, summarizes his belief that America needs electronic health records (EHR) in two simple words: *Paper Kills*.<sup>1</sup>

And yet, anyone advocating for the adoption of HIT as an agent for transformation in healthcare today does so largely on the basis of faith rather than fact. Even in healthcare settings where there is a higher degree of information technology adoption than in long-term care, the direct evidence of its benefit is far less than conclusive. In a large-scale study by Linder et al. published in 2007, the researchers reviewed nearly two billion ambulatory-care patient visits and compared quality indicators in settings where EHRs were used versus those where EHRs were not used. The summary analysis showed no differences in quality indicators between the two settings.<sup>2</sup>

Does this mean, then, that EHRs have no benefit? Linder and his co-authors suggest that, “as EHR use broadens, one should not assume an automatic diffusion of improved quality of care.” Rather than concluding that EHRs provide no benefit, however, they also suggest that improvements in quality will require the use of EHRs in combination with other elements such as decision support, quality reporting, and patient registries.

We agree with the authors’ assertion. Even if every bit of information in healthcare were managed electronically through EHRs, the resulting changes in healthcare quality from this effort alone would be minimal at best; at worst, EHRs not properly employed could theoretically lead to the “more efficient” killing of patients. Plus, the cost of implementing the system would be such that the implementers may never recover their costs.

Is healthcare, then, somehow uniquely resistant to the transformative powers of information technology while other industries are susceptible? No. This is not a question of fit or resistance to change because **information technology in and of itself is not sufficient to achieve the desired transformation**. Information technology is merely the enabler of other transformative change agents—namely, **enhanced information access**, which leads to **information flow and transparency**, which in turn leads to **accelerated and continuous process improvement**.

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<sup>1</sup> Gingrich, *Paper Kills*. ([www.healthtransformation.net](http://www.healthtransformation.net))

<sup>2</sup> Linder, EHRs and Quality.

The lack of information technology is not the cause of our quality problems in healthcare; the fundamental lack of transparency and information flow is the deeper cause, along with the further lack of systems-level methods for process improvement, that keeps us from achieving our goal.

We therefore offer a slight alteration of Speaker Gingrich's conclusion that "paper kills." We assert that, rather than paper, the lack of information transparency and flow is the real enemy: **Fog is fatal.**

Fog is fatal when the decisions made by seniors, their caregivers, and providers must be made blindly without the benefit of information that may exist elsewhere. This information may even be stored in electronic form but cannot be shared because there is no framework for information exchange, no data sharing agreements, or no common language for delivering contextually relevant decision support.

Fog is fatal when electronic information systems push rules that amount to decision control rather than decision support. That system kills when it makes it difficult for astute clinicians to deviate from the current standard of care by applying additional observations not accounted for in the existing rules and then reporting on the resulting outcomes. Rigid protocols inhibit innovations that have been a natural by-product of clinical care for generations; a virtuous cycle of feedback and adaptation built into the system fosters those innovations.<sup>3</sup>

Every sector of healthcare has contributed to the fog of information that exists today. The fog manifests as information silos that prevent information from flowing to the point of need, which contributes to poor outcomes and inefficient care. Fog diminishes our ability to provide quality care, but even more insidiously it actually contributes to the bottom lines of the businesses that provide healthcare products and services:

- So long as quality cannot be easily measured and sources of inferior quality cannot be identified, healthcare providers can continue providing and receiving reimbursement for services that do not lead to improved outcomes.
- If a previously conducted laboratory test is unavailable in a second facility, another test is ordered, and both the ordering physician and the laboratory stand to gain financially from the fog.
- As highlighted in the Commission's vision for long-term care published in 2006, Medicare's prospective payment system motivates hospitals to expedite the discharge of long-term care patients, leaving long-term care providers with inadequate information from hospital discharge planners about the level of care needed for an incoming resident.

Unfortunately, this misalignment of incentives perpetuates the fog and hobbles efforts to lift the fog. If the healthcare community is ever to experience the same technology-enabled transformation that has revolutionized other industries, all healthcare stakeholders must seek to align the incentives that drive our utilization of healthcare resources with the measures that define quality and value.

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<sup>3</sup> This example is in no way intended to be critical of the concept of decision support; healthcare outcomes would be vastly improved if we simply applied our well-established knowledge consistently, a function enabled by decision support systems. But without including the means to provide feedback and assess outcomes, we deprive ourselves of the opportunity to maximize the true value of these tools and run the risk of alienating those we so eagerly seek to have adopt electronic health information systems and decision support.

Our analysis of the root causes of healthcare's current condition leads us to our thesis for this report on technology in long-term care:

HIT can be an enabling force in all aspects of healthcare transformation; yet, while it is essential, HIT is not sufficient for achieving this transformation. To achieve our goal of optimizing quality of life within the constraints of our available resources, we must combine the adoption of HIT with the realignment of incentives for improving consumer-centric outcomes and efficiency. These incentives must be driven through the creation of a healthcare culture focused on systems-level continuous process improvement that is driven by information transparency and flow.

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We explore the various concepts that make up this thesis throughout this report.

### 1.3 Long-Term Care is the Archetype of our Broken System

Thus far, this report has offered precious little insight specific to the long-term care setting, but has focused more on the healthcare system as a whole. In many ways, a discussion about long-term care is the same as a discussion about healthcare. In fact, were this report focused on the role of technology in transforming the entire healthcare system rather than the more specific domain of long-term care, we would still look to long-term care for examples of where technology can serve as an enabler of transformation. Why? Because **long-term care is just like the rest of healthcare, only more so**. Like the reflection in a warped fun house mirror, the challenges facing long-term care are exaggerations of the flaws that exist throughout our healthcare system. To cite just a few examples:

- Long-term care is more fragmented—There are more than 16,000 nursing homes in the United States. This one sector of the long-term care ecosystem cares for approximately 3 million patients annually resulting in more than 20 million physician or physician extender encounters per year. The largest long-term care chains are dwarfed in size by their hospital counterparts<sup>4</sup> Because seniors' need for services changes over time, they must often move from one setting to another, creating many opportunities for loss of information about their current conditions and service requirements, which compromises their care both now and in the future.
- Long-term care deals with a wider spectrum of healthcare issues and with patients who have more chronic, complex health issues.
- Long-term care offerings vary significantly and range from support services for independently living seniors with a few healthcare-related needs to round-the-clock, intensive care services for patients with debilitating illnesses. There is no single face of long-term care. The range of requirements and landscape of intertwining issues in long-term care look like a composite of the healthcare system as a whole.

<sup>4</sup> CMS OSCAR data (June 2006). An analysis of CMS evaluation and management (E&M) code data shows that there were more than 20 million physician/physician extender encounters with nursing facility residents in 2005. ([www.cms.hhs.gov/medicarefeeforsvcpartsb/04\\_medicareutilizationforpartb.asp](http://www.cms.hhs.gov/medicarefeeforsvcpartsb/04_medicareutilizationforpartb.asp).)

- Long-term care funding is in chronically short supply even as our nation’s aging population demands more services with fewer resources, making the issue of funding long-term care even more critical. The Commission has already noted that the further extension of life expectancy among the boomer population presents “unprecedented challenges to every social structure: the family, the workplace, the economy, and public policy.”<sup>5</sup>
- Long-term care faces workforce challenges that are more profound and are characterized by high turnover, large numbers of vacancies, and difficulties attracting new employees at all levels of the profession. A 2001 survey of nursing homes conducted by the American Health Care Association (AHCA) found annual turnover among registered nurses (RNs) averaged almost 49 percent; Licensed Practical Nurse (LPN) turnover averaged more than 50 percent. Facility respondents reported that 18.4 percent of RN positions were vacant, as were 14.4 percent of LPN positions.<sup>6</sup>
- Long-term care has adopted information technology solutions even more slowly than the rest of healthcare. According to a 2006 report created for the Department of Health and Human Services (HHS) Assistant Secretary for Planning and Evaluation (ASPE), the lack of “robust evidence on HIT costs and benefits is especially conspicuous in the post acute care (PAC) and long-term care (LTC) environment.”<sup>7</sup> The California HealthCare Foundation notes that there is minimal use of clinical HIT technologies; HIT systems are not integrated with other systems and, when implemented, they are underutilized.<sup>8</sup>

**Figure 1-3** displays estimates of the current HIT adoption rates for functions within segments of the healthcare community. Compared with hospitals and physician offices, skilled nursing facilities and home health agencies are significantly lagging in their adoption of clinically focused applications.

**Figure 1-3. Estimated Current HIT Adoption Rates among Hospitals, Physicians (MD), Skilled Nursing Facilities (SNF), and Home Health Agencies (HHA).<sup>9</sup>**

HIT Function	Estimated Current HIT Adoption Rates			
	Hospitals	MD	SNF	HHA
Billing/claims	84-92%	78-90%	77%	73%
Eligibility processing	18-24%	10-19%	17%	16%
Results viewing	53-68%	23-35%	8%	6%
EHRs (e.g., demographics, problem list, medication list, allergies, advance directives)	11-18%	9-15%	1%	--
Computerized provider order entry	7-17%	5-9%	1%	--

<sup>5</sup> National Commission, *Out of Isolation*. ([www.qualitylongtermcarecommission.org/pdf/out\\_of-isolation.pdf](http://www.qualitylongtermcarecommission.org/pdf/out_of-isolation.pdf))

<sup>6</sup> AHCA. (2003). *Results of the 2002 AHCA survey of nursing staff vacancy and turnover in nursing homes*. Washington, DC.

<sup>7</sup> Booz Allen Hamilton, *Evaluation Design*.

<sup>8</sup> Hudak, *Health Information Technology*.

<sup>9</sup> Kaushal, *Functional Gaps*.

Because the challenges within long-term care are so pronounced, long-term care is the ideal “poster child” for the cause of technology-enabled transformation in healthcare. Long-term care is a long way from achieving poster child status and is at risk for being underrepresented in our national efforts to hasten healthcare’s transformation through HIT. If policymakers and federal healthcare purchasers place special emphasis on creating solutions applicable to the long-term care setting, not only will we address the needs of the long-term care community, we will also have the opportunity to support the rest of healthcare by broadening the scope and use of these long-term care focused solutions. Healthcare as a whole will benefit as the long-term care sector’s particular emphasis on functional status, wellness, and transition management informs the development of shared solutions.

This is not to say that the long-term care setting has no unique needs that must be specifically addressed. As noted in the AHCA HIT Committee’s report on technology in long-term care, only a few of the emerging regional health information organizations (RHIOs) working to enable local health information exchange are placing any emphasis on long-term care. The RHIOs may not be including long-term care because they believe that the sector can be added at a later, more opportune time. The committee concludes that “this is problematic because the special needs of LTC setting cannot be adequately addressed in a network designed only for acute care.”<sup>10</sup>

*Because the challenges within long-term care are so pronounced, long-term care is the ideal “poster child” for the cause of technology-enabled transformation in healthcare.*

We will discuss these particular needs and how we might address them in future sections. Overall, however, we believe that the interests of long-term care will best be served by seeking shared solutions that are then specialized to serve long-term care unique needs rather than by creating sector-specific solutions that do not align with our healthcare system as a whole.

There is yet another reason to take a holistic approach in addressing these issues: A disproportionate percentage of our healthcare dollars are spent in the final decades of life, though the origins of these expenditures can occur many years earlier. Our seniors experience a lifetime of events and circumstances—including an accumulation of physical and mental insults—that add up to a current state of health and wellbeing. This cumulative result is yet another reason why the necessary solutions for our seniors don’t all focus on seniors, but on people of all ages. Early interventions not only help maintain health throughout a person’s life, but also have the potential to avoid future costs related to more extensive treatments.

*Solutions will come not through a silver bullet, but through a thousand small interventions made throughout the healthcare system to reduce each individual negative input.*

Solutions will come not through a silver bullet, but through a thousand small interventions made throughout the healthcare system to reduce each individual negative input:

<sup>10</sup> AHCA, A Snapshot, p. 9.

- Detecting subtle changes in mental status and providing early intervention to prevent a fall
- Identifying genetic risk factors for disease early in life and providing gene therapy treatment that dramatically changes the course of disease
- Providing appropriately timed immunizations throughout life to prevent the long-term effects of infectious diseases
- Offering better consumer-oriented health education at every level so that our citizenry can make more informed decisions about their health throughout their lives
- Adopting EHRs with integrated decision support tools to reduce medical errors
- Enabling information sharing through lifetime PHRs to decrease treatment redundancy and empower consumers to better understand their personal health

As we keep our sights on our goal of increasing quality of life, the real dividends of these efforts will ultimately accrue to long-term care.

## 2. Overview of the Current Health Information Technology Landscape

We now examine the broader efforts currently underway to improve the adoption and value of information technology in healthcare as a whole so we can discover opportunities for alignment with the long-term care sector.

*Broader efforts currently underway to improve the adoption and value of information technology in healthcare as a whole so we can discover opportunities for alignment with the long-term care.*

### 2.1 Federally Led HIT Initiatives

#### 2.1.1 The Office of the National Coordinator for Health Information Technology (ONC)

The long-suffering souls who are the pioneers of medical informatics (the application of information technology to healthcare) have weathered many disappointing years as they waited expectantly for the advent of ubiquitous electronic health records (EHRs). One can read their bold predictions of widespread EHR adoption “within the decade” since the 1960s. We are hearing declarations of this vision even today. But now they are coming from politicians rather than a just few experts in this little-known field of medicine.

Most notably, in 2004, President George W. Bush signed Executive Order 13335<sup>11</sup> calling for the widespread adoption of EHRs for most Americans within ten years. He also established incentives for the use of health information technology (HIT) and created the position of the National Coordinator for Health Information Technology.<sup>12</sup>

This executive order and the Department of Health and Human Services (HHS) Secretary Tommy Thompson’s subsequent appointment of Dr. David Brailer as the first National Coordinator for HIT set in motion a level of activity over the last three years far exceeding that of the prior three decades.

The HHS Framework for Strategic Action on HIT—or the “Strategic Framework”—was released on July 21, 2004. The Strategic Framework established four major goals and related strategies for achieving those goals in order to realize the vision of improved healthcare for all Americans (see Appendix, **Figure A-1**).<sup>13</sup> Though the Strategic Framework targets the entire healthcare system, it is difficult to find a single recommendation that wouldn’t directly apply to the long-term care setting.

ONC oversees and coordinates a number of federal initiatives that address the goals of the Strategic Framework. The cyclical approach HHS has taken to pursue this agenda involves four basic steps:

1. Develop and prioritize use cases that outline the desired technology-enabled process and information flow by assembling a wide array of thought leaders and industry stakeholders and soliciting input from others.
2. Create interoperability specifications and harmonize standards by empowering standards developers and technical experts to work out the details for information exchange.

<sup>11</sup> The White House Office of the Press Secretary, Executive Order. ([www.whitehouse.gov/news/releases/2004/04/20040427-4.html](http://www.whitehouse.gov/news/releases/2004/04/20040427-4.html))

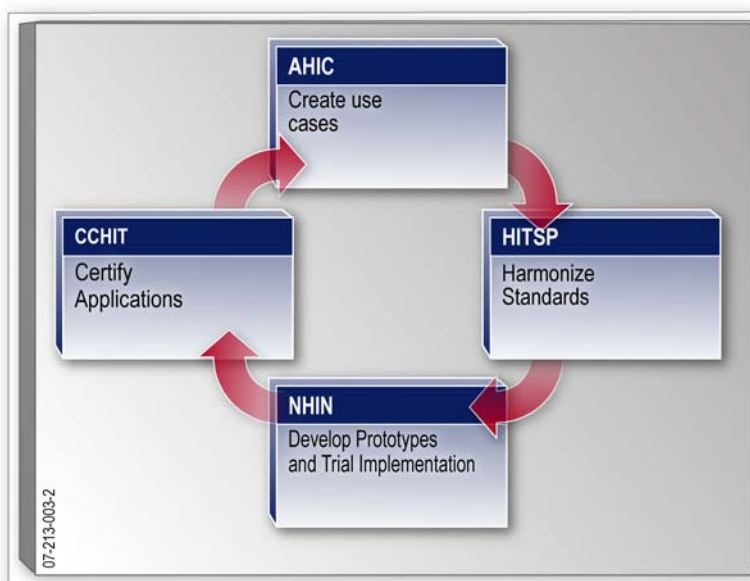
<sup>12</sup> In the spirit of full disclosure, BearingPoint provides management and technology consulting services to ONC and other areas within HHS.

<sup>13</sup> HHS, HIT, Strategic Framework. ([www.hhs.gov/healthit/framework.html](http://www.hhs.gov/healthit/framework.html))

3. Test the approach through prototypes and pilots.
4. Certify applications and systems that support the shared infrastructure and specifications in order to create trust in the marketplace and ensure interoperability.

**Figure 2-1** illustrates this transformation cycle. Sections 2.1.2 through 2.1.5 provide an overview of the entities responsible for these steps as well as their potential impact on long-term care.

**Figure 2-1. HHS Strategy for Cyclically Advancing Healthcare Interoperability**



### 2.1.2 The American Health Information Community (AHIC)

When Michael O. Leavitt assumed the role as Secretary of Health and Human Services in 2005, one of his early actions was to establish the American Health Information Community (AHIC or Community), which was created to advise the Secretary and recommend specific actions to achieve a common interoperability framework for HIT. Along with the Office of the National Coordinator for HIT (ONC), now led by Dr. Robert Kolodner, the AHIC serves as the focal point for prioritizing the federal agenda around HIT adoption and coordination. Notably, of the dozens of advisory commissions established by the Secretary's office, this is the only one which Secretary Leavitt both personally chairs and attends with regularity; he is clearly committed to seeing progress in driving the adoption of HIT.

The Community has established seven workgroups that focus on areas considered to be of highest priority to the Secretary and the Community members. The main objective of the workgroups is to develop recommendations in their broad and specific charge areas to present to the AHIC. The workgroups may also conduct studies and pilot projects and report findings to the AHIC. Under certain circumstances, the AHIC workgroups provide input regarding focus areas and development of use cases, which provide input into standards development. For each workgroup, the broad charge and the first-year specific charge is listed in Appendix, **Figure A-2**.

There is no Long-Term Care Workgroup in the list of AHIC workgroups, but neither is there a Pediatrics Workgroup or Cancer Workgroup. The design of the initial set of AHIC workgroups was to address cross-cutting issues rather than domain-specific ones.

AHIC has gradually expanded the number and scope of the “Breakthrough” issues on which they are focusing, but this escalation is linear and cannot meet the demand of the many interests in healthcare. As a result, some stakeholders have raised questions about the relevance of the AHIC effort in the total scope of healthcare in the United States and about the inability of the Community to adequately represent all interests of the diverse healthcare community.

But AHIC’s original design was never intended to accommodate all the HIT interests and needs within the healthcare system. Instead, the approach was designed to serve as a lightning rod for attracting the scattered efforts of various stakeholders and driving them toward a shared vision for the future.

When Secretary Leavitt first announced the creation of AHIC, he also stressed that this effort would be launched by the federal government but not maintained by the government long term. He envisioned that the Community would be replaced by a successor organization that would take the form of a public-private partnership. True to this promise, HHS has now begun the process of developing a succession plan for the current AHIC and is now proposing and soliciting comments on a design for the AHIC successor organization.<sup>14</sup>

Has the long-term care community effectively participated in this process? No members of the Community or the workgroups are specifically from the long-term care sector. Long-term care issues have been raised at various times in the workgroups, including EHR, Chronic Care, and Consumer Empowerment. The long-term care community needs to fully participate in the process in order to effectively make its voice heard. There are, however, numerous opportunities for public comment and the offering of testimony about the needs of long-term care during all of the public meetings of the Community and its workgroups.

Janice Zalen from the AHCA, for example, expressed her concern that long-term care facilities are not being considered by the EHR Workgroup and that they should be looking at barriers to the adoption of EHRs in long-term care facilities, as well as in physicians’ offices and labs.<sup>15</sup> During the final round of public comment on the 2007 Medication Management use case, signatories from six different long-term care oriented associations expressed concern to ONC that the unique needs of long-term care were not included.<sup>16</sup> ONC acknowledged the unique aspects of portions of their proposed long-term care scenario, but concluded that an additional, unplanned, round of public comment would need to be scheduled if this additional scenario were added to the final use case. The final version of the use case acknowledges that certain long-term care needs are not expressed and will need to be prioritized by AHIC for future development.

A loose collaboration of long-term care stakeholders continues to advocate for establishing greater long-term care representation in AHIC at the leadership level, in the workgroups, and through offering comments and testimony to the Community. These efforts will need to be strengthened if they are to cover the many opportunities to provide input into the AHIC process. Most immediately, the 2008 prototype use cases are now under development and are open for public comment through September 28, 2007. A second round of public comment on the detailed use cases will occur later this year. Work is also underway on prioritizing the many needs in healthcare and clustering them into 2009 candidate use cases. Early involvement in use case design and prioritization can go a long way in shaping the direction of these efforts.

<sup>14</sup> AHIC, Successor. ([www.hhs.gov/healthit/documents/m2007031/7a\\_whitepaper.html](http://www.hhs.gov/healthit/documents/m2007031/7a_whitepaper.html))

<sup>15</sup> AHIC, Webconference Held January 31, 2006.

<sup>16</sup> AAHSA, June 1, 2007 Letter to Robert Kolodner. ([www.ascp.com/advocacy/briefing/upload/JointLTCResponse-MedMgmtDraftDetailedFeedbackForm-FINAL.pdf](http://www.ascp.com/advocacy/briefing/upload/JointLTCResponse-MedMgmtDraftDetailedFeedbackForm-FINAL.pdf))

Ultimately, the transition of AHIC to a “public-private collaboration successor organization” may represent the best opportunity for the long-term care community to assert itself more vigorously as a key stakeholder in our collective effort to transform healthcare.

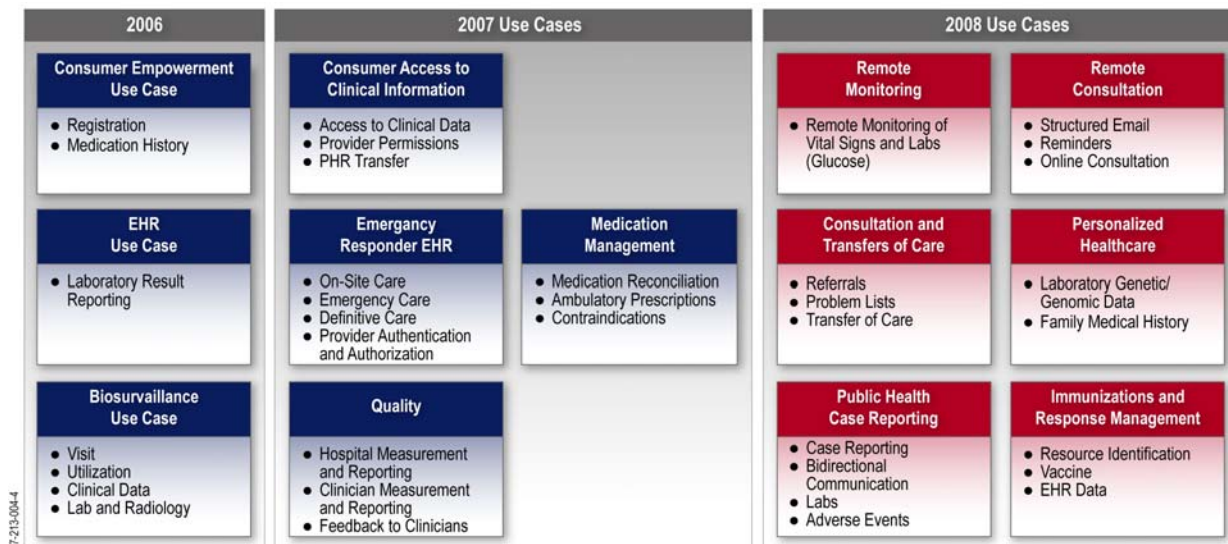
### 2.1.3 The Health Information Technology Standards Panel (HITSP)

HHS contracted through ONC with the American National Standards Institute (ANSI) in 2005 to create the Health Information Technology Standards Panel (HITSP), which serves as a “cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards specifically to enable and support widespread interoperability among healthcare software applications, as they will interact in a local, regional, and national health information network for the United States.” Membership is free and open to all stakeholder organizations.

Functionally, ANSI HITSP serves to create interoperability specifications for health information exchange based upon the use cases recommended by AHIC. Volunteers participate in technical committees, which are formed around the selected use cases and work to harmonize existing technical standards or to recommend the creation of new standards to support the use cases. The resulting interoperability specifications—technical documents that application vendors and systems integrators use to comply with the relevant standards for information exchange—are then published for testing and use.

The Use Case Roadmap illustrated in **Figure 2-2** shows the use cases selected by AHIC for the 2006 and 2007 cycles and the ones being considered for 2008.

**Figure 2-2 AHIC Priorities and Use Case Road Map<sup>17</sup>**



On January 23, 2007, Secretary Leavitt announced his acceptance of the 30 consensus standards recommended by HITSP for the three specific use cases selected for 2006. These use cases covered narrow portions of the broad domains of EHRs (the electronic delivery of lab results to a doctor), biosurveillance (data networks supporting the rapid alert to a disease outbreak), and consumer empowerment (giving consumers the ability to manage and control access to their registration information and medication histories).

<sup>17</sup> ONC presentation to HITSP, July 15, 2007. ([www.hitsp.org](http://www.hitsp.org))

Under an executive order, any new or upgraded federal health information system launched after January 1, 2008, will need to be compliant with the standards recommended by HITSP. This policy puts the purchasing power of the federal government behind the effort to harmonize standards for health information interoperability.

The long-term care community is active in HITSP, though they have had a similar problem garnering the attention of the broader membership to include specialized scenarios necessary to accommodate long-term care interests within the interoperability specifications as they are developed. There is still inadequate representation of long-term care interests at this level in the process; the current number of long-term care HIT experts participating in HITSP can't cover all of the relevant activities. Looking to the list of possible 2008 use cases, one can easily see the relevance of several candidates—Remote Monitoring of Vitals and Labs (Glucose), Referrals and Transfer of Care, Remote Consultation, and Public Health Case Reporting—as being particularly relevant to the long-term care community. The work required to shape any one of these outcomes is significant; without adequate staffing, the interests of long-term care will not be sufficiently acknowledged and accommodated.

#### **2.1.4 The Nationwide Health Information Network (NHIN)**

Central to the effort to transform our healthcare system through HIT is the creation of a Nationwide Health Information Network (NHIN)—a “network of networks” that forms the backbone of a healthcare information interoperability infrastructure. In its earliest form, the NHIN is more of a test bed for demonstrating how various models of interoperability can take shape. Ultimately, it will be the system for connecting providers, consumers, and other entities that need to securely exchange health-related data and services.

The NHIN seeks to achieve these goals by:

- Developing capabilities for national, standards-based, secure data exchange
- Improving the coordination of care information among hospitals, laboratories, physicians offices, pharmacies, and other providers
- Ensuring appropriate information is available at the time and place of care
- Ensuring that consumers’ health information is secure and confidential
- Giving consumers new capabilities for managing and controlling their PHRs as well as providing access to their health information from EHRs and other sources
- Reducing risks from medical errors and supporting the delivery of appropriate, evidence-based medical care
- Lowering healthcare costs resulting from inefficiencies, medical errors, and incomplete patient information
- Promoting a more effective marketplace, greater competition, and increased choice through accessibility to accurate information on healthcare costs, quality, and outcomes<sup>18</sup>

HHS has sponsored several initiatives related to the envisioning, testing, and establishment of the NHIN. These initiatives include:

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<sup>18</sup> HHS, NHIN Background ([www.hhs.gov/healthit/healthnetwork/background](http://www.hhs.gov/healthit/healthnetwork/background)).

- **NHIN Prototype Architectures:** In November 2005, the ONC awarded four contracts for developing prototype architectures for an NHIN to Accenture, Computer Sciences Corporation, IBM, and Northrop Grumman. Each contractor developed a prototype architecture for the NHIN and interconnected three different communities to show how interoperability could be achieved. The work for these prototype architectures was completed in January 2007.<sup>19</sup>
- **NHIN Forums:** In 2006 and 2007, ONC conducted a series of open meetings to discuss the functional requirements, health information security and services, NHIN prototypes, and the business models necessary to support the creation of an NHIN. These forums will continue during the 2007-2008 timeframe.<sup>20</sup>
- **NHIN Functional Requirements—**The National Committee on Vital and Health Statistics (NCVHS), an HHS advisory commission, created a report for the Secretary defining a minimum but inclusive set of functional requirements necessary for nationwide health information exchange activities.<sup>21</sup> They created a similar report on privacy and security issues related to the creation of an NHIN.<sup>22</sup>
- **NHIN Trial Implementations—**A number of trial implementations of the NHIN that build off of the 2006 prototype architectures will be funded in 2007 and will focus on state and regional health information exchanges. The contract awardees will participate in the NHIN Cooperative to further specify the interfaces and transactions they will need to interoperate for core services and breakthrough/priority areas and to test their ability to work together in a cooperative interoperability testing event.<sup>23</sup> Similar multiyear projects are being conducted by the Centers for Disease Control and Prevention (CDC) to examine how public health reporting and information exchange will be conducted through the NHIN.

Long-term care has not been a specific focus of the NHIN development process. Like most specialized uses of the NHIN, the expectation is that the framework and methods for information exchange will be sufficiently generic to support data exchange of all types and for all uses such as the exchange of functional status and wellness content. This assumption must be proved out over time through expanded demonstrations and prototypes. The long-term care community needs to become more active in these discussions and consider how these generalized use cases for information exchange must be adapted for use in long-term care.

### **2.1.5 The Certification Commission for Health Information Technology (CCHIT)**

The Certification Commission for Health Information Technology was created in 2004 by three HIT industry associations—the American Health Information Management Association (AHIMA),<sup>24</sup> the Health Information and Management Systems Society (HIMSS),<sup>25</sup> and the National Alliance for Health Information Technology (The Alliance)<sup>26</sup>—to develop a voluntary

<sup>19</sup> HHS, NHIN Prototype Architecture Contracts. ([www.hhs.gov/healthit/healthnetwork/resources/summary\\_report\\_on\\_nhin\\_Prototype\\_architectures.pdf](http://www.hhs.gov/healthit/healthnetwork/resources/summary_report_on_nhin_Prototype_architectures.pdf))

<sup>20</sup> HHS, NHIN: Public Forums. ([www.hhs.gov/healthit/healthnetwork/forums](http://www.hhs.gov/healthit/healthnetwork/forums))

<sup>21</sup> National Committee on Vital, October 30, 2006, Letter to Michael Leavitt. ([www.ncvhs.hhs.gov/061030lt.pdf](http://www.ncvhs.hhs.gov/061030lt.pdf))

<sup>22</sup> Cohn, June 22, 2006, Letter to Michael Leavitt. ([www.ncvhs.hhs.gov/060622lt.htm](http://www.ncvhs.hhs.gov/060622lt.htm))

<sup>23</sup> HHS, HIT, NHIN Trial Implementations. ([www.hhs.gov/healthit/healthnetwork/trial](http://www.hhs.gov/healthit/healthnetwork/trial))

<sup>24</sup> AHIMA home page. ([www.ahima.org](http://www.ahima.org))

<sup>25</sup> HIMSS home page. ([www.himss.org](http://www.himss.org))

<sup>26</sup> NAHIT home page. ([www.nahit.org](http://www.nahit.org))

certification process for HIT-related products such as EHRs. CCHIT's goal is to accelerate the adoption of HIT by increasing the level of assurance and trust in the marketplace.

In 2006, HHS named CCHIT as a "recognized certification body for EHRs and their networks. They continue to work closely with ONC to develop the certification road map for various elements of the emerging NHIN and the components such as EHRs, PHRs, and electronic prescribing systems.

Long-term care is on the development road map for the expansion of CCHIT certification to professional specialties, care settings, and patient populations. Development on long-term care application certification is slated to begin in October 2007. This work will continue throughout 2008 with the launch of an EHR certification process specialized for long-term care expected in August 2009. Long-term care stakeholders, working collaboratively, are refining the EHR Functional Model to include a long-term care functional profile to meet this timeline. Discussions on a certification process for applications related to the home care setting are currently planned to begin in October 2007, but no specific target dates for launch have been established at this time.

## 2.2 Major Health Information Technology Initiatives and Trends

The marketplace for HIT shows wide variation in terms of the relative maturity of the offerings and rates of adoption and utilization. Pharmacy information management systems enjoy nearly universal adoption in retail and inpatient pharmacy settings. Other applications, such as personal health records (PHRs), are part of an emerging market for consumer-oriented health information products and services and, while receiving significant attention, are still experiencing limited uptake.

Some general trends are clear:

- Overall information technology investments in the healthcare industry are significantly lower than in other industries. Hospitals, which generally have higher rates of information technology adoption compared to other sectors within healthcare, spent less than 3 percent of their total operating budgets on information technology operations in 2005.<sup>27</sup> A typical long-term care investment in technology is in the 1- to 2-percent range.
- Investments that are made in information technology are predominantly focused on applications that support billing, scheduling, and other administrative functions rather than clinical information systems.
- Larger healthcare systems (such as hospitals, integrated delivery networks, and large medical practices) are significantly more likely to adopt clinical information systems than are smaller organizations.
- Clinical information interoperability, the ability to share clinical information between applications and locations, if it even exists within an enterprise or across enterprises, is largely the result of the hard work of one-to-one systems integration and data mapping. The "wiggle room" present in commonly used standards for health information exchange means that having out-of-the-box interoperability without customization remains an uncommon experience.

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<sup>27</sup> HIMSS Analytics™ Database, 2005. ([www.himss.org](http://www.himss.org))

- Common reasons for the lack of adoption of HIT solutions such as EHRs and electronic prescribing systems are the lack of capital resources and a lack of evidence that HIT adoption will improve performance or provide a return on investment in terms of cost or quality. On this last point, where there are apparent returns on investment in the system as a whole, these benefits often accrue to those other than the ones making the investment to adopt HIT.
- Long-term care lags behind on HIT investments and readiness. According to research conducted by the California HealthCare Foundation, HIT implementation is driven by reactions to mandates or crisis rather than strategy. There is minimal use of clinical HIT applications and even if they're used, they are not integrated with other systems or connected outside the immediate environment.<sup>28</sup>

### 2.2.1 Electronic Health Records (EHRs)

EHRs are slowly gaining a foothold in clinical settings, with hospital and large integrated delivery network settings adopting EHRs at a higher rate than physician offices. Long-term care, by all accounts, has been among the slowest of EHR adopters. This fact is not surprising, as the key drivers for EHR adoption—clear opportunities for return on investment, regulatory mandate, evidence for efficiency, and quality gains—are largely lacking in the long-term care space.

EHRs are touted by industry advocates as being the solution for curing what ails healthcare. Yet there remains relatively little evidence that, for all their expense and complexity, EHRs in and of themselves substantially reduce total costs or increase quality. A recent study by Harvard and Stanford Universities published in the *Archives of Internal Medicine* examined 17 quality indicators and found no difference in outcomes between clinicians who used EHRs and those who did not.<sup>29</sup> Another study from the Center for Information Technology Leadership found that, among various IT options for managing diabetes care, only electronic patient registries had the potential to deliver a significant return on investment in terms of total cost of care; the return was bestowed on payers, not the providers who invested in the EHRs.<sup>30</sup>

Are the EHR advocates wrong? Not necessarily. The authors of the study on quality indicators suggest that one cannot assume an automatic improvement in quality will result from EHR adoption, but suggest that “physician practices should carefully consider the inclusion of clinical decision support to facilitate quality care for individuals as well as the availability of tools, like quality, reporting, and registry functions, to facilitate quality care for populations.” In other words, EHR adoption is a step in the transformation process, but only one step in a much longer journey. We will need to carefully count the cost of EHR adoption with the understanding that the returns may take time to accrue and may only accrue to entities other than those making the investments.

In the long-term care setting, one much-heralded study showed significant benefits following the adoption of an EHR system specifically designed for the long-term care setting. Using the Achieve Matrix system to perform long-term care business processes resulted in a number of significant findings:

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<sup>28</sup> Hudak, Are Long Term Care Providers Ready? ([www.chcf.org/topics/view.cfm?itemID=132819](http://www.chcf.org/topics/view.cfm?itemID=132819))

<sup>29</sup> Linder, Electronic Health Record Use. ([www.archinternmed.com](http://www.archinternmed.com))

<sup>30</sup> Bu, Information Technology-Enabled Diabetes Management. ([www.citl.org/\\_pdf/The\\_Value\\_of\\_IT\\_Enabled\\_Diabetes\\_Management.pdf](http://www.citl.org/_pdf/The_Value_of_IT_Enabled_Diabetes_Management.pdf))

- Reduced turnover rates for nurses
- Decreased falls
- Reduced hospitalization rates
- More efficient daily work processes
- Increased job satisfaction for nurses due to the amount of time available to spend with residents

In addition, the researchers concluded that:

- The nursing staff was able to move from one resident's record to another very quickly with an HER.
- The EHR allowed multiple staff to review and document a resident's record at the same time.
- Access to the EHR on each staff's desktop facilitates more efficient work processes and the ability to provide prompt information to residents' families.
- Laptop computers allowed staff to instantly access resident information during care plan and medical meetings and eliminated the need to find charts at the nursing unit.

### **2.2.2 Personal Health Records (PHRs)**

Our current healthcare system tends to treat patients as a collection of largely unrelated episodes of conditions and treatments rather than in a holistic manner. Today's patient medical record reflects this reality. The total healthcare experience of a patient is scattered throughout the healthcare system and is both provider- and episode-centric in its perspective.

A new paradigm is emerging in HIT—the concept of a person-centric, longitudinal health record that provides a more comprehensive view of an individual's overall health and medical history. A commonly accepted definition of PHR is still a matter of debate, but the definitions under consideration generally establish the patient as the owner and controller of the information contained within the PHR—that it represents the equivalent of the paper copies of records a patient might collect from all of his or her healthcare providers plus any personal health diaries (anything from exercise logs and glucose readings to recordings of clinical outcomes from various therapies).

Long-term care can differentially benefit from the movement toward healthcare models that are more person centric rather than provider centric. Long-term care is already more holistic relative to other healthcare sectors; it involves aspects of the senior's life beyond episodic sick care and includes wellness and maintenance of their cognitive and functional status, advance directives, power of attorney and guardianship advice—information that must be efficiently transferred as seniors move from setting to setting. Long-term care is by necessity interdisciplinary and includes not only professional clinicians, but also family members and other care providers with no formal training. The PHR can be the central connection point for all involved in the care of an individual and can facilitate the kind of transformation required to support this person-centric approach to providing care.

PHRs can also serve a critical role in our national emergency preparedness efforts as a portable healthcare record for persons displaced by natural disasters such as Hurricanes Katrina and Rita. By using PHRs as a key mechanism for health information exchange in routine care, we will be much more prepared for unforeseen disasters than we would if we try and build "in case of emergency break glass" types of solutions that are used only in

extreme conditions. Emergency-only solutions are not prone to achieving the desired results because, without significant investments in training and simulation, consumers and care providers alike will not be familiar with how to access the available tools and information. Electronic PHRs that are managed both online and using portable media like smart cards and USB thumb drives can withstand many types of affronts and are uniquely qualified to serve our everyday needs, individual emergencies, and national disasters with equal effectiveness.

Several large-scale efforts are now underway to explore the use of PHRs. In late 2006, several large employers such as Intel, Wal-Mart, Pitney-Bowes, and others announced that they had joined forces to create an internet-based, lifetime PHR. The Dossia Network is still under development, but the founders plan to make this offering available to company employees and their dependents in late 2007. Members of America's Health Insurance Plans (AHIP) and the Blue Cross Blue Shield Association (BCBSA) have been working on a set of standards for exchanging member PHR data among insurers.

Long-term care facilities are also beginning to experiment with the use of PHRs for managing information exchange both within individual settings such as continuing care retirement communities (CCRCs) and with external providers. For example, Erickson Retirement Communities recently deployed PHRs for their residents. More than 2,000 residents now have access to a view of their health record.

These efforts represent only the beginning of what must be a significant collective effort to build the necessary infrastructure to support PHRs and the exchange of health information through PHRs. Many questions surrounding privacy, security, sustainability, effectiveness, and adoption of PHRs remain. Only through continuing investment and study will we be able to usher in a more consumer-centric approach to healthcare based upon PHRs.

### **2.2.3 Electronic Prescribing (eRx)**

Electronic prescribing (ePrescribing or eRx) presents one of the best opportunities for providers to adopt clinically focused information technology in an incremental fashion. The prescribing process often is related to but functionally separate from other clinical care processes. The clinical information contained in a person's medication history is critical to clinical decision-making and patient safety. The applications and communications mechanisms required to support electronic prescribing are often distinct from other clinical processes. As a result, many HIT advocates recommend eRx as a first step toward more comprehensive HIT adoption.

The passage of the Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003, in addition to creating an outpatient prescription drug benefit for seniors (Medicare Part D), mandated the progressive development and adoption of standards for electronic prescriptions over time. This mandate resulted in a significant increase in the level of interest and effort associated with developing standards for the electronic transmission of prescriptions between prescribers and pharmacies along with related transactions such as formulary, prior authorization, and medication history exchange. Industry stakeholders worked together to advance existing standards or create new standards to accommodate these requirements.

Part of the effort involved conducting pilots to determine which standards would be sufficient to meet the requirements of MMA. One of these pilots was led by Achieve Healthcare Technologies and focused on the long-term care setting. Their analysis showed that ePrescribing can be supported, with some technical accommodations to the standards, in long-term care facilities for Part D implementation.

Even in advance of these findings from the MMA pilots, leaders involved in HIT implementations for long-term care recognized the need for modifying existing eRx standards to accommodate the unique needs and workflows found in the long-term care setting. They created a new long-term care-focused workgroup within the National Council for Prescription Drug Programs (NCPDP), the accredited standards development organization that maintains the standards used in ambulatory care electronic prescribing. The proactive creation of this workgroup is an example of the kind of collaborative effort we believe to be the ideal manner in which the long-term care community can best serve its own needs. By building on and modifying existing standards to support long-term care-specific use cases, we can advance the cause of HIT adoption in long-term care more quickly and increase the likelihood that these efforts will find synergies with external but related efforts.

Medication Therapy Management (MTM) is gaining recognition as a method for providing a high-impact intervention within long-term care that can be supported through health information exchange and ePrescribing. MTM services include patient education, medication reviews for patients on multiple medications, refill reminders, and other interventions. MMA includes a requirement for MTM service provision by prescription drug plans who provide Medicare Part D coverage.

The National Association of Chain Drug Stores (NACDS) representing retail chain pharmacies, the National Community Pharmacists Association (NCPA) representing independent pharmacies, and the American Pharmacists Association (APhA) representing professional pharmacists have joined together to launch Project Destiny,<sup>31</sup> an exploration of how community pharmacists can be the key provider of MTM services for their customers.

We believe that this effort represents a key example of how the long-term care community can leverage the work of other stakeholders to enable improved care for seniors. By combining MTM services with PHRs, seniors can be empowered to stay compliant with complex medical regimens and maintain their independence in cases where compliance failures might lead to increasing disability or movement to a higher-level-care setting. The combination also provides seniors with the tools necessary to keep all of their healthcare and long-term care providers informed of their comprehensive medication histories, allergies, and other key health information.

#### **2.2.4 Open Source Software**

The community of healthcare software developers has seen a surge in the number of open source software projects in recent years—especially at the infrastructure level. Open source, in general, means that the source code and underlying components of an application are available to be viewed, modified, and distributed. Applications derived from open source initiatives are often free, but not necessarily so. Even if the software itself is free, the applications still require installation, maintenance, and possibly customization in order to be useful.

One of the primary business drivers behind the acceleration of open source initiatives is the notion that "innovation happens elsewhere".<sup>32</sup> A small team of the world's best programmers locked away in a private effort simply can't compete with the collective and distributed efforts of (at least potentially) everyone—even if the others aren't as talented on an individual level. The operating system Linux perhaps represents the most famous

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<sup>31</sup> In the spirit of full disclosure, the associations sponsoring Project Destiny selected BearingPoint to execute this initiative.

<sup>32</sup> Goldman. Innovation Happens Elsewhere.

example of an open source application. Linux started off as a pet project of an individual (Linus Torvalds) and now supports the majority of the world's web servers.

As open source gains legitimacy, new tools, platforms, and communities such as Eclipse<sup>33</sup> have emerged to support the shared development of applications. Wikipedia lists more than 100 healthcare-related open source projects in various stages of maturity.<sup>34</sup> The Open Healthcare Framework Project within Eclipse is one such example.

The long-term care community should consider sponsoring open source software projects that can facilitate care provision and information exchange within long-term care. Such a strategy can lower the barriers to entry for many long-term care providers that might otherwise not be able to afford to adopt such systems.

### 2.2.5 Telemedicine

Telemedicine is simply defined as the use of telecommunications technology to provide medical services such as diagnosis and patient care while the care provider and patient are separated by distance. For example, some devices allow the patient to take his or her own vitals and transmit them electronically to a physician. Telemedicine as a concept has been in existence for many years, but its potential as a means for significantly extending the reach and efficiency of healthcare delivery is dramatically enhanced with internet-related technologies. According to the Center for Aging Services Technology (CAST), "research has demonstrated that, on average, patients managing their congestive heart failure (CHF) via telehealth can reduce their health care utilization (physician office visits, emergency department visits, and rehospitalizations) by 30% . . . If nothing changes, the cumulative costs of CHF from 2005-2030 will be nearly \$1.5 trillion. If telehealth could reduce CHF health care utilization by 30% during this period, there would be a cost savings of approximately \$442 billion."<sup>35</sup>

Whether these estimates prove accurate or not, it is clear that the long-term care community needs to more deeply explore the strategic use of telemedicine services for enhancing care provision. Long-term care stakeholders will also need to overcome a number of regulatory and reimbursement issues in order to see more widespread utilization of telemedicine. Current state licensure restrictions and other state and federal regulations make it difficult to provide care remotely or emergently across state lines. Various experiments are underway now to examine these issues and develop specialized telemedicine licenses and streamline the application process while still ensuring proper oversight of medical professionals' activities and providing adequate consumer protections.

It will take more than just changes in policy and reimbursement schedules to enable the widespread use of telemedicine; it will also require effective data exchange between many types of portable devices and the tools that can manage those data—namely PHRs and EHRs. Vendors are working to establish interoperability standards for information exchange among devices that can support telehealth and telemedicine through the Continua Health Alliance.<sup>36</sup> More than 120 companies now participate in Continua as they seek to create strict guidelines for applying interoperability standards to devices such as scales, blood pressure monitors, implanted devices, fitness equipment, and glucometers. Continua then plans to create a certification program for these devices and the systems that connect to

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<sup>33</sup> Eclipse home page. ([www.eclipse.org](http://www.eclipse.org))

<sup>34</sup> Open source healthcare software. ([en.wikipedia.org/wiki/List\\_of\\_open\\_source\\_healthcare\\_software](http://en.wikipedia.org/wiki/List_of_open_source_healthcare_software))

<sup>35</sup> Lehmann, Economic Benefits of e-Technology.

<sup>36</sup> Continua Health Alliance home page. ([www.continuaalliance.org](http://www.continuaalliance.org))

them—providing the consumer with a level of assurance that the product will connect with an interoperable healthcare environment. They are targeting to deliver its first set of standards in the December 2007/January 2008 timeframe and anticipate having Continua-certified devices on the market in 2008.

### **2.2.6 Secondary Uses of Data**

The creation of the ONC and AHIC dramatically intensified the ongoing dialogue on electronic health information exchange. Increasingly that dialogue is focusing on who owns health data and who has the right to access data. The entire notion of data ownership becomes quite complex when moving from the paper world to the electronic world. There is no single paper record that can be possessed; data can be copied, aggregated, transformed, combined with other data, shared, deleted, archived, encrypted, and otherwise manipulated in myriad ways.

In this electronic environment, issues of record ownership morph into questions about data stewardship, distribution control, and access rights. Public health authorities already have certain data access rights related to reportable diseases. Clinical researchers also have a need to glean information from clinical data in order to understand clinical outcomes, detect adverse events, discover unmet needs, and identify new uses for existing therapies.

The data coming from long-term care offer several advantages due to the fact that the data on medications and other interventions are enhanced with functional and cognitive status data. Pharmaceutical and device manufacturers, clinical service providers, and others interested in using these data for purposes other than providing direct clinical care already pay millions of dollars each year to secure access to such information. The proliferation of electronic sources of data represents a significant opportunity for accelerating innovation through clinical research. They also represent a potential source of revenue for supporting HIT adoption in long-term care.

As with using data for quality purposes, we believe that a consumer-controlled mechanism for facilitating data sharing may be the best approach for ensuring that secondary uses of data align with the interests of seniors. Seniors or their guardians can determine what level of data sharing they are comfortable with and for what purpose.

### 3. Information Technology as an Enabler of the Commission's Vision for Long-Term Care

Theoretically, if information-technology-enabled solutions were unavailable, we could still accomplish our goal of Quality-of-Life Curve optimization. But we could neither reach as far nor advance as rapidly as is possible when leveraging the accelerative power of data exchange and

information processing that technology affords. We are not saying that technology will be the salvation of long-term care any more than it will be the salvation of healthcare.

Information technology is not a panacea, but it can contribute positively to practically every aspect of the long-term care landscape. **Figure 3-1** provides some examples of the role information technology can play in key areas.

*Information technology is not a panacea, but it can contribute positively to practically every aspect of the long-term care landscape.*

#### Figure 3-1. Opportunities for Transformation through Information Technology

The six areas for change as outlined in the Commission's vision for long-term care—culture transformation, empowering individuals and families, workforce, technology, regulation, and finance—are enabled by health information technology (HIT):

- Culture Transformation—HIT can enable information sharing through electronically enabled communities of practice and other forms of social networking, online educational programs, the raising of expectations through quality reporting and outcomes transparency.
- Empowering Individuals and Families—HIT can help reduce isolation among seniors and caregivers through electronically enabled social networks, online training for caregivers, and personal health records (PHRs) that can be shared with caregivers and remote family members.
- Workforce—HIT can enable streamlined, coordinated training through learning management systems and modular educational programs; efficient resource-to-need matching and optimization of workforce scheduling and distribution of effort through Enterprise Resource Planning applications and related technologies.
- Technology—Technology can enable the improved application of other technologies by supporting the HIT infrastructure such as the emerging Nationwide Health Information Network (NHIN); the network effect of HIT results in greater utility of previous technology investments (for example, widespread adoption of electronic health records make them more effective as information sharing tools among healthcare providers and create new opportunities for implementing more advanced technology solutions)
- Regulation—HIT can help reduce reporting burdens through data extraction and automatic report generation and can deliver greater consistency in reported data through the use of reporting requirements based upon unambiguous, computable queries; rapid-cycle refinement of reporting requirements, made possible through HIT, can result in reports that are more aligned with quality outcomes and process improvement.
- Finance—HIT can support greater transparency of actions and outcomes that enable greater alignment of financial incentives and reimbursement models with quality outcomes.

#### 3.1 Quality and Continuous Process Improvement in Long-Term Care

You are what you measure. The popular book *Freakonomics* provided convincing examples of how the introduction of quality or performance metrics into a system can significantly affect that system. Measure something and publish the results, and you invariably see improvements in what you are measuring.

But improving metrics may not necessarily get you what you ultimately desire. Measure and reward teachers for improving a class's scores on a standardized test and you get improved test scores, but not necessarily children who are more prepared for success in life. Unfortunately, you may also discover that some teachers are gaming the system by cheating to improve their students' test scores and to falsely enhance the perception of their own performance.

Quality improvement gurus tell us that if we can't measure it, we can't improve it. The deeper lesson from experiences such as the ones depicted in *Freakonomics* is that we need to be careful that we're measuring the right things.

We are experiencing the same thing in healthcare. Right now, we get high-cost, inefficient, and only partly effective healthcare at a systems level because we measure (and reward through reimbursement) activities over outcomes and outcomes over process improvement. Instead, we should be targeting measures that ensure we are constantly working toward process improvement. Information technology can facilitate this process by helping us measure more effectively and more efficiently.

There are different drivers behind the need to measure quality and these drivers impact the types of data that need to be measured.<sup>37</sup> The measures for quality improvement tend to be much more rapid cycle and are used for behavior change; measurements for public accountability tend to be more longitudinal, cross-sectional, and aggregated and are used for decision-making. Both of these groups of measurements can be accommodated by technology that supports data collection and analysis.

The goals of Total Quality Management (TQM), Six Sigma, and other quality initiatives can all have some beneficial impact on the state of long-term care. HIT can support these efforts by improving the quality and quantity of data collected while reducing the burden associated with data collection.

"This call may be monitored for quality and training purposes." We've all heard this notice many times when weaving our way through a customer service call center. In a similar way, we need to help seniors understand the benefits of data monitoring and aggregation for the purposes of improving overall patient care. Further, we need to ensure that data can be appropriately shared for quality and training purposes in the long-term care setting—this requires agreements for data sharing, appropriate methods for de-identification and aggregation of person-specific data, and standardized criteria for querying those data so that apples-to-apples comparisons can be made among disparate data sources. These agreements should be driven by consumer preferences and their purposes should be made clear to consumers

**Systems-Level Six Sigma.** Six Sigma<sup>38</sup> refers to a set of practices originating in the manufacturing sector—but increasingly used in the service sector and other industries—that seeks to improve processes by eliminating defects. Six Sigma was a product of the TQM and Continuous Quality Improvement (CQI) movements, all of which attempt to improve processes using various analytical methodologies.

While Six Sigma and related methodologies have revolutionized the approach many industries have taken to improve quality, the uptake in healthcare has been relatively slow. It is, however, growing—as is the evidence of its effectiveness in optimizing healthcare processes.<sup>39</sup>

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<sup>37</sup> Capitman, Long-Term Care Quality. ([www.nqcltc.org/pdf/txBgground03-10-05FINAL.pdf](http://www.nqcltc.org/pdf/txBgground03-10-05FINAL.pdf))

<sup>38</sup> The technical definition of a six sigma level of quality is the ability of a process to produce at defect levels below 3.4 defects per one million opportunities.

<sup>39</sup> Trusko, *Improving Healthcare Quality*.

As slow as the adoption is in healthcare overall, long-term care is not looking at these issues at nearly the same level. For every one million references for Six Sigma on the Internet, there are about 17,000 on Six Sigma in healthcare and less than two on Six Sigma in long-term care.<sup>40</sup> We find similar ratios for other process improvement techniques.

Six Sigma and other process improvement methodologies involve much more than collecting quality indicators; they are systematic methodologies for rooting out the fundamental causes of errors and revising processes to avoid errors or defects. HIT is a significant enabler of continuous process improvement because it streamlines the delivery of the fuel that makes the process improvement engine run. In other words, HIT makes data collection, aggregation, and analysis more efficient, more consistent, and therefore more effective in determining what changes can bring about maximal improvements in outcomes.

Electronic data sources allow for a level of analysis that is prohibitively complex and expensive in a paper-based world. Data mining techniques, anonymized data queries, and mash-ups of data from disparate sources are all possible. In contrast, paper-based systems create data sources that are inherently low in value because of the extensive human effort it takes to extract information from paper records and make it useful for process improvement. As a result, instead of frequent incremental improvements that add up to significant change, only dramatic changes are worth pursuing because of the costs associated with simply getting useable data.

Six Sigma techniques are often applied in institutional or commercial settings where there is a clear line of site between an intervention and the bottom line. Some efforts will require making changes in one department or organizational silo to accrue benefit elsewhere in organization. Such interventions will require the backing of a leader high enough in the organization so that he or she is responsible for outcomes in both departments. Jack Welch, the former GE CEO who famously championed the use of Six Sigma throughout the organization, could tell the accounting department to make a \$1 million investment to improve the efficiency of manufacturing and save the company \$10 million.

In healthcare, there is no Jack Welch equivalent who can tell a physician group to make changes that, while dramatically reducing the total cost of care or improving quality, does not accrue benefits to them directly but benefits other sectors of the healthcare system. Under such conditions, we will see only localized process improvement, which may do little to impact the total cost of care or the Quality-of-Life Curve.

We would like to see the long-term care community engage in systems-level Six Sigma activities—process improvement initiatives that look beyond the individual silos of healthcare delivery and look toward creating solutions that are more holistic in nature. Doing so will require a significant level of collaboration among stakeholders, a willingness to look beyond existing processes and traditional roles for solutions, a method for exchanging value across stakeholder groups, and, most significantly for the purposes of this report, a health information exchange infrastructure that can support these multi-stakeholder efforts. Such an approach will not be easy, but we believe it represents our best opportunity for achieving our goal for optimizing our Quality-of-Life Curve.

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<sup>40</sup> Summary of search data using Google on 7/3/2007: "Six Sigma"—1,950,000; "Six Sigma in Healthcare" and variants—34,308; "Six Sigma in Long-Term Care" and variants—3.

Long-term care initiatives like Quality First<sup>41</sup> and certification programs administered through the Commission for Accreditation of Rehabilitation Facilities (CARF)<sup>42</sup> and others can serve as the foundation for applying information technology to enhance outcomes and improve quality. By creating computable, unambiguous quality metrics from sources such as the Minimum Data Set (MDS) using standards (e.g., HL7's Guideline Expression Language called GELLO)<sup>43</sup> certification and accreditation, entities can begin moving away from paper-based quality reporting methodologies, thereby reducing the burden of reporting and enabling more rapid-cycle quality assessment.

### 3.2 The State of the Workforce in Long-Term Care

*There is a well-documented shortage of competent professional and paraprofessional personnel to manage, supervise and provide long-term care services in facility-based and home care settings—the result of high turnover, large numbers of vacancies and difficulty attracting new employees.*

*The instability of today's long-term care workforce has contributed to:*

- *service access problems for consumers and, in many cases, has seriously compromised their safety, quality of care and quality of life;*
- *excessive provider costs due to the need to continuously recruit and train new personnel and use temporary, higher-cost contract staff;*
- *extreme workloads for both nurses and paraprofessional staff, inadequate supervision, less time for new staff to learn their jobs and high accident and injury rates exceeding those in the construction and mining industries.*

*As a result of growing demand from aging baby boomers and a shrinking of the traditional caregiver labor pool, the future will be immeasurably worse without decisive action by both the public and private sectors.*

The Long-Term Care Workforce: Can the Crisis be Fixed?  
Institute for the Future of Aging Services  
January 2007

Information technology offers many opportunities to address this very present and growing workforce crisis in long-term care. We have stressed throughout this report the importance of reducing demand for intensive long-term care services through disease and disability prevention and by extending the duration of senior independence through technology-enabled support services. Even if we are successful by any measure of the term in curtailing demand for long-term care services, these efforts will not be sufficient to address the looming boomer resource capacity crisis, nor will expansion of the current workforce.

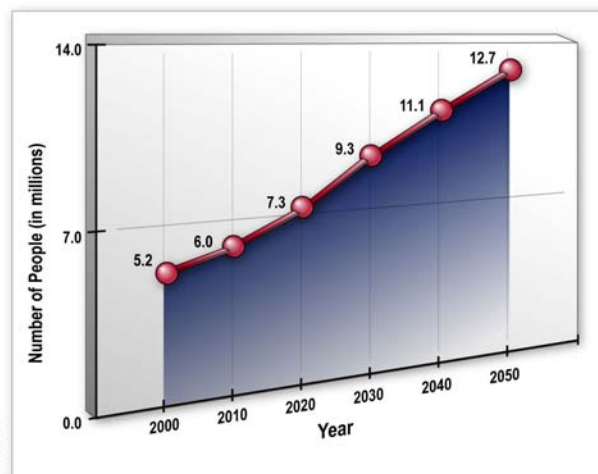
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<sup>41</sup> AHCA, Quality First ([www.ahca.org/quality/qf\\_index.cfm](http://www.ahca.org/quality/qf_index.cfm)).

<sup>42</sup> CARF home page. ([www.carf.org](http://www.carf.org))

<sup>43</sup> Health Seven, Inc., home page ([www.hl7.org](http://www.hl7.org)) and GELLO home page. ([www.gello.org](http://www.gello.org))

**Figure 3-3. Estimated Population with ADL Limitations through 2050 (Assuming Current Prevalence)**



Source: Friedland, Georgetown Long-Term Care (<http://ltc.georgetown.edu/pdfs/caregiversfriedland.pdf>).

Addressing the labor shortage in long-term care will require a combination of efforts if we are to remotely approach the growing demand. Some of the levers available to us include information technology solutions as well as more physically oriented technologies such as mobility-enhancing devices and machines as well as simpler tools for both assisting individuals in managing their own care and helping caregivers assist seniors.

The curve of people who are limited by their ability to perform activities of daily living (ADLs) as shown in **Figure 3-3** is, of course, tightly matched by the curve of the total number of people of advancing age. Not all of these individuals will suffer the limitations of age and one can expect that a more senior workforce will be called into action to address the growing demands for labor in long-term care—both because of their availability and because of their own financial needs. But we can expect the rest of the marketplace to display a similar interest in older workers. Direct care of people with ADL limitations is physical work and fraught with safety concerns. Our worst-case scenario would be realized if, in meeting this need with a senior workforce, our workers move from labor-providing asset to labor-requiring liability due to a work-related injury. Clearly, we must anticipate this trend by investigating the use of labor-saving technologies that focus on worker safety and injury prevention.

Information-technology-based solutions can play a role in promoting workforce safety and efficiency through a number of mechanisms. Foremost among these solutions is the power that is brought through information flow:

- Information empowers seniors and their caregivers to make better decisions and reduce rework and inefficiencies at the point of care. Every reduction in duplicative effort not only decreases the costs associated with the repeated work, but also reduces risk of injury for both the senior and the caregiver. The Commission envisions a long-term care system “where transitions between home, hospitals, rehabilitative care, home care and skilled nursing facilities are seamless and tailored to the medical and social needs of the individual.”<sup>44</sup> HIT can facilitate these transitions as we discuss in other sections of this report.

<sup>44</sup> The National Commission, *Out of Isolation*. ([www.qualitylongtermcarecommission.org/pdf/out\\_of\\_isolation.pdf](http://www.qualitylongtermcarecommission.org/pdf/out_of_isolation.pdf))

- Electronically enabled educational programs expand the reach of these offerings with minimal incremental cost increases. MedBiquitous ([www.medbig.org](http://www.medbig.org)) is a standards development organization driving the movement toward creating shared learning objects and standards for making contextually relevant information available at the point of care. Increasingly, it is becoming possible to create reusable content that simulates real-world environments with simple interfaces that even those unfamiliar with computer-based training can embrace.
- The long-term care industry is buried under an increasing burden to document and report on their activities and outcomes. Documentation and reporting are absolutely essential in providing the basic fodder for process improvement, but often there are diminishing returns in data collection when it becomes an end unto itself—for regulatory compliance, for reimbursement, for protection against liability—rather than a means to transformation. Information technology can help make data collection, documentation, and reporting more efficient and more accurate, freeing up resources to provide care.
- As we discuss in the next section, the constructs of social networking technologies lend themselves to extending the capabilities of the long-term care workforce by reducing or delaying demand, connecting resources to needs, and keeping seniors and their caregivers connected and informed.

### 3.3 Extending the Capabilities and Independence of Seniors

Our greatest opportunity to affect the cost of care and the Quality-of-Life Curve for seniors is through extending their level of independence and productivity for as long as possible. In addressing this challenge, we will need to think very differently from years past and recruit seniors as willing partners in this endeavor and not just subjects of our care and concern. The boomer generation has long shown its willingness to strike out in new directions and adopt new ways of approaching challenges. We should expect nothing less of them as they enter the later chapters of their lives.

*The notion that older persons cannot or will not adopt technologies is changing. The Association for Advancement of Retired Persons (AARP), the largest organization for aging Americans, reports that in 2004, 60% of its membership was regularly online, up from 46% in 2002. This trend can be expected to continue and, perhaps, accelerate as older persons are provided with adequate training and realize the benefits of technology. Electronically connected seniors are more likely than younger users to send and read email (94% vs. 91% for all Internet users) and more likely to obtain health information online (66% for Mature Seniors and 70% for Boomers versus 56% of users age 18-29). Half of all online Boomers seek financial information over the Internet versus 31% of younger computer users. These are but a few examples pointing to the likelihood that those " Boomers " who are technologically savvy will continue to accept technology as they age.*

Technology and Innovation in an Emerging Senior/Boomer Marketplace

The ubiquitous connectivity generated by the Internet has produced an explosion in the reach of social networking that extends far beyond what we typically imagine as "social"—dating, friendship, common interests—and is now moving into deeper societal contexts. Through social networking, we are creating marketplaces for every imaginable need—from ad hoc ride sharing in Boston to, unfortunately, raising the next generation of terrorists. Social networks work by combining a market for value exchange with a framework for building trust; people show a willingness to send thousands of dollars to someone they will never meet not only because they can find something they value to

purchase, but also because the transparency built into the system—based upon the experiences and validation of other buyers and sellers—provides assurance that they won't be cheated or treated poorly.

One can quickly see how the long-term care sector can leverage the power of connection to match caregivers and providers to needs, optimize resource utilization, and even tap into the population of care receivers to match capabilities and deficits in a way that allows individuals to be both care givers and care receivers.

Social networking can also be used in a much more "traditional" manner by providing an engaging social environment for those who face mobility challenges but are still seeking to live independently without becoming completely isolated. The Center for Aging Services Technologies (CAST) video "Imagine—the Future of Aging" paints a vivid picture of the role Internet technologies can play in helping seniors maintain a sense of connectedness while avoiding a loss of independence.<sup>45</sup>

These same technologies can serve as the basis for information exchange among providers, family members, and other caregivers who are part of a person's inner circle of care. Again, the CAST video illustrates the power of information flow leveraged in this manner. Active monitoring becomes a subtle, nearly invisible thread in the overall tapestry of everyday life in the video's central character—a beloved family patriarch who, though continuing to live in his home miles from his grown children, is closely connected to them and his providers through monitoring and messaging. Even his online game of cards he plays with friends around the country through his television's remote control becomes a source of information about his cognitive status that serves as a harbinger of injury or failing health and allows his providers and caregivers to proactively respond.

*Creating the Healthy Home—Designing environments that are suitable for multi-generational families to enable homecare to be accessed by family member for family members.*

*In supporting our most senior citizens in home design, care team connectivity, mobility, cognition, entertainment, learning and employment, might we reorient our support for citizens and their families around a more home-centered approach that reinforces independence, productivity, connectivity and efficient application of limited resources?*

*As connectivity reaches a critical mass, with the expansion of the Internet, broadband networks and wireless WiMax technology, multiple innovative applications from corporate and academic centers of excellence are progressing in mass toward market introduction. Predicted to arrive in full force by 2010, smart appliances, sensors, home diagnostics, lifespan planning tools, and converging, image-rich human interfaces are each seeking out their appropriate place in a different type of society where health is about reaching your full human potential regardless of age and disability, and where disease is something to avoid rather than something to treat.*

Dr. Mike Magee – Pfizer  
Presented at NCQLTC Meeting, Washington, DC, June 12, 2007

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<sup>45</sup> CAST home page. ([www.agingtech.org](http://www.agingtech.org))

We can improve senior productivity and independence in other ways as well:

- **Medication Therapy Management (MTM)**—As discussed earlier, comprehensive MTM services help provide seniors with the support tools they need to manage their medications effectively through home medication dispensing devices that reduce the likelihood of self-administration errors and provide compliance and adherence feedback.
- **Consumer-directed education**—Informed patients are better patients and are more likely to make good choices for their health and wellbeing. Information technology provides a means for delivering contextually sensitive educational information at various reading levels and in multiple languages based upon the same building blocks or learning modules.
- **Tools for end-of-life planning**—Seniors often need assistance in making sometimes difficult decisions about their own life choices related to living wills, advance directives, and related end-of-life planning issues. Information technology can be a means of guiding seniors through the process before the need arises and then for making those documents available and actionable at the proper time. By making the documentation of advance directives and living wills available at any provider facility through PHRs or other electronic mechanisms, providers will be able to make clinical treatment decisions based upon the wants and needs of the individual.

## 4. Requirements for Transformation

In this section, we discuss some of the practical steps the Commission can take to move the transformation of the nation's long-term care industry forward.

### 4.1 The Need for Leadership

We often expect the federal government to provide leadership in solving problems of national scope, but at times the compartmentalized nature of our federal system makes it difficult to work through the bureaucracy and develop forward momentum. Today we are seeing the increasing employment of an approach that emphasizes public-private partnerships.

The American Health Information Community (AHIC or the Community) is but one example of a federal effort to create such a public-private partnership. AHIC has helped mobilize the healthcare community around health information technology (HIT) issues at an unprecedented level. It has also brought to the fore the fragmented nature of our government, society, and the healthcare community. While long-term care issues have been included in the discussions advanced by AHIC and the Office of the National Coordinator (ONC), it will be through organizations like the Commission that such talk is converted into action.

Throughout this report, we have highlighted examples where thought leaders, medical informatics experts, forward-thinking business owners, and others within the long-term care community have worked to advance the cause of adopting information technology in long-term care. In many instances, they have formed loose coalitions to work toward common goals—advocating for long-term care in the AHIC use case development process, ensuring that long-term care specialized electronic health records (EHRs) are included on the Certification Commission for Health Information Technology (CCHIT's) roadmap for certification of HIT applications and modifying National Council for Prescription Drug Program (NCPDP) standards for electronic prescribing to accommodate the unique medication ordering and administration workflow that exists within the long-term care setting to name but a few examples.

In June 2007, the long-term care community convened the third annual Long-Term Care Health Information Technology (LTC HIT) Summit in Chicago, Illinois. Co-sponsors included:

- American Association for Homes and Services of the Aging (AAHSA)—[www.aahsa.org](http://www.aahsa.org)
- American Health Care Association (AHCA)—[www.ahca.org](http://www.ahca.org)
- American Health Information Management Association (AHIMA)—[www.ahima.org](http://www.ahima.org)
- American Medical Directors Association (AMDA)—[www.amda.com](http://www.amda.com)
- Center for Aging Services Technology (CAST)—[www.agingtech.org](http://www.agingtech.org)
- National Association for the Support of Long Term Care (NASL)—[www.nasl.org](http://www.nasl.org)
- National Association of Home Care and Hospice (NAHC)—[www.nahc.org](http://www.nahc.org)
- National Center for Assisted Living (NCAL)—[www.ncal.org](http://www.ncal.org)

The LTC HIT Summit was founded by a loose collaboration of provider, vendor, technology, professional, and governmental stakeholders to establish and advance a road map for long-term care HIT. At this year's conference, attendees were able to learn about a range of accomplishments that were achieved by the long-term care community. In addition to the accomplishments noted above, long-term care stakeholders participated in the development

of the Integrating the Healthcare Enterprise (IHE)<sup>46</sup> functional status assessment profile<sup>47</sup> and now have an opportunity to include long-term care functional status assessment exchange as part of the IHE “Connectathon” in 2008—raising awareness of the opportunities brought through interoperability and health information exchange.

**Figure 4-1** lists other recent HIT events where long-term care was a primary focus.

### Figure 4-1. Recent HIT Events Focused on Long-Term Care

#### Moving Toward Interoperability - a National Summit

The Center for Aging Services Technologies (CAST) reached out to the U.S. Department of Commerce's Technology Administration and National Institute of Standards and Technology (NIST) to build momentum and support for a national agenda based on public and private collaboration to drive technology solutions for an aging population. HHS Secretary Michael Leavitt and Intel Chairman Craig Barrett provided the opening keynote address.

[www.itl.nist.gov/Healthcare%20Summit/intro.htm](http://www.itl.nist.gov/Healthcare%20Summit/intro.htm)

#### White House Conference on Aging Technology Pavilion

CAST sponsored a 35,000-square-foot pavilion of emerging technologies that could help improve care and services for our aging population. Department of Health and Human Services (HHS) Secretary Leavitt, Intel CEO Craig Barrett, and Veterans Affairs Secretary Jim Nicholson toured the pavilion along with more than 4,000 appointed delegates and members of the media. More than 175 million people were reached through over 300 media stories.

[www.agingtech.org/whcoa\\_tech\\_exhibitors.aspx](http://www.agingtech.org/whcoa_tech_exhibitors.aspx)

While there now seems to be good agreement within the long-term-care community that standards are important and that long-term care needs a seat at the table, long-term care stakeholders still need to get behind these efforts to fully realize this growing collective vision. As opportunities for funding and piloting arise, the community needs to be fully prepared to leverage those opportunities. Even better, long-term care should not wait for funds to be handed out, but should move proactively toward consumer-centric care.

## 4.2 The Need for Awareness

The federal government and long-term care insurers have been actively promoting awareness of long-term care options and resources within the last few years. For example, the launch in 2005 of the federal Web site [www.longtermcare.gov](http://www.longtermcare.gov)—an initiative of the Department of Health and Human Services (HHS) under the eGov program and managed by the National Clearinghouse for Long-Term Care Information—marked a significant step forward for long-term care stakeholders with internet access.

The response by consumers to the first two phases of the “Own Your Future” Campaign exceeded expectations, both in terms of consumer interest and in initiating long-term care planning actions. Based on the success of the initial Campaigns, Congress provided additional support for long-term care education initiatives by establishing the National Clearinghouse for Long-Term Care. Information under the Deficit Reduction Act of 2005. Under Section 6021(d) of the Act, Congress appropriated \$15 million in funding for the National Clearinghouse over five years, including \$3 million in funding for FY 2006.

Parallel to the need for basic long-term care information will be the need to dramatically expand long-term care user, provider, payer, and caregiver awareness of related technology products and services. The Clearinghouse would be a natural “strategic partner” of the Consortium called for in the proposed legislation discussed below in Recommendation 3 of

<sup>46</sup> IHE home page. ([www.ihe.net](http://www.ihe.net))

<sup>47</sup> IHE, Trial Implementation. ([wiki.ihe.net/index.php?title=PCC\\_TF-1/FSA](http://wiki.ihe.net/index.php?title=PCC_TF-1/FSA))

this report, but the communication established between these entities must be multi-directional to include feedback to technology providers on the needs and requirements of the user community. The Web site [www.longtermcarelink.net](http://www.longtermcarelink.net), managed by the non-profit National Planning Council, also serves as an example of a site that informs visitors about available resources.

The long-term care community can promote HIT awareness through public service announcements (PSAs). The Ad Council gives ten PSAs to worthy causes each year and will pay for the production as well. This could be a good opportunity for the Commission to promote its vision while building the nation's awareness of other issues within long-term care.

We can expect advocates for the use of HIT in long-term care to be asked many questions about its value: "How well does it work?" "How much will cost?" "Do the benefits outweigh the costs?" "Are the studies of good quality, and are they objective and meaningful?" To the extent that the Commission can begin to answer these questions and set up mechanisms for engaging consumers in the process, it can begin to promote HIT in long-term care as supporting a consumer-centric approach to care provision while promoting awareness.

#### 4.2.1 Clinical Studies

Despite dramatic growth in federal and private funding for medical and healthcare research (e.g., the National Institutes of Health budget grew 70% between FY2000 (\$17.9 billion) to 2008 (\$28.9 billion),<sup>48</sup> there appears to be much less activity throughout the federal government for funding efficacy or cost-benefit research for long-term care technologies, even though the need has been recognized for several years. What emerges is a "Catch-22" situation where progress for HIT and other technologies in long-term care is hindered without supporting evidence created by quality studies, but quality studies are not being undertaken because of lack of coordination, funding, or focus.

The example of telehealth is a useful one in that telehealth practitioners—and, by definition, their technology vendors—depend upon positive "national coverage determinations" (NCDs) by Centers for Medicare and Medicaid (CMS) to make a business case for buying and selling systems.<sup>49</sup> Despite numerous clinical efficacy and cost effectiveness studies, CMS maintains its need for more and better quality evidence before considering coverage. Only within the last two years has the Agency for Healthcare Research and Quality (AHRQ) agreed to evaluate telehealth cost and quality, despite the industry having one of the more effective associations lobbying on its behalf.

The long-term care community needs a strong advocate to support the completion of sufficient studies that demonstrate the benefits of HIT in long-term care. Because the advocate will be representing the "industry" as well as providers, patients, and caregivers, it will need to effectively mobilize the community, enlisting the help of like-minded associations (such as the American Association of Retired Persons (AARP) and those listed in Section 5.3 below); these collaborative efforts will prove more effective in achieving the focus and funding needed to generate the level of evidence required by CMS, other payers, insurers, patients, and providers.

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<sup>48</sup> [www.nih.gov/about/director/budgetrequest/index.htm](http://www.nih.gov/about/director/budgetrequest/index.htm)

<sup>49</sup> Although Medicare is only one of the many third-party payers, it is often looked to by other payers for leadership on coverage decisions.

#### 4.2.2 Cost/Benefit Analysis

Reports by organizations already engaged in optimal health management provide evidence of lives and money saved through the application of HIT in long-term care. Georgia-based WellStar Health System has demonstrated improvements in blood glucose control in individuals participating in their diabetes disease management programs, leading to improved health and cost savings related to decreased hospital admissions and ER visits.<sup>50</sup> Like clinical studies, objective cost-benefit analyses require funding support in order to ensure broad acceptance of their findings.

The American Telemedicine Association maintains an extensive library of clinical studies that justify investment and reimbursement coverage on the bases of health improvement value.<sup>51</sup>

#### 4.2.3 Scoring Models

CMS and other payers make funding decisions and rationalize those decisions to Congress based on “scoring models” where costs to Medicare and Medicaid are based on estimates of usage. The telehealth community has a good deal of experience with CMS scoring models that significantly overestimated usage and led to negative decisions on coverage as a result. It is important, then, that CMS and other payers “get it right” the first time with scoring models and usage estimates. The Commission and, possibly, the Consortium may find themselves needing to engage in the development and/or testing of scoring models to ensure that financial projections for reimbursement coverage for HIT for long-term care comply with Congressional Budget Office (CBO) and payer requirements.

Consumer-centric healthcare can only be made a reality through improved transparency of costs and the measurement of quality. The publication *Consumer Reports* has over many years established a reputation as an objective, well-qualified evaluator of cost, quality, and value. While the use of objective quality measures and the consistent evaluation of costs and benefits are important goals for healthcare in general, the Commission should add its voice to the national debate on quality, cost, performance, and value by calling for the development of a similar arbiter of unbiased evaluations of HIT solutions for long-term care.

#### 4.2.4 Business Case

In their 2006 white paper “Pushing Long Term Care onto the Nation’s Health Information Technology Agenda,” the AHCA and NCAL stated that “the long term care profession must make a strong business case for return on HIT investment. This data will motivate individual providers to move more rapidly toward adoption of HIT and, perhaps more importantly, to immediately adopt an interoperable EHR when available.”<sup>52</sup> For HIT in long-term care, the business case must focus on one or more of its featured benefits, such as reduced healthcare costs, improved quality of care and quality of life, greater productivity of caregivers, etc. A business case must also be made for those who would invest in the research, development, and marketing of long-term care technology products and services, such as venture capital firms.

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<sup>50</sup> Newt Gingrich. (opus cit)

<sup>51</sup> [www.americantelemed.org/news/policy\\_issues/policy\\_issues.htm](http://www.americantelemed.org/news/policy_issues/policy_issues.htm)

<sup>52</sup> [www.ahima.org/meetings/ltc/documents/AHCA\\_WhitePaper.pdf](http://www.ahima.org/meetings/ltc/documents/AHCA_WhitePaper.pdf)

We noted earlier that there is little evidence in the literature to support the business case for HIT adoption in long-term care.<sup>53</sup> Until this dearth of evidence is remedied, it will be difficult to convince rational business owners in the long-term care industry to put their organizations at risk by blindly adopting technology for technology's sake.

### 4.3 The Need for Partnership

One of the more significant results of the 2005 White House Conference on Aging (WHCOA) was not the conference itself, but the creation of a vast network of aging-related organizations throughout the country that could be used to inform and mobilize the nation's long-term care providers, patients, and other stakeholders. There has been very limited follow-up on the WHCOA and its set of recommendations; the Commission, however, is well-positioned to embrace that network as its own. The network includes nearly every public and private aging-related organization at the federal, state, local, and grassroots levels and may offer the Commission new channels and willing partners for expanding awareness, lobbying, and even fund-raising.

Partnership with other industry and healthcare associations such as those listed in the previous section offers the advantage of combining or leveraging those resources as well. Although the term "public-private partnership" has been a buzz phrase around Washington for many years, the concept has proven to be a key ingredient for many of this nation's most important achievements, such as AHIC's progress to date.

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<sup>53</sup> Booz Allen Hamilton, *Evaluation Design*.

## 5. Recommendations

The following recommendations summarize many of our findings and conclusions and can be viewed as representative of the many opportunities for leadership and transformation that will increasingly present themselves to the Commission and all those who want to see more for long-term care in the United States. For each recommendation, we have included suggestions on specific tactics that may be employed to advance the high-level recommendation.

### 1. Make quality long-term care a national priority.

While the reasoning behind this recommendation may be obvious, it should not be assumed that policymakers, politicians, and even healthcare leaders consider long-term care to be worthy of any more emphasis and funding than any other healthcare setting. On the other hand, even a small number of organizations like the Commission that are dedicated to promoting quality long-term care technology as a national priority can have a significant impact. As we have asserted throughout this report, a key enabler of quality improvement in long-term care is information technology.

### 2. Accelerate industry-wide collaboration and leadership around the use of HIT in long-term care.

Early collaborative efforts are already underway and include the Center for Aging Services Technologies and the Long-Term Care Health Information Technology Summit series. These informal initiatives need significant investments of dedicated resources and financial support from all stakeholders in long-term care. By working together, the voice of the long-term care community will be heard and the needs of long-term care will be addressed within the larger context of healthcare's transformation.

Other industries have found success through the creation of trade associations such as the American Telemedicine Association or AdvaMed, the Advanced Medical Technology Association. Existing organizations such as CAST or the Continua Alliance could be expanded to include education, training, and advocacy with federal entities.

The disabilities and the long-term care communities do not always coordinate their separate agendas or strategies. Perhaps this is because the former does not want to be considered aging, and the latter does not want to be considered disabled. Whether they choose to acknowledge the overlap or not, in reality nearly 20 percent of elderly Americans have one or more disabilities and these disabilities often lead to the need for long-term care.

Deeper cooperation between these two communities can help deepen our nation's support for accelerated development of assistive technologies, which can benefit both communities.

### 3. Explore legislative options to promote long-term care's transformation through HIT.

One hopes that any piece of legislation supporting HIT in long-term care will be thoughtfully and carefully crafted. Senate Bill S. 908, "The Consortium on the Impact of Technology in Aging Health Services," was introduced in March 2007 and appears to present a good basis for a comprehensive, systems approach to advancing the use of HIT in long-term care. The main objective of this legislation is to create a consortium that will evaluate and advance the potential of new technologies to help the United States prepare for the unprecedented growth of the elderly population and the impact this demographic shift will have on the nation's healthcare system. The "Consortium" will make recommendations to the President and appropriate committees of Congress regarding policies supporting technology and

assistive health services for seniors and whether to establish a National Resource Center on Aging Services Technologies.

The Commission should work closely with the Bill's sponsors and other stakeholders to ensure that the HIT and long-term care industries are adequately represented in the Consortia, and that the title of both the Consortium and the National Resource Center include "Long-Term Care." The Commission should also advocate that this center closely aligns itself with the activities of the Office of the National Coordinator for Health Information Technology (ONC) and the American Health Information Community (AHIC) successor organization. Two current shortcomings in this Bill are the small Consortium budget and the lack of any specific authority or mandate to ensure cooperation from federal long-term care, HIT, and research programs such as the National Institutes of Health (NIH), the National Institute for Disability and Rehabilitation Research (NIDRR), National Science Foundation (NSF), and Veterans Affairs (VA).

#### **4. Establish federal leadership entities and positions dedicated to long-term care technology.**

The White House Office of Science and Technology Policy (OSTP) advises the President and Cabinet Departments on science and technology policies and programs. The OSTP acts as an advocate for the President's science and technology policies and initiatives within the broader business and academic communities as well. The Office also has a role in the annual budget process to ensure that research and other science and technology interests are included. The creation of a position of Senior Technology Policy Analyst dedicated to aging services and long-term care within the OSTP would ensure that the interests of the long-term care community are represented at the highest levels of government and industry. This position could be included in an amended S908 to give the position legislated permanence.

Other methods for building dedicated support within the federal government for long-term care include creating an effective interagency workgroup that serves to coordinate federal long-term care technology efforts. While some people are critical of the overall effectiveness of interagency workgroups, from our experience, they can work well if positioned, staffed, and funded properly. The Interagency Committee for Disability Research (ICDR) seems to be an example of an interagency task force that works fairly well. One reason for this anomaly is that the ICDR is directly controlled and funded by the Department of Education's National Institute for Disability and Rehabilitation Research. It also enjoys strong support from the disability community.

The Commission should also closely examine the recommendations coming out of the 2005 White House Conference on Aging and add those related to long-term care to its agenda for discussion with the White House, Congress, and other national policymakers. While there appears to have been very limited follow-up to the report and recommendations of the Conference, the Commission is in a good position to select its most appropriate recommendations and claim the support of the hundreds of groups and thousands of individuals that brought those recommendations to the Conference.

#### **5. Support the development of innovative technologies and the adaptation of existing technologies for use in the long-term care setting.**

This recommendation can also be considered a call to expand industry awareness of long-term care needs and to expand awareness of the long-term care and healthcare communities of industry research and product development. This would include such initiatives as the increased cross-referencing of and support for small- and medium- size technology firms to exhibit their products in healthcare, IT and aging-related conferences and exhibitions.

Many technologies and products are developed in federal labs or through the support of federal programs such as the Small Business Innovation and Research (SBIR) program and the Department of Defense's (DoD's) technology partners program. One "low-hanging fruit" would be to get Small Business Administration (SBA) to add long-term care technologies to its list of SBIR "topics" and then get the SBIR agencies to include this topic in the next fiscal year SBIR planning and funding.

As opportunities for technology convergence continue to grow, the long-term care community needs to create and maintain a mapping of existing and emerging innovations from other industries that can apply to long-term care (such as social networking and remote monitoring technologies) and then look for ways to attract capital to fund further development of these potential solutions.

According to a survey of Baby Boomers conducted by the Center for Aging Services Technology (CAST), "Ninety percent of the participants were willing to pay \$50 or more per month, out of pocket, for technology that effectively meets their need to stay healthy and independent. Over 50 percent were willing to spend \$100 or more a month . . . Many participants were very interested in having a device to maintain all of their health related information. They were interested in having some control over who can have access to this information and how it may be used."

Building awareness about such trends with the venture community will help stimulate investments in consumer-oriented technologies that empower seniors to maintain a level of independence beyond what is possible today.

Technology transfer is another means by which existing technologies created by federal laboratories can be made available for public commercialization. The federal government is, in fact, required to work with the nation's private sector to transfer technologies developed in its hundreds of laboratories and other research institutions. Only anecdotal information is available to estimate how much innovation in healthcare and especially long-term care technologies takes place in federal laboratories.

For example, NASA's Smart Medical Systems and Technology Development teams are currently developing remote monitoring technology for space shuttle flights that will also be used to provide mobile osteoporosis screenings at retirement communities and nursing homes. Projects exploring intranasal delivery of medications and the use of ultrasound to control internal bleeding also will impact patient care.

The challenge lay in identifying prospective technologies and alerting product developers and investors to their existence. Communications of developments can take many forms, both public and private. The public website [www.longtermcare.gov](http://www.longtermcare.gov) and the private website [www.longtermcarelink.net](http://www.longtermcarelink.net) are but two examples.

There are a few organizations that specialize in tech transfer, including the Federal Laboratory Consortium (FLC) which has a legislative mandate to assist with the transfer of assistive technologies developed in federal labs. The long-term care community should explore the possibility of promoting legislation that would specifically require the FLC to support long-term care and aging-related technologies as well.

Another specific example of how to stimulate innovation is to publicly recognize advances in long-term care technology by academia, technology vendors, and others by creating a Presidential medal similar to the National Medal of Technology (NMT) administered by the National Institute for Standards and Technology (NIST). A "National Medal for Aging and Long-Term Care Technology" can bestow prestige upon the recipient while stimulating awareness of the need for innovation as well as the business opportunities available within long-term care.

## **6. Reduce or remove barriers to innovation and the adoption of technology in long-term care.**

There are numerous policy, economic, and legal barriers that may discourage innovation and adoption. One economic barrier, for example, is the “valley of death” for financing which occurs after the phase of research where the capabilities of the technology is proven but a marketable product has not yet been developed and commercialized. Other barriers include the inherent liability risks involved in creating products for seniors with chronic illnesses and serious disabilities or the lack of standards that support interoperability and market confidence. As AHIC has realized, waiting for standards can be a “show-stopper”; therefore, standards development is a parallel and concurrent (and not sequential) effort that should not detract from or delay innovation and product development.

In order to remove barriers to innovation, the long-term care community must first identify, analyze, and understand the social, economic, and political dimensions of those barriers before recommending and pursuing strategies for removing those barriers. Changing laws, regulations, policies, economic incentives, and socio-cultural norms is usually a very long process that requires committed resources. The long-term care community should be prepared to shoulder this responsibility until federal resources such as an OSTP advisor and the National Resource Center become available. At that time, the strength of the existing leadership within the long-term care community can ensure that a robust public-private partnership can emerge to further this work.

## **7. Pursue regulatory reform and professional licensure enhancements to enable the expanded use of remote care.**

Telemedicine, online consultation, and other methods for extending the reach and availability of services can maximize the utilization of our overburdened workforce and help seniors maintain a level of independence that would not be possible otherwise. The regulatory hurdles impeding the use of telemedicine and its reimbursement need to be addressed in order to fully exploit this method of care delivery.

The American Telemedicine Association, the Center for Telehealth and eHealth Law, and the eHealth Initiative have conducted a great deal of research into these areas and should be considered natural allies by the Commission. AHIC Workgroups are also discussing the professional licensure issues. To the extent that the issues are well known and researched, the Commission would be best advised to stake out a position on the issues, then offer political and organizational support to industry and public policy groups that have been working the issues.

Advocates for electronic prescribing have made significant progress in modifying archaic state laws and regulations that prohibited the use of electronic messaging for prescriptions. An exception to this good news concerns the electronic prescribing of controlled substances (EPCS). Despite years of consideration, the Drug Enforcement Agency (DEA) has yet to create a framework for permitting EPCS. Seniors are disproportionately affected by this limitation. The long-term care community will need to work with the DEA and Food and Drug Administration (FDA) to find mutual solutions that will permit the safe and legally enforceable EPCS.

## **8. Develop a global market for long-term care technology through information exchange and market development.**

For many years, the NSF has conducted international surveys of developments in various sectors of science and technology. NSF typically recruits survey team members from among NSF-sponsored researchers; as a result, these surveys tend to focus on academia more than industry.

With sufficient financial support, the Consortium could undertake the same type of international survey. The results of such a survey would not only inform policy-makers and researchers, but should be very useful for the nation's technology manufacturers as they seek to establish themselves in the global marketplace.

In support of this goal, the long-term care community should seek to organize a conference and exposition on long-term care technologies in the United States and get American industry behind it. Then, encourage the Commerce Department promote the "first ever" show (with conference) through its Foreign Buyer Program as a Certified Show. As it emerges as the world's premier gathering of buyers and sellers of long-term care technologies (similar to the role the Paris Air Show plays in aerospace), such a long-term care technology exhibition would go far in establishing a leadership role for U.S. businesses.

The Commerce Department's International Trade Administration's healthcare technologies group is fairly limited to medical devices and information technology and does not pursue research, marketing, or trade policy opportunities for other healthcare technologies or HIT. Encouraging Commerce to hire an industry specialist who would focus on trade information, export opportunities and exporter assistance would be a fairly inexpensive way to raise the profile of U.S. long-term care technology products and services overseas.

**9. Promote a research agenda to evaluate the cost, quality, and efficiency benefits of applying information technology solutions to long-term care in order to establish scoring models for Centers for Medicare and Medicaid Services (CMS) and other third-party coverage decisions.**

The long-term care industry will not enjoy the benefits of widespread adoption of information technology unless there is a body of referenceable demonstration projects and benefit validation research conducted by credible sources.

The Agency for Health Research and Quality (AHRQ) is one source of funding for objective outcomes studies on the use of HIT in long-term care. AHRQ was required to fund such studies for telehealth just in the last two years. The VA would an ideal test bed for some of these investigations as they have already

We suspect that there are few examples of long-term care HIT technologies that may be reimbursed by Medicare, Medicaid, VA, or a third-party insurer. One of the reasons for this may be the long lead times and evidence needed by CMS to designate coverage for a new technology.

Because Medicaid, SCHIP, and other third-party payers often take their cue on technology coverage from Medicare, CMS' Council on Technology and Innovation (CTI), the Council serves as a key player in reimbursement decisions, overseeing "the agency's cross-cutting priority on coordinating coverage, coding and payment processes for Medicare with respect to new technologies and procedures...as well as promoting the exchange of information on new technologies between CMS and other entities.

The CTI depends on evidence of a technology's value added and efficacy before making any coverage decisions. That body of evidence is currently managed by the Medicare Evidence Development & Coverage Advisory Committee (MedCAC), which was established to provide independent guidance and expert advice to CMS/CTI on specific clinical topics. The MedCAC is used to supplement CMS' internal expertise and to allow an unbiased and current deliberation of state-of-the-art technology and science.

Since the evidence and time for review required by MedCAC and CTI can be impractical for a small, innovative technology business, the process may be shortened and made more widely affordable through the development of various evidence and scoring models.

## **10. Pursue sustainable funding models that accelerate the adoption of HIT in long-term care.**

HIT adoption and utilization is an essential requirement for creating a state of continuous process improvement in long-term care. But there is a significant lag between the time HIT investments are made and the time benefits begin accruing. In many instances those benefits accrue to those other than the ones making the investment. Funding models that are self-sustaining and built upon the benefits accrued from utilization of HIT will be the most successful in achieving the goal of optimizing quality. Revolving loan funds have proven to be successful models in other domains such as local transportation development and environmental issues. Such a method could create a sustainable source of capital for investing in the HIT infrastructure.

## **11. Encourage the adoption and application of consumer-centric, continuous process improvement methodologies in long-term care.**

Building continuous process improvement into the fabric of long-term care means that we need to look at data use in an entirely different way. Secondary uses of data for clinical research and the continuous evaluation of how we can better serve the needs of our seniors should not play second fiddle to the primary use of data for direct patient care. Changing our perspective from one where primary and secondary data uses are sharply divided to one where they are both part of a virtuous cycle of care delivery, evaluation, and innovation will require building partnerships with patients. We will also need to establish robust protection methodologies to ensure that patient data are not improperly used. It will also require that we build market awareness about the importance of secondary uses of data to improve care.

Continuous process improvement would also require that management and quality assurance methods employed in other industries be applied to long-term care. Six Sigma, for example, can play an important role in the continuous improvement of nursing home care or even home health care. The creation of industry benchmarks for HIT applications can also contribute to accepted cost-benefit analyses.

## **12. Support the development of longitudinal PHRs, PHR-related standards, and consumer-centric mechanisms for linking long-term care providers and other settings through PHRs.**

The PHR has the potential of becoming a key means for sharing patient information between different care settings in long-term care. They can also extend the time during which a senior stays independent by providing them with personal medical decision support tools. The Commission should work through AHIC to ensure that long-term care scenarios are included in the development of future PHR-related use cases.

## **13. Support the foundational work required to create the standards, common tooling, and shared infrastructure necessary to support health information exchange and semantic interoperability.**

The transformation of long-term care—as for the rest of healthcare—requires an investment in the low-level infrastructure and architecture that enables interoperability and information exchange. The work required is far removed from direct patient care and doesn't grab headlines. It is also slow to yield noticeable returns. But it is absolutely essential to reaping future benefits from our investments in HIT and it will not receive the necessary attention and support it deserves without leadership and direction from entities like the Commission. The Commission should work to expand support for the ongoing collaborative efforts of long-term care stakeholders and AHIC as they engage in standards development and harmonization.

Ongoing demonstrations such as the Integrating the Healthcare Enterprise (IHE) showcases held at the HIMSS annual conference each year establish a proving ground for advancing solutions involving HIT. The long-term care community should get involved in these efforts to raise awareness of the opportunities for applying standards for interoperability.

The need for a physical technology infrastructure supporting broadband communications and information exchange is neither unique to long-term care nor healthcare as a whole, but permeates every facet of our society, including emergency services, education, our personal communications, and our ability to compete in the global marketplace. Other countries have already committed to making wireless broadband a ubiquitous offering and consider it a competitive advantage; local municipalities in the United States are beginning to do the same.

While this need isn't specific to long-term care, it does represent a key benefit of developing a robust telecommunications infrastructure that reaches every home in the country and would require an effort rivaling that of the push to provide electrical service to rural America through the Tennessee Valley Authority (TVA) in the 1930s.

#### **14. Promote information flow and outcomes transparency as a fundamental driver for transformation.**

If we are ever going to break out of the cycle of information withholding and misaligned incentives, we will have to acknowledge the danger of information fog and develop a concerted, systemic transformation of healthcare. No single sector can afford to fall on the sword of transparency without all sectors committing to the same goal.

When we achieve total information transparency—i.e., omni-directional information flow in the healthcare marketplace (i.e., total transparency), all sectors of healthcare will begin aligning with optimal health outcomes because any other behavior will become readily discoverable and will be ferreted out.

#### **15. Promote the use of open source software solutions to address some of long-term care's technology needs—especially for infrastructure and shared requirements.**

Open source software applications are especially useful when a need exists for which there are resource constraints for funding that need. Development and adoption of open source software solutions reduce the initial investment requirements (though still require implementation and maintenance investments). This reduction in start-up costs for adoption helps align the timing requirements for investment with the timing of returns on that investment. This formula fits well with the need within long-term care to adopt technologies with limited capital resources.

**Figure 5-1** provides suggestions regarding which stakeholders are best suited to serve as primary leaders or supporters of these recommendations.

**Figure 5-1. Matrix of Recommendations on HIT and Long-Term Care and Suggested Stakeholder Leadership Roles**

No.	Subject	Legislation Required?	Funding Required?	NCQLTC	S.908 Proposed Consortium	White House	Congress	ONCHIT	CMS	AHRQ	Commerce	NSF	Other Federal	Other Organizations		
1	LTC as National Priority	Y	Y	P	P	P	P	S	S	S	S	S	S	P		
2	Industry Collaboration	N	TBD	P	P	S	S				S		S	P		
3	Legislative Options	Y	Y	S	S	P	P	S					S	S		
4	Federal Leadership	Y	Y			P	S						S			
5	LTC Technology Innovation & Commercialization	TBD	TBD	S	P	P	S				P	S	P	P		
6	Barriers to Innovation & Investment	TBD	TBD	P	P	P		S			S		S	S		
7	Barriers to Remote Care	TBD	TBD	P	S	S	P	S			S		S	P		
8	Global Markets	N	TBD	S	P	S	S				P	P	S	S		
9	Evidence for Payer Coverage	N	Y	S	S	P	P	S	P	P		S	S	S		
10	Funding Models	TBD	TBD	P	P	P	S	S	P	P		S	S			
11	Continuous Improvement	N	N	P	P	P		S	S	S			S	S		
12	Personal Health Records	N	N	S	S	S		P	S	S			S	S		
13	HIE and Interoperability	TBD	TBD	P	P	P	S	P	S	S	S		S	S		
14	Transparency	N	N	P	P	P	S	S	S				S	S		
15	Open Source Solutions	N	N	P	P	P		P	S	S		P	S	S		
<b>Key</b>																
					<b>Potential Stakeholder Leadership Role</b>											
Y=Yes		N=No		TBD=To Be Determined					P=Primary			S=Supporting				

## 6. Conclusion

Some have likened the goal of transforming healthcare through health information technology (HIT) to the goal set by President Kennedy in the early 1960s to beat the Russians and to go to the moon within the decade. This bold and audacious goal captured the imagination of our nation. More than a few detractors said it was a waste of taxpayers' money and shouldn't be done. More than a few detractors said it was a fool's journey and couldn't be done.

But for all the similarities in terms of the audacity and challenge of the goal, transforming healthcare through HIT is not like sending a man to the moon. It is harder still.

When we went to the moon, there were no space shuttles flying to the moon and back or buildings crowding the moon's surface to impede our progress. Our objective followed a precisely known path—we didn't have to guess where the moon would be on the day Apollo 11 rocketed skyward. But to transform healthcare, not only do we have to build a better healthcare system, we have to accomplish this task while maintaining and navigating the current system as we continue to serve patients.

No, transforming healthcare is not like putting a man on the moon; transforming healthcare is more like a national version of Boston's Big Dig: We have to tear up all the existing interstates of healthcare and run them through underground tunnels—all without disrupting the current flow of patient traffic.

The recent collapse of Interstate 35W in Minneapolis serves as a tragic reminder of the need for extensive investments in the repair and rehabilitation of our nation's aging transportation infrastructure. In healthcare, there are no equivalent sentinel events in healthcare. Buildings full of seniors don't collapse en masse; jumbo jets full of patients don't fall out of the sky, though the estimated numbers of patients suffering harm or dying as a result of medical errors or a lack of access to care likely exceeds a fully loaded 747 every week. These tragedies don't capture our attention because of their insidiousness; they are so common they become white noise, practically unnoticeable and sadly tolerated.

*Transforming healthcare through information technology is not like sending a man to the moon. It is harder still. To transform healthcare, not only do we have to build a better healthcare system, we have to accomplish this task while maintaining and navigating the current system as we continue to serve patients.*

Even the aftermath of Hurricanes Katrina and Rita or the likelihood of a pandemic flu sweeping across the globe haven't proved alarming enough to prompt a rush of investment in our nation's fragmented, paper-based healthcare system. Without a sentinel event to awaken our collective consciousness and provide a focal point to our rallying cry for change, we will not see sufficiently organized movement unless leaders come to the fore and lead.

If the picture we have painted in this report seems overly bleak, this is not our intent. We believe our current situation represents an unprecedented opportunity for the leaders in long-term care: To demonstrate the collective vision and fortitude and find the means to invest in a coordinated, shared infrastructure for moving our entire healthcare system into the 21st century. Far from being an afterthought in healthcare's transformation, with the right leadership and the right strategy, the long-term care community can serve as the transformation's focal point, the beacon for other healthcare stakeholders to follow. Without a common vision, we will never find success. With a common vision and the will to pursue it, we cannot fail.

**We must not fail. The patient is waiting.**

## Appendix

### Figure A-1. The Department of Health and Human Services (HHS) Framework for Strategic Action on Health Information Technology (HIT)

**Goal 1: Inform Clinical Practice.** Informing clinical practice is fundamental to improving care and making health care delivery more efficient. This goal centers largely around efforts to bring EHRs directly into clinical practice. This will reduce medical errors and duplicative work, and enable clinicians to focus their efforts more directly on improved patient care. Three strategies for realizing this goal are:

- Strategy 1. Incentivize EHR adoption
- Strategy 2. Reduce risk of EHR investment
- Strategy 3. Promote EHR diffusion in rural and underserved areas

**Goal 2: Interconnect Clinicians.** Interconnecting clinicians will allow information to be portable and to move with consumers from one point of care to another. This will require an interoperable infrastructure to help clinicians get access to critical health care information when their clinical and/or treatment decisions are being made. The three strategies for realizing this goal are:

- Strategy 1. Foster regional collaborations
- Strategy 2. Develop a national health information network
- Strategy 3. Coordinate federal health information systems

**Goal 3: Personalize Care.** Consumer-centric information helps individuals manage their own wellness and assists with their personal health care decisions. The ability to personalize care is a critical component of using health care information in a meaningful manner. The three strategies for realizing this goal are:

- Strategy 1. Encourage use of personal health records
- Strategy 2. Enhance informed consumer choice
- Strategy 3. Promote use of telehealth systems

**Goal 4: Improve Population Health.** Population health improvement requires the collection of timely, accurate, and detailed clinical information to allow for the evaluation of health care delivery and the reporting of critical findings to public health officials, clinical trials and other research, and feedback to clinicians. Three strategies for realizing this goal are:

- Strategy 1. Unify public health surveillance architectures
- Strategy 2. Streamline quality and health status monitoring
- Strategy 3. Accelerate research and dissemination of evidence

**Figure A-2. Workgroups of the American Health Information Community (AHIC)<sup>54</sup>**

### **Chronic Care (CC)**

**Broad Charge:** Make recommendations to the Community to deploy widely available, secure technologies solutions for remote monitoring and assessment of patients and for communication between clinicians about patients

**Specific Charge:** Make recommendations to the Community so that within one year, widespread use of secure messaging, as appropriate, is fostered as a means of communication between clinicians and patients about care delivery.

### **Electronic Health Records (EHR) Workgroup**

**Broad Charge:** To make recommendations to the Community on ways to achieve widespread adoption of certified EHRs, minimizing gaps in adoption among providers.

**Specific Charge:** Make recommendations to the Community so that within one year, standardized, widely available and secure solutions for accessing current and historical laboratory results and interpretations is deployed for clinical care by authorized parties.

### **Consumer Empowerment (CE) Workgroup**

**Broad Charge:** Make recommendations to the Community to gain widespread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered.

**Specific Charge:** Make recommendations to the Community so that within one year, a pre-populated, consumer-directed and secure electronic registration summary is available to targeted populations. Make additional recommendations to the Community so that within one year, a widely available pre-populated medication history linked to the registration summary is deployed.

### **Population Health and Clinical Care Connections (PH/CCC) Workgroup (formerly Biosurveillance)**

**Broad Charge:** Make recommendations to the Community to facilitate the flow of reliable health information among population health and clinical care systems necessary to protect and improve the public's health.

**Specific Charge:** Make recommendations to the Community so that within one year, essential ambulatory care and emergency department visit, utilization, and lab result data from electronically enabled health care delivery and public health systems can be transmitted in standardized and anonymized format to authorized public health agencies within 24 hours.

### **Quality Workgroup**

**Broad Charge:** Make recommendations to the Community so that health information technology (HIT) can provide the data needed for the development of quality measures that are useful to patients and others in the health care industry, automate the measurement and reporting of a comprehensive current and future set of quality measures, and accelerate the use of clinical decision support that can improve performance on those quality measures. Also, make recommendations for how performance measures should align with the capabilities and limitations of HIT.

**Specific Charge:** Make recommendations to the Community that specify how certified HIT should capture, aggregate, and report data for a core set of ambulatory and inpatient quality measures

### **Confidentiality, Privacy, and Security (CPS) Workgroup**

**Broad Charge:** Make recommendations to the Community regarding the protection of personal health information in order to secure trust and support appropriate interoperable electronic health information exchange.

**Specific Charge:** Make actionable confidentiality, privacy, and security recommendations to the Community on specific policies that best balance the needs between appropriate information protection and access to support and accelerate the implementation of the consumer empowerment, chronic care, and EHR-related breakthroughs.

### **Personalized Health Care (PHC) Workgroup**

**Broad Charge:** Make recommendations to the AHIC for a process to foster a broad, community-based approach to establish a common pathway based on common data standards that encourage the incorporation of interoperable, clinically useful genetic laboratory test data and analytical tools into electronic health records to support clinical decision making for the health care provider and patient.

**Specific Charge:** Make recommendations to the AHIC to consider means to establish standards for reporting and incorporation of common medical genomic test data into electronic health records and provide incentives for adoption across the country, including federal government agencies.

<sup>54</sup> HHS, HIT, AHIC Workgroups. ([www.hhs.gov/healthit/ahic/index.html](http://www.hhs.gov/healthit/ahic/index.html))

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