Beyond HIPAA: Building Blocks for a National Health Information Infrastructure

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Janet M. Marchibroda
Chief Executive Officer, eHealth Initiative
Executive Director, Foundation for eHealth Initiative
Executive Director, Connecting for Health

Overview of our Presentation

- Laying the Groundwork for the Discussion: What Problems are We Trying to Solve and the Role of a National Health Information Infrastructure
- Activities Within the Private Sector and Congress– Janet Marchibroda
- Overview of the Federal Government's Work on the National Health Information Infrastructure – Helga Rippen, MD, MPH, PhD
- Overview of the Work of the Consolidated Health Informatics Initiative – Karen Trudel

What Problems are We Trying to Solve?

- Looming Healthcare Crisis
  - Changing demographics: Americans age 65+ will increase from 12% of population in 1997 to 20% of population in 2003
  - Rising healthcare costs: Premiums increased 12.7% at the beginning of 2002 and are likely to be higher this year
  - Physicians leaving practice as a result of rising malpractice costs; shortfall of 400,000 nurses nationwide
  - Number of uninsured approx. 15.8% or 44 million of U.S.

What Problems are We Trying to Solve?

- Quality and Safety Issues Abound
  - Unacceptable rates of practice variations lead to $450 billion in unnecessary spending
  - Between 44,000 and 98,000 Americans die in hospitals each year as a result of medical errors…the cost is approximately $37.6 billlion annually
  - Estimated 770,000 people are injured each year due to adverse drug events. Inadequate availability of patient information is directly associated with 18%

What Problems are We Trying to Solve?

- Quality and Safety Issues Abound
  - Estimated 770,000 people are injured each year due to adverse drug events, and up to 70% may be avoidable
  - Adverse drug events in 5% to 18% of ambulatory patients
  - In a 2001 Robert Wood Johnson survey, 95% of doctors, 89% of nurses and 82% of health care executives say they have witnessed serious medical errors

What Problems are We Trying to Solve?

- Big Gap Between "What we Know" and "What We Do"
  - American adults, on average, receive only 54.9% of the healthcare recommended for their conditions
  - Nearly one-third of patients with congestive heart failure are discharged from the hospital without being given ACE inhibitors, even though it's been known for a decade that these drugs provide life-saving benefits
  - Takes about 17 years for new knowledge in clinical trials to be incorporated into every data medical practice

What Problems are We Trying to Solve?

- Public Health Threats Continue
  - Traditionally, public health surveillance has been conducted manually, by phone fax and mail
  - The SARS outbreak highlights gaps and weaknesses in ability to perform disease surveillance and protect the public from natural diseases as well as potential bioterror threats

A Reality Check for Patients

- Our healthcare system is fragmented….care is delivered by a variety of independent physicians, hospitals and other providers
- We interact with many plans and providers over a lifetime making continuity of our personal health information a challenge
- Clinicians sometimes provide care without knowing what has been done previously and by whom…which can lead to treatments that may be redundant, ineffective or even dangerous

A Reality Check for Patients

- Vital data sit in paper-based records that can neither be accessed easily nor combined into an integrated form to present a clear and complete picture of our care
- Our paper hospital records are unavailable when needed about one-third of the time
- Physicians spend an estimated 20-30% of their time searching for and organizing information

A Reality Check for Patients

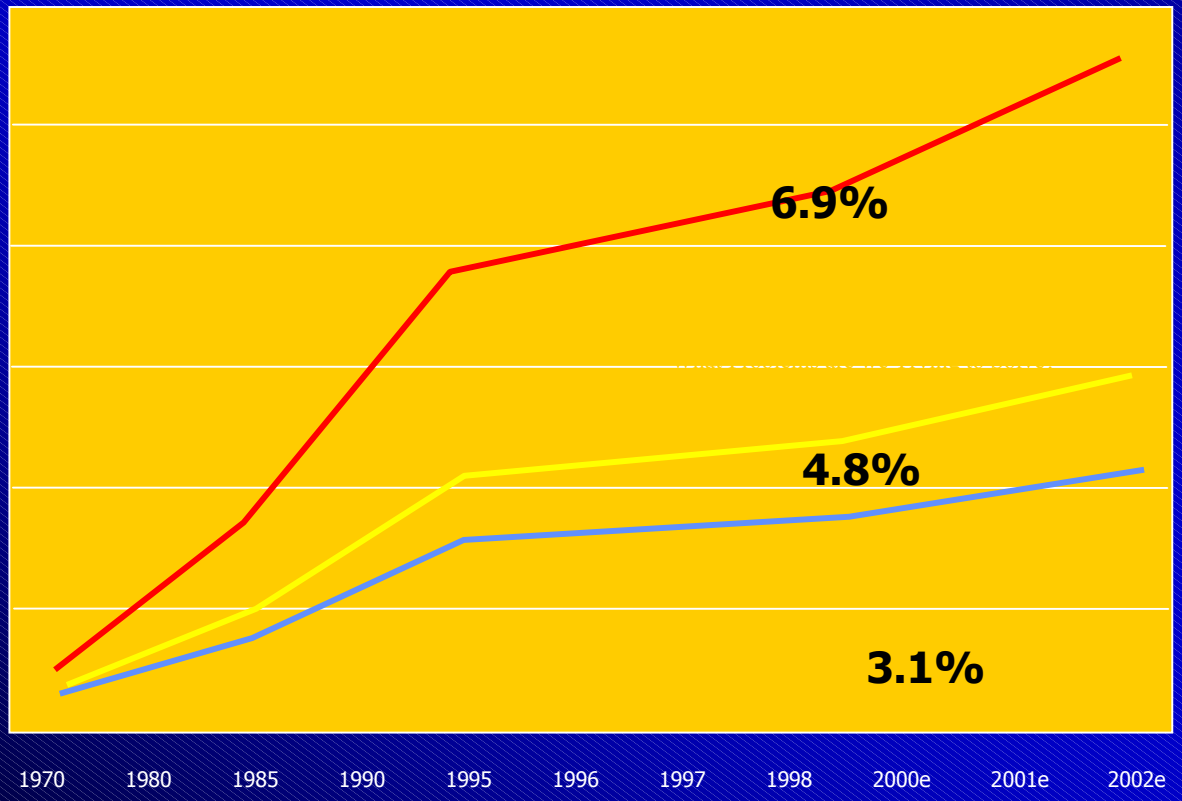
- Because it is impossible to bring full clinical knowledge to the point of care without IT…and it is beyond human cognition to be able to store all of that information in one's head while delivering care…the result can be a gap between what clinicians do and the latest evidenced-based clinical protocols

- Appointments are often scheduled by phone and we waste precious time during our clinician-patient visits, providing our history…. over and over again…

Some Visuals to Remember

What Problems are We Trying to Solve?

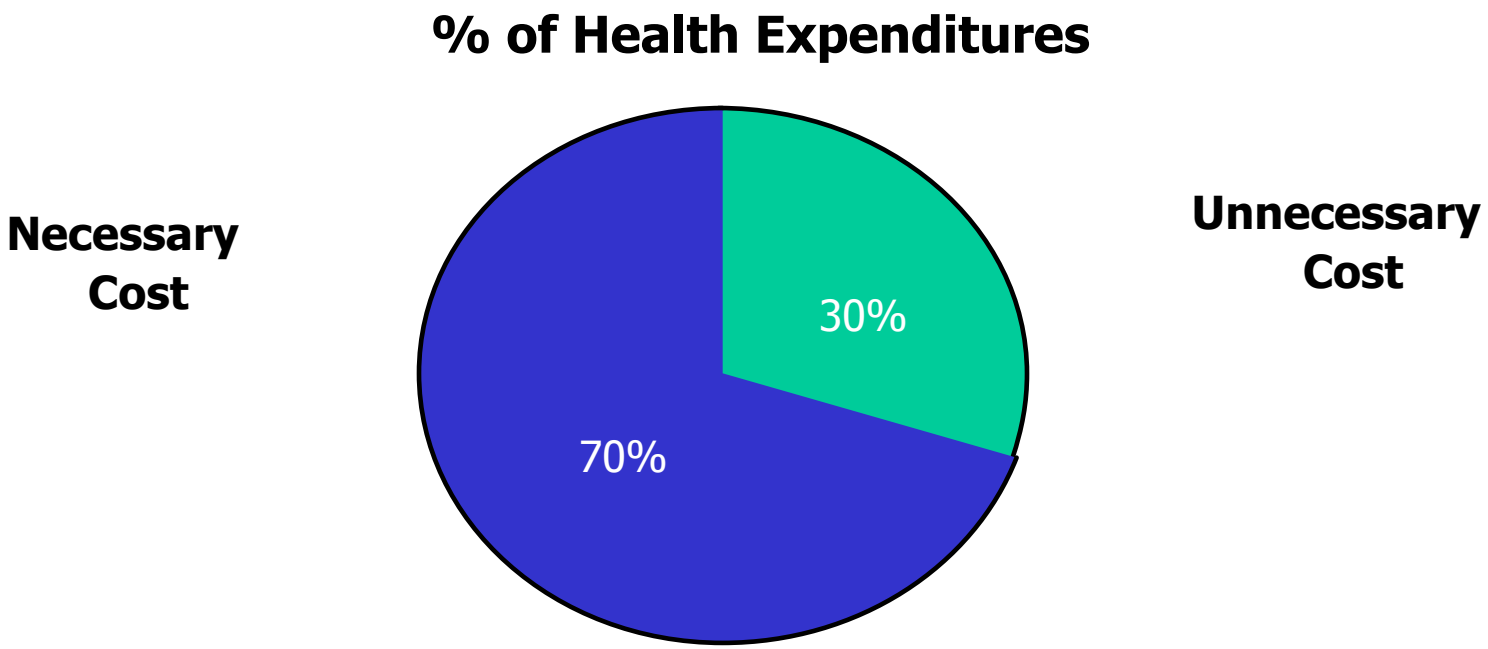
Healthcare Spending Per Capita



US	$5,473
5 Countries	$2,876
G-7	$2,191

Source: *Health, United States, 2002*
Five Countries: Luxembourg, Canada, Germany, Norway, Switzerland
G-7 Countries: Canada, France, Germany, Italy, Japan, United Kingdom

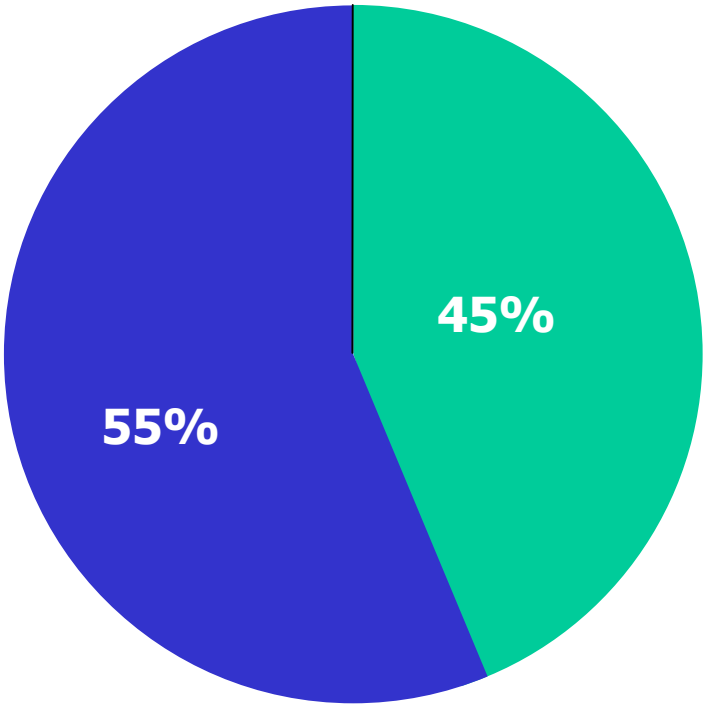
What Problems are We Trying to Solve?



Project Hope, Wennberg et.al., 2003

What Problems are We Trying to Solve?

Right



Wrong

RAND, 2003

"...44,000 to 98,000 deaths..."
- IOM Report: To Err is Human, 1999

"...17 years..."
- IOM Report: Crossing the Quality Chasm, 2000

What Problems Are We Trying to Solve?

Why Information Technology Matters

- It Improves Quality and Saves Lives
  - Center for Information Technology Leadership recent study indicates prevention of more than 2 million adverse drug events and 190,000 hospitalizations per year could be realized from adoption of CPOE in the ambulatory care environment.
  - Computerized physician order entry reduced error rates by 55%--from 10.7 to 4.9 per 1,000 patient days and reduced serious medication errors by 88% at Brigham &Womens Hospital

Why Information Technology Matters

- It Improves Quality and Saves Lives
  - Recent study of intensive care patients by Kaiser Permanente found that when physicians used a computerized system, the incidents of allergic drug reactions and excessive drug dosages dropped by 75%

Why Information Technology Matters

- It Makes it Easier to Navigate the Healthcare System
  - Scheduling appointments, handling quick questions and refilling prescriptions online saves time and headaches
  - Having access to one's comprehensive health information (lab results, EHR information) helps patients and their clinicians keep better track of care
  - Accessing educational information about conditions prior to coming in for visits enables more quality time between the patient and the clinician

Why Information Technology Matters

- It Saves Money
  - CITL study indicates $44 billion in savings per year could be realized from adoption of CPOE in the ambulatory care environment.
  - CITL also released research findings that indicate that standardized healthcare information exchange among healthcare IT systems would deliver national savings of $86.8 billion annually after full implementation and would result in significant direct financial benefits for providers and other stakeholders

Why Information Technology Matters

- It Saves Money
  - A recent cost benefit analysis of electronic medical record systems showed that their use by primary care providers could result in $86,000 in savings over five years. Benefits include reduced drug spending, reductions in radiology, and decreased billing errors.
  - Kaiser Permanente study found that when physicians used a computerized system, the average time spent in the unit dropped by 4.9 days to 2.7, slashing costs by 25%

Why Information Technology Matters

- It Saves Money
  - Regenstrief Institute study indicates that one hospital's use of a community-based clinical data sharing network resulted in reduction in emergency room charges of $26 per encounter

Increasing Demand from Consumers

- A Harris consumer interactive poll found that:
  - 80% want personalized medical information on-line from their physicians
  - 69% want on-line charts fir tracking chronic conditions
  - 83% want to receive their lab tests on-line

Increasing Demand from Consumers

- Clinicians receiving computerized patient symptom assessments prior to a patient visit addressed 51% of their patients symptoms, compared with only 19% of those not receiving assessments

- 63% of consumers in a February 2004 survey agreed it would be "very valuable" to have their complete medical history stored in one computer file that can be accessed anywhere in the hospital

Increasing Demand from Consumers

Foundation for Accountability Survey for Connecting for Health

- Over 70% of consumers surveyed believed a personal health record would improve quality of care
- Consumers surveyed believed that having health information online would:
  - Clarify doctor instructions – 71%
  - Prevent medical mistakes – 65%
  - Change the way they manage their health – 60%
  - Improve quality of care – 54%

Increasing Demand from Consumers

Foundation for Accountability Survey for Connecting for Health

- In response to question: "if you could keep your medical records online, what would you do?"
  - Email doctor – 75%
  - Store immunization records – 69%
  - Transfer information to specialist – 65%
  - Look-up test results – 63%
  - Track medication use – 62%

So Despite all of This, Adoption is Slow!

- More than 90 percent of the estimated 30 billion health transactions each year are conducted by phone, fax or mail
- Healthcare lags behind all industries when it comes to spending on IT. While 11.10%, 8.10% and 6.5% of revenues were invested in IT in the financial services, insurance and consumer services industries, respectively in 2002, only 2.2% of healthcare industry revenues were spent on IT
- Only a third of hospitals nationwide have computerized physician order entry (CPOE) systems completely or partially available. Of those, only 4.9% require their use.
- Fewer than 5% of U.S. physicians prescribe medications electronically

Barriers to Adoption of Information Technology

- Leadership - Within the public and private sectors…at the national level, at the community level, within provider institutions and clinician practices
- Funding and a Business Model - Misalignment of incentives among those who pay for IT and those who benefit from it. The need for upfront and a sustainable business model to support investment
- Standards – The lack of interoperability and standards to support mobilization of information and connectivity across systems
- Organizational and Work-Flow Change – Migrating to an electronic system is difficult

eHealth Initiative Purpose

- eHealth Initiative was formed to clear barriers to the adoption of information technology and a health information infrastructure to drive improvements in quality, safety and efficiency for patients…focusing on:
  - Leadership
  - Funding and Business Model
  - Standards
  - Organizational and Work-Flow Change

eHealth Initiative Mission and Vision

Our Mission: Drive improvement in the quality, safety, and efficiency of healthcare through information and information technology

Our Vision: Consumers, providers and those responsible for population health will have ready access to timely, relevant, reliable and secure health care information and services through an interconnected, electronic health information infrastructure to promote better health and healthcar

eHealth Initiative's Members

- Health care information technology suppliers
- Health systems and hospitals
- Health plans
- Employers and purchasers
- Non-profit organizations and professional societies
- Pharmaceutical and medical device manufacturers
- Practicing clinician organizations
- Public health organizations
- Research and academic institutions

We Have Had Impact…Increasing Momentum

- Increasing Momentum for the Use of IT in Healthcare
  - Congress
  - Administration
  - Private Sector

Momentum Building in Congress

- *Medicare Prescription Drug, Improvement, and Modernization Act of 2003*
  - Electronic Prescription Program: real-time eRx, electronic transmittal of medication history, standards, safe harbor from penalties, and voluntary demonstration project
  - Grants to Physicians requiring matching funds
  - Payment Demonstrations: four sites, QIO involvement Electronic Prescription Program
  - Commission on Systemic Interoperability

Momentum Building in Congres

- *Medicare Prescription Drug, Improvement, and Modernization Act of 2003*
  - Chronic Care Improvement plan which includes the use of monitoring technologies that enable patient guidance through the use of decision support tools and the development of a clinical information database to track and monitor each participant across settings and evaluate outcomes

Momentum Building in Congress

- National Health Information Infrastructure Act
  - Development of NHII Strategic Plan
  - Assessment of the best practices in the development, purchase and maintenance of medical information technology and existing legal requirements for communication standards to the HHS Secretary.

Momentum Building in Congress

- Health Information for Quality Improvement Act (S. 2003)
  - NHII Office and comprehensive NHII strategic plan
  - Set of voluntary national data and communication standards to promote interoperability
  - Grants to hospitals and other healthcare providers
  - Establishment of Medical Systems Safety Initiative to conduct and support research related to IT and impact on quality, safety
  - Development of authentication and identification standards

Momentum Building in Congress

- Health Information for Quality Improvement Act (S. 2003)
  - e-Gov initiative to develop, implement and evaluate procedures to enable patients to access and append personal health data through personal health records
  - Grants for conduct of research on innovative approaches to improve patients' understanding and comprehension of electronic health record

Momentum Building in Private Sector

- Connecting for Health led by Markle and Robert Wood Johnson Foundation drives consensus and promotes the adoption of clinical data standards
- HL7 developing functional model for electronic health record
- IOM issues report on patient safety data standards
- A number of payment pilots and other incentive programs emerging from employer and plan communities, including Bridges to Excellence
- Leapfrog Group announces Fourth Leap to accelerate adoption of eRx, electronic transmission of lab results

eHealth Initiative Focus for 2004: Overview

- In our early years, we focused on raising general awareness of the need for IT and tackling one of the key barriers to adoption—data standards
- In 2004, we will:
  - Expand our work on two other areas that will help to achieve our mission: "making the business case and securing financing" and "developing the field" in key challenge areas…
  - Continue to focus on data standards

eHealth Initiative Focus for 2004

- Align incentives and promote public and private sector investment in improving America's healthcare through IT and an electronic health information infrastructure
  - Drive *investment in research related to the value* of IT in addressing quality, safety and efficiency challenges
  - Fund *strategic demonstration projects* through *Connecting Communities for Better Health* that evaluate and demonstrate impact of IT and further development of strategies and tools for accelerating IT adoption and electronic connectivity - $4 million program, additional $3 million secured and growing

eHealth Initiative Focus for 2004

- Align incentives and promote public and private sector investment in improving America's healthcare through IT and an electronic health information infrastructure
  - Develop *policy options to align incentives and enable* public and private sector *investment in IT* and health information infrastructure – first set of policy papers to be released in March 2004
  - Dramatically increase national awareness of the role of IT in addressing healthcare challenges through the Investing in America's Health campaign

eHealth Initiative Focus for 2004

- Develop the field to enable more widespread and effective implementation of IT and an electronic health information infrastructure
  - Engage national experts to aggregate and develop *knowledge, resources and tools* for key challenge areas related to IT and a health information infrastructure – first report…on *computerized prescribing* to be released in April 2004
  - Provide resources and tools to help communities and stakeholders implement IT and a health information infrastructure through the Connecting Communities for Better Health Community Learning Network and Resource Center

eHealth Initiative Focus for 2004

- Develop the field to enable more widespread and effective implementation of IT and an electronic health information infrastructure
  - Expand information sharing beyond the U.S. by facilitating a global dialogue on the challenges and strategies for implementing an electronic health information infrastructure through the Leadership in Global Health Technology Initiative, in partnership with the International eHealth Association

eHealth Initiative Focus for 2004

- Continue to drive adoption of standards to promote an interoperable, interconnected healthcare system through work with key partners
  - Leverage the work of the *Connecting for Health*, a public-private sector collaboration funded the Markle and Robert Wood Johnson Foundations, that is developing an *incremental roadmap* for U.S. electronic health information infrastructure, and addressing key issue areas such as *data standards; organization and sustainability*; *linking patient data*; and the *personal health record*

Areas of Interest

Areas Critical to IT and Health Information Infrastructure

- Upfront Funding and Sustainable Incentive Models
- Technical (Architecture, Standards, Security)
- Protecting Patient Privacy
- Clinician Adoption and Clinical Process Change
- Application of Clinical Knowledge
- Organization and Governance
- Legal Issues
- Engaging Patients and Consumers

Momentum Building in Administration

"By computerizing health records, we can avoid dangerous medical mistakes, reduce costs and improve care"

President George W. Bush - State of the Union Address, January 20, 2004

Momentum Building in Administration

- Council for the Application of Health Information Technology (CAHIT) – DHHS interagency IT coordinating body launched by Secretary Thompson
- AHRQ $50 million HIT Program…planning and implementation grants with emphasis on multi-stakeholder involvement and matched funding…large rural component…also $10 million focused on evaluating value…similar amounts in proposed 05 budget along with additional $50 million in DHHS Secretary's budget
- CDC PHIN Program promotes integration and use of standards and leveraging data that already resides in the system – e.g. Biosense - $130 million in proposed FY 05 budget

Momentum Building in Administration

- CMS launching four demonstration programs to test incentives for quality outcomes and use of IT
- FDA developing alternative approaches to adverse event monitoring using IT
- Considerable work within the DoD and the VA
- President's Information Technology Advisory Committee launches Health Subcommittee – focus to date on security, architecture for sharing data across institutions within communities

Momentum Building in Administration

- NCVHS – several work groups focusing on these issues…Subcommittee on Standards and Security, Subcommittee on Privacy and Security, Work Group on the NHII
- Consolidated Health Informatics signs off on first set of clinical data standards
- Senior Advisor for the NHII put in place…convenes stakeholders in July 2003, develops paper on "LHIIs"

What Does All of this Mean?

- We are *finally* building momentum…the "stars are aligning"
- Momentum has resulted from leadership and collaboration across every segment of the private sector as well as government…
- The focus has shifted from "whether we should" to "how will we do this?" and your *leadership* has had a lot to do with making this happen…

Conclusions

This work will create lasting and significant changes in the U.S. healthcare system…how clinicians practice…how hospitals operate….how healthcare gets paid for…*how patients manage their health and navigate our healthcare system*